



*Accelerate, Coordinate, Evaluate (ACE) Programme*

# Lung Cancer Pathways: Interim Report

Variations in performance and practice

An NHS England initiative supported by Cancer Research UK  
and Macmillan Cancer Support

ACE Lung Cancer Pathway Cluster

**March 2016**

# ACE Programme – Variations in lung cancer performance and practice

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# 1. Introduction

## 1.1 The ACE Programme

The ACE Programme (ACE) began in June 2014 with the aim of exploring ways of achieving earlier diagnosis through streamlining diagnostic pathways. The programme was designed to enable learning to take place by monitoring and evaluating local projects as they implemented changes to their cancer pathways.

The full programme includes 60 local projects grouped into topic based clusters including colorectal pathways, bowel screening uptake, and use of decision support tools in primary care, but this report covers only early learning in relation to **lung cancer**.

## 1.2 ACE Lung clusters

The ACE Lung workstream includes 12 projects grouped into two clusters – one cluster focusses on the *lung cancer pathways* of patients that present with symptoms and the other explores the impact of taking *proactive approaches (mostly offering CT) to people at higher risk of lung cancer*, many of whom will be asymptomatic. The Proactive Lung projects are mostly working to a longer timeframe than the Lung Pathways projects, so this interim report focusses on Lung Pathways particularly.

Learning is being gained in a number of ways: by monitoring the experiences of ACE projects during implementation, through debates within cluster meetings and in discussions with lung cancer experts. National data sets are also being analysed to add richness and to provide important context. At project level, data collection and analysis are taking place and a summary of those results will be part of the final report.

## 1.3 National cancer requirements

An important consideration for NHS organisations is the need to deliver the NHS planning guidance: *Delivering the Forward View*. One of the 9 national “must dos” for 2016/17 includes the need to deliver the 62 day cancer waiting standard as well as the two week and 31 day standards. The need to improve one-year cancer survival rates by increasing the numbers of cancers diagnosed early and by reducing those diagnosed via emergency admissions is also explicit. Additionally, within the NHS Mandate’s 2020 goals, it stipulates that patients should be given a definitive cancer diagnosis, or all clear, within 28 days of being referred by a GP.

These are important but challenging standards within an NHS that also expects the achievement of many other standards as well as substantial efficiency targets.

## **1.4 Aims of ACE Lung**

The ACE Lung programme aims to help commissioners and providers to meet these standards by providing evidence of the impact of implementing particular changes, and by providing relevant information and tools that can be used to improve local services.

ACE also aims to influence policy makers by bringing to their attention some of the local consequences of national policies and by sharing information about what is likely to facilitate or impede local service improvement.

## **1.5 Contributing to ACE**

This is an interim report and provides an opportunity to share some of the information gathered so far and to introduce the next phases of the process. Even though the ACE Lung Pathway Cluster is structured around the six ACE Lung pathway projects (listed in Annex 2), we are also keen to understand pathways in place in other localities to help us identify the pathway features most linked with positive performance.

We would therefore welcome input from other localities who are willing to share information about their own pathways and/or views about the most effective ways of improving lung cancer services. If you are interested in staying in touch with ACE Lung and/or willing to contribute, please complete and return **Annex 1**.

## 2. Lung cancer context

### 2.1. Opportunity for improvement

The lung cancer community is already aware that the UK has comparatively poor survival rates for lung cancer. There is also awareness that lung cancer outcomes vary considerably across the UK. There is however, a more limited understanding of the reasons why this variation exists and even less understanding about how we can reduce the variation to achieve consistently high performance across England.

ACE Lung is aiming to explore the extent to which there may be a correlation between clinical performance and lung cancer pathways, with particular focus on the speed and timeliness of lung diagnostic/staging pathways. This is because reducing time to diagnosis of lung cancers leads to more timely treatments, and earlier interventions extend survival and/or improve quality of life. It is also the case that of all common cancers, lung cancers are more likely to be diagnosed following an emergency presentation where outcomes are poorer, rather than through a managed referral (2013 Routes to Diagnosis: 35% diagnosed following emergency presentation, 28% via Two week wait and 21% via GP referral) .

Better organised diagnostic/staging pathways are also likely to be more cost-effective and to provide better patient experience. And because of the very large numbers of patients with lung cancer and the very high rates of early death, the potential for improving outcomes, including one-year and longer-term survival, is probably greater than for many other cancers and could make a significant contribution to meeting commissioner targets for improving overall cancer survival rates.

### 2.2 National process

The national Lung Clinical Reference Group, Chaired by David Baldwin, is leading a process that will produce a National (Standard) Clinical Pathway for Lung Cancer and a National Optimal Lung Cancer Pathway. It is expected that these will be published in spring 2016 together with commissioning guidance. The ACE Programme is working alongside this process and is intending to produce complementary/supporting documents and resources – taking into account a range of audiences e.g. commissioners, lung cancer service providers and national policy makers.

A key benefit of ACE is that it can provide a link between national expectations/aspirations and the reality of lung cancer services ‘on the ground’. Since the aim is to improve performance it is important that there is greater understanding of why performance is as it is – and what national and local changes could lead to improvements.

## 3. ACE Lung Pathway projects

There are six ACE projects within the Lung Pathway cluster, testing a range of different pathways and/or pathway elements as well as communication methods and motivation

techniques. The majority of projects are trying to achieve better/faster access to CT. One project is testing 'GP direct access to CT' following a normal chest X-ray (CXR), while several others are implementing 'straight to CT' arrangements following abnormal CXR. The best way of dealing with 'equivocal' CXR has also been an important topic considered by the lung pathway cluster.

Several projects are focussing on the interface between primary and secondary care and are introducing changes to improve communications and the transfer of relevant clinical information. Others are re-examining processes within secondary care to ensure timeliness and best use of resources. Communications with patients are also being considered to understand how, when and by whom they should receive information and/or results, including good news.

The positive and negative impacts of the introduction of new pathways will be assessed in the final report. This will cover the speed/length of the new pathways as well as clinical outcomes including, where possible, the proportion of patients receiving potentially curative treatment. The views of clinicians - and patients/patient groups, will be gathered where possible. And cost differences between 'before' and 'after' pathways will be considered.

More information about the six ACE Lung Pathway projects is provided in **Annex 2**.

## **4. Variation in lung cancer outcomes and pathways**

### **4.1 Examining variation**

While the ACE projects are progressing, time is being devoted to examining national data sets. Time is also being spent looking at the variety of lung cancer pathways currently in place. A detailed survey of pathway features in 10 localities was carried out and even though the sample is small, it has flagged up interesting differences.

Local circumstances differ. In some localities single trusts provide the full range of diagnostic, staging and treatment options while in other areas these are provided in a variety of locations/organisations. The majority of lung cancer patients receive care in more than one NHS trust so geography will have a bearing on local arrangements. The pressures on local resources vary too, with imaging capacity for testing and reporting being a particular concern in many areas. Stretched nursing, administrative and other clinical resources, such as CT biopsy and EBUS (endobronchial ultrasound) will also have an impact on pathways.

Whilst some variation is to be expected, there is variation that is less easy to explain. The following 2 sections explore variation, both in terms of what is apparent in national data sets and in local cancer pathways 'on the ground'.

## 4.2 Variation identified across national data sets

An examination of newly released 2014 data from NHS England, PHE and the National Lung Cancer Audit enables us to see a range of performance indicators related to lung cancer pathways across England. Variation in these indicators is apparent in the ranges presented below. The Cancer Waiting Times (CWT) data (last 3 bullets) exclude statistical outliers.

- There is a three-fold variation in case mix adjusted median survival – and in unadjusted days the median range is **91 days to 332 days post diagnosis**.
- The median number of days from GP referral to treatment start date varies across trusts from **35 days to 63.5 days**.
- The median number of days between the date first seen by a specialist and the decision to treat ranges from **21 days to 43 days**.
- Two Week Wait pathways vary from 6 – 13 days and more interestingly, conversion rates vary from **7% to 31%**.

One element of CWT data not explored here is information about patients who have been put on the 62 day pathway following a consultant upgrade rather than starting the pathway with a two week wait referral. These data have been requested and that further analysis will be included in the final report.

There is anecdotal evidence suggesting wide variation in access to and timeliness of diagnostic imaging. Analysis of the relatively new national Diagnostic Imaging Dataset (DID) is proceeding and we expect to have information in the final report about variation in imaging activity across the country.

## 4.3 Variation in local pathways

In an attempt to understand what is behind the differences apparent from national data sets, ten localities agreed to complete a detailed questionnaire about their current pathways. The majority, but not all, of the localities surveyed are linked to an ACE project, but not necessarily in the Lung Pathway cluster.

Particular areas of variation identified by the survey are set out below.

### 4.3.1 Referral routes available to GPs

Within *all* the localities, GPs have direct access to CXR. They can also make referrals to a local respiratory clinic or make two week-wait referrals if cancer is suspected on the basis of NICE referral guidance.

Within 2 of the 10 localities surveyed, GPs also have the option of directly requesting a CT scan – often referred to as ‘Direct access to CT’. This can be useful if a CXR is normal but symptoms persist or if symptoms do not present in line with NICE guidance for a two week-wait (2WW) referral. One of the ACE Lung projects is specifically testing a GP Direct to CT pathway.

Three of the localities surveyed also have formal arrangements in place for GPs to be able to get advice from secondary care regarding the best referral route to use when the decision is not straightforward.

#### **4.3.2 CXR results – what happens next**

In all localities, GP requested CXR results go back to the GP but in some localities, an abnormal result also triggers a fast track CT scan referral – known as ‘Straight to CT’ . This can prevent delay and ensure GPs do not miss significant results. Several ACE projects are introducing these pathways.

Some GPs have commented that CXR results can be unclear in terms of what is being recommended by the radiologist, which can add delay or result in a missed opportunity. Prompted by expert input at a Cluster meeting, two ACE projects have developed *Radiology Decision Support Tools* that provide a way of categorising and then communicating CXR results. Once tested with experts, a Radiology Decision Support Tool will be available as an ACE output for others to use, if helpful.

Although the 10 localities surveyed reported turn-around times (for CXR reports) ranging from 1 – 3.5 days, other national studies have revealed much longer delays in some places and considerable backlogs. Delays in reporting could mean delays in diagnosing cancers and in treating life-threatening problems such as large airway obstruction, large pleural effusion etc. The increasing demand for imaging and the inadequacy of current capacity to meet this demand has been explored thoroughly in other reports. In particular, *Horizon Scanning: An evaluation of Imaging Capacity across the NHS in England* which was commissioned by CRUK and published in September 2015.

The use of trained radiographers to report on CXR is in place in 2 out of the 10 localities surveyed and is regarded by them as being useful and successful. This may be a helpful way forward for others to consider, where shortages of radiologists are particularly acute.

#### **4.3.3 The diagnostic decision making process**

The CT scan is core to the diagnostic process for lung cancer. It is the first step in the pathway when lung cancer is suspected following an abnormal CXR or normal CXR with a clinical suspicion of lung cancer, and provides clinicians with the information needed to decide if/what further tests are required to achieve a diagnosis and staging and determine appropriate treatment options.

In the 10 localities surveyed, there were different arrangements in place for this part of the process. Four of the 10 localities hold a weekly diagnostic MDT meeting to make these decisions. In the other localities the decision is made primarily by the lung physician who can access advice more informally from clinical colleagues such as radiologists as/when needed. There were also some hybrid arrangements where to prevent delay, colleagues are consulted informally if the MDT meeting has just occurred.

The advantage of the informal arrangements includes flexibility with timing but the advantage of the diagnostic MDT is that it ensures that different clinical perspectives are involved in the decision-making.

#### **4.3.4 Communications with patients**

##### ***The Cancer Clinic vs other arrangements***

Six of our localities reported that 95%-100% of 2WW patients are seen within a dedicated cancer clinic. Two localities reported that they do not have dedicated cancer clinics and that their patients are either seen within dedicated slots in routine respiratory clinics, or by arrangement throughout the week.

Although national guidance (NICE CG121) suggests that potential cancer patients should be seen in dedicated cancer clinics, those offering a different arrangement point out the advantages of being able to see potential cancer patients throughout the week and say that Clinical Nurse Specialists (CNS) are just as involved as they would be within a cancer clinic.

##### ***Communicating good news***

In some localities, a clear CT scan result is communicated back to the GP/patient by letter from secondary care which then obviates the need for the patient to attend a cancer clinic. Where this arrangement is in place physicians comment that they are then able to spend more time on patients that have cancer, which is a better use of their skills and expertise.

Other services feel that all patients who are referred on a 2WW need to be seen in an outpatient clinic before they are 'discharged' regardless of the CT result.

What has become apparent from ACE discussions is that the arrangements and use of 2WW referrals varies considerably across localities and that some interpretations of the rules do not necessarily encourage good practice. This is explored further in section 5 below.

#### **4.3.5 Commissioning arrangements**

The survey indicates that 6 out of 10 localities have Cost and Volume contracts in place for most elements of the lung cancer pathway e.g. CXR and CT scans, while the other 4 use Block Contract arrangements.

When asked about incentives and sanctions, none of the localities reported having incentives for good performance in their contracts, but several contracts include sanctions if performance standards are not met.

When asked about monitoring arrangements and which metrics attracted most local discussion, performance against CWT targets appear to dominate local discussions.

## **5. The urgent (2WW) cancer referral – a help or a hindrance?**

What has become known as the '2WW' pathway was introduced in 2001 in order to speed up cancer referrals from primary to secondary care, with the ultimate aim of achieving earlier cancer diagnoses.

The introduction of this pathway had a galvanising impact, but now needs re-thinking. Each type of cancer is different and therefore a 'one size fits all' pathway is unlikely to be equally effective across all types of cancer. For lung cancer, ACE has found that 'the 2WW' is causing perverse behaviours and needs urgent review.

When the 2WW was introduced, it stipulated that a consultant outpatient appointment (OPA) should take place within 2 weeks of the GP referral, and systems were then set up to enable this to happen.

The rules were amended in 2011 to enable the 2WW clock to be stopped at an appropriate diagnostic test, which in the case of Lung Cancer is the CT scan. Unfortunately, this important change was not picked up by all and some Trusts are still focussing their 2WW efforts on getting their patients to an OPA within 2 Weeks, even if the CT scan has not yet taken place.

As one consultant said, 'if the CT scan hasn't happened, the outpatient appointment is a wasted event'. But this still happens in a number of places – possibly because lung pathways weren't reviewed when the rules were altered and because the need to avoid 'breaching' can override other considerations. Within the 10 localities surveyed, the range of patients seen in an OPA who had not yet had a CT scan ranged from 2% - 84%, with 4 of the trusts quoting percentages of 20% or over.

Best practice indicates that not only should the CT scan have taken place but the Radiology report of the scan should also be available for the Consultant to consider before determining the best course of action for a particular patient.

In a significant proportion of cases, imaging reports are not available for the OPA and if a Radiologist is not part of the decision making process, a physician may decide on the next actions based on their own interpretation of the scan. If the radiology report then arrives

indicating something different than the physician had noticed, the patient may then need to be re-contacted and advised to follow a different course of action than had been originally discussed. This is distressing to patients, can lead to an inefficient use of resources and may necessitate additional clinic visits.

But even when the 2WW referral process does focus on getting patients to a CT scan – the rule allows the clock to stop when the scan takes place rather than when the imaging report is available. While some Imaging departments are able to turnaround reports quickly, others report considerable delays, which then extends the time to diagnosis. In our small survey, turnaround times from scan to report ranged from 2 – 10 days. It is therefore possible that a trust which shows good performance in relation to the 2WW standard is still taking longer than necessary to achieve a diagnosis.

It is helpful that the 2020 mandate indicates that a future standard will focus on the ‘referral to diagnosis’ interval. This proposed change is welcome but the precise definition of when that clock will start and finish needs careful consideration to ensure other perverse behaviours don’t enter the system.

It is important to reiterate that the most appropriate diagnostic pathway in terms of timeliness for each type of cancer will be different, and is even different between small cell and non-small cell lung cancers. If just one timeframe is set for all e.g. 28 days, it is likely to be too long an interval for some types of cancers while being appropriately challenging for others.

## 6. More/less effective use of resources

It is always important to use scarce resources as effectively as possible. But without regular review and challenge, it is easy for less efficient practices to get embedded in routines. Without spending time and effort as a team to review local pathways, it is hard for any one person to see the whole pathway and to spot where practices are less efficient or effective than they could be.

Listed below are areas where local pathways vary in ways that may impact on the use of resources. Some local services may make deliberate decisions to continue using resources in a particular way, but others may not realise that things could be done differently. This list is included only to prompt local discussion, not as recommendations of how things should be done.

- All patients to have had CT test/imaging report before the outpatient appointment.
- Use of letters to discharge patients back to primary care following clear CT results rather than using a cancer clinic/outpatient slot to deliver the good news.

If the above two arrangements are in place, a greater proportion of people attending cancer clinics will be people who have cancer, and team resources can then focus on their needs.

- Putting in place a formal or semi-formalised way for GPs to seek advice from secondary care re potential lung cancer symptoms could reduce inappropriate referrals.  
(Telephone consultation - approximately £30, outpatient appointment £180+)
- Use of trained radiographers to report on CXR could reduce delay and reduce requirement for more expensive radiology time.
- Use of a standardised image reporting tool could help radiologists and ensure GPs understand what actions are being recommended.
- Multiple diagnostic tests occurring on the same day could reduce the number of patient attendances.

## 7. Drivers of change

Since the longer term aim of ACE is to drive and encourage service improvement in services outside of the programme, the programme has examined what motivated ACE project teams to want to change their pathways, the challenges they faced during implementation, and what they regarded as key to being able to sustain their projects. On the basis of their inputs and ACE observations, a summary is set out below.

### 7.1 Motivating factors – which helped to get projects started

Most teams involved with ACE linked their desire to be part of ACE with their poor local survival rates as identified within national data sets. Local capacity pressures and poor CWT performance were also frequently noted as local motivators.

Nearly all areas mentioned that the encouragement of their local CCG was another important motivating factor. In one locality, an inspirational talk from a colleague helped to galvanise local activity and influence their direction of travel.

### 7.2 Challenges along the way

The complexity and the time-intensive nature of stakeholder engagement took many projects by surprise. This also led to delays in project timetables in many cases.

Clinical leaders commented that it was difficult to give enough time to the project alongside their clinical workload. But where there was strong project manager support, they managed much better.

There was some frustration involved in getting sufficient local data together to analyse local problems – some resorted to carrying out audits to identify their problems and to convince wider stakeholders of the need for change. This lengthened project timetables and required project support to carry out.

Some projects found that clinical perspectives varied and that problems identified by primary care clinicians were not necessarily recognised as problems by secondary care colleagues, and the absence of good local data extended these discussions.

### **7.3 Project sustainability**

*Clinical leadership* – has been important to all projects, and where it exists at both primary and secondary care levels, the benefits are greater.

*Project management/support* – was seen as essential to all projects even though the arrangements and amount of support varied between the projects.

*Motivated team* – pathways can't be changed by keen individuals alone, and where projects had a motivated team, willing and able to take time out to discuss the changes, progress was made more quickly.

*Supportive CCG/local accountability structures* – projects were more robust and were better able to maintain momentum where CCGs were involved in the project and where there was a clear timetable and clear local reporting structures back to the lead CCG.

These factors are important to consider if other localities wish to embark on a pathway review/change process. Once expectations are raised, it is important to be able to follow the process through, and this needs considerable local commitment.

## **8. Next stages**

The first phase of ACE Lung workstream is scheduled to conclude by the end of 2016. This will include the completion of the six local project evaluations as well as further analysis of national data sets in comparison with actual lung pathway features.

This latter process will include a wider but also more focussed analysis of pathways in place in organisations outside of ACE to see whether there is a correlation between performance within national datasets and pathways 'on the ground'. This additional analysis will depend on the cooperation of a larger number of Trusts being willing to provide information to ACE on their pathways, which we hope can be achieved.

In addition to the local and national data analysis processes, the programme is aiming to produce a set of helpful tools and resources. These will be produced for different target

audiences and will be complementary to the National Optimal Lung Cancer Pathways and Service Specification.

Likely outputs from ACE Lung Pathway workstream include:

- A radiology decision support tool, and reporting proforma
- A Days to Diagnosis Pathway Chart format
- Individual Case Studies
- Examples of well-regarded referral forms
- Commissioner guidance – subject to further discussion with commissioners
- A Final Report - which will include a summary of the 6 project evaluations as well as more pathway analysis.

It is hoped that the final report will be useful to NHS policy makers, as well as other audiences, and will inform NHS England as they consider future arrangements, guidance and/or incentives for improving lung cancer services.

## 9. Conclusion and interim findings

This interim report has identified that:

- There is both wide variation in lung cancer outcomes across the UK, and considerable variation in local lung cancer pathways. The link between these will be explored further.
- There is considerable scope to improve local lung cancer pathways, which is likely to lead to a better use of expertise, scarce resources, better patient experience and more timely diagnoses.
- To achieve improvement in Lung Cancer performance localities will need the support of their commissioners, a project structure with dedicated project management, and clinical leadership – ideally from both primary and secondary care.
- There will be benefits in sharing the learning developed through ACE more widely – in the form of evidence, case studies, sample forms and tools across Lung communities.
- The targeting of support and guidance to low performers could yield substantial benefits, achieve better national performance and reduce unwarranted variation.
- The next stages of the ACE Lung Pathway will help to identify any relevant correlations between local pathway arrangements and local performance.

## 10. Contact ACE

If you have any queries about ACE, please contact the team at: [ACEteam@cancer.org.uk](mailto:ACEteam@cancer.org.uk)  
In addition, you can visit our webpage: [www.cruk.org/ace](http://www.cruk.org/ace) where we will publish news and reports.

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**The ACE Programme**  
*Accelerate, Coordinate, Evaluate*

## Help ACE and stay in touch

<b>Name &amp; Email Address:</b>		
<b>Organisation:</b>		
<b>Role:</b>		
		Yes/No
1.	I am interested in the ACE Lung Programme and would like to receive a soft copy of any further reports produced.	
2.	I would be willing to assist the ACE Programme by completing questionnaires, sharing information about our local service or by receiving visits from the ACE team.	
3.	If an opportunity were to arise, I would be interested in working with ACE to improve our local Lung cancer pathways.	
4.	The biggest challenges we face in our local lung cancer services are:	
5.	The most interesting features of our local lung cancer pathway are:	
6.	Comments/Questions/Areas of interest regarding this Interim Report:	

Please return this form to [Barbara.Gill@NHS.net](mailto:Barbara.Gill@NHS.net)

# ACE Lung Pathway Projects

## Key Features

### **Crawley CCG & Horsham and Mid Sussex CCG**

#### **Surrey & Sussex Healthcare NHS Trust**

- Produced/agreed new CXR referral form & patient information leaflet
- Started new Straight to CT pathway in October 2015
- Abnormal CXR Results coded Z5
- Z5 patients referred straight for CT and cancer team alerted
- GPs kept informed

### **Horsham & Mid Sussex CCG**

#### **Brighton & Sussex University Hospitals NHS Trust**

- Produced/agreed new CXR referral form & patient information leaflet
- Started new weekly diagnostic MDT in December 2015
- New Straight to CT pathway to be implemented imminently
- GPs to be kept informed using updated, standardised reporting from radiology
- New pathway to include; near patient testing and pathway co-ordinator to track patients

### **Somerset CCG**

#### **Taunton/Yeovil**

- Improve Primary/Secondary integration and communications
- GPs to spend longer with each patient prior to referral explaining process
- New referral form includes more clinical information and enables straight to CT
- New Radiology decision support tool created for clearer CXR reporting

### **Nottingham CCGs/Nottingham University Hospitals Trust**

- GPs given 'Direct access to CT' - if CXR normal but symptoms persist
- Expect low cancer pick up but high levels of reassurance
- Addresses the fact that some cancers not detected on CXR
- Impact on 2ww referrals to be monitored

### **University Hospitals of North Midlands**

- Straight to CT being rolled out to south part of patch
- Robust Radiographer training and reporting is in place
- Patients discharged without follow up, if CT is clear

### **Manchester Cancer**

- Merging MDTs to create 4 Sector MDTs
- New data system, clinician led and managed
- Data fed back to teams & teams agree improvement plans
- Using local Data input/analysis and peer support to drive improvements