

ACE: Lung Cancer Pathways Cluster

Qualitative Research Results

Introduction and purpose

A key aim of the ACE lung cancer pathways work stream has been to gain a better understanding of lung cancer pathways 'on the ground'. National guidance recommends some pathway configurations over others, and the ACE programme presented an opportunity to test this in practice - with the overall aim of finding ways to achieve earlier diagnosis of lung cancers.

Six local projects within the ACE programme have been implementing new lung cancer pathways and evaluating the results of their efforts over the past two years. Much has been learned through this process but it was felt that having some broader understanding of other pathways in place would be useful too.

It was therefore decided that a small scale survey would be carried out to gather information about lung cancer pathways in place at other Trusts. And to generate as much learning as possible it was decided to approach Trusts that were at both ends of the scale in terms of median performance on 31 and 62 day pathways according to 2014 datasets.

The hypothesis was that there were likely to be more 'recommended pathway features' in place at Trusts performing well on their pathways than in place at Trusts that were struggling with their pathway performance.

This short paper provides the results of this small telephone survey which involved interviews with 20 Trusts about their lung cancer pathways. Many these findings are now embedded within the ACE Lung Cancer Pathways Final Report, which also includes the results of the 6 ACE lung pathway projects as well as expert views and commentary on national guidance.

Structure of the qualitative research

Participating Trusts were chosen because they were either within the top 20 Trusts on both 62 and 31 day median pathway performance in the 2014 Cancer Waiting Times dataset or they were one of the bottom 20 Trusts in relation to median pathway performance.

The reason for choosing these Trusts – at extreme ends of pathway performance – was that they might more clearly show if particular pathway features were more associated with top or bottom end pathway performance.

It is important to state that a large number of indicators can be used to assess performance such as survival rates, resection rates and patient experience. But since this work stream is focussing on pathway performance, median day performance in terms of 62 and 31 day

standards were identified as being the most relevant indicators to use. Throughout this paper, there are references to 'Top' and 'Bottom' performers but this only relates to Trusts in terms of their pathway performance in 2014 in relation to 62 and 31 days. The quotes will be dropped for ease of reading, but the reader should bear in mind this very narrow definition of performance.

Process

Telephone interviews, rather than questionnaires, were chosen as the information gathering method since preliminary discussions showed that terminology was used differently by different people and/or organisations. Phrases such as 'Straight to CT' and 'Direct Access to CT' were confused frequently, so a postal questionnaire may have generated inaccurate results.

The telephone interviews were informal but followed a semi-structured format which was modified after the first few interviews, to improve flow. The aim was to gather qualitative information during the interviews as well as information about pathway configurations. Participants were not asked to provide hard data or precise numbers but were sometimes asked to provide estimates e.g. % of patients that have CT prior to OPA.

The informal style provided participants with the flexibility to emphasise the positive and negative aspects of their pathways, and to share their views on some relevant topics, such as the 28 day standard.

All of the telephone interviews were carried out by the ACE Lung programme lead and in most cases the interview was with the Lead Lung cancer physician at the Trusts, although in some cases the interview was with the cancer manager or lead CNS.

All participating Trusts were assured that their responses would be presented anonymously.

Results - Introduction

The results are mostly presented by comparing top and bottom performers but it will also be useful for readers to see the range of different arrangements in place across a number of Trusts.

The first set of information presented relates to pathway configurations in place across the 20 Trusts. This information was gathered through telephone conversations and not through examination of hard data. National guidance (and NOLCP?) recommends a number of arrangements such as CT prior to OPA, 'Straight to CT' following abnormal CXR, Diagnostic MDTs and Cancer Clinics. GP Direct Access pathways are also generally seen as useful to have in place. The questions therefore focussed on these features to see if they were more often present in Top performers.

The second part sets out views expressed by participants during the telephone interviews about their local services and sometimes about wider issues. Some interviews lasted longer

than others and participants varied in terms of their areas of interest, so not all questions were covered by each Trust.

Results PART 1 – Pathway Configurations

What happens following an Abnormal CXR Result?

The responses to this question revealed a range of pathways **from** the more *Traditional* i.e. CXR Report sent to GP and the GP then decides what action to take next, **to** what could be described as a *Straight to CT* arrangement where secondary care assumes responsibility when an abnormal CXR result is identified, and decides what needs to happen next, which generally is for the patient to have a CT scan as quickly as possible.

The Chart below shows the Trusts grouped into broad categories, relating to both the mechanism that is used (2WW or Consultant Upgrade) and *who* is responsible for making things happen.

Table 1: After Abnormal CXR detected.....

	2 Week Wait	2 Week Wait	Consultant Upgrade
	GP responsible for making things happen after CXR Report received	Trust starts action and chases GP if 2WW form not submitted promptly	Secondary care assumes responsibility and informs GP of actions taken
TOP Trusts	T1, T2, T4,	T3, T5, T8, T10, T11,	T7, T13
BOTTOM Trusts	B8	B2, B4, B6, B10, B13, B14	B7, B9, B12

The table above shows that:

- ❖ The majority of Trusts use the 2WW mechanism to trigger the start of the cancer pathway, although some use the Consultant Upgrade mechanism.
- ❖ The most common arrangement is that the Trust initiates action immediately, but requests and chases (where necessary) a 2WW referral form in order to ‘start the clock’.
- ❖ There was no marked difference between top and bottom performers in terms of this stage of the pathway.

What happens after a Normal CXR Result, when the GP still has concerns?

The most common response to this question was that ‘The GP can/should make a 2WW referral’ and some Trusts added that the GP could also seek advice. Some Trusts had Direct Access to CT pathways and indicated that this would be an option. The full list of responses is provided in the table below, which shows that:

- ❖ The 2WW referral is seen as the answer to this situation in most cases
- ❖ There are no marked differences between top and bottom performers in relation to this aspect.

Table 2: Normal CXR result but continuing concerns...

	Top Performers	Bottom Performers
2WW Referral	3	7
2WW Referral or Phone for advice	3	-
2WW or Direct Access to CT	2	2
Direct Access to CT	1	-
Urgent referral to Respiratory OPA		1

Do local GPs have direct access to CT?

Of the 20 Trusts asked, most said 'no' (13) and 7 said 'yes' to this question. One Trust said they had this pathway in place since 2012 and another Trust said that they were just about to start a direct access to CT pathway.

When Trusts were asked about the criteria for using this pathway, answers were fairly vague and it seemed to be mostly up to the GP's discretion.

In terms of the split between top/bottom performers, 5 top performers answered 'yes' to having direct access pathways in place as opposed to 2 of the bottom performers.

Table 3: GP Direct Access pathway to CT?

Top	Bottom
5 said Yes	2 said Yes
5 said No	8 said No

Which comes first CT or Out Patient Appointment (OPA)?

Responses to this question ranged from one end of the scale to the other, with some Trusts saying that the OPA was always done first and others saying that the CT was always done first. Five Trusts have 'one stop shop' arrangements for at least some of their patients which means that they are generally done on the same day.

Interestingly, two Trusts explained that the order varied depending on whether the patient was on a 2WW pathway or a Consultant Upgrade pathway. And even more interestingly, one of those Trusts does CT before OPA for 2WWs but OPA before CT for Consultant Upgrades and the other Trust does it the other way around i.e. the OPA before CT for 2WWs and CT before OPA for consultant upgrades.

When questioned further about these arrangements, the logic generally related to the patient communication arrangements. Where the pathways included arrangements for the patients to be told that a CT might be needed after the CXR, the CT was arranged without

the need for a prior OPA. Where patients weren't generally prepared for this possibility, it was felt that an OPA was needed first to prepare them.

Table 4: What happens first CT or OPA?

	OPA Always or Mostly First	Same Day (One Stop Shop)	CT Always or Mostly first (60%, 90%, 100%)
TOP Trusts	T4, T5, T7,	T2, T8,T10	T1, T3, T11, T13
BOTTOM Trusts	B6(2WW), B7(2WW) B9(CU), B10	B7(CU), B8	B6 (CU), B2, B4, B9(2WW), B12,B13,B14

What stops the 2WW Clock?

The vast majority (11) of respondents in both Top and Bottom categories said the OPA, stopped their 2WW clock. Two Trusts said, 'whichever comes first' and 3 Trusts said the CT scan stopped the 2WW clock. Two Trusts said that they didn't realise the clock could stop at the CT Scan.

Table 5: what stops 2WW Clock?

	OPA	CT	Whichever happens first
TOP (+ one don't know)	T2,T4,T5,T7,T8,T10	T3, T11	T1
BOTTOM	B6, B7, B8, B9, B12, B14	B2,B13	B4, B10

Who decides what further diagnostic tests are required post CT?

Most of the Trusts have diagnostic MDTs in place to discuss and agree what further tests are needed in order to achieve a complete staged diagnosis. In some Trusts the discussion happens between the Physician and Radiologist – formally or informally. And in other Trusts, the respiratory physician takes lead responsibility but seeks advice as and when he/she feels it would be helpful.

❖ There were no significant differences between top/bottom performers

Table 6: Who decides further diagnostic tests?

	Top	Bottom
Diagnostic MDT	4	3 (1 MDT is clinician only and OoH)
Done as part of Tx MDT	1	-
Phys/Rad together	1	2
Physician mostly on own, but will seek advice for complex pts.	4	4
Mixture of above	-	1

Are cancer patients seen in a cancer clinic or in a general respiratory clinic?

In response to this question, the Trusts were fairly evenly split between those that saw patients in a cancer clinic and those that saw patients in dedicated slots in general respiratory clinics. Respondents felt that the use of slots in respiratory clinics added more flexibility to scheduling and allowed for more flex in the system to take into account fluctuations in demand. CNS involvement appeared to be part of both arrangements.

Table 7: Cancer Clinics vs slots in Respiratory Clinics

	TOP	BOTTOM
Cancer Clinics	5	5
Slots in Respiratory clinics	4	1
Mixture of both	1	4

Are further diagnostic tests coordinated to happen on the same day?

Table 8:

	TOP	Bottom
Yes	6	
Where possible		1
Mostly not	3	
No	1 (because of different sites)	6
We try but rarely succeed		1

The table above describing the amount of same day testing taking place shows the largest variation between top and bottom performers, with considerably more same day diagnostics taking place in top performers.

RESULTS PART 2 - Participant Views

What are the Strengths and Challenges of your local Lung Cancer Pathway/Service?

Two tables which include the responses provided by both top and bottom performers is attached as Annex 1 but a summary of their responses is provided below. Overall, strengths focussed on leadership and relationships, while challenges were mostly identified as capacity constraints.

Whilst focussing on similar aspects when describing their strengths and challenges, there were differences of emphasis and breadth between top and bottom Trusts. The challenges identified by Top performers tended to be more specific in nature, while Bottom performers mentioned more systemic organisational problems. In terms of strengths, Top performers were quick to list a number of strengths including organisational performance strengths,

such as performance management, while Bottom performers struggled more with listing strengths and tended to focus on team members.

Table 8: Strengths/Weaknesses summary

	STRENGTHS	CHALLENGES
TOP	Leadership/team members/Team work Good relationships/communications Small team with flexibility & ownership Strong patient tracking arrangements One Stop Clinic Quick turnaround times for some tests	Capacity, particularly radiology and oncology Complex patients and tertiary referrals Insufficient clinical information in GP referrals Lack of consistency/waiting for MDT decisions
Bottom	Strong leadership/engagement/'buy-in' Team working/relationships Patient tracking/performance monitoring	Capacity – particularly radiology & oncology Complexity of patients/second opinions GP referrals – patients not sufficiently primed Communication issues/ Insufficient data

Topic based comments made by participants

Since the interviews were only semi-structured and informal, there were opportunities for participants to share their views on a number of topics. Some were prompted and other views were offered freely and were made at various stages of the interview. These additional comments have been grouped together by topic and are presented below.

Comments about Two Week Wait Referrals

- Several respondents commented on the huge increase in 2WW referrals over the past 4 years which had almost overwhelmed the services....
- Several expressed concern that GPs were referring too many people, and making some inappropriate referrals.
- There were a number of comments about GPs not providing sufficient clinical information on the referral form - one participant said it was too easy for GPs to tick boxes on 2WW referral forms and would it be better to go back to letters/free text.
- There were several comments about GPs not preparing patients sufficiently before making the referral, which then led to pathway delays later.
- 'Most 2WW referrals lack sufficient information to justify a CT scan so need to have an OPA first to get clinical information, and once assessed 70% do not need CT. Full clinical assessment taking into account co-morbidity should be taken into account before subjecting someone to radiological exposure'

Size of Trusts – Small can deliver good quality care

Several participants commented on the importance of all team members having a personal stake in the service and being equally committed. This point was often linked to smaller services, with their smaller size regarded as mostly an asset, offering more flexible and tailored services. The main drawback was not always having full MDT cover from oncology and thoracic surgeons particularly.

Comments provided regarding the new 28 Day Standard

- Most respondents expressed reservations about being able to achieve this, with some saying it would be a 'massive challenge'
- Most said that this could be achieved for a proportion of lung cancer patients but not for the complex patients. Some felt it would be achievable for 50% of lung cancer patients and others estimated that it would only be achievable for 30%, without significant additional investment.
- With regard to when the clock would start and stop, clinicians commented that they wanted it to be at points that would be meaningful to patients. The preference seemed to be for the clock to stop at histological diagnosis, even though it would be more challenging to achieve.

Comments provided about the National Optimal Lung Cancer Pathway.

- Nearly all respondents were aware of the Lung CRG's optimal lung cancer pathway even though this has not yet been published by NHS England.
- A number of the Trusts had already or were in the process of auditing their local pathway in relation to the NOLCP.
- Several commented that they would like to put the NOLCP in place but they did not have enough capacity to do so. Pathology turn-around times were mentioned as being particularly unrealistic or unattainable within local services.

Wider Cancer Planning Structures

- One cancer manager commented that the new Cancer Alliance geography was too big and the STP geography too small for sensible discussions about Lung Cancer pathways.
- Another cancer manager said 'Things fell apart after the cancer networks were disbanded, things have been chaotic since then'.

Tertiary Hospital Perspective

- Current standards were not written with tertiary services in mind. It would be helpful for tertiary services to be judged on things they have control over.
- NICE guidance is helpful but doesn't take into account complex patients sufficiently

Conclusions (Preliminary and in relation to the survey only)

It is clear from this small qualitative study that there are a variety of lung cancer pathways in place across NHS Trusts.

There were no very distinctive differences between top and bottom performers in terms of their pathway configurations.

Pathway features recommended in good practice guidance, are apparent in some Trusts but do not appear more frequently in Top Trusts than Bottom Trusts.

Participants frequently expressed the importance of leadership, good team work, relationships and flexible, positive attitudes as being key to a good service.

Capacity constraints were identified as a key barrier to achieving targets but some Trusts appear to be using resources more effectively than others.

Some of the Trusts were keen to improve their services and would welcome further guidance on how this could be done. Case studies of good performers and practical tools were mentioned particularly.

Barbara Gill, November 2016

Annex 1 – Tables of Strengths/Challenges responses

TOP Performers – Views on own Pathway/Service

Strengths?	Most Challenging Aspects?
Good patient tracking and escalation Good CNS Support Good Respiratory/Radiology relationships EBUS on site	Need more consistent approach to pathway More protocols needed MDT a bit rigid/too much waiting for next MDT
Individuals in team/slick processes good dialogue	Referrals on to Tertiary centre, particularly for surgery results in frequent breaches
Relatively small so everyone has a personal stake in making it work. Fast histology turnaround times – 48 hours	Threat of histology moving off site Inadequate clinical information from GPs Access to PET CT, but it isn't too bad
Strong and involved lead clinician Strong team with experienced CNS and MDT Coordinator	Capacity is a challenge. We struggle but pathway is well managed. Radiology is key pinch point.
Tailored approach to individuals because small Histopathology turnaround is fast Access to CT and CT Reports	Bottlenecks – CT guided biopsy slots EBUS delays Access to PET CT
Relationships with tertiary centre MDT office patient tracking arrangements Relationships with departments, CNSs and CEO (have weekly meeting with CEO re cancer performance)	Clinic capacity/Diagnostic capacity Reporting times Second opinions from histology
Small team, works well together Good patient experience Respiratory works well with Radiology One stop lung clinic	Getting local oncology input is a challenge More surgeons needed too But better to stay small and manage, than combine MDTs
One Stop Clinic/team approach Clinical leadership and teamwork	Need EBUS and PET CT on site
Good chasing from admin staff Quick access to CT and flexible slots Prompt reporting/fast turnaround times Quick bronchoscopy and CT guided bronch	Need thoracic surgeon at our MDT Lack of oncology clinic slots Delay in accessing PET CT Occasional histology delays
Newly streamlined front of pathway	Complex patients Cardiology referrals and patients that need multiple investigations
Flexibility/We see patients when required Ambulatory pathway works very well, keeping patients out of hospital Pathology very good	Access to EBUS and PET CT
SUMMARY: Leadership/team members/Team work Good relationships/communications Flexibility/tailored approach to patients Strong patient tracking/chasing arrangements Quick turnaround times for some tests	SUMMARY: Capacity, particularly radiology and oncology Complex patients and tertiary referrals Insufficient clinical information in GP referrals Lack of consistency/waiting for MDT decisions

BOTTOM Performers – Views about own Pathway/Service

Strengths?	Most Challenging aspects?
Good Team, Good governance/performance monitoring.	Lung Cancer is challenging. Getting Lung cancer prioritised when resources limited. Access to Pet CT.
Strong Leadership/dedicated team	Inappropriate referrals and/or patients not primed to know what to expect. Patient expectations are important./Lack of investment
Team keen and engaged	Getting diagnostic tests done quickly, need extra capacity to meet local aspirations. Not having CT before OPA/ CT Guided biopsy and EBUS delays. Poor comms with Radiology
Excellent 'buy in'/Good People in team/Good MDT/Access to Research/High resection rate	Capacity - particularly radiology and Cancer clinic slots. Better data management needed – to help practice and business case. Patient tracking arrangements are weak.
Leadership and engagement, Real desire for system change.	Capacity constraints – CT, CT Guided biopsy, Bronchoscopy and EBUS – all challenging.
Straight to CT consultant upgrade pathway works well.	Delivering Straight to CT for 2WWs, vacancy rate, imaging/biopsy capacity
Ownership of pathway and positive attitudes - Good lung MDT/Good CNS/Good Data collection of COSD	Increasing demand on everything. PET CT site issues. Quality of GP referrals/ inadequate priming of patients re expectations
Clinical leadership and interest in Cancer Good MDT coordination and patient tracking. Interest/discussion of cancer at top of trust	Complexity of patients and second opinions.
Front end of pathway, self-referral CXR and Straight to CT arrangements.	Capacity – it can take 3 weeks to get an oncology appointment. Access to PET CT. Need more/better data.
SUMMARY: Strong leadership/engagement/'buy-in' Team working/relationships Patient tracking/performance monitoring	SUMMARY: Capacity – particularly radiology and oncology Complexity of patients/second opinions GP referrals – patients not sufficiently primed Communication issues/ Insufficient data