UNITED KINGDOM
LUNG CANCER COALITION

DRIVING QUALITY IMPROVEMENTS IN UK LUNG CANCER:

Utilising good practice and innovation to deliver optimal care and outcomes

February 2024

About 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 and charities, which is supported by healthcare companies who have no input into the group's activities, views or opinions.

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
- Improve lung cancer services
- Empower patients to take an active part in their care

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Clinical Advisory Group Membership

The UKLCC's Clinical Advisory Group is a panel of senior clinicians, each representing specialities involved in the care of lung cancer patients, from the time of first suspicion to diagnosis, and through to palliative care.

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Consultant Radiographer and Clinical Academic, University College London Hospitals NHS Foundation Trust & Canterbury Christ Church University

Conference speakers

Prof Robert Rintoul	Professor of Thoracic Oncology, Cambridge University; Honorary Consultant Respiratory Physician Royal Papworth Hospital Foundation Trust, UKLCC Clinical Advisory Group Lead.	Introduction
Dr Neal Navani	Consultant Respiratory Physician, University College London Hospitals NHS Trust; Senior Clinical Lead, National Lung Cancer Audit	Recent data from the National Lung Cancer Audit
Prof Matt Evison	Professor - Thoracic oncology, pleural & tobacco dependence, Manchester University	Making the optimal pathway as easy as possible for patients
Prof Alastair Greystoke	Professor of Precision Oncology, Newcastle University, Honorary Consultant in Medical Oncology	Impact of delays in molecular diagnostics – how can we speed things up?
Dr Craig Dyer	Respiratory Consultant, Cardiff and Vale UHB, Welsh Thoracic Oncology Group Lead	Lessons learned from tackling the Molecular Profiling Pathway for Lung Cancer – the Welsh perspective
Vaaraki Thirumoolan	TLHC Programme Manager, NHS England	How do we ensure that Lung Health Checks have the maximum impact?
Dr Melanie MacKean	Consultant Medical Oncologist, NHS Lothian, Chair of the SCAN Lung Tumour Specific Group	Driving improvements in lung cancer in Scotland
Dr Wendy Anderson	Consultant Respiratory Physician, County Antrim, Former Northern Ireland Lung Cancer Co-Lead	Driving improvements in lung cancer in Northern Ireland
Tracey Cole RN	Darzi Clinical Fellow, Cancer Genomics Programme Education and Training Lead – North Thames Genomic Medicine Service	The CNS view on optimising patient engagement
Prof David Baldwin	Honorary Professor of Respiratory Medicine, University of Nottingham; Consultant Respiratory Physician, Nottingham University Hospitals	How what we have heard fits in with National Policy
'Lightning talks'		
Dr Will Ricketts	Consultant Chest Physician, Barts Health NHS Trust	Improving lung cancer outcomes through MDT
Dr Adam Januszewski	Consultant Medical Oncologist, Barts Cancer Institute	What we are learning from the ctDNA pilots
Dr Louise Medley	Consultant Medical Oncologist, Torbay & South Devon NHS Trust	Using transport to reduce turnaround time for molecular diagnostics
Katie Lee	TLHC Project Manager, Nottingham & Nottinghamshire ICB	Reducing health inequalities in the TLHC programme
Lizzie Barrett	TLHC Communications Manager, Nottingham & Nottinghamshire ICB	Reducing health inequalities in the TLHC programme
Janina Barnett	TLHC Programme Manager, University Hospitals of North Midlands NHS Trust	Improving uptake in the TLHC programme through invitation model and service model
Session Chairs		
Dr Emma O'Dowd	Consultant Respiratory Physician Nottingham University Hospitals NHS Trust, Honorary (Consultant) Associate Professor, University of Nottingham	
Dr Will Ricketts	Consultant Chest Physician, Barts Health NHS Trust	

Acknowledgements

The content of this report was based on presentations made at the UKLCC 'Driving Improvements in Lung Cancer Care' Conference in London on 10th November 2023. We are grateful to the speakers, chairs and delegates who provided us with their data, experience and ideas, some of which are captured in this report.

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 a list of our partners, please visit our website at: **www.uklcc.org.uk** or contact our Secretariat: **info@uklcc.org.uk**

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Foreword

Professor Robert Rintoul,
Clinical Lead

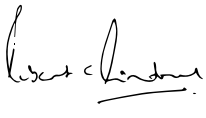
Professor Michael Peake OBE,
Chair

We are living and working in an exciting time for the diagnosis and treatment of lung cancer. We now have the prospect of detecting many more cancers at a potentially curable stage, of more precisely defining the molecular make-up of tumours and treating them with an ever-increasing range of surgical, radiotherapy-based and systemic therapies. Together, these advances are radically improving the survival chances of people unfortunate enough to develop this common cancer.

However, the consequence is that the diagnosis, staging and treatment of lung cancer has become far more complex and specialised and, inevitably, expert services are not available on every street corner. We also know that there is wide variation in care and that there is a large deprivation gap between rich and poor, in terms of treatment options and outcomes for lung cancer. With the increasing likelihood of having to travel to different centres along an optimal care pathway, it is very likely that this variation and deprivation gap will only widen.

The UKLCC's 2023 conference, reported here, is an attempt to get people responsible for the care of lung cancer patients thinking about how they, in their own localities, can take steps to improve the quality and outcomes of their services thereby reducing these inequalities. In planning this conference we were keen that the event and this report, would not be the end of the process, but rather would encourage clinicians and managers to take up the challenge of learning from the presentations and discussions and set up their own local and regional initiatives to address how they might improve their services as they see the problems impacting their own areas. While it is clear that some issues require additional funds or national initiatives to drive improvements, many problems, often on a small scale, can be addressed locally leading to significant improvements. Here, local ownership and leadership are key elements in such quality improvement. Therefore, we challenge all those reading this report to consider how they might influence change for the good in their own areas. The UKLCC is here to support such work, to share examples of good practice and to help facilitate local interactive meetings aimed at ensuring that all lung cancer patients have access to optimal care and the best possible outcomes.

Professor Robert Rintoul,
Clinical Lead



Professor Michael Peake OBE,
Chair

Executive Summary

This *Driving Improvements in UK Lung Cancer* report starts with an overview of the current situation in lung cancer in all four devolved nations using the latest available data. This shows overall positive progress in services and patient outcomes in the UK. However, there is a good deal of variation at both national and local levels. Sharing and adapting best practice at local level is very important, both in reducing the level of variation and in driving overall improvement.

The innovations and examples of good practice highlighted here are happening now at both national and local levels - and cover diverse aspects of service quality. This diversity may make some parts of the document more relevant than others to the reader. An alternative to reading it cover-to-cover is to use this summary and the table of contents to navigate to the parts of greatest interest.

The examples are grouped into three major areas:

1. Reducing inequalities in access to optimal and timely care

Adhering to the National Optimal Lung Cancer Pathway (NOLCP), supplemented by local knowledge, is likely to reduce local variation, resulting in overall faster diagnosis. At local level, this may lead to a more efficient use of existing resources *[CASE STUDY: Greater Manchester Single Queue Diagnostics (SQD); [CASE STUDY: Manchester One Stop Lung Cancer Clinic].*

The MDT is central to reducing inequalities at diagnosis or treatment stages. There is evidence showing the benefits of having not only separate treatment and diagnostic MDTs, but also of evolving their membership as the circumstances change *[CASE STUDY: Improving lung cancer outcomes through the MDT}.*

Patients need to be engaged and involved in improving and implementing services and this can be achieved through co-production in a no-blame culture, bringing together all members of the lung cancer diagnostic and treatment teams and involving patients *[The CNS view on optimising patient engagement].*

Scotland is making significant progress in implementing the Scottish Optimal Lung Cancer Pathway (SOLCP), supported by non-recurring funding of £3m in December 2022. The initiative consists of four elements *[BEST PRACTICE EXAMPLE: Four major improvements provide opportunities to move forward in Scotland].*

2. Improving timely access to molecular diagnostics

Molecular diagnosis results should be available and discussed at the MDT meeting. If this is to become standard practice, the time taken for molecular diagnosis testing and delivery of results must be shortened. Many improvements are possible at minimal cost *[BEST PRACTICE EXAMPLE: Speeding up the molecular diagnostics].*

An effective molecular profiling pathway has been set up in Wales *[BEST PRACTICE EXAMPLE: Developing and introducing a molecular profiling pathway for lung].*

Speeding up molecular diagnosis testing may involve the use of new plasma markers. Circulating tumour DNA (ctDNA) is one that is currently being piloted *[CASE STUDY: ctDNA pilots]*. In addition, improving efficiency in the logistics involved in transporting tissue samples may speed up the process *[CASE STUDY: Transport and reducing turnaround time for molecular diagnostics].*

3. Optimising the impact of a lung screening programme

To date, more than one million people have now been invited to take part in a Targeted Lung Health Check. However, the variance in uptake of different local projects ranges from 20% - 79%. Assessing the value of opt-in or opt-out invitations and of virtual versus face-to-face checks should be considered *[Optimising implementation and roll out of TLHCs across the UK].*

The way in which communications campaigns are designed may have a significant impact on uptake, including in high deprivation communities *[CASE STUDY: Communications Campaign with The Roy Castle Lung Cancer Foundation (RCLCF)].*

Understanding the reasons why people in different communities do, or do not, engage with the programme is valuable *[CASE STUDY: Reducing health inequalities in the TLHC programme]*. This may give rise to different invitation and service models, depending on the needs of different local communities *[CASE STUDY: Improving uptake in the TLHC programme through invitation and service models].*

The Optimal Lung Cancer Pathways, the Targeted Lung Health Checks and soon, the national screening programmes are available to help identify and achieve improvements in lung cancer services. Their successful implementation relies on the development of services based on local knowledge, producing benefits for local people, that collectively result in visible improvements nationally. *[Making it happen].*

Summary of recommendations

The recommendations in this report are intended to encourage and support health professionals throughout the UK to carry out their own assessment of the quality of their lung cancer services and to develop their own programmes to improve them with appropriate support.

01

Health care professional teams diagnosing and treating lung cancer patients should look carefully at the situation in other nations and in other trusts or health boards, not only to compare their own performance, but also to learn of initiatives and ideas that they might use, or adapt for use, in their own services.

02

Limitations and pressure on existing resources should not automatically be considered as barriers preventing change. Zero- or minimal-cost programmes can be effective ways of improving quality in services (see our case studies).

03

Measuring existing services throughout the entire pathway (including quality and capacity) is important in deciding what actions to take. Doing so will often identify ways of improving efficiency, areas where there is previously unseen spare capacity and ways of running the service more efficiently and effectively for patients.

04

Assessing service quality and developing ideas for improvement should be carried out by bringing together all members of the lung cancer diagnostic and treatment teams and involving patients, who have a crucial role to play. This must be done as a single team in a no-blame culture that encourages co-production.

05

Improving the quality and effectiveness of services is a constant and ongoing need. Regular assessment of services facilitates their evolutionary development, taking into consideration changes to patient needs and resources within Trusts/Health Boards.

06

Molecular diagnostic testing should be carried out on all appropriate patients and the results, where relevant, should be available for discussion at the MDT within two weeks.

07

It is important to maintain a broad view of services, looking beyond medical/surgical services to any elements where quality can be improved, or time or resources can be freed up.

08

When establishing Targeted Lung Health Checks in your area:

- Initially try both opt-out and opt-in invitations to assess which is most effective.
- Initially offer virtual and face-to-face appointments to assess which is best.

09

Targeted Lung Health Check programmes must be based on thorough local knowledge of the communities and areas, and must take into consideration the social and lifestyle needs of the people who live in them.

10

More meetings should be held at national and particularly regional and local level, to provide opportunities for the exchange of best practice and innovative ideas to enhance the quality of lung cancer services and drive forward improvements.

11

Information hubs should be set up at national level and/or cancer alliance level. These should contain tools, exemplars and case studies, plus the ability to contact people wherever they are working to generate new ideas and gain advice on improving the quality of lung cancer services.

1. The current situation in UK Lung Cancer

Lung cancer is the UK's biggest cancer killer with around 34,800 deaths each year (2017-2019 data)[1]. Five-year survival rates for the four UK nations lag behind the US and other European countries. This is caused by many diverse challenges, not least the level of late-stage diagnosis, marked variation in access to care, workforce shortages and delays in implementing the National Optimal Lung Cancer Pathway (NOLCP).

There has been a good deal of positive progress in lung cancer services and patient outcomes in the UK in recent years. However, the extent of these improvements varies within England and across the devolved nations, with examples of best practice and opportunities for improvement also very variable. This suggests that sharing and adapting best practice at local level will have a significant role to play in making further progress and reducing variation.

EXPERT INSIGHT

"We are recovering from the pandemic better than predicted, but there are key areas in which we can improve, such as providing systemic therapies to patients with advanced disease, and emergency presentation rates.

Dr Neal Navani. Senior Clinical Lead, National Lung Cancer Audit

England

The National Lung Cancer Audit (NLCA) covers both England and Wales. The following is based on the most recent report from the NLCA containing the latest available data from 2021[2]. (N.B. The next report, covering data on patients diagnosed in 2022 will be published in April 2024.) To reflect recent developments in diagnosis and treatment of lung cancer, the NLCA is being expanded to cover genomic data from the genomic laboratory hubs. Ways to gather data on adjuvant therapy are also being considered.

The data show the number of patients diagnosed in England in 2021 returned to pre-pandemic levels with 34,478 patients diagnosed with lung cancer compared to 31,371 in 2020. However, the proportion of patients presenting with stage 4 disease appears to be increasing and it is also worth noting that the data show over one in three patients were still being diagnosed via emergency presentation.

PATIENT PERSPECTIVE

"It's been a long road - getting onto a targeted therapy I could tolerate and at the right dose for me - and having to shield during Covid. However, I now feel I have my life back."

Gillie (69 years)

34,478
patients were diagnosed with lung cancer in 2021
31,371 in 2020 **33,091** in 2019

74 years **age at diagnosis (median)**

83%
of patients **with stage I/II disease, performance status (PS) 0-1** had pathological confirmation of their diagnosis: **77%** in 2020 and **84%** in 2019

48%
of patients presented **with stage IV disease**: **44%** in 2020 and **43%** in 2019

35%
of patients diagnosed via **emergency presentation**: **35%** in 2020 and **31%** in 2019

Courtesy of the National Lung Cancer Audit

The most recent national statistical data for England show that for patients diagnosed in 2017, 19.8% were alive at five years from the date of diagnosis.[3]

Curative treatment rates increased. The proportion of patients in England with stage I/II and performance status 0-2 Non-Small Cell Lung Cancer (NSCLC) undergoing curative-intent treatment (surgery or radical radiotherapy) increased from 73% in 2020 to 80% in 2021. In stage IIIA, Performance Status 0-2 patients it increased from 51% to 59%.

According to the Audit, 61% of patients with NSCLC stage IIIB-IV and Performance Status 0-1 received systemic anti-cancer therapy in 2021, compared with 55% in 2020, but still short of the audit standard of 65% or more. This figure has been low historically, and it could be an area where there is opportunity for further improvement at trust and cancer alliance level.

Surgery for non-small cell lung cancer (NSCLC)

17% **of patients with NSCLC had surgical treatments for their cancer**

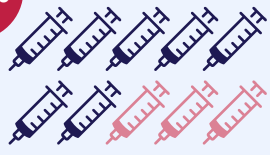
≥17% Audit standard

15% in 2020
20% in 2019

Chemotherapy for small cell lung cancer (SCLC)

70% **of patients with SCLC received treatment with chemotherapy**

≥70% Audit standard



66% in 2020
69% in 2019

Courtesy of the National Lung Cancer Audit

The post-pandemic recovery has not been uniform and in the proportion of patients with NSCLC having surgery, it has been relatively slow. Nearly one in five (17%) of patients had surgery in 2021 compared with15% in 2020. However, this is still some way short of the proportion in 2019 before the pandemic which was 20%.

Access to chemotherapy for small cell lung cancer has improved; in small cell lung cancer the proportion of patients receiving chemotherapy increased, reaching the audit standard of 70% in 2021, versus 66% in 2020.

92% **of patients* were assessed at diagnosis by a lung clinical nurse specialist:**
75% in 2020 80% in 2019

≥90%
?
Audit standard *

*** information available for only 59% of patients so this is uncertain**

Courtesy of the National Lung Cancer Audit

Access to lung cancer specialist nurses appears to have exceeded the Audit standard in England, though data completeness is relatively poor (59%) so this result should be treated with caution.

The main challenge in improving these metrics lies at cancer alliance and trust level. A more detailed examination of the NLCA data sheets reveals wide variation across England in all of these metrics. So, tackling these variations at local level will be important moving forwards.

Wales

The following information is based on the latest report of the NLCA.[2]

In Wales, the COVID-19 pandemic in 2020 had a significant impact on the numberof patients diagnosed in Wales, which fell from 2,240 in 2019 to 2,067 in 2020. However, this has recovered in 2021 to 2,244.

As in England, surgery is slow to recover and the proportion of NSCLC patients having surgical treatment is still below both the audit standard and the level reached in 2019. However, the proportion of patients receiving chemotherapy for small cell lung cancer has not only recovered beyond pre-pandemic levels, but also has exceeded the audit standard of 70% in 2021.

Curative treatment rates are an important metric across all devolved nations. In Wales the proportion of NSCLC patients with stage I/II and good performance status 0-2 who were treated with curative intent was similar in 2020, 66% and 2021 65%, a fall from 73% in 2019. This is an area where there may be opportunities to improve. For patients with stage IIIA disease, curative treatment rates were higher in 2021 than 2019, after a fall in 2020.

Access to lung cancer specialist nurses exceeded the Audit standard in 2020 and rose again to 94% in 2021.

94% **of patients* were assessed at diagnosis by a lung clinical nurse specialist:**

93% in 2020 **90%** in 2019

≥90% ✓ Audit standard

Courtesy of the National Lung Cancer Audit

2,244 patients were diagnosed with lung cancer in 2021

2,067 in 2020 **2,240** in 2019

73 years age at diagnosis (median)

85% of patients **with stage I/II disease, performance status (PO) 0-1** had pathological confirmation of their diagnosis: **83%** in 2020 and **86%** in 2019

50% of patients presented **with stage IV disease**: **49%** in 2020 and **48%** in 2019

24% of patients were diagnosed via **emergency presentation**: **28%** in 2020 and **29%** in 2019

Courtesy of the National Lung Cancer Audit

Surgery for non-small cell lung cancer (NSCLC)

13% **of patients with NSCLC had surgical treatments for their cancer**

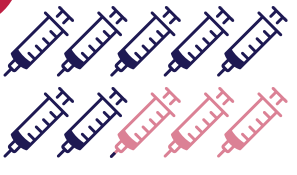
≥17% ✗ Audit standard

11% in 2020

16% in 2019

Chemotherapy for small cell lung cancer (SCLC)

71% **of patients with SCLC received treatment with chemotherapy**



≥71% ✓ Audit standard

58% in 2020

65% in 2019

Courtesy of the National Lung Cancer Audit

Scotland

The number of lung cancer diagnoses in Scotland is slowly returning to pre-pandemic levels. During the nine months of the pandemic in 2020 (April-December), the number of patients diagnosed with lung cancer was 9% lower than would have been expected in this period had COVID-19 not happened. In 2021, there were 4,940 people diagnosed with Lung Cancer in Scotland. This is an increase on the 4,555 diagnosed in the whole of 2020 but is still lower than the 5,136 diagnosed in 2019.

EXPERT INSIGHT

"We have a lot of good things going on: we have national trials, we have national conversations, the Scottish Government have said they support the implementation of Scotland's new optimal lung cancer pathway - but we have a long way to go."

Dr Melanie McKean. Consultant Medical Oncologist, NHS Lothian, Chair of the SCAN Lung Tumour Specific Group

As in many areas, in Scotland, lung cancer disproportionately affects people living in more deprived areas (29.9% of those diagnosed in 2019/20 were from most deprived areas vs 12% from least deprived).[4]

Rapid diagnosis remains a major challenge. According to unadjusted waiting times data, 39.1% of people with lung cancer waited longer than the current target for Health Boards of 62 days.[5]

The five-year survival rate for lung cancer in Scotland is the among the lowest of any cancer at just 16.1% (compared to, for example, 74.2% for breast cancer)[6] and also lower than the average five-year survival in England. The five-year+ survival rate for males is only around 12.5% and 18.6% for females.

Resources for lung cancer services are a serious problem in Scotland and this is reflected in the data above. For example, the shortage of consultant radiologists means that 54% of posts in the north of Scotland will not be filled and the provision of PET scanners per million population is almost half that in England.

The UKLCC report 'Scottish Pathways Matter'[7] has been produced in support of the implementation of the Scottish National Optimal Lung Cancer Diagnostic Pathway (SNOLCDP) and provides a review of cancer services in 2023 in Scotland.[8] It is important that the SOLCDP is rolled out throughout Scotland. This may highlight areas where local service improvements are possible with zero or minimal budget impact.

The UKLCC report 'Scottish Pathways Matter' has been produced in support of the implementation of the Scottish Optimal Lung Cancer Diagnostic Pathway (SOLCDP) and provides a review of cancer services in 2023 in Scotland. It is important that the SOLCDP is rolled out throughout Scotland. This may highlight areas where local service improvements are possible with zero or minimal budget impact.

Northern Ireland

The latest Northern Ireland Cancer Registry data indicatethat more than 1,300 people in Northern Ireland arediagnosed with lung cancer each year, with around 1,000deaths. 45% of cancer patients in Northern Ireland are diagnosed at the later stage III/IV. The 'Cancer: Northern Ireland' Research and Information Service briefing, produced for the Northern Ireland Assembly also highlights delays with diagnostic tests, shortages of radiologists, severe pressures on GPs and disparities for patients in terms of access to treatments and travel times, especially for people in rural areas.[8,9]

EXPERT INSIGHT

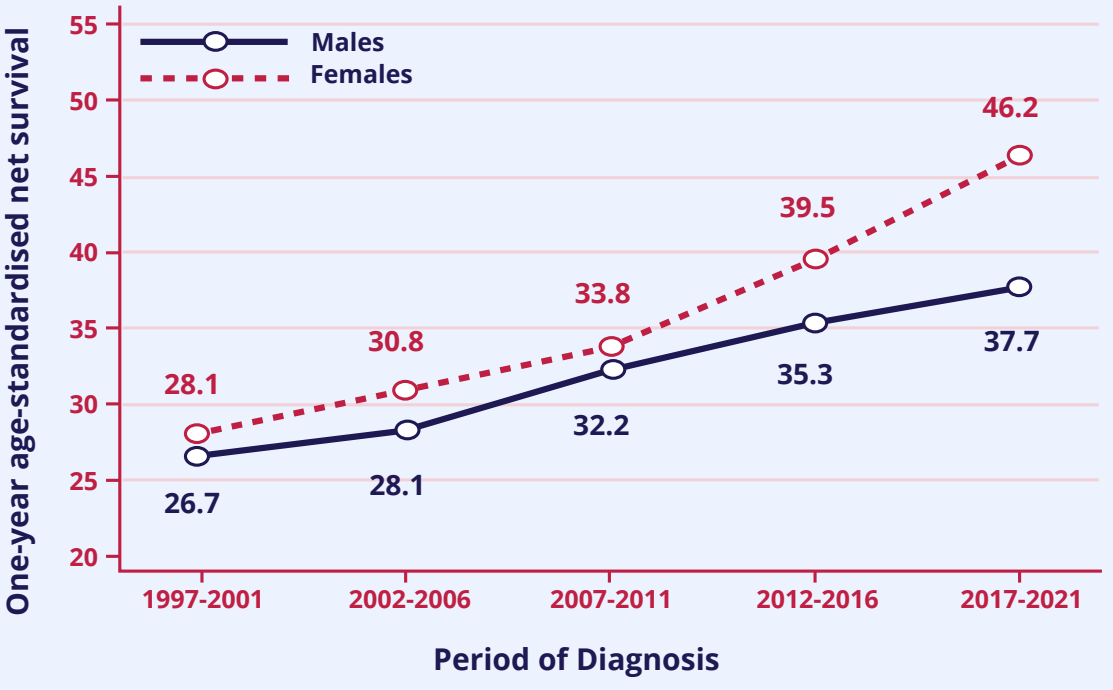
"Without a screening programme in Northern Ireland improvements in survival rates will lag behind those in England."

Dr Wendy Anderson. Consultant Respiratory Physician, County Antrim, Former Northern Ireland Lung Cancer Co-Lead

The age standardised incidence of lung cancer fell, but absolute numbers rose at a rate that did not match resources. Consequently, the system was generally stretched by demand. Radiology, and pathology services have slowed and demand for other respiratory services including the acute admissions are rising.

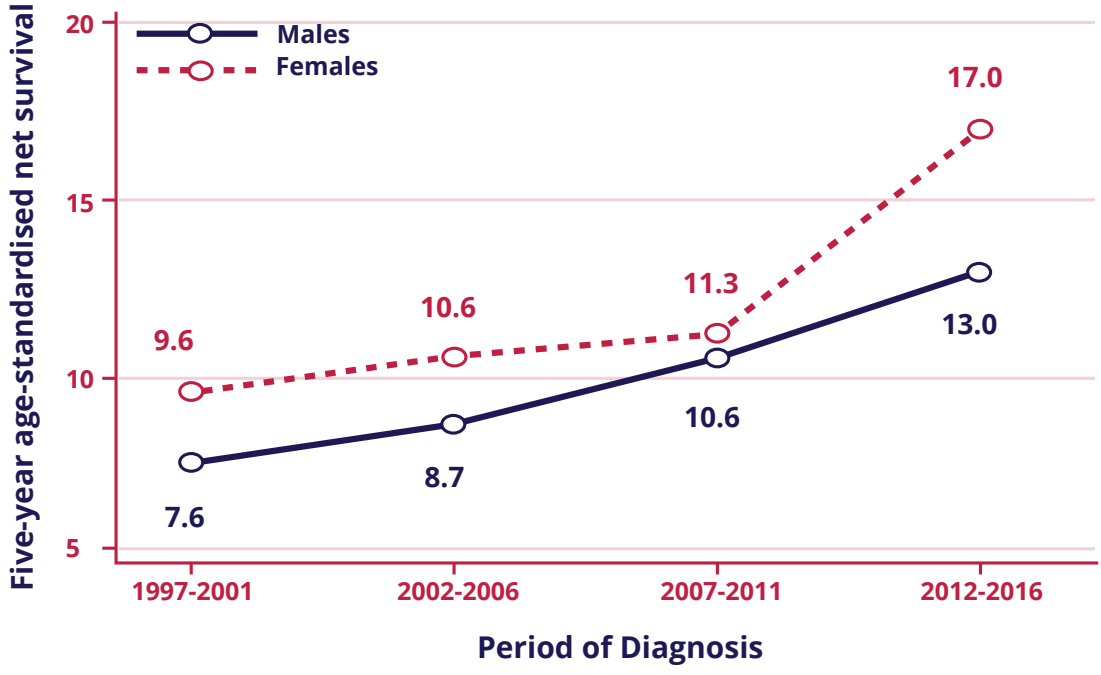
One year survival in Northern Ireland was around 42% in 2019, but with an improving trajectory. Extrapolating from the 2014 figure of 15% of patients alive at 5 years, Northern Ireland may meet the UKLCC target of 25% survival for patients presenting in 2025, but in the absence of screening Northern Ireland will lag behind other nations in terms of 1 year and 5 year survival.

One-year age-standardised net survival (males and females)



Courtesy of Dr Wendy Anderson. Presented at UKLCC Conference 2023

Five-year age-standardised net survival (males and females)



Courtesy of Dr Wendy Anderson.
Presented at UKLCC Conference 2023

In 2022, of 1300 lung cancers diagnosed, 235 had radical oncology treatment.

The joint clinic in Belfast (with chest physicians, surgeons and oncologists) has restarted. The capability this gives, of combining opinions from three specialties is proving useful in assessing complex cases. A report (awaiting submission for publication) demonstrates a reduction of 14 days in time lines.

As part of an overall increase, the level of activity in radical radiotherapy doubles every five years and there has been a further unexplained rise from the end of 2022.

01

Recommendation

Health professional teams diagnosing and treating lung cancer should look carefully at the situation in other devolved nations and in other trusts or health boards, not only to compare their own performance, but also to learn of initiatives and ideas that they might use, or adapt for use, in their own services.

02

Recommendation

Limitations and pressure on existing resources should not automatically be considered as barriers preventing change. Zero- or minimal-cost programmes can be effective ways of improving quality in services, (see our case studies).

2. Reducing inequalities in access to optimal and timely care

The UKLCC's report 'Bridging the Gap'[10], highlighted a wide range of health inequalities in lung cancer and made ten recommendations on measures to mitigate their impact on patients. Many of these recommendations were focussed on actions that could be taken at local level. Here we look at some of the progress being made and opportunities for further initiatives to bridge the gap.

There is much variation across England in achieving faster diagnosis. Adhering more closely to the National Optimal Lung Cancer Pathway (NOLCP) and implementing each step in a more systematic way at local level, using local knowledge, is likely to reduce local variation, resulting in overall faster diagnosis.

Delivering the NOLCP needs a multi-faceted approach at every point. The Greater Manchester Cancer Alliance is leading two initiatives to tackle two specific facets that were identified as opportunities for improvement.

CASE STUDY:

Greater Manchester Single Queue Diagnostics (SQD) Programme

The underlying principle of this work programme is sharing diagnostic capacity throughout the Greater Manchester Cancer Alliance in order to optimise resource. There is variation in capacity and service resilience throughout the region. Trusts vary in the specialist diagnostic procedures they carry out. For example, PET-CT scanners are distributed by region which can cause variation in access at trust level; similarly Endobronchial Ultrasound (EBUS) services do not exist in every trust. The median wait times for EBUS varies from 6-11 days, so the speed with which a patient can get an EBUS varies according to where they live. The objective of the SQD Programme is to deliver these diagnostics within five days, according to a GIRFT (Getting It Right First Time) target.

Before this programme began, information on waiting times for EBUS services across Greater Manchester were not available to the referring teams. So EBUS scheduling was the responsibility of the provider organisation but the accountability remained with the referring hospital. There was no patient choice because referral pathways were rigid.

Before the introduction of SQD, the system was one in which individual centres had rigid protocols that channelled patients through specific diagnostics centres without taking capacity into consideration. Through optimising and sharing capacity locally, the SQD System has changed this to one in which patients can choose the centre at which they have their EBUS, based on their personal needs and the waiting times at each centre.

EXPERT INSIGHT

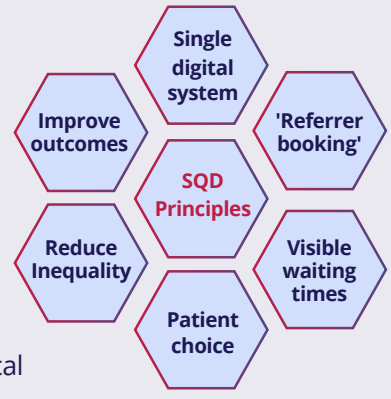
"Delivery of the National Optimal Pathway needs a multi-faceted approach, including every little point in the pathway."

Prof. Matt Evison. Professor - Thoracic oncology, pleural & tobacco dependence, Manchester University

CASE STUDY continued:

The network is operated according to a set of principles. The single digital system sits above all providers and allows referrers to book an EBUS from any provider in Greater Manchester and to do so whilst the patient is still in the consulting room. The system calculates the earliest available appointment and can also coordinate appointments for different procedures e.g. PET-CT scan and EBUS.

Making changes such as this takes time: this system has taken three years to develop and fully implement. However, the median wait time for EBUS under the SQD system is five days, but crucially all of the long wait times (>18 days) have been eliminated and 40% of patients are moving to alternative providers to save time. The system is being expanded. So thoracoscopy services are now 'live' and offering a 'one-stop model' (clinic AND procedure).



Courtesy of Prof. Matthew Evison. Presented at UKLCC Conference 2023

CT-guided lung biopsy is about to be launched under the SQD system. This has been a challenge in overcoming variations in technical protocols (such as what might be biopsied in one centre versus others). Enabling shared capacity has required an unprecedented level of collaboration, locally, across thoracic radiology. The system allows biopsy procedures to be vetted and their complexity graded and matched against services that can perform the appropriate procedures to the required level of complexity.

One further crucial point is that patients' travel costs are met within the programme. This was an overarching recommendation relating to lung cancer services to reduce inequity within the 'Bridging the Gap' report.

Comments and tips from break-out sessions – Encouraging greater collaboration

- *"Many of the changes needed to make the pathway easier for patients to navigate, involve better communications within the team and the different specialties involved. Improving communication and starting up local initiatives based on local knowledge are extremely valuable, e.g. in some areas better communications between CNSs is an opportunity to improve."*
- *"Setting up a daily triage service leads to significant improvements. Setting up and running the services needs collaboration between different members of the team. There are examples of different specialties leading such a service, e.g. radiology-led, and nurse-led."*
- *"There may be access to funding support from Cancer Alliances, e.g. transformation funding. So it is important to ensure they are involved in planned local changes."*

CASE STUDY:

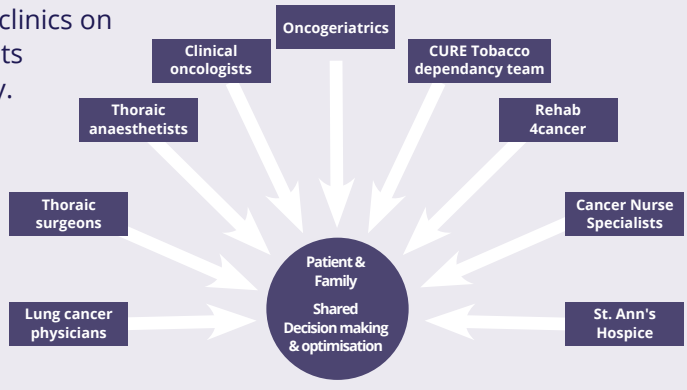
Greater Manchester One Stop Lung Cancer Clinic

Prior to the introduction of the One-Stop Lung Cancer Clinic in Greater Manchester, patients with early stage disease who were suitable for curative intent treatment (surgery or radiology) but high risk for surgery were waiting around 30 days from MDT to treatment decision. This was because the patients had to visit different specialists on different sites.

To overcome this, all specialists now run clinics on the same site at the same time, so patients can see everyone they need to in one day.

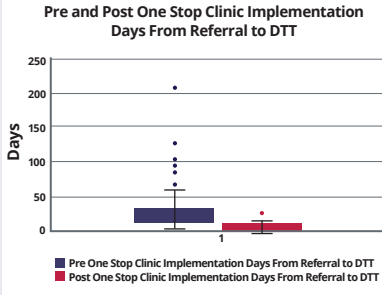
This apparently simple intervention took a long time to set up, but the results are extremely positive.

There is evidence the one-stop clinic improves pathway times and reduces inequality. In addition, other services can be included such as frailty management.

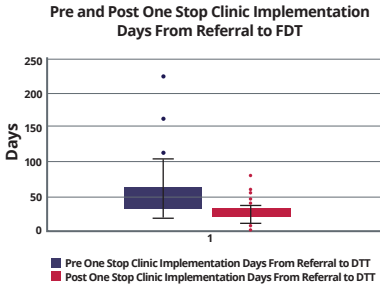


Courtesy of Prof. Matthew Evison. Presented at UKLCC Conference 2023

GM One Stop Lung Cancer Clinic: Outcomes (115 pts)
88% of patients made a treatment decision on the day of clinic



Mean 5 days: **Saving of 23 days**
Mean 4 days: **Saving of 16 days**



Mean 27 days: **Saving of 21 days**
Mean 26 days: **Saving of 15 days**

Underpinning this programme, patient transport is provided, and information is produced in all languages and is easy to read.

Other approaches to address similar challenges in other parts of the UK are also being introduced. For example, NHS Lothian has implemented a similar system, which is making a positive difference.

Courtesy of Prof. Matthew Evison. Presented at UKLCC Conference 2023

03
Recommendation

Measuring existing services throughout the entire pathway (including quality and capacity) is important in deciding what actions to take. Doing so will often identify ways of improving efficiency, areas where there is previously unseen spare capacity and ways of running the service more efficiently and effectively for patients.

PATIENT PERSPECTIVE

"My mental and emotional health has definitely suffered since my diagnosis – both as a result of the diagnosis but also because of the subsequent challenges and delays faced along the way. I live alone, but I am lucky to have the support of a lovely family and great network of friends."

Jane (61)

Comments and tips from break-out sessions - Getting the practical things right

- *"Measuring local data, knowing local problems and their impact is essential before deciding what action to take, e.g. the Single Queue Diagnostics Programme in Manchester (described earlier). The National Lung Cancer Audit is needed as a benchmark against which to measure local data."*
- *"Transport can be a major barrier. Understanding local public transport services and their limitations, and mitigating these to ensure patients are supported in order to travel to and from appointments can be every bit as important as utilising the latest diagnostic or treatment techniques."*
- *"When considering in which languages to provide patient information it is important to ensure that these are the main languages spoken in the local areas by people who are 50 – 80 year-old smokers (i.e. at high risk of lung cancer). These languages may be different from the overall top five languages in the area."*
- *"Local service quality audit is important, but on a day-to-day basis, setting individual gold standards as to what every patient should receive and measuring against this is a good practical way of ensuring quality of care."*

EXPERT INSIGHT

"We have been doing well. We should be doing better. But actually we need to do better things through relational co-productive working with our colleagues and our patients."

Tracey Cole. Darzi Clinical Fellow, Cancer Genomics Programme Education and Training Lead –NT GMS

The CNS view on optimising patient engagement

Improving outcomes and enhancing patient care is about many factors, including not only clinical developments, organisational change and financial investment, but also collaboration between different services towards a common goal, as we have already seen in the previous case studies. In addition, patients need to be engaged and involved in not only improving services, but also in implementing them and using them to maximum benefit.

Comments and tips from break-out sessions - Improving engagement with patients and \public

- *"It is vital that more work is done to understand how the effectiveness of campaigns and programmes aimed at specific groups can be improved. This is particularly important for campaigns to get people into the pathway early and those aimed at people who are reluctant to engage with health services. Doing so may help decrease the proportion of patients who are performance status 0-1 who do not receive Systemic Anti-Cancer Treatment (SACT), reduce the number of people who do not turn up for TLHC appointments and those who present through A&E."*
- *"When looking for the barriers limiting uptake of TLHCs, we should ensure we speak to patients and sometimes the public, who will know what the barriers are. Engaging community leaders can be helpful in doing this."*

Encouraging patient engagement is a major challenge in all parts of the UK; improving it relies on compassionate and relational leadership across different systems in health and in community care. As recommended in the 'Bridging the Gap' report, integrating health and community services and providing supportive and personalised care are important in building patient engagement. In England, the Integrated Care Boards (ICBs) should prove valuable in health and community service integration and consequently patient engagement.

As we have seen in the two Greater Manchester case studies, central to the concept of systems leadership, which drives change for social good across multiple systems, are ways of thinking, perceiving, feeling, relating and doing. These allow people working on different systems to interact, take decisions and work together in a highly collaborative way. The role of the Cancer Nurse Specialist (CNS) is fundamentally important in managing overall patient wellbeing and CNSs, along with pathway navigators, are likely to be part of the key link between health and community services.

The need is to transform the perception of people working within the systems in order to change them from passive recipients to equal partners who are supported to optimise the skills they have. The emphasis is on networks across services based on reciprocal relationships where responsibilities and expectations are held mutually.

This helps remove tightly held boundaries e.g. between health professionals and recipients (patients) who can take a shared role with more control over their care. Throughout this, showing empathy and having a connection with a patient is extremely valuable.

04

Recommendation

Assessing service quality and developing ideas for improvement should be carried out by bringing together all members of the lung cancer diagnostic and treatment teams and involving patients, who have a crucial role to play. This must be done as a single team in a no-blame culture that encourages co-production.

Ghate et al (2013). Courtesy of Tracey Cole RN
Presented at UKLCC Conference 2023

If this is done correctly, patient engagement shifts to becoming co-production where people using the services are in an equal partnership with the people responsible for delivering them. The ACCEND framework (NHS Health Education England)[11] mainly supports the development of nurses and commissioners of services. It provides guidance and detailed capabilities required when caring for people affected by cancer. Patients are able to use this to understand what they can expect from the cancer workforce. One of the core competencies for advanced- and consultant-level nurses in that framework is the engagement of "people with cancer to improve and co-produce person-centred, quality services" (section 1.9, p41 ACCEND Framework 2023).

In terms of lung cancer care, there are many things that are done well, but in addressing the opportunities for improvement, the ability to establish co-productive working with colleagues and with patients, will be crucial. The central role of CNSs in caring for the patient's well-being, also places them at the centre of improving patient engagement and through this, improving services for patients.

Comments and tips from break-out sessions - The need to tailor national initiatives locally

- *"The introduction of new roles such as pathway navigators and support workers alongside CNSs is a welcome improvement, but in some areas their respective roles need to be clarified."*
- *"Overall, there has been a huge amount of work undertaken since the publication of the National Optimal Lung Cancer Pathway, and we must ensure we build on this and apply it locally, based on local knowledge."*
- *"The benefits of one-stop clinics out-weigh the challenges in establishing them."*

Best Practice Example:

Four major improvements provide opportunities to move forward in Scotland

In Scotland, lung cancer is the most common form of cancer, and its incidence is increasing. Yet a large proportion of patients are diagnosed at a late stage. These challenges have been met by a major commitment from the Scottish Government and NHS Scotland to improve services and outcomes in lung cancer. Supported by non-recurring funding of £3m in December 2022 for the implementation of the Scottish National Optimal Lung Cancer Diagnostic Pathway (SNOLCDP), there is a feeling of real progress. The initiative consists of four elements.

01 Scottish National Optimal Lung Cancer Diagnostic Pathway - Dec 2022

02 Launch of national lung cancer guideline (TMG) - Sep 2023

03 CSO funded pilot in lung cancer screening (LUNGSCOT)

04 Launch of Scottish Expert Advisory Group for lung cancer screening with SG - Aug 2023

Courtesy of Dr Melanie McKean. Presented at UKLCC Conference 2023

***TMG** - Tumour Management Guidelines*
***CSO** - Chief Scientist Office*
***SG** - Scottish Government*

1. The Scottish Optimal Lung Cancer Timed Pathway. The pathway provides a framework to guide Health Boards in identifying local priorities and it supports them in identifying their own local actions to achieve the standards set out in it. To stimulate the process of change at local, regional and national level, in its report 'Scottish Pathways Matter', the UKLCC has made 17 recommendations, including the expansion of the 'single point of contact' pilots to all Health Boards, ensuring MDTs have sufficient oncologist and cardiothoracic surgical cover at all times, and a minimum of 1 whole-time equivalent lung CNS for every 80 new lung cancer patients. Rural Health Boards are also encouraged to explore innovative solutions to capacity challenges with the purpose of reducing inequalities in the time to access treatment for patients living in rural areas. In Scotland, approximately 60% of the population live more than 50 miles from the nearest hospital.

'Scottish Pathways Matter' also recommends getting more people into the NHS lung cancer pathway at an earlier stage, before their cancer spreads, by implementing targeted lung cancer screening in Scotland following the UK National Screening Committee recommendation and approval in England. This should also include the provision of Lung Health Checks.

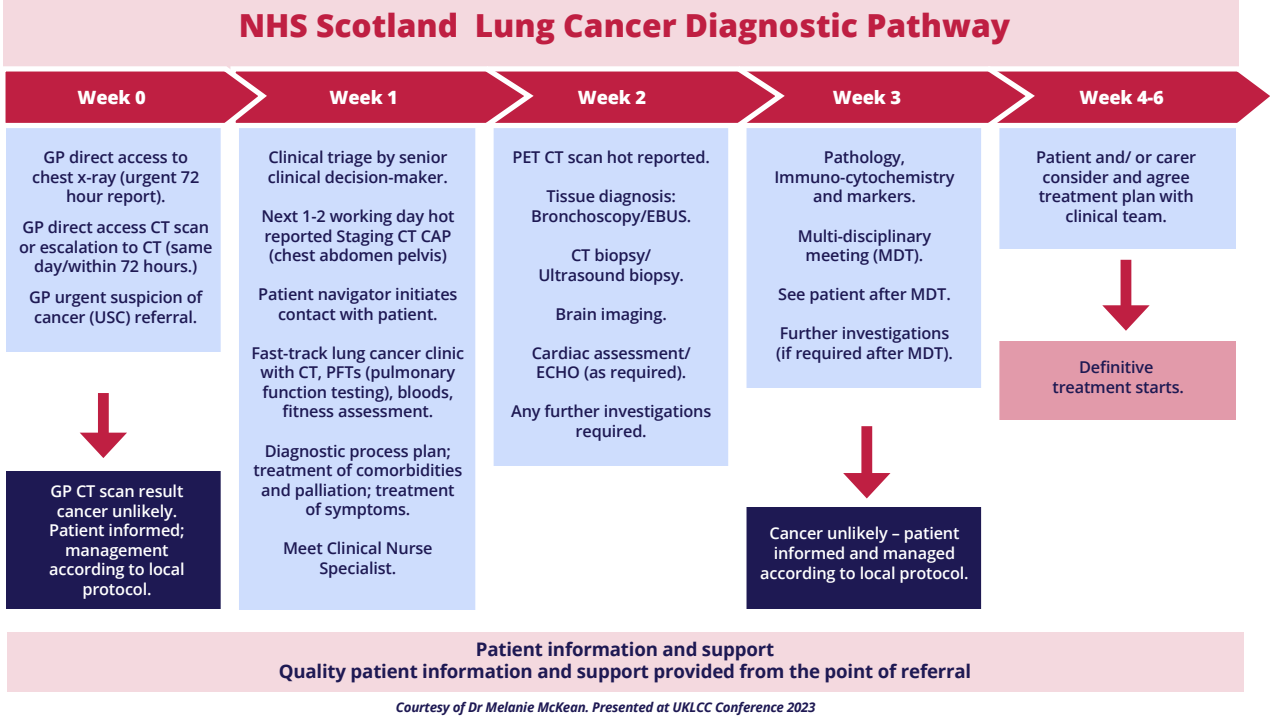
The report goes on to recommend everyone suspected of having lung cancer move through the pathway quickly, so that they receive treatment before their disease advances. This includes:

- Every patient to have access to an offer of a CT scan within 72 hours of an abnormal chest x-ray.
- Increasing imaging and in particular PET infrastructure and capacity in Scotland.
- Reducing the time for full pathology and molecular testing of good quality samples, increasing co-ordination and support for patients on the pathway - using cancer trackers, single points of contact (SPOC), lung cancer nurse specialists (LCNS), prehab, and bundles of investigations.

PATIENT PERSPECTIVE

"Throughout the six weeks between diagnostics and treatment I could not concentrate. I withdrew from academic life as I didn't know what the future held. I didn't sleep much either so combination of tiredness – and terror - influenced what I could do. I was grateful for this excellent time frame from investigations to treatment, but it was a terrifying emotional rollercoaster and I still have flashbacks.

Annie (71)



Courtesy of Dr Melanie McKean. Presented at UKLCC Conference 2023

2. The National Lung Cancer Guideline was launched in September 2023 by the Scottish Intercollegiate Guidelines Network (SIGN), though it is not yet publicly available. This will provide additional support to health professionals and resource managers and planners in Health Boards to identify priorities in their areas and to establish standards that will motivate improvements as well as indicating when standards are being met.

The guideline covers:

- Prehabilitation
- Diagnostics and staging
- Pathology
- Surgery
- Radiotherapy
- Systemic Anti-Cancer Therapy (SACT)

3. & 4. Lung Cancer Screening Pilot and Scottish Expert Advisory Group for Lung Cancer Screening For information on these, please see 'Scotland looking into the feasibility of lung health checks' in section: *'Improving access to Targeted Lung Health Checks (TLHCs)'* later in this document.

CASE STUDY

Improving lung cancer outcomes through the MDT

The MDT has a unique role in reducing inequalities at diagnosis or treatment stages. However, MDTs need to be reviewed regularly to ensure they are capable of meeting their requirements. Barts Health NHS Trust has demonstrated the benefits of adapting the structure, capabilities and membership of MDTs to optimise effectiveness and match local needs.

Since the establishment in 2015 of the Trust's first centralised treatment MDT by amalgamating several somewhat fragmented MDTs within the Trust, the surgical resection rate increased from under 20% to over 40% and one-year survival increased from approximately 40% to 50%. Also in 2015, the existing diagnostic MDTs were enhanced and strengthened but were not centralised.

Since then, adopting a data driven improvement process in 2016 has helped the MDTs understand more about patients' profiles, leading to new services and justifying the purchase of new equipment, both of which have meant better access to treatment for patients who were previously considered difficult or unfit to treat. For example, a significant proportion of patients considered unfit to receive treatment due to cardio-respiratory comorbidities was identified. This led to the establishment of a prehabilitation service.

In the same year, Barts Charity was able to purchase equipment to carry out navigational bronchoscopy, which gave surgeons greater confidence in operating on small nodules they know to be malignant.

In 2017, the number of surgeons was sufficient to allow a surgeon to attend each of the diagnostic MDTs, which unlike the centralised treatment MDT, had remained separate. The following year the concept of collaboration between MDTs was expanded into a much wider MDT project that included all cancer, and many benign MDTs. The resulting collaboration allowed MDTs to learn from one another to establish best practice.

EXPERT INSIGHT

"Data has driven our improvement journey."

Dr Will Ricketts.
Consultant Chest Physician
Barts Health NHS Trust

05

Recommendation

Improving the quality and effectiveness of services is a constant and ongoing need. Regular assessment of services facilitates their evolutionary development, taking onto consideration changes to patient needs and resources within trusts/Health boards.

3. Improving timely access to molecular diagnostics

Timely and comprehensive molecular diagnosis is a key component of lung cancer diagnosis and treatment that helps to drive up outcomes.

Comments and tips from break-out sessions

Improving the pathway for timely access to molecular diagnostics

- *"In general, by looking all the way along the pathway, it is often possible to identify small areas where a relatively minor improvement can make a big difference."*
- *"Lung cancer has changed and the way in which health professionals talk to patients about it has changed e.g. treatment modality, life expectancy and treatment expectations. Some centres have looked into this and have created up-to-date information assets for patients to help them understand and navigate what is a complex, and at times, stressful pathway."*

PATIENT PERSPECTIVE

"Everything was quick once the oncologist had the mutation details. It was the genetic test results that had held everything up. I was never given an explanation as to why it had taken so long but assumed it was because of the Christmas period."

Derek (58)

Best Practice Example:

Speeding up the molecular diagnostics pathway

Currently approximately 40% of patients with advanced non squamous NSCLC patients can have access to a targeted treatment in the NHS. However, as a result of funding restrictions, a quarter of patients can access targeted treatment only if it is given first line. This means patients waiting for molecular diagnostics results cannot be treated with chemotherapy or immunotherapy whilst they wait. If they were treated in this way, a large proportion would be prevented from accessing their optimal targeted therapy once their results came through, because it would then be classed by the NHS as second line.

So patients often have to wait without treatment until their molecular diagnostic results are received. Added to this there are data demonstrating clinical disadvantages to giving patients a cycle of chemotherapy and or immunotherapy before a targeted therapy. Hence the need for early access and rapid reporting of molecular diagnostics results.

Currently, targeted therapies are available on the NHS for nine different lung cancer biomarkers. In the appropriate patients, targeted therapies are capable of showing substantial benefits, not only in survival, but also in the relief of symptoms and improved quality of life. These benefits can only be fully realised if biomarkers are identified accurately at the time of diagnosis and before the start of treatment. The accurate determination of the cancers biomarker profile not only impacts on which targeted therapy to use, but may also indicate which other treatments are likely to be most effective and patients' response to them. This is the case even when there isn't a first line targeted therapy available. So what might be seen as an initially negative result for pointing to an effective first line targeted therapy, still provides useful information on subsequent treatment and further development of the cancer.

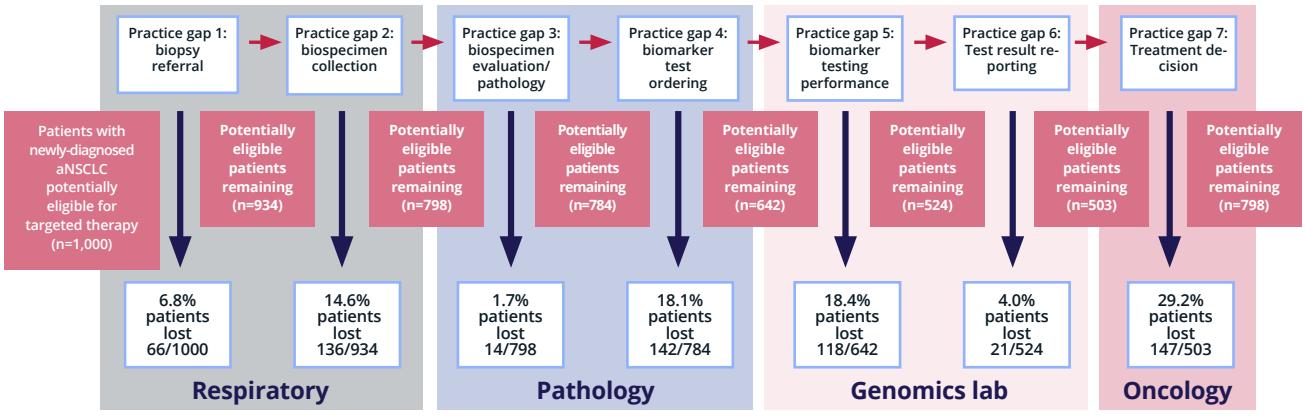
All of this strongly suggests that molecular diagnosis results should be available and discussed at the MDT meeting, but this happens rarely at present. If this is to become standard procedure, the time taken for molecular diagnosis testing and delivery of results must be shortened.

Comments and tips from break-out sessions - Optimising the quality of biopsies

- *"The quality of biopsies varies. Centres providing EBUS (Endobronchial Ultra Sound) and CT-guided biopsies may not all perform the same and developing standardised feedback would be useful, e.g. does every EBUS obtain NGS (Next Generation Sequencing) results? If not what are the reasons? This would reduce the number of late failures and re-biopsies."*

- *"There is an opportunity to share good practice in the way biopsy samples are handled to maximise the information obtained from them, e.g. looking at the day on which the biopsy is taken to reduce the time they spend in formalin waiting to be processed. Communication with the pathology team is vital in dealing with this and in some areas a fast-track process has been devised through collaboration with pathology laboratories so that patients who need results."*

Barriers to Precision Therapy: a Team Problem



Impact of Clinical Practice Gaps on the implementation of Personalized Medicine in Advanced Non-Small-Cell Lung Cancer. Sadik et al. JCO Precision Oncology 2022 :6

The process from initial referral for biopsy to patients receiving the appropriate treatment is complex. It involves many individuals (not just the clinician and the laboratory staff) and can fail at multiple points. For instance, an inadequate biopsy may require a repeat sample, or a quality control failure during molecular testing may require repeat testing. For each step in the pathway, some patients will be lost. A recent study from the United States shows that only around one in three patients referred for biopsy will start on appropriate treatment.[12]

The diverse nature of different challenges to be over-come is summarised in this diagram. Overcoming these challenges requires teamwork throughout the entire molecular diagnosis pathway based on good communications and a mutual understanding of priorities and the reasons for them.

There are plenty of opportunities to improve the molecular diagnosis pathway and many of these can be achieved at minimal cost.

Biology	Technical	Organisa-tional	Society
Small Biopsies	Evolving testing/ technologies	Complexity of pathways: limited ownership	Pressure from patient/family
Necrosis/ Low tumour content	Evolving treatment landscape	Artificial split between genomic tests and pathology tests	Pressure from Government/ Management
Rare but significant abnormalities	Fusions/ Complex abnormalities	Limited involvement of end users in set-up of centralisation model	Pressure from colleagues
Deteriorating patient	Incompatible requesting and reporting systems	Separation of Test Directory from funding decisions	Data protection legislation. Risk-averse/ poor knowl-edge in IG department
	Separate funding for hardware	Funding decisions match to trial entry criteria	
		Time-limited funding	

Courtesy of Prof. Alastair Greystoke. Presented at UKLCC Conference 2023

Best Practice Example:

Developing and introducing a molecular profiling pathway for lung cancer

An effective molecular profiling pathway has been set up in Wales. This case study explains how this was achieved and some of the barriers that were overcome.

The geography and population distribution in Wales poses a further challenge to developing a molecular profiling pathway. The population is unevenly distributed with the majority living in the south, a smaller but significant number living in the north, and a sparsely populated rural area in the centre with no major hospital.

Despite these factors a good molecular profiling pathway must deliver the same diagnostic standards and outputs for any patient regardless of where they live and which hospital they are seen in. When developing such a pathway for Wales, there were three priorities:

- The pathway had to be simple for health professionals to use and understand, regardless of the level of their sub-specialist interest in lung cancer.
- It must have equitable access, regardless of where in Wales the patients live.
- It must incorporate excellent communications between people with different specialities working throughout the pathway.

The first step, with the backing of the Welsh Cancer Network, was to carry out an options appraisal looking at the advantages and disadvantages of creating a pathway versus doing nothing. The outcome of this was the decision to create a comprehensive genomic profiling sub-pathway.

The NOLCP had existed in Wales since 2019. A genomics working group was formed, consisting of a wide range of medical and non-medical specialists including staff from the genetics laboratory, pathway coordinators and transport and logistics managers. The breadth of this membership proved to be one of the main factors for its success.

The sub-group carried out an audit of genomics services in Wales as a baseline to measure the extent of variation across the Welsh Health Boards. This showed significant geographical variation and patient selection with regards to genomic profiling. The design and implementation of the pathway took 12 months. Ensuring that everyone was communicating in the same way, based on a common understanding of the pathway and what it needed to achieve was crucial to its day-to-day functioning. It was also vital in building understanding and eventually support from other stakeholders.

Reflex testing (PDL-1 and Next Generation Sequencing) was fully integrated into the NOLCP. Reflex testing in this way, ensures biopsies are sent in a timely manner for reflex testing, allowing appropriate discussion at MDT and management plans to be decided.

For the occasions where NGS testing fails to provide a comprehensive genomic profile, the team created a 'Salvage Pathway'. This utilises reflex FISH testing in order to help provide clinicians with essential genomic profiling to aid treatment decisions. The salvage pathway is carried out independent of requesting clinicians, and is evidence of the commitment the wider MDT has to providing high quality results for patients. Where there is insufficient material provided for either NGS or Fluorescence in-situ hybridisation, a re-biopsy is suggested if clinically appropriate.

A unified view from oncologists, as to what information is crucial for treatment decisions, is important in reaching a satisfactory compromise between data quality and time, so that sufficient information is obtained in the shortest time.

EXPERT INSIGHT

"It's important to understand that developing and introducing your first pathway is a big achievement, but it doesn't end there. There will always be problems to solve, new treatments options for patients and so on. The pathway has to be updated regularly to stay relevant and effective."

Dr Craig Dyer. Respiratory Consultant, Welsh Thoracic Oncology Group Lead, Cardiff and Vale UHB

Key learning points:

Molecular testing should be carried out on all patients and the results should normally be available for discussion at MDT. There may be exceptions where this is not possible, e.g. where a patient is deteriorating rapidly, but normally a lung cancer diagnosis should include molecular profiling.

Reports are widely available using the national electronic results system (Welsh Clinical Portal), allowing all results to be available to the MDT in order for them to be discussed with patients.

The patient voice has been crucial in generating support to prompt the start of the pathway development process and introduction.

A unified view from oncologists, as to what information is crucial for treatment decisions, was important in reaching a satisfactory compromise between data quality and time so that sufficient information is obtained in the shortest time.

Comments and tips from break-out sessions - Integrating the pathology team

- *"The pathology team should be integrated into the MDT to provide early feedback on biopsy samples, especially where re-biopsy is advised. This would reduce late failures."*
- *"Good communication between pathology and genomics laboratories, e.g. integrating a genomics co-ordinator into the team improves two-way communications so that clinicians know when the samples are being processed and can plan accordingly. A national IT system for reporting results is essential for timely results and communication."*

06
Recommendation

Molecular diagnostic testing should be carried out on all patients and the results should normally be available for discussion at the MDT.

PATIENT PERSPECTIVE

"I waited a month before I had the respiratory appointment at the end of December. And I eventually had the CT scan at the end of January 2020 - and that's when things started to look suspicious. The specialist said I needed a PET scan and biopsy to confirm a diagnosis of lung cancer. I was obviously devastated. My tissue would also be sent off for genetic testing... It was the 22nd of April before I received the results of the genetic tests."

Nicola (51)

CASE STUDY:

ctDNA pilots

The role of circulating tumour DNA (ctDNA) in lung cancer is being evaluated in various settings. While its role in the early detection setting is unclear and remains the subject of clinical trials, ctDNA does appear to be helpful for molecular analysis of cases of advanced lung cancer.

Currently molecular testing on cancer biopsies is only performed after a pathologist has confirmed that the patient has lung cancer. This can mean a delay of between 2-4 weeks after diagnosis before molecular testing is complete. The ctDNA pilots are looking at the value of performing molecular analysis on a blood sample taken as soon as a radiological diagnosis of stage III/IV disease has been obtained. The hope is that appropriate molecular tests will be available sooner allowing the patient to commence treatment more quickly.

Demographics	
Female	23 (49%)
Median Age	64 (26 - 92)
Performance Status	
PS O	13 (28%)
PS 1	20 (43%)
PS >=2	9 (19%)
Unknown	5 (11%)
Stage	
Stage 3	8 (17%)
Stage 4	39 (83%)
Smoking Status	
Never smokers	8 (17%)
Smoker	27 (57%)
Unknown	12 (26%)

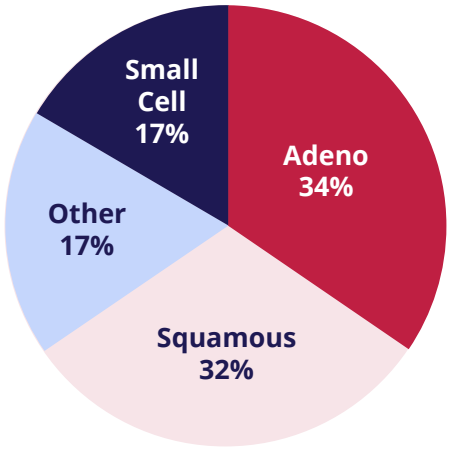
Local Data - A snapshot

47 Participants with ctDNA samples

78% Had an informative sample

12% Cases (4/34) identified additional genomic information (1 x METex14 and 1 x METamp in SqCC and 1 x *EGFR* L858R and 1 x *EGFR* Exon 19del

24% Cases (8/34) molecular results were expedited through ctDNA



Courtesy of Dr Adam Januszewski. Presented at UKLCC Conference 2023

Experience from Barts Health NHS Trust:

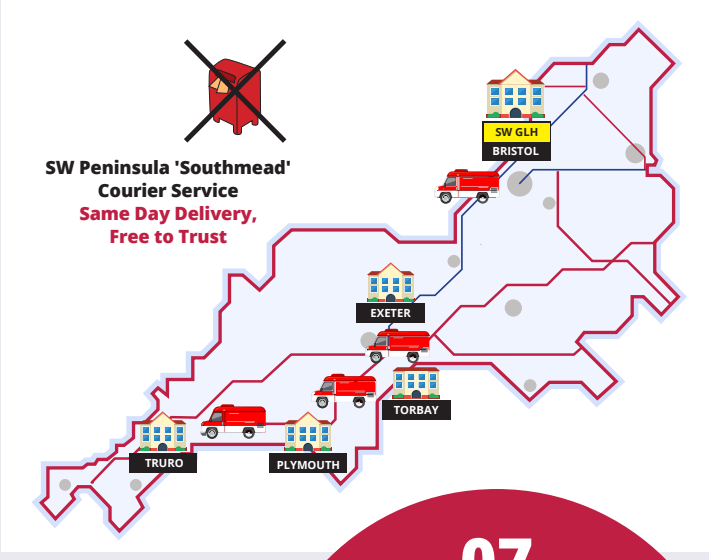
The results showed that for patients with biopsied tissue samples, the median time from radiological diagnosis to molecular diagnosis report was a median of 64 days (range 32 – 81 days). In patients who had ctDNA tests, this time was halved to 29 days (range 7 – 52 days).

The results from this one pilot centre suggest that ctDNA can improve patients' pathways and experience and that there are broader benefits outside the pathway. However, to maximise the benefits there may need to be logistic and organisational changes. N.B. The formal health economic review has not yet been completed.

CASE STUDY:

Transport and reducing turnaround time for molecular diagnostics

In the Torbay & South Devon NHS Trust, most lung cancer services are provided on site, but patients have to travel to Exeter for EBUS and to Plymouth for video-assisted thoracoscopic surgery and thoracic surgery. This means that some patients have tissue samples at three different locations which can make full molecular testing more difficult (and lengthy).



To improve this situation, a pathway navigator assessed the molecular diagnosis pathway step-by-step, identifying the factors that were within the control of Torbay NHS Trust, and two particular factors were identified as opportunities for improvement.

The first was the introduction of reflex testing through collaboration with the histopathology team; in particular the histopathology secretaries. This one change reduced the sample turnaround time by two days.

The next action was to look at the way in which samples reach the Genomic Laboratory Hub in Bristol. By changing from Royal Mail tracked delivery to an existing local transport service* funded by Southmead Laboratory (Bristol), the turnaround time was reduced from 4 days to 0-1 days.

(*An HPV van is funded by Southmead Laboratory (Bristol) and travels from Cornwall to Bristol daily, picking up all cervical HPV specimens from every hospital for analysis in Bristol.)

The overall impact of these two interventions has been a reduction in sample turnaround time of five days.

To ensure equity of delivery of tissue to facilitate personalised treatment, other sites in the South West have been encouraged to use the same transport service.

07

Recommendation

It is important to maintain a broad view of services, looking beyond medical/surgical services to any elements where quality can be improved, or time or resources can be freed up.

EXPERT INSIGHT

"We have shown that small changes can make a big difference in pathways for our patients, reducing molecular diagnostics turnaround times and getting patients onto treatment quicker."

Dr Louise Medley.
Consultant Medical Oncologist,
Torbay & S. Devon NHS Trust

4. Optimising the impact of a lung screening programme

Targeted Lung Health Checks (THLCs) are being rolled out in England with strong UK Government support. By August 2023, more than one million people have been invited to take part in a TLHC, over 485,000 of whom attended a TLHC.

As a result of the programme, up to August 2023, 2,705 lung cancers have been found, of which 74% were at stage I/II. Previously, without this early intervention the rate of early stage diagnosis was 28.9%. In addition, other cancers are frequently detected as incidental findings including breast and kidney cancer.

In 2023 the Government announced the start of the roll out of the National Lung Screening Programme. This makes the role of TLHCs even more important, and as the TLHC Programme expands, incremental improvements will be made to the programme.

The rate of TLHC uptake is increasing. Between April 2022 and April 2023, the rate increased by 10% to 42%. The variance in uptake of different local projects is of interest, ranging from 20% - 79%. There are several reasons for this variation.

One important factor is the way in which people are invited. There are two basic options:

• Opt out, where the person receives a letter inviting them to attend an appointment at a specific time and date.
• Opt in, where the person receives a letter asking them to contact their local service to make an appointment.

Initial data show that the opt out approach tends to be more effective, however the current TLHC Programme data has many caveats. New projects are advised to try both options to see which is best in their area.

A second key factor is whether the checks are delivered virtually or face-to-face. The latter shows a slightly higher uptake than virtual, but most TLHCs are delivered virtually. Again, the current data comes with many caveats so we currently are unable to say which approach will result in higher uptake from a national perspective. New projects are advised to initially offer a choice between the two, to see what works best for their local population.

EXPERT INSIGHT

"Nationally, uptake of TLHCs has grown by 10% from April 22- April 23, to 42%"

Vaaraki Thirumoolan. TLHC Programme Manager, NHS England

08

Recommendation

When establishing Targeted Lung Health Checks:

• Initially try both opt-out and opt-in invitations to assess which is most effective

• Initially offer virtual and face-to-face appointments to assess which is best

Comments and tips from break-out sessions – Broadening the roll out

- *"The TLHC programme is only being rolled out in England. Issues remain in Wales, Scotland and Northern Ireland. Whilst there are pilot schemes being tested in other devolved nations, it is time for sustained TLHC programmes to be rolled out across the whole UK. Particularly as the UK National Screening Committee's recommendation to commence a lung cancer screening programme is a UK-wide proposal."*
- *"Quality assured smoking cessation services must be within and outside TLHC programmes throughout the UK."*
- *"Learning from other existing screening programmes will be useful. The quality assurance team working on the lung cancer programme also works on the breast screening programme and this is a good opportunity to cross-fertilise ideas."*
- *"The rapid roll out needs to be quality assured and a standardised approach recommended."*
- *"More shared learning events that bring together different trust-level TLHC programmes are needed to spread best practice and ideas."*

CASE STUDY:

Communications Campaign with The Roy Castle Lung Cancer Foundation (RCLCF)

This is a collaboration between the RCLCF and NHS England. It is being carried out in two phases:

Phase 1: This includes communications about the national programme emphasising the importance of attending a TLHC by conveying the message that early stage lung cancer can be asymptomatic. Adverts are being funded on social media in postcodes where the programme is 'live'.

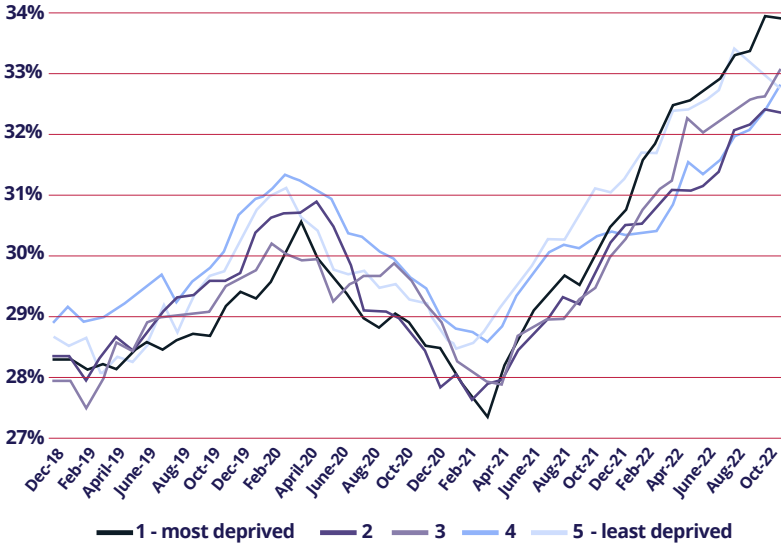
Phase 2: This will include a GP toolkit and an animation of what the lung health check entails. Much of the communications work is being tested by a behavioural science unit through surveys with TLHC participants and staff to optimise uptake of the tests. The results have so far identified two interventions that could be tested to improve uptake:

- Re-branding the TLHC programme and the initial LHC appointment to make the name easier to understand.
- Using behaviourally-informed framing to encourage attendance at LHC appointments, which will refine the messages that are used to attract people.

TLHCs and inequalities

To help tackle health inequalities, initial TLHC projects were rolled out first in areas of high deprivation. The rate of lung cancer early diagnosis shows that TLHCs have had an impact. Up to October 2022, the rate of early diagnosis in deprivation quintile 1 (the most deprived) has risen from around 28.5% to 33.9% and now has the highest rate of all deprivation quintiles.

12-month moving average of lung cancer Early Diagnosis Rate by deprivation quintile, Rapid Registration Data



Rapid Cancer Registration, 2023 *Courtesy of Vaaraki Thirumoolan. Presented at UKLCC Conference 2023*

Local projects differ markedly in the way people's needs as identified in TLHC are met, e.g. smoking cessation. External providers are used in delivering services along the pathway to varying extents. In the long term, the results of these pilots will help to develop what may become an overarching specification of minimum requirements to provide a TLHC programme and to support its outcomes.

TLHCs in prison communities

Smoking prevalence in prisons is generally high, and this population forms an important part of the eligible population. The first TLHC pilot in prisons took place in early 2023 in HMP Hull. There are specific challenges in offering TLHCs in prisons: gaining prisoner buy-in and uptake is very difficult and there are practical difficulties such as getting the mobile CT scanner into prisons. This first pilot has resulted in interest from other Cancer Alliances, who are looking to develop their own pilots soon.

Scotland looking into the feasibility of lung health checks

A lung screening pilot encompassing lung health checks is underway in NHS Lothian, funded by the Chief Scientist's Office in Scotland. Recruitment in Lothian has been slow initially. The reluctance of people to engage is probably due to a lack of knowledge and awareness - many people have not heard of lung screening. Further research into the reasons is being carried out with a view to improving uptake.

The programme has funding for 12 months beyond the end of the pilot and three new health boards have been recruited (NHS Greater Glasgow and Clyde, NHS Grampian and NHS Highlands). The study set-up is in process in these areas and the plan is to carry out another 250 scans across the three health boards.

The Scottish Expert Advisory Group for Lung Cancer Screening has been formed in collaboration with the Scottish Government and this should help drive forward the work to implement a national programme.

Comments and tips from current practice – broadening the roll out

- *"We need to look at how we communicate with people as part of a rolling programme so that they attend for subsequent scans."*
- *"We need to consider future-proofing the programme, e.g. how and when to re-invite people at a later stage who have just fallen below the eligibility threshold and how to tell them they are currently below the threshold but encourage them to stay in touch and re-engage in the future."*
- *"We must embed high quality research across the programme to improve quality."*

CASE STUDY:

The role of primary care

The extent to which primary care is involved in TLHC programmes varies. In many cases, primary care does not have resources to be involved. GPs may find it difficult to set up TLHCs for the relevant patients on their list and this can be perceived as a barrier to implementation.

One example of tackling this problem comes from Nottingham where TLHCs were organised without involvement from primary care. The results of CT scans are shared with primary care, but not the full report, as doing so resulted in a large number of clarification requests to different specialties, mainly regarding incidental findings. Instead, incidental findings are managed in house through a weekly screening review meeting in which all incidental findings are reviewed. Template letters are automatically sent to those with moderate or severe emphysema and coronary artery calcification, which means these are not taken into the screening review meeting. The majority of recommendations made in incidental findings is about lifestyle, smoking cessation and seeking assessment for statins (if the patient is not already taking them).

The National Cancer Programme Team are now developing national pathway guidance for incidental findings. This will make it much easier to deal with them and might automate the approach to some of the most common ones.

CASE STUDY:

Reducing health inequalities in the TLHC programme

One important factor in reducing health inequalities in the TLHC programme lies in understanding the reasons why people do, or do not, engage with the programme.

The Stoke on Trent TLHC programme is an in-house service that has begun to address health inequalities based on its own independent database. One of the key strengths of the Stoke on Trent TLHC programme has been the IT support it has had in managing its own data, culminating recently in its own database. The data have been key in enabling the TLHC programme to investigate the reasons why people do, and crucially do not, engage with the programme. In addition to following up people who joined the programme, it was possible to do the same where people had either declined an appointment or not shown up. This provides a useful insight helping to develop more effective communications strategies. In this case it has made it possible to identify a group of people not being effectively reached and to correct what is in fact a health inequality.

In the period studied, there were 157 patients who did not attend appointments who went on to develop cancer. 50% of the patients were over the age of 70, and 60% were from areas of poorest deprivation. 42% were stage 4. The majority of patients who came forward to join the programme were men and 10% of these were stage 4, many of whom presented through emergency access points.

Of 86 patients who were invited but did not take part in the programme, seven declined and 72 did not attend their appointment. In many cases it was possible to ask these patients why they declined or did not attend (DNA).

Those who declined were busy individuals, looking after grandchildren who said they felt well. Of those DNAs who gave reasons, most also said they were busy. When audited against found cancers, comparing; age, smoking history, ethnic origin and deprivation – there was little difference.

EXPERT INSIGHT

"Much of the time we know exactly where we are targeting and where we are going. However, particularly when trying to understand the underlying causes of health inequalities, sometimes changing perspective and looking at things in a different way can draw out much more valuable information that can lead to benefits for patients."

Janina Barnett,
TLHC Programme Manager,
University Hospitals of North Midlands NHS Trust

However, focusing on the DNAs who subsequently went on to develop cancer, showed one difference compared with the found cancer group, which was marital status. The patients who had come forward to join the programme were mainly married men who had been encouraged by their wife/family to do so. The DNAs who went on to develop cancer were thought to be younger men. However, the follow up data showed they were mainly women who were widowed and who had multiple family commitments. These patients put their family commitments before their own health.

By stepping back and looking at the service from a different point-of-view, coupled with the follow up data, it had been possible to identify an unexpected group of patients who had not been reached properly, and to go on to target them.

The programme now has open appointments so that anyone can join. Younger men are still targeted e.g. through advertising at sports venues, but the over 70s population is a prime target. There are various initiatives aimed at reaching them including advertising on the bags used to wrap up prescription medicines handed out at pharmacies, as well as advertising through GPs, social groups, public houses, and Salvation Army events. Advertising on daytime local radio has been particularly effective. Finally, family events are also valuable, often reaching younger members of the family who encourage their older relatives to come forward.

Comments and tips from break-out sessions - tackling health inequalities

- *"It is worth remembering that the present financial crisis is widening the inequality gap. Lung cancer services must ensure everything is done to minimise this effect, and act as a voice for patients at national level to advocate more help to address inequalities."*
- *"We need to do more to understand and address local needs (cultural, religious, literacy) to increase engagement from local people with programmes such as TLHCs."*
- *"At present some elements of the pathway at local level tend to widen health inequalities by not following up people who do not engage. This is an opportunity to improve."*
- *"Often the impact of larger NHS Trusts in England has not resulted in better use and distribution of resources, which might have reduced health inequalities in access to care."*

CASE STUDY:

Improving uptake in the TLHC programme through invitation and service models

The Nottingham TLHC programme has invited over 35,000 people to TLHCs since April 2021, with some GP uptake rates as high as 70%. The success of this lies in a detailed understanding of the local communities on which is based a service model and communications that are flexible and tailored to all relevant groups of people. This can be split into three main elements:

Invite approach: This is an opt out approach in which people receive a letter telling them that they will receive a telephone call in the next 14 days. They are also sent a text giving them a number to call if they prefer to do so at a time that suits them.

This is coupled with open invitations to target various age groups, which is designed to overcome barriers to patients who have not disclosed their smoking status to their GP.

Service model: This begins with a telephone-based lung health assessment that determines the person's risk score. This provides a convenient way for patients to take part and also a low-cost method of filtering out people who are low-risk and who do not need a CT scan, thus optimising the use of the CT scanner.

The mobile CT scanner is sited in community locations using local population knowledge to identify the best places, such as shopping centres, social hotspot locations and well-known community venues. Public transport routes are also taken into consideration to make the locations as easy to reach as possible. If travelling is a real barrier, people can be offered transport. Appointments are offered seven days per week between 8am and 8pm to fit in with the lifestyle of most people, including those who work.

Targeted communications and engagement: Understanding the target audiences and their behaviours is important and has been a central part of this programme.

These may vary from one community to another, and it may be necessary to make available material in different languages. In Nottingham, materials are available in nine different languages from a dedicated website which also has translated videos, frequently asked questions, localised case studies and letters. The website also has a translation plug in, allowing users to view the website in their

view the website in their preferred language.

Local radio advertising is carefully targeted and also created in different languages depending on the area. Paid for social media advertising is effective and can be targeted by postcode, age etc.

Getting material to the right places has relied heavily on a network of social prescribers, community champions, resident development officers and clinical pharmacists.

The programme has targeted community events such as Indian community centres, 'Stub It' events and markets, and found these extremely effective.

A diagram of the patient journey appears on the back of the letters sent out to people. This provides an alternative for people who do not like to read a lot of text.

All of the above is tailored according to local surveys, which provide useful feedback on what works and what does not.

Not everyone is registered with a GP, and this is another barrier. So the programme has a leaflet that can be given to people explaining how to register.

In addition, the programme is working with local prisons and the severely multi disadvantaged partnership groups.

EXPERT INSIGHT

"The way we invite people to TLHCs, as well as the way we provide them, has to be closely related to their lifestyles, which can vary enormously. So, the key thing for me is understanding our audiences and learning about the behaviours for each of the communities that make up our area"

Lizzie Barrett. TLHC Communications Manager, Nottingham & Nottinghamshire ICB

Comments and tips from break-out sessions - Getting it right locally

- *"Guidance is needed to explain to sites what components are needed in a National Screening Programme versus a TLHC programme, including what are the evidence-based interventions that should be added on to this."*
- *"Dealing with incidental findings requires guidance to standardise the approach beyond the actual reporting."*
- *"The need to provide the same standard of care regardless of where patients live presents variable and different challenges (e.g. rural vs urban areas) and so the balance between central control and local knowledge must be carefully considered (e.g. in some areas a hub-and-spoke model may be appropriate)."*
- *"It may be necessary to use the Community Diagnostic Centres (CDCs), in which case we need to look at how we use and integrate them into the programme."*
- *"We need to address the needs of people who do not attend in order to increase their engagement".*
- *"A single IT system is essential to enable communication with all types of screening, and across all areas. This should include access to old screening data and should support screening review meetings."*

09

Recommendation

Targeted Lung Health Check programmes must be based on thorough local knowledge of the communities and areas within the trust's catchment area and must take into consideration the social and lifestyle needs of the people who live in them.

N.B. Data are available on the uptake and route of diagnosis. This means it is possible to monitor treatment rates for patients diagnosed via screening for quality assurance

5. Making it happen

Nationally, tools are available to help identify and achieve improvements in lung cancer services and more are being developed. The Optimal Lung Cancer Pathways, the Targeted Lung Health Checks and soon the national screening programmes are all examples of these tools and are gradually being implemented or being planned throughout all the UK nations. However, successful implementation requires local knowledge and local leadership from the people working in the NHS, in the many different areas and communities that make up the UK. So, improvements to services rely on what people do with the tools and how they do it.

The changes and improvements to lung cancer services outlined in this document are examples of improvements being made mainly at local level throughout the UK. In some cases these are with national government support, but mostly they are changes to local services based on local knowledge producing benefits for local people, that collectively result in visible improvements nationally.

Each nation has bodies that have an overarching role in shaping lung cancer services, e.g. Regional Cancer Teams or Cancer Alliances. These bodies have a major role in supporting or leading initiatives to improve lung cancer services.

Above all, we ask that you keep in contact with UKLCC and tell us about your projects (new and ongoing), describing your successes and telling us about remaining challenges – we may be able to help, or we may know someone else who can.

Where to start

From the outset it is important to work collaboratively and to build a common understanding across all teams of the need and the reasons for improvement. Talking to other members of the team and trying to understand the problems they face may be a good way to start. By doing this, you are building informal networks of people who have a broadly common view and objective. In such a co-operative and supportive culture it is likely that local leadership will emerge to develop and drive the enthusiasm to make improvements happen.

Measurement

Objective measurement provides invaluable evidence, not only of what needs to change and possible ways in which this might be achieved, but in demonstrating the need for improvement in the first place.

However, initiating audits etc. must be done collaboratively, preferably in partnership with the providers of the services being measured. Failing to do this risks alienating them and may make progress more difficult.

What to measure will depend on the local situation and the expert views of the staff involved.

Measurement should be ongoing in many cases. It will be important to identify what needs to be constantly monitored – these will be the Quality Performance Indicators (QPIs) and deciding what these are is paramount. Scotland already has a functioning set of QPIs. Other metrics may be measured just once to provide more detailed information.

There are two fundamental factors that should be measured:

1. The extent to which the new activity has been implemented. (This is usually the easiest thing to measure).
2. The extent to which the new activity has worked. This will partly depend on the previous factor, but it will determine if the activity was the right thing to have done. The QPIs are likely to be helpful in this case.

Meetings

As illustrated in many of the examples and case studies, success depends on good communications, which build a mutual understanding across teams from various medical specialties. Regular contact between these teams is essential, through digital media, but also through meetings, the

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Recommendation

More meetings should be held at national and particularly regional and local level to provide opportunities for the exchange of best practice and innovative ideas to enhance the quality of lung cancer services.

number and length of which must be balanced against workload.

The timing of the first meeting is important. It must not be too early. If the results of the audits and other investigations are not available, the meeting may be perceived as of limited value. Although it is more time consuming, reaching the point where there is sufficient agreement for the audits to go ahead may be best achieved by networking and one-to-one meetings.

The initial meeting should set out the need, based on evidence, and allow it to be discussed, culminating in an agreement on the need and overall priorities. If examples of good practice are known, they should be included to give people at the meeting an idea of what might be achieved.

As new initiatives are set up, people working in them should be encouraged to share their experience and to measure and publish their results. This information should be stored in a repository that can be accessed easily by any lung cancer professional anywhere in any nation. *(See next point on 'Beyond meetings').*

In subsequent meetings, more of these examples should be identified and presented. This will share best practice, encourage more people to become involved and may also seed additional ideas and inspire new people to take leadership roles. The size of the meetings should be tailored to their purpose. When examining local initiatives and discussing implementation, attendees should be from the providers involved, though it may be useful to involve individuals working in a similar scheme in another part of the nation or a different one. If wanting to share and pick up new ideas, a meeting with a wider attendance may be more effective. These might be meetings set up by Cancer Regions or Cancer Alliances.

Beyond meetings

Meetings are important but have their limitations. For groups looking to design and implement a new activity, information needs to be available whenever they need it. Meetings cannot do this.

A digital on-line information hub containing examples of best practice, general advice from experts and with the facility for users to contact others who have relevant experience, would be ideal to foster and encourage more new projects.

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Recommendation

Information hubs should be set up at national level and/or cancer alliance level. These should contain tools, exemplars and case studies, plus the ability to contact people wherever they are working to generate new ideas and gain advice on improving the quality of lung cancer services.

Final remarks

The drive in all nations to diagnose all cancers at an earlier stage is generally complimented by initiatives to increase five-year survival, improve outcomes in terms of quality of life as well length of life and reduce variation (in both outcomes and service quality).

Screening and faster diagnosis as discussed in this report are two key factors in delivering the above in lung cancer. The third is early symptomatic diagnosis. This requires more work throughout all devolved nations.

The UK Clinical Expert Group is producing a new service specification that amongst other things will help to justify applications for additional staff and resources. There is also a new national optimal clinical pathway in development. This includes a molecular diagnosis pathway, based on the Welsh pathway.

This document highlights three priority areas: reducing inequalities in access to optimal and timely care; improving timely access to molecular diagnostics; improving access to optimising the impact of a lung screening programme. It shows that in many parts of the country, considerable work is underway to tackle them.

More needs to be done by more people in more parts of the UK, and UKLCC appeals to all health professionals working in lung cancer, to look at the entire pathway and the services they provide, and to identify one area in which they can make an improvement. This is the start of what we hope will be a continuous process of improvements for patients.

EXPERT INSIGHT

"Moving forward, reaching a shared understanding and common priorities across the whole lung cancer community is essential. This has been demonstrated at the UKLCC Conference – Driving Improvements in Lung Cancer, and more events such as this that bring together everyone to share ideas are needed, particularly at regional or local level."

Professor David Baldwin, Honorary Professor of Respiratory Medicine, Nottingham University.

PATIENT PERSPECTIVE

"My treatment is going well. There are no new mets and my primary lung tumour has shrunk. I'm now off on holiday with my lovely grandson. I'm extremely thankful for that."

Julie (72)

References

1 Lung Cancer Mortality Statistics. Cancer Research UK website. *https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer#heading-One Last viewed 22 Jan 2024 at 10:07*

2 State of the Nation Report 2023. Results of the National Lung Cancer Audit for patients in England during 2021 and Wales during 2020 2021 Version 3 November 2023 *https://www.lungcanceraudit.org.uk/reports/nlca-state-of-the-nation-report-2023/ Last viewed 22 Jan 2024 at 10:36*

3 Cancer Registrations Statistics, England. NHS Digital. *https://digital.nhs.uk/data-and-information/publications/statistical/cancer-registration-statistics Last viewed 22 Jan 2024 at 11:05*

4 Detect Cancer Early (DCE) Staging Data 2018/20. Public Health Scotland, *https://www.publichealthscotland.scot/publications/cancer-staging-data-using-2018-to-2020-dce-data-the-impact-of-covid-19/cancer-staging-data-using-2018-to-2020-dce-data-the-impact-of-covid-19/ Last viewed 22 Jan 2024 at 11:16*

5 Cancer waiting times January-March 2023: unadjusted waits. Public Health Scotland (2023). *https://publichealthscotland.scot/media/20337/2023-06- 27-cwt-table-6-unadjusted-waits.xlsx Accessed August 2023 at 15:28*

6 Cancer survival statistics, People diagnosed with cancer during 2015 to 2019, Estimates of survival from lung cancer. Public Health Scotland (2022). *https://publichealthscotland.scot/media/13863/estimates-of-survival-fromlung-cancer.xlsx Accessed August 2023 at 15:46*

7 'Scottish Pathways Matter'. A review of lung cancer services in 2023 to support the implementation of the Scottish National Optimal Lung Cancer pathway. 2023. The United Kingdom Lung Cancer Coalition. *https://www.uklcc.org.uk/our-reports/november-2023/scottish-pathways-matter Last viewed 22 Jan 2024 at 11:16*

8 'Cancer: Northern Ireland'. The Roy Castle Lung Cancer Foundation. *https://roycastle.org/lung-cancer-in-northern-ireland/ Last viewed 22 Jan 2024 at 11:21*

9 Dr Lesley-Ann Black and Dr Keara McKay, 'Cancer Northern Ireland'. 2017. Research and Information Service Research Paper for the Northern Ireland Assembly. *http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2017/health/3217.pdf Last viewed 22 Jan 2024 at 11:37*

10 Bridging the Gap: The challenges of mitigating health inequalities in lung cancer. 2022. The United Kingdom Lung Cancer Coalition. *https://www.uklcc.org.uk/sites/default/files/2022-11/UKLCC%20Bridging%20the%20Gap%20Report%202022%20FINAL.pdf Last viewed 22 Jan 2024 at 11:42*

11 Career Pathway, Core Cancer Capabilities and Education Framework for the Supportive, Assistive and Registered Nursing and Allied Health Professions Workforce (ACCEND Framework). NHS Health Education England. *https://www.hee.nhs.uk/our-work/cancer-diagnostics/aspirant-cancer-career-education-development-programme/accend-framework Last viewed 22 Jan 2024 at 11:56*

12 Sadik et al. Impact of Clinical Practice Gaps on the Implementation of Personalized Medicine in Advanced Non–Small-Cell Lung Cancer. JCO Precision Oncology 2022 :6. ASCO Publications. *https://ascopubs.org/doi/full/10.1200/PO.22.00246 Last viewed 22 Jan 2024 at 12:03*

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