

# Faster Testing, Better Outcomes Genomic Testing in Lung Cancer

The time from taking a lung cancer biopsy to reporting pathology and genomics test results should take no longer than 14 days. Here, we set out how to make that happen. **People living with a lung cancer diagnosis have waited long enough.** 

March 2025

The UKLCC is grateful for the support it has received for this project and would like to thank members of our Clinical Advisory Group for their input, as well as the following individuals providing lung cancer services across England, Scotland, Wales and Northern Ireland who contributed to the report through semi-structured interviews:

#### Dr Wendy Anderson

Respiratory consultant Northern Health and Social Care Trust Northern Ireland

#### Professor David Baldwin

Consultant respiratory physician Nottingham City Hospital

Honorary Professor of Respiratory Medicine at University of Nottingham

#### Professor Kevin Blyth

Professor of Respiratory Medicine School of Cancer Sciences University of Glasgow Honorary Consultant

in Respiratory Medicine Queen Elizabeth University Hospital

#### Paula Chadwick

CFO Roy Castle Lung Cancer Foundation

#### Lorraine Dallas

Director of Information, Prevention and Support Roy Castle Lung Cancer Foundation

Dr Craig Dyer Respiratory Consultant University Hospital of Wales

#### Professor Alastair Greystoke Professor of Precision Oncology

Newcastle University Honorary Medical Oncologist

Newcastle's Northern Centre for Cancer Care

#### Dr Alex Haragan Consultant Thoracic Pathologist Royal Liverpool University Hospital

**Professor Virginia Harrison** Research Trustee EGFR+ UK Lung cancer patient, diagnosed in 2021

#### Professor Andrew Nicholson

Consultant Histopathologist Royal Brompton and Harefield Hospitals Guy's and St Thomas' NHS Foundation Trust

Honorary Professor of Respiratory Pathology National Heart and Lung Institute Imperial College

#### **Professor Sanjay Popat**

Chair British Thoracic Oncology Group (BTOG) Steering Committee Lung Cancer National Specialty Lead NIHR Consultant Medical Oncologist The Royal Marsden Professor of Thoracic Oncology Institute of Cancer Research

**Dr Emily Scott** Clinical Research Fellow East of England Cancer Alliance

#### Paula Shepherd

Lung Cancer Nurse Specialist Liverpool University Hospitals NHS Foundation Trust

#### Dr Angela Silmon

**Operational Director** North East and Yorkshire Genomic Laboratory Hub

#### David Wells

Chief Executive Institute of Biomedical Sciences Scientific Lead for Pathology London Region NHS England Honorary Fellow Royal College of Pathologists

<b>^</b>	-		-	
	nr	11(	20	TS
	•••			

Foreword	2
Introduction	3
Genomics pathway – summary of recommendation	s 5
Achieving a 14-day turnaround	7
Phase 1: Pre-genomics	
Sample acquisition	7
Pathology laboratory testings	8
Samples in transit	9
Phase 2: Genomics	
Testing within the genomics laboratory	10
Phase 3: Post-genomics	
Reporting results	12
Whole pathway adaptations	13
Closing remarks	14
References	15



### Dr David Gilligan Chair. UKLCC

Consultant Clinical Oncologist Cambridge University Hospitals and Royal Papworth Hospitals

## Foreword

Over the last 20 years an increasing range of targeted therapies for patients with advanced stage lung cancer that bear a mutation, in some cases, years. Knowledge of mutations is also a pre-requisite for decisions to undertake peri-operative or neo-adjuvant chemo-immunotherapy.

Up to 30,000 lung cancer patients each year will require genomic testing. However, for many patients the path to these ground-breaking treatments is fraught with delay due to slow diagnostics processes. Testing of samples in pathology laboratories and subsequent transfer to specialist genomics laboratories to identify whether a cancer bears a mutation amenable to treatment is taking much, much longer than it should in many cases. Despite the recommended maximum 14-calendar day turnaround from tissue biopsy to full genomic result reporting, patients in some regions are experiencing delays extending into weeks. This is wholly unacceptable, causing significant physical and mental harm to patients as they endure prolonged waits before commencing optimal treatment.

While efforts to expedite processes in certain areas are commendable, consistency across all four UK nations is imperative. Accelerating genomic testing can streamline treatment pathways ensuring that lung cancer patients get the treatment best suited to them. In turn this will prolong patients' lives while at the same time being more cost-effective for the NHS.

This report is action-driven, not only highlighting the challenges within the complex genomics pathway but offering solutions for timely, accurate, and quality results. It also includes examples of successful practices across the UK, emphasising the need for collaborative efforts to improve processes.

Greater accountability, transparency and use of fairly basic digital technology across the testing pathway are critical to success. We owe it to our patients to ensure that they receive the most appropriate and effective treatment as swiftly as possible. No one diagnosed with lung cancer should wait more than 14-calendar days for genomic test results.

#### About UKLCC

The United Kingdom Lung Cancer Coalition (UKLCC) is the country's largest multi-interest group in lung cancer. It was established in 2005 to tackle the UK's poor lung cancer survival outcomes – by reducing variation in access to treatment and services - and driving-up standards across the UK. The coalition comprises leading lung cancer experts, senior NHS professionals and charities, and is supported by healthcare companies who have no input into the group's activities, views or opinions.

To find out more about the UKLCC's work and its membership, visit: www.uklcc.org.uk or email: Info@uklcc.org.uk.

The UKLCC is a private company limited by guarantee without share capital and incorporated as a Community Interest Company (CIC) registered at Companies House (Registration Number 11914752) and operating throughout the United Kingdom. VAT Registration Number 403495410.

The UKLCC is sponsored by AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Johnson & Johnson, Lilly Oncology, Merck Group, MSD and Roche. This report has been produced by UKLCC using an independent policy consultancy, contracted and paid for by the UKLCC, and supported by input from clinicians and interviewees as shown on the previous page. Editorial control for all UKLCC reports is held exclusively by UKLCC. Our primary consideration is ensuring that our independence is not in any way compromised and we are free to act in the best interests of the lung cancer community.



**Professor Robert Rintoul** Clinical Lead, UKLCC Professor of Thoracic Oncology University of Cambridge Honorary Consultant Respiratory Physician Royal Papworth Hospital NHS Foundation Trust

# have become available. Patients who, previously, would have died of their disease within months are enjoying good quality life for,

## Introduction

The field of lung cancer is going through an incredible period of innovation.<sup>1,2</sup> However, significant resource and capacity challenges within the NHS mean that people diagnosed with the disease do not always experience the full benefit.<sup>3</sup> Currently, only 60% of patients in England receive treatment within 62 days<sup>4</sup> – with those who are eligible to receive modern, targeted treatments often waiting the longest due to the necessity for further tests to determine the best course of treatment.<sup>5</sup>

For patients, waiting for treatment can be anxiety-inducing, agonising, unbearable:

# You're in shock and in a state of panic [after your diagnosis]. You're given a lot of complex information that you can't understand, especially given your current state of mind. You want everything now and don't understand why you have to wait. Waiting in limbo is hell, absolute hell."

Gini Harrison Research Trustee of EGFR+ UK, diagnosed with lung cancer in 2021

Not only is this anxiety from patients understandable, it is also justified. A lung cancer patient's journey through the diagnostic pathway can have a major impact on their wellbeing and outcome. Lung cancer can progress quickly – delays in receiving care can result in deterioration in a patient's fitness, a stage-shift in their disease with a resultant significant impact on their survival.<sup>6</sup> One study reported a 1% decline in five-year survival for every week treatment was delayed.<sup>7</sup> Delivery of timely, optimal treatment is therefore crucial to improving cancer outcomes – early diagnosis will only reap rewards if patients receive treatment before their disease progresses and patients will only benefit from innovative treatments if they are fit and well enough to receive them. This timeline is particularly important for patients awaiting a decision on peri-operative or neo-adjuvant chemoimmunotherapy where molecular testing is required prior to commencement of treatment.

Turnaround times for tests that guide treatment, such as pathology and genomic testing, have been identified by the UKLCC and National Lung Cancer Audit as a major bottleneck in the lung cancer pathway.<sup>5,89,10</sup> This is partly due to the volume of tests – the UKLCC estimate that up to 30,000 lung cancer patients in the UK per annum require testing – as well as the fact there are a number of complex steps involved in delivering these tests, which can be separated into three distinct phases; 'pre-genomics', 'genomics' and 'post-genomics'.

#### Phase 1: Pre-genomics

- Once a patient is suspected of having lung cancer, careful planning is required by the patient's clinical team to ensure that biopsies of the patient's tumour offer maximum information about staging as well as being of sufficiently high-quality to allow successful pathology and genomic testing.
- Following rapid delivery of the sample to the pathology lab, a pathologist will determine whether the biopsy shows lung cancer and what type of lung cancer it is. If shown to be non-small cell lung cancer (NSCLC), further testing is required to determine whether the tumour may be suitable for targeted therapies. Some of these tests can be performed in the same pathology laboratory by means of immunohistochemistry but others require testing in a specialist genomics laboratory.

#### Phase 2: Genomics

 NSCLC samples requiring genomics testing are sent to the nearest regional genomics lab, where they are tested for changes in tumour DNA and RNA to determine whether the tumour may respond to certain types of drug.

#### Phase 3: Post-genomics

 Results from these tests are reported back to the clinical team managing the patient, who will use the pathology and genomics information to discuss treatment options with the patient. In June 2023, a meeting was convened in London by Genomics England and it was agreed, following a review of the evidence for harm caused by long waits in the more aggressive cancers, that the turnaround time from sample acquisition to full pathology and genomic results availability to the treating clinician should be no more than 14 days. To date, despite a guidance document being written, there is no publication from NHS England.

Although testing turnaround times are not routinely published – despite UKLCC's persistent campaigning – our members are aware from personal experience or anecdotal evidence that many services are far exceeding the targets set out in the National Optimal Lung Cancer Pathway in England,<sup>11</sup> or the equivalent optimal pathways in Scotland<sup>12</sup> and Wales.<sup>13</sup> Delays in receiving test results were also called out in Cancer Research UK's latest report on genomic research and healthcare in the UK,<sup>14</sup> and by Lord Darzi, who reported in his recent review of the health service that only 60% of genomic tests are delivered on time in England.<sup>15</sup>

To ensure patients receive optimal treatment as quickly as possible, it is crucial that delays in pathology and genomic testing turnaround times are addressed. We are delighted that NHS England has launched a Cancer Genomic Improvement Programme (CGIP) to assess regional performance of turnaround times from tissue acquisition to genomics reporting<sup>16</sup> – and that the national lung cancer pathways in Scotland<sup>12</sup> and Wales<sup>13</sup> have recently been updated with more ambitious turnaround times in mind. It is vital that the data that feed into these programmes, or result from them, are published, so that learnings can be taken forward and progress made.

In producing this report, in the absence of data from the devolved NHS administrations, we have interviewed experts from across the lung cancer community – from patients and front-line NHS staff (nurses, respiratory physicians, oncologists); to the pathologists and clinical scientists working hard behind the scenes – to unite on the actions needed to bring about meaningful change.

For each step in the pathway, we set out:

- What should be happening
- What is currently happening
- Examples of best practice
- · Recommendations for change

#### ON THE HORIZON: LIQUID BIOPSIES FOR LUNG CANCER

Both England and Wales have been piloting circulating tumour DNA (ctDNA) testing – also known as liquid biopsies or cancer blood tests – to detect genetic mutations that can be targeted by different types of cancer drugs.<sup>17,18</sup> Blood samples are taken from patients with suspected lung cancer without waiting for a tissue biopsy and pathology results, meaning that genomic testing on blood can happen in parallel to pathology, resulting in faster treatment decision making in appropriate cases.

Although this technology may become more widespread in the future, it does not mean we should ignore the current tissue-focussed pathway. Tissue sampling and pathology testing will still be required to make a treatment decision in most cases and therefore we must continue to streamline the current, gold-standard pathway. Liquid biopsies and tissue testing should be seen to be complementary rather than competitive.



## **Genomics pathway – summary of recommendations**



DAY

14

#### **POST-GENOMICS**





#### RECOMMENDATION

The devolved health administrations must ensure all clinicians in the lung cancer pathway have access to a single online platform for rapid receipt of results.

#### RECOMMENDATION

Genomics labs across the four nations should adopt standardised reporting templates for genomics to improve the consistency and understanding of reports.

#### RECOMMENDATION

(12)

The Department of Health and Social Care must commit to delivering the increase in healthcare scientists' training places as set out in the NHS Long Term Workforce Plan. Counterparts in Northern Ireland, Scotland and Wales must commit to specific targets in line with growing demand for services, and to make funding available with immediate effect.

## Achieving a 14-day turnaround

## **PHASE 1: Pre-genomics**

#### Tissue acquisition



The first step in the process of determining what course of treatment is best for a patient is the acquisition of lung cancer tissue – taking samples to determine what type of lung cancer the patient has and the treatments they are eligible for. Getting this right first time is crucial to the success of achieving a 14-day turnaround. If the initial sample is not of sufficient quantity or high enough quality, then pathology and genomic tests can fail to provide a conclusive result and patients may be required to have a further biopsy taken. While generally safe, sample collection procedures can be uncomfortable and having to repeat a procedure can significantly delay test results and the start of treatment – sometimes by weeks. Waiting can place a great toll on patients' emotional wellbeing.

#### What should be happening?

- Clinicians experienced in diagnostics, often respiratory physicians in conjunction with interventional radiologists, should plan the optimal biopsy for each patient. These should be designed to provide as much staging information as possible along with providing high quality material for pathological and genomic testing.
- Clinicians undertaking biopsies should have detailed knowledge of the case to facilitate maximising sample quality and quantity.
- Clinicians involved in undertaking a given type of biopsy should be performing them regularly and should audit their success rates both in terms of procedure success rate and sample quality. Review of technical ability should form part of the annual appraisal process.

#### What is currently happening?

 Lung cancer biopsies (CT guided needle biopsy and bronchoscopic procedures including endobronchial ultrasound (EBUS)) are challenging to undertake well and success rates and sample quality and quantity vary significantly between operators. Not infrequently, initial attempts are unsuccessful necessitating repeat attempts or a referral to a specialist lung cancer diagnostic service.

#### EXAMPLES OF BEST PRACTICE

In Northern Ireland: the health system puts extra investment into this part of the lung cancer pathway – employing a pathologist or cytologist to be present during tissue sample acquisition at most EBUS lists to provide a real-time analysis of the samples being obtained to determine if the sample is of high enough quality or if another needs to be taken. While this investment is admirable, it may not be replicable everywhere due to local workforce capacity. The onus must be on the local health service and respiratory physician undertaking the procedure to get it right first time.

In Cambridge: procedure operators have adapted their procedures over time to collect more tissue samples than they used to. This helped to ensure that sufficient material is available for genomic testing in addition to standard pathology, and minimise the need for repeat biopsies. Regular feedback from the pathology and genomics laboratories about failure rates and re-biopsy rates helps maintain high technical success rates.

#### RECOMMENDATION



Clinicians undertaking biopsies for lung cancer diagnostics should plan each case carefully to ensure that samples provide as much information as possible about staging, while ensuring sufficient, high-quality material for pathology and genomics testing – and a regular audit of success rates should form part of the annual appraisal process.



#### Pathology laboratory testing



#### What should be happening?

- The type of lung cancer (including immunohistochemistry where required) is determined by pathologists within a maximum 4 calendar days of tissue acquisition.
- Reflex genomic testing sending NSCLC for genomic testing to the regional genomic laboratory immediately, without waiting for MDT meeting confirmation.

#### What is currently happening?

In general, our interviewees found pathology procedures for lung cancer to be streamlined. Almost all interviewees suggested they would confirm a diagnosis of cancer within 1-2 days and complete immunohistochemistry within the same week. Reflex genomic testing is standard in Scotland and Northern Ireland and regularly employed in England. Only in Wales are pathology services reported to present a challenge, due to a shortage of trained pathologists across the country.



#### EXAMPLES OF BEST PRACTICE



Running pathology and genomics pathways in parallel in Glasgow: An audit of samples within the pathology lab found that 98% of patient biopsy samples were successfully diagnosed without the need to access all of the available tumour material. The centre then worked collaboratively between pathology and genomics services to calculate the number of slides required for both services, ensuring that these were cut at the same time. This approach not only reduced turnaround time by 1-2 days, it also improved the quality of the material preserved for genomics testing. In order to ensure there was no delay in waiting for pathologists to prepare sample blocks for testing, the genomics clinical scientists were trained to prepare the sample blocks themselves when necessary.<sup>5</sup>

#### RECOMMENDATION

All pathology labs across the four nations should:

- Confirm a tissue diagnosis of lung cancer including sub-type (with immunohistochemistry where necessary) within a maximum 4 calendar days of sample receipt.
- Initiate reflex genomic testing as soon as a diagnosis of NSCLC is made without waiting for MDT meeting confirmation.

#### RECOMMENDATION

Pathologists and genomics clinical scientists should work together to optimise processing of samples to speed up time to full pathology and genomic results.



Genomic testing is performed in specialised laboratories which cover large areas of the country. There is only one genomics laboratory in Northern Ireland and Wales, four laboratories in Scotland and seven Genomic Laboratory Hubs (GLHs) in England. In relatively few instances are genomics laboratories co-located with a pathology laboratory, where samples are prepared. Most samples need to be sent to a regional genomics laboratory from a local pathology laboratory for testing.

#### What should be happening?

- Daily inter-site transport: Lung cancer tissue samples should be couriered from pathology to genomics laboratories. Sample deliveries should be timed so they arrive before genomic testing commences on a given day.
- Digital tracking: The private sector has long used digital tracking systems – for example, helping logistics companies to remotely track the location of parcels they courier and accurately predict the time to delivery. As the NHS increasingly looks to centralise testing of samples in hubs within each region of the UK, it is vital that systems capable of monitoring and tracking individual samples are put in place. This will support service planning and allow identification of where delays are occurring, as well as facilitating resolution of issues down to individual sample level.

#### What is currently happening?

- ✓ In Northern Ireland, Wales, many Health Boards in Scotland and some regions in England, there are daily inter-site vans that transport lung cancer samples from pathology to genomics labs. Some of the more successful labs have also tried to time the sample deliveries as described above.
- ★ For many laboratories, the transit process inevitably leads to delays, and the length of the delay varies significantly across the country. UKLCC has heard of examples of secondclass post being used to send samples to genomics labs. In other areas, samples have to be booked in and out before transport, leading to significant delays, especially if multiple transport steps are required – between a district general hospital, a cellular pathology centre and a genomic laboratory hub.
- Clinicians and pathologists report frustration at not being able to track when samples have been sent to, or received by, laboratories; and therefore are not sure who to contact in the event of delays. Likewise, pathology and genomics laboratory staff are not made aware of when patient samples are due to arrive, which makes planning for testing procedures difficult. This is especially concerning where hundreds of samples are being sent to regional genomics labs each day.<sup>19</sup>

#### EXAMPLES OF BEST PRACTICE

Transport network in Torbay & South Devon NHS Trust: Historically, samples were transported from NHS pathology labs to the Bristol genomics hub using Royal Mail tracked delivery – a process which could take up to 4 days. By switching to an existing hospital transport service, which was already transporting HPV samples to the Bristol hub, the transit time was reduced to 0-1 days.

Sample tracking in NHS Wales: In Wales, all lung cancer tissue samples are tracked from acquisition, through pathology testing and up until the sample reaches the genomics lab - through an interconnected IT system which everyone involved in a lung cancer patient's care can access. Clinicians would like this tracking to include progress within the genomics lab, for example when testing has commenced, finished and likely to be reported.

#### RECOMMENDATION





#### RECOMMENDATION

The devolved NHS and Government administrations must invest in a single digital tracking system for patient samples so they can be tracked at every point of their journey, whether in transit or within a laboratory.

## **PHASE 2: Genomics**

10

I was told by my local hospital I would require more tests, to check for a genetic mutation. I found out more detail when I met with the oncologist. He explained there were different types of mutations in never smokers, and he hoped that mine would be a more treatable one. I then felt in limbo for a month or so until my genetic test results finally came back in middle of March 2021. Once I had my confirmation of ALK positive, I started my targeted treatment within a week."

Stacy Diagnosed with lung cancer in 2021

#### **Testing within the** genomics laboratory



There is no published data on the time genomics labs take to test and report sample results, from any of the four nations. Therefore, we have to rely on the accounts of our interviewees, who paint a varied picture across the UK.



#### What should be happening?

- The lab is adequately staffed to meet demand.
- Samples arrive at the genomics laboratory, are processed and testing commences the day of arrival.
- A medium size panel of around 30 to 50 markers is used to test lung cancer patient samples.
- Genomic testing is run every day.
- The genomics labs are working to the same target as the rest of the clinical pathway - therefore time from samples arriving in the GLH to reporting should be no more than 7-8 calendar days.

## **PHASE 3: Post-genomics**

# Reporting results

#### What should be happening?

- Standardised templates, which are easy to understand and interpret, should be used by genomics labs to report results.
- The results should be available immediately to everyone in a lung cancer multi-disciplinary team (MDT) via an online system.
- Patient appointments should be booked ahead of receiving results with a given date knowing a timely result will be available.

#### What is currently happening?

- Our interviewees reported inconsistencies in approaches to reporting of pathology and genomics results – including in the quality and speed of reporting, and how easy they are for clinicians to interpret. In some cases, genomics results were reported back to the pathologist for them to incorporate into the pathology report and report back to the clinicians in a lung cancer MDT. In some cases, this is due to incompatibility of IT systems.
- Inconsistencies and delays in genomics turnaround times can mean a reluctance to book in a follow-up appointment with an oncologist until the results are received.

However, there are examples across the UK where solutions have been found to speed up reporting.



#### What is currently happening?

Most of our interviewees reported a 2-4 week wait for genomic testing results – which significantly exceeds the turnaround time we are trying to achieve for the full pathway from tumour tissue acquisition to genomics reporting.

There are several challenges faced by genomics labs across the country:

- Target mismatch: There is a discrepancy between targets set for the genomics labs to turnaround samples, and for the wider lung cancer pathway. For example, in Scotland<sup>20</sup> and England,<sup>21</sup> the lab's own target is 14 days for running the genomics test alone, yet the pathway targets from sample acquisition to genomics reporting (including pathology) in Scotland and England are 10 and 14 calendar days, respectively. Realistically, genomics testing and reporting must take no longer than 7-8 calendar days.
- Capacity: Workforce and general resourcing are a key issue impacting turnaround times. The more that cancer care improves across all cancer types, the more demand there will be on genomics services. This was acknowledged in NHS England's Board meeting in February 2024, with the operational performance update stating: "As a result of increased growth in testing in the NHS Genomics Medicine Service (GMS), compliance with turnaround times has been impacted." <sup>22</sup>
- **Batch testing:** Due to the need to make efficiencies, samples are often run in batches, sometimes only twice a week, depending on the volume of samples coming into that particular lab. This means sample testing could be delayed by up to 4 or 5 days while waiting for the next run of tests.
- Panel size discrepancy: Labs are also using different sized panels to test samples. A 500-panel test is common in central genomics laboratories, but it is rarely necessary to test for that many genomic markers to make a treatment decision or to identify patients eligible for a clinical trial. Those who use a medium-size targeted panel of around 30 to 50 markers can more quickly prepare and run testing.

Poor turnaround times from their regional GLH led staff at Liverpool University Hospitals NHS Foundation Trust to find alternative solutions to speed up time to treatment of their lung cancer patients. They reported to us a 27-day turnaround from sample delivery to full reporting of results from their GLH, and that 27% of their samples were failing genomic tests, adding significant delays to patients receiving treatment. In response to these delays and high fail rates, given they already had considerable in-house molecular genomic experience, they chose to purchase their own next-generation sequencing platform and conduct genomic testing in-house, using a panel of 30-40 markers without receiving reimbursement from NHS England or the GLH. Liverpool's approach has patient's welfare at its heart. However, it is the opinion of the UKLCC that returning genomic testing in-house should not become the direction of travel. To ensure a consistent service, that can cope with increasing demand, we must ensure that the national genomics services are sufficiently resourced to meet expected standards and patients are not left to suffer.

There are genomics laboratories in the UK that have worked hard to overcome these challenges and have achieved impressive results.

#### **EXAMPLES OF BEST PRACTICE**

Achieving an 8-day turnaround for genomics in the North East: The North East GLH run lung cancer samples every day – they cover a large geographical area and use smaller, faster NGS platforms so they don't need to limit when they run tests. They use a panel of 50 markers – which is sufficient for determining both optimal treatment and eligibility for clinical trials. The result is a relatively slick process that delivers results in an average of 8 days, but do often complete the process in 7 days, and always less than 10 days.

#### RECOMMENDATION



The devolved NHS and Government administrations must adjust genomic laboratory turn-around-time targets for lung cancer samples to 7 days. To realistically achieve this, the laboratories must be sufficiently resourced, operating a 7-day working model.



#### **EXAMPLES OF BEST PRACTICE**



Standardised reporting to unified IT systems in Northern Ireland and Wales: Healthcare professionals have access to a single IT system. When genomics results are ready, they are uploaded to the system and all clinicians involved in a lung cancer patient's care can access the results instantaneously. They have also developed standardised report templates so that the results are easy to read and interpret. In complex cases, clinicians should have easy access to the regional Genetics Tumour Advisory Board (GTAB) for best practice advice.

A pragmatic approach in Newcastle: In lieu of having compatible IT systems in England, Newcastle upon Tyne Hospitals NHS Foundation Trust has piloted running a single inbox for genomics results, that oncologists all have access to, and which is regularly monitored by several members of staff. The oncologist then has the result in front of them as soon as possible, cutting out time sending reports back to the pathologist first. Reports from the North East GLH are also standardised within their region.

**Pre-booking oncology appointments:** In Northern Ireland, Scotland, Wales, and centres such as Newcastle, clinicians are able to book patients into clinic for results, with confidence, since the turnaround times are relatively consistent.

#### RECOMMENDATION

The devolved health administrations must ensure all clinicians in the lung cancer pathway have access to a single online platform for rapid receipt of results.

#### RECOMMENDATION

Genomics labs across the four nations should adopt standardised reporting templates for genomics to improve the consistency and understanding of reports.

## Whole pathway adaptations

There are several underlying challenges that must be addressed to ensure sustainable improvements to services, reduce variation in turnaround times, and improve accountability in local and regional services.

#### Patient information and communication

Patients often report to lung cancer charities and patient support groups that they are not provided with sufficient information about pathology and genomic testing - why it is needed, how long they should be waiting for results, what the results mean, and in language they can understand.

#### RECOMMENDATION

Patients and their loved ones must be either provided with, or signposted to, appropriate information regarding pathology and genomic testing, for example, Roy Castle Lung Cancer Foundation's guide, *Genomic* testing in lung cancer.23

#### Data collection and publication

Without broader transparency on service performance, the drive for meaningful change will continue to be unnecessarily challenging – what isn't measured, isn't managed.

#### RECOMMENDATION

10

9

To ensure pathology and genomics laboratories are held to account over their role in delivering timely lung cancer care, it is imperative that data is collected and published by devolved health administrations on the turnaround times for:

a. tissue diagnosis including immunohistochemistry b. genomic testing

#### Accountability

Frontline staff, in particular lung cancer nurse specialists, often have the difficult job of having to apologise to the patient for long waits - but they are not responsible for meeting targets for pathology and genomic turnaround times within cancer pathways, and it is currently unclear who is accountable.

Within each pathology and genomics laboratory,

there should be a named individual responsible for

overseeing the entire testing pathway and ensuring

laboratory processes are optimised to meet clinical

mechanisms should be employed, should a service

laboratories, with funding flows to follow the sample.

consistently fail to meet targets, including the option for

samples to be processed in alternative, higher performing

pathway turnaround time targets. Accountability

#### RECOMMENDATION



#### Training of pathologists and genomics laboratory scientists

14

A common issue raised by interviewees regarding the timely delivery of pathology and genomic test results across all four nations was that of laboratory workforce. England has seen an estimated 30% increase in histopathology activity since 2018/19; however, the workforce grew by only 8% in that period.<sup>24</sup> The Royal College of Pathologists estimate that shortfalls in the pathology workforce across specialities (including those working in genomics) ranges from 15-30%, and are forecast to increase by 20% over the next 10 years.<sup>25</sup>

The NHS workforce plans across the four nations vary in their attempts to address this shortfall. Plans for Scotland, 26,27 Northern Ireland<sup>28</sup> and England<sup>29</sup> acknowledge the shortfall in scientists and their crucial role in diagnostics, but only England has committed to a target of increasing training places by 13% by 2028/29, and more than 30% by 2031/32. The Welsh health and social care workforce strategy doesn't mention pathologists or clinical scientists at all.<sup>30</sup>

## **Closing remarks**

Throughout the UK, adherence to a 14-calendar day turnaround target from tissue acquisition to genomic reporting is far from consistent. While some areas acknowledge delays and have proactively taken steps to make progress towards this goal, learnings are not being shared or translated to other regions in need of improvement.

In this report, we have set out recommendations for governments and NHS leaders, frontline staff and service providers, to reduce lung cancer waiting times and improve the lives of people living with the condition. We have included examples of steps taken by services across different parts of the country in the hope that this short report will help inspire change.

While, of course we deem everything set out in this report to be important for delivering the best possible patient care, we must not forget that for those facing a distressing diagnosis of lung cancer, very few of these details matter. For patients, the time spent in an information vacuum, waiting for test results before they can begin treatment, can be a mentally and emotionally draining experience that can impact their overall health.

We owe it to our patients to ensure tests that inform their care are carried out as efficiently and quickly as possible. Nothing should stand in the way of achieving that goal.

#### **Experience of diagnosis is unsettling and disruptive for those affected by lung cancer.** We hear this from the thousands of contacts with patients and carers each year. Timely access to details of tumour types and sub-types is vital to ensure people have rapid access to effective treatment."

Lorraine Dallas Director of Information, Prevention and Support, Roy Castle Lung Cancer Foundation

#### RECOMMENDATION



The Department of Health and Social Care must commit to delivering the increase in healthcare scientists' training places as set out in the NHS Long Term Workforce Plan. Counterparts in Northern Ireland, Scotland and Wales must commit to specific targets in line with growing demand for services, and to make funding available with immediate effect.



## References

1 UK National Screening Committee (2022). Adult Screening Programme: Lung Cancer. Available at: https://view-health-screening-recommendations.service. gov.uk/lung-cancer/ Accessed January 2025

2 Gálffy et al. (2024). Targeted therapeutic options in early and metastatic NSCLC-overview. Pathol. Oncol. Res., Volume 30 - 2024 | https://doi.org/10.3389/pore.2024.1611715

**3** Royal College of Radiologists (2023). The SACT Capacity Crisis in the NHS. Available at: https://www.rcr.ac.uk/media/updj5x5h/rcr-policy\_policy-briefing-thesact-capacity-crisis-in-the-nhs.pdf

**4** NHS England (2024). **Cancer Waiting Times for November 2024 – 25** (**Provisional**). Available at: https://www.england.nhs.uk/statistics/wp-content/ uploads/sites/2/2025/01/NOVEMBER-2024-CWT-CRS-PROVIDER-WORKBOOK-PROVISIONAL.xlsx

5 UKLCC (2023). Scottish Pathways Matter. Available at: https://www.uklcc.org. uk/sites/default/files/2023-10/Final%20UKLCC%20Scottish%20Pathways%20 Matter%20report\_Nov%202023.pdf

6 UKLCC (2018). Millimetres Matter. Available at: https://www.uklcc.org.uk/ sites/default/files/2021-06/UKLCC-Millimetres-Matter.pdf

**7** Sud, A. et al. Effect of delays in the 2-week-wait cancer referral pathway during the COVID-19 pandemic on cancer survival in the UK: a modelling study. Available at: doi: 10.1016/S1470-2045(20)30392-2

8 UKLCC (2019). Molecules Matter. Available at: https://www.uklcc.org.uk/sites/ default/files/2021-06/Molecules-Matter.pdf

9 UKLCC (2019). Pathways Matter. Available at: https://www.uklcc.org.uk/sites/ default/files/2021-06/UKLCC-Pathways-Matter-Report.pdf

10 National Lung Cancer Audit (2020). Spotlight on Molecular Testing in Advanced Lung Cancer. Available at: https://www.hqip.org.uk/wp-content/uploads/2020/01/REF100\_NLCA\_Spotlight-Molec-Test\_FINAL-TYPESET\_web\_20200108.pdf

11 Lung Clinical Expert Group (2017). NOLCP Implementation Guide. Available at: https://www.roycastle.org/app/uploads/2019/07/Lung\_Cancer\_ Implementation\_Guide\_August\_2017.pdf

12 NHS Scotland (updated February 2024). Optimal Lung Cancer Diagnostic Pathway. Available at: https://www.nhscfsd.co.uk/media/iyufsear/nhs-scotland-optimal-lung-cancer-diagnostic-pathway-v12.pdf

**13** NHS Wales (2022). **National Optimal Pathway for Lung Cancer: 2nd Edition.** Available at: https://executive.nhs.wales/functions/networks-and-planning/ cancer/workstreams/suspected-cancer-pathway/scp-accordion/nationaloptimal-pathway-lung-cancer-and-genomics/ Accessed February 2025

14 Cancer Research UK (2024). Sequencing Success: Genomics for Cancer Research and Care. Available at: https://www.cancerresearchuk.org/sites/ default/files/sequencing\_success\_-genomics\_for\_cancer\_research\_and\_care\_full\_report\_november\_2024.pdf?11

**15** Lord Darzi (2024). **Independent investigation of the NHS in England**. Available at: https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england Accessed February 2025

**16** NHS East Genomics (2024). **Cancer Genomic Improvement Programme** (CGIP). Available at: https://www.eastgenomics.nhs.uk/about-us/genomicmedicine-service-alliance/Transformation\_Projects/nhse-cancer-genomicsimprovement-programe/ Accessed January 2025 17 NHS England (2024). Thousands more lung cancer patients to get innovative blood test as part of NHS pilot. Available at: https://www.england.nhs. uk/2024/03/thousands-more-lung-cancer-patients-to-get-innovative-blood-test-as-part-of-nhs-pilot/ Accessed February 2025

18 Welsh Government (2023). New test to revolutionise lung cancer diagnosis rolled out in Wales. Available at: https://www.gov.wales/new-test-revolutionise-lung-cancer-diagnosis-rolled-out-wales Accessed January 2025

19 NHS England (2025). The NHS Genomic Medicine Service: achievements in 2024. Available at: https://www.england.nhs.uk/long-read/the-nhs-genomic-medicine-service-achievements-in-2024/ Accessed February 2025

**20** Scottish Government (2023). **Genomic Test Directory: Cancer.** Available at: In Scotland the TAT Is 14 days https://www.nss.nhs.scot/media/4220/ssngmcancer-test-directory-may-2023-v2.pdf (page 22)

21 NHS East Genomics. NHSE Test Directory turnaround times. Available at: https://www.eastgenomics.nhs.uk/about-us/quality/nhse-test-directory-turnaround-times/ Accessed February 2025

22 NHS England (2025). Operational performance update. Available at: https:// www.england.nhs.uk/long-read/operational-performance-update-4/ Accessed February 2025

**23** Roy Castle Lung Cancer Foundation (2024). **Genomic testing in lung cancer**. Available at: https://roycastle.org/app/uploads/2024/03/Genomic-Testing-in-Lung-Cancer.pdf

24 Institute of Biomedical Science (2023). Long Term Biomedical Scientist Workforce Plan. Available at: https://www.ibms.org/resources/documents/ ibms-long-term-workforce-plan/ibms-long-term-biomedical-scientist-workforceplan-final.pdf

**25** Royal College of Pathologists (2024), **The college calls for urgent investment** in the pathology workforce to delivery the Government's 10-Year Health Plan. Available at: <u>https://www.rcpath.org/discover-pathology/news/the-royal-collegeof-pathologists-calls-for-urgent-investment-in-the-pathology-workforce-to-deliverthe-government-s-10-year-health-plan.html Accessed January 2025</u>

26 Scottish Government (2021). National Workforce Strategy for Health and Social Care in Scotland. Available at: https://www.gov.scot/binaries/content/ documents/govscot/publications/strategy-plan/2022/03/national-workforcestrategy-health-social-care/documents/national-workforce-strategy-healthsocial-care-scotland/national-workforce-strategy-health-social-care-scotland/ govscot%3Adocument/national-workforce-strategy-health-social-carescotland.pdf

27 Scottish Government (2024). Genomic medicine strategy 2024 to 2029. Avaiable at: https://www.gov.scot/publications/scotlands-genomic-medicinestrategy-2024-2029/pages/3/ Accessed February 2025

28 Northern Ireland Assembly Department of Health (2016). HEALTH AND SOCIAL CARE WORKFORCE STRATEGY 2026. Available at: https://www.healthni.gov.uk/sites/default/files/publications/health/hsc-workforce-strategy-2016.pdf

**29** NHS England (2023). **NHS Long Term Workforce Plan.** Available at: https:// www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforceplan-v1.21.pdf

30 NHS Wales (2020). A Healthier Wales: Our Workforce Strategy for Health and Social Care. Available at: https://heiw.nhs.wales/files/a-healthier-wales-ourworkforce-strategy-for-health-and-social-care/ Accessed January 2025