NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Lung cancer in adults

Date of quality standards advisory committee post-consultation meeting:
18th September 2019

1. Introduction

The draft quality standard for lung cancer in adults was made available on the NICE website for a 6-week public consultation period between 15 July and 23 August 2019. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 21 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

1. Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

4. For draft quality statement 4: Is there currently variation in the extent to which the different investigations (PET-CT, brain imaging, spirometry and TLCO) are used in local areas?

5. For draft quality statement 5: Is it helpful to focus this statement on adults with advanced non-small-cell lung cancer or should it focus on a wider population?

6. For draft quality statement 6: Are adults with non-small-cell lung cancer stage IIIa always assessed for treatment with curative intent and if so, is this routine practice? Please explain what happens in your area.

7. Do you have an example from practice of implementing the NICE guidelines that underpin this quality standard? If so, please submit your example to the [NICE local practice collection](https://www.nice.org.uk/about/what-we-do/into-practice/local-practice-case-studies/submit-a-case-study-example) on the NICE website. Examples of using NICE quality standards can also be submitted.

1. General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

* Stakeholders were generally supportive of the quality standard and the areas identified for quality improvement.
* It is important to ensure that focussing the quality statements on specific groups (when other groups may receive the same treatment) does not conflict with the Standards of Care algorithms that are being developed to support the National Optimal Lung Cancer Pathway.
* There should be more focus on improving diagnosis and treatment for all people with lung cancer regardless of stage of cancer.

### Consultation comments on data collection

* It was suggested that data collection should already be in place.
* There was a concern that it can be difficult to get a current national view of lung cancer treatment and outcomes because the National Lung Cancer Audit only reports annually using data from 2 years previously.

### Consultation comments on resource impact

* Local areas may lack the resources required to deliver the quality standard. Specific concerns included:
	+ public awareness campaigns
	+ smoking cessation services
	+ availability of lung cancer nurse specialists
	+ clinical imaging – workforce and equipment
	+ radiotherapy and oncology provision – workforce and equipment.

### Consultation comments on equality and diversity considerations

* + In the statements on treatment, emphasise the importance of treating people with suspected lung cancer who are HIV positive in the same way as everyone else.
1. Summary of consultation feedback by draft statement
	1. Draft statement 1

Local authorities and their partners use coordinated campaigns to raise awareness of the symptoms and signs of lung cancer and encourage people to seek medical advice if they need to.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

* General
	+ It would be helpful to highlight that non-smokers can get lung cancer given that incidence is increasing in this population.
	+ There was some confusion about whether the statement includes national campaigns.
	+ There is currently very limited funding available for public awareness campaigns.
* Statement
	+ The statement should be reworded to ‘Local health bodies and their partners…’
* Measures
	+ It may be difficult to collect meaningful data for the structure measures given the lack of live lung cancer datasets.
	+ Outcome c) should include diagnosis at all stages.
* Definitions
	+ It is important to highlight that lung cancer in the never smoking population can affect adults of any age, not just those over 40.
	+ Symptoms should include back, neck or shoulder pain which is unexplained and does not respond to standard approaches.
* Equality and diversity considerations
	+ It is important to highlight the need to raise awareness of lung cancer among ethnic minority groups e.g. translation of awareness materials
	1. Draft statement 2

Adults with suspected or confirmed lung cancer who smoke are referred to an evidence-based stop smoking service.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

* General
	+ Cuts to local authority public health budgets and the impact on the provision of stop smoking services could make it difficult to achieve this statement in some areas.
	+ It may not be practical to implement the statement because stop smoking services are not available in hospitals and therefore people will need to self-refer to community services.
	+ Stop smoking support should not be regarded as a separate function but instead should be delivered as part of routine clinical care.
* Statement
	+ Wording should be revised to: *“Adults with suspected or confirmed lung cancer who smoke are referred to, and provided with, evidence-based stop smoking support within the NHS as part of their clinical treatment.”*
	+ The statement should be ‘offered a referral’ because it is not cost effective to make a referral if the person does not want it.
* Measures
	+ The Cancer Outcomes and Services Dataset and The National Lung Cancer Audit should be added as a data source for the process measures.
	+ Data on referrals to stop smoking services may not be recorded.
	+ It was queried why the quit rate is only 4 weeks.
* Audience descriptors
	+ It should be clearer that service providers should be able to provide stop smoking support. Additional/amended wording suggested: *Providers to ensure that they have trained stop smoking advisor capacity which is able to deliver stop smoking support to smokers*. Providers to *also have* referral pathways to *other sources of* evidence-based stop smoking *support”.*
	+ It was suggested that therapeutic radiographers should be added as a healthcare professional.
	+ Currently CCG’s and NHSE do not commission stop smoking support.
	+ It should be clear that commissioners should commission in-house stop smoking support within the NHS. Amended wording suggested: “Commissioners ensure that they commission services which *provide tobacco dependence treatment to* adults with suspected or confirmed lung cancer who smoke, *in addition to being able to refer smokers to other sources of evidence-based stop smoking support*”.
	1. Draft statement 3

Adults with suspected or confirmed lung cancer have access to a named lung cancer clinical nurse specialist.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

* General
	+ The statement may be difficult to achieve given the current pressures on the workforce in many areas.
* Statement
	+ The statement should include a timescale for access to a nurse specialist.
* Measures
	+ Structure a) – The data source should be amended to reflect that the recommendation on ‘1 whole-time equivalent nurse for an annual caseload of 80 new patients’ is based on National Commissioning Guidance.
	+ Process c) - it was queried if the National Cancer Patient Experience Survey is a helpful data source given that people may find it difficult to distinguish between different nursing roles.
	+ Additional measures were suggested: frequency of interactions with a lung cancer nurse specialist; average length of time spent with a patient.
* Definitions
	+ Could a definition of ‘access’ be added to include email, telephone and face to face contact?
	1. ***Draft statement 4***

Adults with lung cancer have investigations to complete diagnostic staging and assess lung function before starting treatment with curative intent.

**Consultation comments**

Stakeholders made the following comments in relation to draft statement 4:

* General
	+ There is currently considerable overlap between statements 4 and 5 and they could be combined into 1 statement focussed on ensuring that all people have a full diagnostic, staging and biomarker work-up appropriate to their stage.
	+ The statement in its current form is ambiguous.
	+ It will not be possible to achieve 100% because some people will not be able to have all the tests e.g. due to claustrophobia.
* Statement
	+ The term ‘diagnostic staging’ is not in mainstream usage and should be clearly defined.
	+ The population should be everyone who is potentially suitable for treatment with curative intent rather than those starting treatment. There may be good reasons why someone doesn’t start treatment with curative intent, but they will still need staging and lung function.
	+ The statement should not be limited to treatment with curative intent. It should ensure that all people with non-small-cell lung cancer have full diagnostic, staging and molecular pathological testing so that they are offered the most appropriate treatment. There was a concern that the focus of the current statement could rule out treatment options for many people who are not curable.
	+ It would be helpful if the statement could include a timescale (e.g. based on the National Optimal Lung Cancer pathway) as timing is the most significant problem.
* Measures
	+ The national lung cancer audit can be added as a data source for process a) and c) for spirometry. Process c) can also identify the cancer outcomes and services dataset as a data source for transfer factor.
	+ 1-year and 5-year survival rates may not be appropriate outcomes for improvements in the diagnostic pathway.
* Audience descriptors
	+ Commissioner descriptor – What does ‘without delay’ mean?
	+ Advanced/consultant radiographers could be added to the list of healthcare professionals.
* Definitions
	+ Treatment with curative intent should include immunotherapies as per the NICE pathway.

### Consultation question 4

Stakeholders made the following comments in relation to consultation question 4:

*Is there currently variation in the extent to which the different investigations (PET-CT, brain imaging, spirometry and TLCO) are used in local areas?*

* There was agreement that there is local variation.
* Some areas do not have access to PET-CT which leads to additional costs, delays to diagnosis and treatment and travel requirements for people with suspected lung cancer.
* There is currently wide variation in practice in the use of brain imaging. Some areas do not have capacity for MRI and therefore use CT instead. This variation in practice also affects people with later stage lung cancer and can impact on access to systemic treatments.
* Full lung function is available everywhere, but timeliness is an issue in many areas.
* There are significant limitations in many areas for the necessary rapid turnaround times required for all necessary investigations e.g. there can be delays of up to a month between requesting a PET-CT scan and receiving the report.
	1. ***Draft statement 5***

Adults with non-small-cell lung cancer stage IIIb, IIIc or IV who are having tissue samples taken, have them taken in a suitable form for pathological diagnosis and assessment of predictive biomarkers.

**Consultation comments**

Stakeholders made the following comments in relation to draft statement 5:

* General
	+ The emphasis on thoracic radiologists and lung biopsy was queried given that the statement is more likely to involve neck node or metastases sampling rather than lung biopsy.
	+ The statement does not mention less invasive liquid biopsy as a first option for molecular testing in advanced non-small-cell lung cancer. It was suggested that wider access to liquid (blood) biopsy could improve the numbers of people eligible for targeted therapies.
	+ There is currently no agreed method for assessing the quality of tissue samples for molecular testing.
* Statement
	+ Should image-guided lung biopsy for people being considered for treatment with curative intent be included in the statement?
* Measures
	+ Structure b) may be challenging to evidence as there is not a common approach to testing across the country.
	+ Structure c) should indicate how performance of EBUS/EUS should be measured.
	+ Structure c) should also include audit of local test performance for lung biopsy.
	+ Process b) should focus on people with good performance status (0-1) as it is this group that will benefit from pathological confirmation.
* Definitions
	+ The definition of ‘samples taken in a suitable form’ should be revised to:
		- acknowledge that there is always a risk to the person
		- identify the benefits of reflex immunohistochemical testing/genetic analysis
		- highlight the importance of waiting for test results before making a decision on treatment options
		- also include ROS-1 gene mutations.

### Consultation question 5

Stakeholders made the following comments in relation to consultation question 5:

*Is it helpful to focus this statement on adults with advanced non-small-cell lung cancer or should it focus on a wider population?*

* There was some agreement that it is reasonable to focus this statement on people with advanced non-small-cell lung cancer.
* Assessment of the full range of markers for people with earlier stage lung cancer does not influence treatment as it does in people with advanced lung cancer.
* The statement should include a wider population because treatment intentions can change, and targeted treatment is given to people with cancer at other stages.
* The focus of the statement should be extended to all people with lung cancer in order to improve diagnoses at stages I or II and to contribute to survival rates.
* The statement is not suggesting that all people with advanced lung cancer should have these tests, just that when samples are taken, they are of sufficient quality. The population should therefore include all people who are having these tests. It is particularly important to include stage IIIa.
	1. ***Draft statement 6***

Adults with non-small-cell lung cancer stage I or II and good performance status have treatment with curative intent.

**Consultation comments**

Stakeholders made the following comments in relation to draft statement 6:

* Statement
	+ It would be better to focus on assessment for treatment with curative intent and how that assessment should be carried out.
	+ The statement should include all adults with non-small-cell lung cancer and all treatments including immunotherapies.
* Measures
	+ Should there be a separate measure for the surgical resection rate?
	+ The data source for outcome a) is not appropriate because the survey does not identify lung cancer stage or performance status.
	+ It was suggested that health-related quality of life may not be a relevant outcome for this statement.
* Definitions
	+ There should be more emphasis on the complete implementation of SABR in the definition of treatment with curative intent.

### Consultation question 6

Stakeholders made the following comments in relation to consultation question 6:

*Are adults with non-small-cell lung cancer stage IIIa always assessed for treatment with curative intent and if so, is this routine practice? Please explain what happens in your area.*

* People with stage IIIa should be considered for treatment with curative intent and are discussed at MDTs.
1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* Earlier diagnosis including referral from primary care (including timescale)
* Communication between presentation and diagnosis
* Holistic care for people with advanced lung cancer
* Treatment with immunotherapies

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# Appendix 1: Quality standard consultation comments table – registered stakeholders

| **ID** | **Stakeholder** | **Statement number** | **Comments[[1]](#footnote-1)** |
| --- | --- | --- | --- |
| 1 | British HIV Association (BHIVA) | General | We suggest that, as part of statements about the treatment of lung cancer, the following is included:“Patients known to be HIV positive with suspected lung cancer should be investigated and treated in the same way as those in the general population. All HIV positive patients with a lung cancer should be initiated on antiretroviral therapy and, if commencing anti-cancer therapy, particular attention to be paid to potential drug-drug interactions. Prophylaxis against opportunistic infections should be considered in all HIV positive patients undergoing systemic anticancer therapy for lung cancer.” |
| 2 | Clinical Expert Group for Lung Cancer NHSE | General  | The CEG are currently developing the Standards of Care algorithms that will support the National Optimal Lung cancer Pathway and this QS. Restricting the standards to particular groups, where other groups receive the same treatment (in some cases) may conflict with these SOCs. |
| 3 | EGFR POSITIVE UK (Patient Group) | General | The draft quality standards do accurately reflect the key areas for quality improvement and as a patient group we are delighted to see recognition of the crucial work done by lung cancer nurse specialists. Having a lung cancer nurse specialist transforms the experience of patients and provides vital support for not only for them but their families. We would like to see, however, some consideration of the issues raised above which are based on the real-life experiences of our seventy plus members.  |
| 4 | Primary Care Respiratory Society | General | No specific comments |
| 5 | Roche Products and Roche Diagnostics UK | General | We believe it is important that the Quality Standards includes a stronger focus on Early Diagnosis.Earlier diagnosis in lung cancer is crucial to improve patient experience and treatment outcomes because there are limited treatment options when presenting with advanced lung cancer (at Accident and Emergency for example). We are aligned with this priority highlighted in the NHS long-term plan1 and we support the Accelerate, Coordinate, Evaluate (ACE)2 Programme by CRUK.Earlier diagnosis is a key area for improvement because there is a wide variation in the referrals of lung cancer across the UK. Patients are diagnosed at different stages of disease progression, highlighting a variation in service requirements We suggest that a publication quantifying these differences would be highly beneficial to focus resources on areas which need it the most. This data could then be pooled at a Clinical Commissioning Groups level enabling the comparison between the number patients receiving diagnosis in primary care to those diagnosed in A&E - when indeed, the disease has progressed significantly enough that the patient presents at secondary care.Furthermore, the NHS Long Term Plan set out an ambition that 55,000 more people will survive their cancer – to achieve this, the plan also included an ambition to increase the number of cancers diagnosed at stages one and two from half to three-quarters of cancer patients. Cally Palmer, national cancer director at NHS England, said: “Catching more cancers early is a cornerstone of the NHS Long Term Plan to save a further 55,000 lives a year and targeted lung health checks is one of the first projects to roll out following publication. Lung cancer scanning trucks that operate from supermarket car parks are being rolled out across the country in a drive to save lives by catching the condition early, NHS England announced” (8 Feb 2019)31. NHS long term plan (2019). Available at: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>2. Barbara Gill (2017) ACE Lung Cancer Pathway Cluster. Improving diagnostic pathways for patients with suspected lung cancer. Available at: <https://www.cancerresearchuk.org/sites/default/files/ace_lung_pathways_final_report_v1.5.pdf>3. NHS Long Term Plan (2019) Lung cancer screening rollout: <https://www.longtermplan.nhs.uk/nhs-to-rollout-lung-cancer-scanning-trucks-across-the-country/> |
| 6 | Royal College of Nursing | General | Nurses caring for people with Lung Cancer were invited to review the draft quality standard. There are no further comments to make on this document on behalf of the Royal College of Nursing. Thank you for the opportunity to participate. |
| 7 | Royal College of Physicians (RCP) | General | The RCP is grateful for the opportunity to respond to the above consultation. We have liaised with our National Lung Cancer Audit (NLCA) Team and would like to make the following comments.* The NLCA supports the quality standards and will do it’s best to reflect them in its data collection, analysis and reporting.

It is disappointing that there is no QS that reflects the quality of holistic care given to the majority of patients with lung cancer who have advanced incurable disease and who succumb quickly to their illness. |
| 8 | Roy Castle Lung Foundation | General | No substantive comments. |
| 9 | The Society and College of Radiographers | General | The Society and College of Radiographers wonder if one of the quality statements should address the variation that occurs during the period between presentation and diagnosis and before the clinical nurse specialist is involved? <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/11/Annual-Statistical-Release-2017-18-PDF-1.6MB-1.pdf>. This signifies a difficult time for patients, filled with uncertainty and anxiety for the whole family where no one really knows what is happening or how long it is going to take. The Society and College of Radiographers would welcome a statement that ensures better communication with the patient at an earlier stage. The standard no longer indicates a timescale for referral to a cancer specialist (as in statement 2 of the 2012 QS17) which given the increasing pressures on diagnostic imaging services may contribute to increased waiting times in the future. |
| 10 | The Society and College of Radiographers | General | The Society and College of Radiographers welcomes the inclusion of new statements 2,4 and 6. |
| 11 | Society for Cardiothoracic Surgery in Great Britain and Ireland | General | Our comments have been included in the response submitted by the UK Lung Cancer Coalition.  |
| 12 | Astrazeneca | Question 1 | Yes, the Quality Standard accurately reflects the key areas for quality improvement |
| 13 | British Thoracic Society | Question 1 | Yes – it is comprehensive in its content |
| 14 | MSD | Question 1 | The overarching quality standard is welcome in its ambition and reflects many of the priority areas in lung cancer, such as the important role played by Clinical Nurse Specialists and the importance of effective and rapid diagnostics.However, this consultation’s focus on Stages I-II cancer patients does not reflect the vast majority of lung cancer cases diagnosed at Stages III-IV (66.3%). The diagnostic recommendations made throughout the quality standard are relevant across all stages of lung cancer, given the speed with which lung cancer can progress many diagnostic tools will need to be deployed along the pathway in order to make sure the most appropriate treatment option is considered for all patients. The quality statement focuses on treatments for curative intent (i.e. surgical resection) versus SACT (which 65% of late stage patients with good performance status receive) xiv, whilst all treatments should be a key area for quality improvement especially due to the large number of patients who are diagnosed at Stages III-IV. There is, for example, a complete omission of the mention of immunotherapies when in fact immunotherapies have become an integral part of lung cancer treatment, as well as being specifically referenced in the NICE treatment pathways. |
| 15 | The Society and College of Radiographers | Question 1 | Overall yes, taking briefing information into account. The Society and College of Radiographers understand that it is not the remit of the NICE quality standards group to advise with regards to screening programmes but wish to highlight the importance of further research / evidence base to investigate the contribution of screening toward early diagnosis for lung cancer patients.The Society and College of Radiographers feels there should be reference to raising public awareness amongst ethnic minority groups, e.g. translation of ‘awareness’ materials into a range of languages appropriate to the locale; this should be measurable in the same way as stated in the guideline. Interestingly, equality and diversity is considered in some statements but not all.Smoking cessation – The Society and College of Radiographers feels strongly that there is a role here for therapeutic radiographers too, though they are not mentioned. This seems to be the case with cancer guidelines in general. Radiographers could also discuss smoking cessation with family members/carers and could be measured locally.Outcome a) 4-week quit rate for adults with lung cancer who smoke – Is this the only outcome measure – why only 4 weeks? |
| 16 | British Thoracic Society | Question 2 | Yes – many data collection systems may well already be in place |
| 17 | The Society and College of Radiographers | Question 2 | With regards to diagnostics, treatment and surveillance in clinical imaging and radiotherapy departments, computer information systems are readily available to inform data collection / audit.Will the collection of this data be standardised across healthcare providers? |
| 18 | British Thoracic Society | Question 3 | This is a crucial question – and most difficult to answer. It is unlikely that all local services are currently equipped to deliver these standards – particularly; increasing public awareness, smoking cessation, lung cancer nurse specialist recruitment, CT and PET scan provision, and oncology provision (both number oncologists and treating services. Investment in all these areas is essential to deliver these standards. Naturally investment in public awareness and smoking cessation may well lead to cost savings in the future due to reduced incidence of lung cancer. |
| 19 | MSD | Question 3 | Local health authorities (e.g. CCGs, STPs and the Cancer Alliances) have very limited or no budgets for public awareness campaigns currently, and Public Health England has recently cut its national budget in this area. See further comments in table below. |
| 20 | The Society and College of Radiographers | Question 3 | Time scales for clinical imaging and radiotherapy procedures may prove challenging considering workforce shortages and aging/availability of clinical imaging and radiotherapy equipment. In particular the capacity of CT and MR imaging services to provide timely diagnosis (brain imaging) is affected by other system wide targets, for example NICE head injury guidelines, A&E waiting time targets, NICE Stroke imaging guidance etc. |
| 21 | UK Lung Cancer Coalition | Question 7  | The thoracic surgical unit in Bristol have recently updated their online surgery booking form so that on-screen pop-ups appear to remind clinicians to book/check head CT or MRI when a TNM stage consistent with stage 2 or 3 disease is recorded. It does the same thing to "nudge " documenting a Herder score when no pre-op tissue diagnosis is recorded, or to book a CPET when DLCO/FEV1 are low.  |
| 22 | EGFR POSITIVE UK (Patient Group) | Statement 1 | Public awareness is key to early diagnosis. Too many patients - 90% of our members – are diagnosed in A&E at stage IV, particularly amongst the non-smoking population. Lung cancer is increasing in the non-smoking population and there is still a strong public perception that only smokers can get lung cancer. Both GPs and the public need to be aware that this is not the case. We have seen little evidence of campaigns which seek to get this message across either locally or nationally and are concerned that current resources will not support this aim. We also feel that the definition of terms in this statement need to be broadened. A common symptom of lung cancer experienced by our members is back, neck or shoulder pain which is unexplained and does not respond to standard approaches. The emphasis on people aged 40 or over is also limiting. Lung cancer, particularly in the never smoking population, can affect adults of any age and we have members of our group who are in their twenties or thirties.  |
| 23 | MSD | Statement 1 | Structure (a)There are rich data sources available across the lung cancer pathway and related services, much of which are publicly available or available on request. This is to be welcomed and presents significant opportunity for detailed analysis. However, it may be hard to assess the local need to raise awareness, to evaluate locally coordinated campaigns and to measure the outcomes of such campaigns proposed within this statement. Much of the data is disjointed and uncollated, often relying on the impetus of individuals or organisations to pull together the data in a meaningful way. Those working in the field of lung cancer are often reliant on the National Lung Cancer Audit, which only reports annually using data from two years previously, as such it is often challenging to take a current national view of lung cancer treatment and outcomes.There are a number of different national and local organisations that hold data on lung cancer diagnosis and activity, such as:1. Public Health England
2. NHS Digital
3. Office for National Statistics
4. Local patient administration systems
5. Bespoke data collected for the National Lung Cancer Audit

The databases held within the different organisations can be linked, however a user or researcher must apply for access through the Office of Data Release or Data Access Request Service. There are also inconsistencies in the types of data collected and the quality of that data at local level potentially increasing the difficulty of evidencing and measuring the Quality Statement.[[2]](#endnote-1)Many of these datasets do not automatically interrelate and specific access must be requested to obtain them. Therefore, to support the system in analysing disparate lung cancer data that is made publicly available through the Open Government Licence, MSD has created a digital tool (CanSEE) to bring this information together and present it in a digestible and user-friendly format. The aim of the tool is to assist health professionals and commissioners, so that they can easily assemble evidence to commission lung cancer related services and establish population need.Furthermore, lung cancer data has been collated in a way that has often been slow to report. The most recent Lung Cancer Audit was for 2018, which analysed 2017 data, but did not report until May 2019. This time lag in live information will make it challenging for commissioners to assess the impact of public engagement programmes, or other related lung cancer interventions. In the absence of unified datasets in a live format through which to track the data, services will need support by way of data infrastructure, to best evidence and capitalise on any public campaigns they may wish to run.  |
| 24 | MSD | Statement 1 | Structure (b)As stated above, a lack of live datasets will make it challenging to monitor local initiatives such as the lung screening truck programme rolled out by NHS England.[[3]](#endnote-2) The stated ambition is that the “roll out has the potential to reach around 600,000 people over four years, detecting approximately 3,400 cancers and saving hundreds of lives across the country.” Given the way data is currently collected and the uncertain future of the National Lung Cancer Audit, it is unclear as to how the stated ambition will be measured or whether that information will be publicly available. |
| 25 | MSD | Statement 1 | Outcome (a-c)The measurements should encapsulate diagnosis of lung cancer at all stages rather than just Stages I-II, given that 66% of patients are diagnosed at stage III-IV patients i.  |
| 26 | Royal College of General Practitioners | Statement 1 | Can the committee consider advocating national campaigns in addition to local campaigns |
| 27 | University Hospital Birmingham | Statement 1 | Be clear on cancer campaigns NAEDI are intermittent, and impact evaluation at a local service level would be challenging, and I believe they campaigns are evaluated by NCRAS?  |
| 28 | UK Lung Cancer Coalition | Statement 1- Question 1  | Why are the words ‘Local authorities’ used here? There is a national commitment in the NHS Long term plan to fund two National Cancer Public Awareness Campaigns per year, so at least some of this work should be at a national level. At a local level should it not state that local health bodies and their partners use…..” ?As Chair of the ‘Be Clear on Cancer’ Steering Group (see above), which is responsible for overseeing the national and regional cancer public awareness campaigns, I would stress the need to re-consider the wording of statement 1 along the lines suggested above. |
| 29 | UK Lung Cancer Coalition | Statement 1- Question 2 | It is not clear how this could be measured unless it were to be part of the commissioning process in some way.Again, as Chair of the ‘Be Clear on Cancer’ Steering Group, I would confirm that there is no current method of assessing this. |
| 30 | UK Lung Cancer Coalition | Statement 1-Question 3 | Local Health authorities (e.g. CCGs, STPs and the Cancer Alliances have very limited or no budgets for public awareness campaigns and the current instructions from NHSE for the spending of Transformation Funds does not allow for spending in this area.PHE has been responsible for developing the marketing materials and strategy around these public awareness campaigns and has very recently had its budget to deliver on the NHS’s Long Term Plan’s commitment to running two national ‘Be Clear on Cancer’ campaigns each year halved, so is unable to fulfil this ambition. The evidence for the impact of these campaigns is greater for lung cancer than for any other cancer (I can send you that evidence if you need it).  |
| 31 | Action on Smoking and Health (ASH) | Statement 2 | This quality statement accurately reflects a key area for quality improvement.Smoking cessation following diagnosis of lung cancer can substantially increase life expectancy, quality of life and enable better management of the condition, with recent research showing that those who stopped smoking and survived treatment lived 1.97 years on average compared to only 1.08 years for those who continued to smoke after lung cancer diagnosis. [[4]](#endnote-3)The delivery of smoking cessation interventions for lung cancer patients who smoke is poor. 87% of male and 84% of female lung cancer cases in the UK are attributable to smoking. Nearly a third of lung cancer patients still smoke at diagnosis and estimates of between 13% to 60% of smokers with lung cancer continue to smoke after diagnosis.[[5]](#endnote-4) It is essential that all smokers with lung cancer are given advice to quit and are referred to specialist support, in line with NICE guidance NG92.[[6]](#endnote-5)Yet, findings from an analysis of over 12,000 electronic patient records show that cancer patients receive less support from their GP to quit smoking than patients with coronary heart disease, despite the former having higher rates of smoking prevalence at diagnosis (32.0% vs 18.2%, respectively. Just 24% of cancer patients were offered advice to quit, and only 13% were prescribed treatment.[[7]](#endnote-6) One year on from diagnosis, 61.7% of cancer patients still smoked, compared to 55.4% of coronary heart disease patients, demonstrating the consequence of failure to deliver smoking cessation treatment.vi Smoking cessation treatment can increase a smoker’s chances of quitting up to fourfold.[[8]](#endnote-7) Treatment for smoking cessation also only costs between £300-£6,000 per QALY,[[9]](#endnote-8),[[10]](#endnote-9) thus proving to be highly cost-effective. Indeed, smoking cessation interventions compare favourably with new, high-cost lung cancer treatment drugs like pembrolizumab, which costs around £86,913 per QALY for an increased life expectancy of 1.32 years over chemotherapy according to recent research.[[11]](#endnote-10)The recent Royal College of Physicians report, Hiding in Plain Sight: Treating Tobacco Dependency in the NHS (2018) interrogates the issue of NHS treatment of tobacco addiction in detail. The report examined NHS practices in addressing harms and costs arising from smoking among patients and argues for a comprehensive approach to treating their addiction: “smoking cessation should be incorporated… as a systematic and opt-out component of all NHS services, and delivered in smoke-free settings. It is unethical to do otherwise”.[[12]](#endnote-11) The recent NHS Long Term Plan vindicated this conclusion, committing to offer all people admitted to hospital who smoke NHS-funded tobacco treatment services by 2023/24.[[13]](#endnote-12) It is therefore an opportune moment to improve the provision of smoking cessation support for those diagnosed with lung cancer who smoke and this is right to be included in the draft quality standard. |
| 32 | Action on Smoking and Health (ASH) | Statement 2 | There should be no barriers to data collection as the local systems required are already in place: smoking status is recorded and local authority commissioned stop smoking services also record their performance. |
| 33 | Action on Smoking and Health (ASH) | Statement 2 | The statement is achievable by local services however there is a legitimate resource concern given the cuts to local authority public health budgets and the impact this has had on the provision of stop smoking services.Whilst the vast majority (97%) of local authorities still commission services which help people who smoke to quit, budgets are being squeezed by central government cuts. Between 2014/15 and 2017/18, total local authority spending in England on stop smoking services and wider tobacco control fell by £41.3 million (30%). Spending per resident smokers fell from £17.87 to £14.86. The principle reason cited for budget cuts have always been cuts to the public health grand and wider reductions in central government funding for local authorities.[[14]](#endnote-13) Therefore, whilst this statement is achievable by local systems, it could be better met with better funding of local authorities.[[15]](#endnote-14) |
| 34 | MSD | Statement 2 | Structure (a-b)The significance placed on the standing of Stop Smoking Services to lung cancer patients’ wellbeing, is welcomed given the importance of quitting smoking to lung cancer patients. It is important that a patient stops smoking during treatment, not only to improve the effectiveness of their treatment, but also their prognosis and general health[[16]](#endnote-15). Macmillan Cancer Support understand it as a crucial part of patient prehabilitation [[17]](#endnote-16). However, there has been a significant reduction in the number and resourcing of Stop Smoking Services [[18]](#endnote-17). Though it is suggested that this is in part due to the general drop in smoking rates, 72% of lung cancer cases are smoking related with many patients still being current smokers at diagnosis [[19]](#endnote-18). It is therefore vitally important that they are supported appropriately to maximise their treatment opportunities. As this consultation’s briefing paper highlights, there has been a decline in other forms of prehabilitation, with the 2017 national lung cancer organisational audit indicating that access to on-site pulmonary rehabilitation decreased from 81% in 2014 to 67% in 2017 [[20]](#endnote-19). Therefore, though the Quality Statement’s premise is welcome, it is unlikely to be achievable given the reduction in resources which may result in patients unable to access support they will need to stop smoking [[21]](#endnote-20).  |
| 35 | MSD | Statement 2 | ProcessAs above, though it is important that patients with lung cancer have access to services and are encouraged to stop smoking, most hospitals do not have on site stop smoking services. Given the patient demography of lung cancer, the rapid progression of lung cancer, and the late stage it is normally diagnosed, it may not be realistic to expect a patient to engage Stop Smoking Services over and above the urgent treatment they require. Furthermore, it may be challenging for the patient to engage Stop Smoking Services if the facilities are off site from the hospital. Also addressed in response to Quality Statement 3, the lack of access to effective smoking cessation is exacerbated by the lack of clinical nurse specialists available for lung cancer patients, who play an important role in smoking cessation advice as explored in an evidence briefing from the University of Sheffield and the National Lung Cancer Forum for Nurses (Evidence Briefing on Smoking Cessation/Tobacco Addiction Nurse-led Services) [[22]](#endnote-21).  |
| 36 | Public Health England Tobacco Control Team | Statement 2 | The recommendations throughout the Quality Standard to an evidence based “stop smoking service” might be better expressed as “evidence-based stop smoking support”. This better reflects the different structures in which stop smoking support can be provided, and also fits with the comments below which recommend that the NHS shouldn`t regard stop smoking support as a separate function, but one that the NHS should be looking to deliver as part of routine clinical care. |
| 37 | Public Health England Tobacco Control Team | Statement 2 | what the QS meansFor service providers, this should also include the provision of stop smoking support, in addition to referral. Suggested text (addition in italics): “Service providers such as primary care, community services, secondary and tertiary care) ensure that processes are in place to provide advice to adults with suspected or confirmed lung cancer who smoke about why it is important to stop smoking. Providers to ensure that they have trained stop smoking advisor capacity which is able to deliver stop smoking support to smokers. Providers to also have referral pathways to other sources of evidence-based stop smoking support”. |
| 38 | Public Health England Tobacco Control Team | Statement 2 | what the QS meansFor commissioners, this section should also reflect the need to commission in-house stop smoking support within the NHS. Suggested text (addition in italics): Commissioners (such as clinical commissioning groups and NHS England) ensure that they commission services which provide tobacco dependence treatment to adults with suspected or confirmed lung cancer who smoke, in addition to being able to refer smokers to other sources of evidence-based stop smoking support”. |
| 39 | Public Health England Tobacco Control Team | Statement 2 | what the QS meansThe final sentence for commissioners is currently misleading as CCGs and NHSE do not commission stop smoking support. Our comments above recommend that NHS commissioners should in future require their providers to deliver stop smoking support, rather than just referring smokers into a SSS. If these suggestions are accepted, then the final sentence would then be valid. |
| 40 | Public Health England Tobacco Control Team | Statement 2 | Linked to the suggested changes above, this should be amended to read, “Adults with suspected or confirmed lung cancer who smoke are referred to, and provided with, evidence-based stop smoking support within the NHS as part of their clinical treatment.” [new 2019] |
| 41 | Royal College of General Practitioners | Statement 2 | Can the committee consider adding “are offered” to the statement so it reads: Adults with suspected or confirmed lung cancer who smoke are offered referral to an evidence based stop smoking service. Patient choice is essential. It is not cost effective to make referral if the patient does not want it and will therefore not attend the appointment. |
| 42 | Royal College of Physicians (RCP) | Statement 2  | * The NLCA has lobbied for additional questions about tobacco addiction (i.e. smoking) to be added to the COSD dataset. These data items include whether lung cancer patients have a smoking status recorded, and whether they are treated for tobacco addiction. The NICE QS should specifically mention the NLCA/COSD as the data source to provide evidence of compliance.
* It would be helpful for a standard to be set for the process and outcome measures against which audit can be carried out.
 |
| 43 | University Hospital Birmingham | Statement 2 | From a hospital trust perspective it would be challenging to provide data on referral to stop smoking services in this region given the absence of hospital based stop smoking services, relying on patients to self-refer to community services. Community services would need to provide data on participation and quit rates. Resources should be available to deliver smoking cessation treatment to all active smokers with confirmed lung cancer within the organisation. |
| 44 | UK Lung Cancer Coalition | Statement 2- Question 2 | This will be difficult to measure because records of referral to smoking services are not currently kept, so a new method would have to be introduced. |
| 45 | UK Lung Cancer Coalition | Statement 2- Question 3 | Smoking cessation services, both community and hospital based, are very limited in many areas, so many, if not most, would struggle to meet this target. |
| 46 | MSD | Statement 3  | Structure (a-b)Access to a lung cancer nurse specialist (LCNS) is one of the important contributing factors to improving long-term patient survival. Data shows where patients are seen by a lung cancer nurse specialist within a fully-functioning multidisciplinary team (MDT), they are more likely to have a good experience of care and this can often lead to better outcomes. Patients seen by a lung cancer nurse specialist are also more likely to receive active treatment [[23]](#endnote-22). The National Lung Cancer Audit (NLCA) recommends 1 whole-time equivalent nurse for an annual caseload of 80 new patients, but the average caseload for lung cancer nurse specialist across the UK is closer to 200 patients. The UK Lung Cancer Coalition has also reported on the role that an LCNS plays in MDT [[24]](#endnote-23). Current capacity levels will add extra burdens on an LCNS’s ability to effectively participate in MDTs.Furthermore, the National Lung Cancer Forum for Nurses highlights concern that specialist nursing posts are often placed under threat during times of financial austerity [[25]](#endnote-24). This issue, combined with issues around the definition of the role of a clinical nurse specialist (CNS), and increasing capacity burdens, is a significant concern in terms of workforce wellbeing. Additionally, the pressures CNSs are under may impact patient experience, both in terms of the quality of their interaction with their nurse as well as the capacity of the nurse to stay abreast of latest treatments and best options for their patients.71% of patients were assessed by a LCNS, the audit standard is 90%. In summary, the above comments highlight the difficulty of achieving this in light of the current workforce challenges. In England only 58% of patients had a CNS present at diagnosis when the audit standard is 80% [[26]](#endnote-25).  |
| 47 | MSD | Statement 3  | Process (c)It is challenging to validate the National Cancer Patient Experience Survey results regarding whether a patient has received a named nurse due to the ambiguity around the definition of the CNS role, and whether patients are able to distinguish between one nursing role and another.[[27]](#endnote-26)  |
| 48 | MSD | Statement 3  | Outcome (a)It would be valuable to establish nursing capacity to validate NLCA data on CNS access for patients. This could be done through questionnaires that establish/explore the frequency (i.e. number of interactions whilst on treatment) or length of time spent with the patient on average. In addition, questions which assess how supported patients feel after their interaction with the nurse may also assist in quantifying the important role CNSs play. |
| 49 | Roche Products and Roche Diagnostics UK | Statement 3 | The rationale for statement 3 explains “Lung cancer clinical nurse specialists can provide specialist guidance and support at all stages of care and treatment for adults with lung cancer and their family and carers.” To increase the quality of standard of care for lung cancer patients in this area a time frame for access to the service should be included. We suggest an expansion of the statement to a more generic version such as “Adults with suspected or confirmed lung cancer have access to a named lung cancer clinical nurse specialist within an appropriate time scale.” This would support an increased awareness from the patient regarding their diagnosis and access to timely and appropriate treatment as identified by two papers below;1.Stewart & Tata (2018) Are working practices of lung cancer nurse specialists associated with variation in peoples’ receipt of anticancer therapy? <https://doi.org/10.1016j.lungcan.2018.07.022> 2. Tod et al., (2015) Lung Cancer treatment rates and the role of the lung cancer nurse specialist: a qualitative study <https://doi.org/10.1136/bmjopen-2015-008587> Both alluding to the idea that earlier nurse specialist contact is associated with an increased receipt of therapy whether it is suspected or confirmed. |
| 50 | Royal College of General Practitioners | Statement 3 | Can the committee consider expanding the sentence to detail how the access to the nurse specialist should be available and consider including the use of email, telephone and face to face appointments |
| 51 | Royal College of Physicians (RCP) | Statement 3  | * Although it is stated that ‘Royal College of Physicians National Lung Cancer Audit recommends 1 whole-time equivalent nurse for an annual caseload of 80 new patients’, this is itself based on National Commissioning Guidance which should be referenced in the text.
* It would be helpful if a standard could be set for the proportion of patients with access to a specialist nurse, perhaps by referencing the standards set by the NLCA.
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| 52 | University Hospital Birmingham | Statement 3 | The data is available– requires specific retrospective audit data collection. Clinical pathways are in place locally and therefore variation should not be found although work is in progress to align pathways in different sites within the merged organisation. |
| 53 | UK Lung Cancer Coalition | Statement 3 - Question 2 | Whether a patient has seen a Lung CNS is a field in the Cancer Outcomes & Services Dataset (and therefore the National Lung Cancer Audit - NLCA) but does not explicitly ask whether that CNS contact implies the allocation of them as a key worker. |
| 54 | UK Lung Cancer Coalition | Statement 3- Question 3 | Most areas of the country have numbers of lung CNS well below that proposed in the Commissioning Guidance of 1 wte per 80 new cases per year. CNSs are also being asked to take on basic nursing duties in many areas, further limiting their capacity to meet this standard.  |
| 55 | Alliance Medical Ltd | Statement 4 | PET CT is a vital element in assessment with patients with curative disease – in practice a number of cases with clear evidence of stage 4 disease are referred for PET CT, this does not add anything to the outcome. Will guidance on when examinations should be considered / not appropriate be reviewed at some point?  |
| 56 | British Society of Thoracic Imaging | Statement 4 | Staging with PET-CT and brain imaging- the statement in its draft form is a little ambiguous: “ Adults with lung cancer have investigations to complete diagnostic staging and assess lung function before starting treatment with curative intent.”  Does this mean 100% of patients should have the tests?  This should be aimed for but will not be achievable because of claustrophobia etc.. |
| 57 | British Society of Thoracic Imaging | Statement 4 | “Commissioners ensure that providers can offer brain imaging to adults with non- small-cell lung cancer without delay. “ This seems to mean that all these patients being treated for cure should have brain imaging as above. We don’t routinely perform MRI, and what is without delay? |
| 58 | British Society of Thoracic Imaging | Statement 4 | There is wide variation in practice with regard use of CT and MRI for imaging the brain in candidates for curative intervention. For instance one respondant from the BSTI working at a major UK teaching hospital commented that: “We are struggling to cope with the new recommendations on head scans and I still don’t believe the evidence is there for asymptomatic stage II patients. We are only doing CT - don’t have the capacity for MRI.” |
| 59 | Clinical Expert Group for Lung Cancer NHSE | Statement 4 | The term “Diagnostic Staging” is not in mainstream usage and should be clearly defined |
| 60 | Clinical Expert Group for Lung Cancer NHSE | Statement 4 | Although the intention here is supported, it is not clear why this statement is restricted to curative intent. A significant proportion of patients that are initially thought suitable for curative intent do not receive the treatment for good reasons but still need staging and lung function – a quality measure here is how this approach is applied to all POTENTIALLY suitable for curative intent treatment |
| 61 | EGFR POSITIVE UK (Patient Group) | Statement 4 | All NSCLC patients should have full investigations to complete diagnostic staging whether the treatment is with curative intent or not. Whilst accepting the point on curative intent, we are concerned this may rule out treatment options for many patients who are not curable. Some members report local hospitals telling them there is no point in mutation testing because they are already stage IV. However, targeted therapies have changed the outlook for many patients who have stage IV disease, many of whom have can have a good quality of life for many years.There is also, from the experience of our members, too much local variation in imaging for NSCLC. Of serious concern is the approach to brain MRIs whether intent is curative or not. 50% of NSCLC patients develop brain metastases and knowledge of the existence of brain metastases is key both at the start of treatment and as treatment progresses. Some oncology departments do not offer brain MRIs until symptomatic whilst others routinely offer on diagnosis and then every six months. This is often baffling and distressing for patients who, on occasions, are forced to battle to have the brain MRIs they need. It would be useful if there were standard guidelines on the use of brain MRIs which, we believe, should be offered routinely with a diagnosis of stage III or IV NSCLC. This is particularly relevant as some targeted treatments have better CNS benefit than others and there is an argument that all those facing systemic treatments should be assessed fully included a brain MRI before embarking on SACT. Ultimately, this would reduce costs as patients would be receiving treatment appropriate to full staging and diagnosis. |
| 62 | MSD | Statement 4 | Definitions of terms used in this quality statementThe definition of treatment for curative intent is limited, since it does not appear to reflect recent advances in treatment options. It specifically references “surgery; radiotherapy; chemotherapy and chemoradiotherapy” and makes no reference to immunotherapies, which now play a common and vital role in SACT. This is despite the fact that an immunotherapy is listed through the NICE treatment pathways under curative intent [[28]](#endnote-27). This quality statement should not be limited to treatment with curative intent but ought to encompass all treatment options to allow patients to be offered the most appropriate treatment.  |
| 63 | Roche Products and Roche Diagnostics UK | Statement 4 | We would like to take this opportunity to raise two areas that we believe would also be important to highlight in statement 4 for the Quality Standards: 1. The inclusion of ‘curative intent’ implies the statement reflects only patients with early stage disease who could be cured.  Lung cancer patients with metastatic disease/later stage also require investigations to complete diagnostic staging and assess lung function before treatment.
2. A time frame could be included within the statement in which the pathological diagnostic tests results are available. The guidance from the National Lung Cancer pathway is within 3 days for subtype and 10 days for molecular markers (<https://www.cancerresearchuk.org/sites/default/files/national_optimal_lung_pathway_aug_2017.pdf>). Further, it may prove useful to measure whether regions across the country are meeting these timelines and to identify where services need to be focused.
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| 64 | Royal College of Physicians (RCP) | Statement 4  | * The NLCA will look to include analysis and reporting on brain imaging in future.
* The proportion who have PET-CT before treatment is already measured and reported by the NLCA and so this can be referenced within the text.
* The proportion of patients who have spirometry is already measured and reported by the NLCA and so this can be referenced within the text. TLCO is a COSD field and so the NLCA will look to include analysis and reporting on this in future.
* We are not convinced that measuring 1-year and 5-year survival are good ways to determine the quality of diagnostic pathways.
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| 65 | The Society and College of Radiographers | Statement 4 | The Society and College of Radiographers welcomes the inclusion of quality statement 4: Adults with lung cancer have investigations to complete diagnostic staging and assess lung function before starting treatment with curative intent, but we feel it does not go far enough. The importance of early/immediate referral should be stressed to give patients the chance of curative treatment, including minimal delays between range of investigations; a role for advanced/consultant radiographers specialising in lung cancer to ensure this happens – have they been considered? |
| 66 | University Hospital Birmingham | Statement 4 | The data is collected and should be available by audit of case records  |
| 67 | UK Lung Cancer Coalition | Statement 4 - Question 1 | It is not clear why this indicator is limited to patients with curative intent; surely every patient needs full diagnostic, staging and molecular pathological work-up? Suggest simply removing the words ‘…with curative intent.’ from the statement. |
| 68 | UK Lung Cancer Coalition | Statement 4- Question 2 | The NLCA collects data on many aspects of the diagnostic and staging pathway, but the completeness of many fields is poor and some items are not well covered, e.g. EBUS and Lung Function. |
| 69 | UK Lung Cancer Coalition | Statement 4 - Question 3 | Most patients will in theory have access to all the necessary investigations, the most common problem is timeliness. There are significant limitations in many areas for the necessary rapid turn round times for PET-CT Scanning, EBUS and Molecular Pathology. Turn-round times for PET-CT are getting very slow in some areas. Access to brain MRI is significantly limited in some areas. |
| 70 | British Thoracic Society | Statement 4 - Question 4 | The main variation will be in availability of diagnostic tests – which may indirectly lead to a degree in variation in usage – in order to minimise pathway lengthening. Almost every secondary care service will adhere to the NICE guidance for the investigation of lung cancer – hence the desired use of diagnostic tests will not vary much at all. |
| 71 | The Society and College of Radiographers | Statement 4- Question 4 | Yes – GIRFT review of lung cancer services are expected to highlight variation. There is wider data available, for example via model hospital dashboard. Anecdotally, Radiographers report via The Society and College of Radiographers imaging networks that there is current variation.The demand for PET-CT has grown over the past few years <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/11/Annual-Statistical-Release-2017-18-PDF-1.6MB-1.pdf> and not all diagnostic services have access to PET-CT <http://www.ncri-pet.org.uk/pet_facilities.php>. This may introduce additional costs and delays to diagnosis and treatment and impose travel requirements on patients and carers. |
| 72 | UK Lung Cancer Coalition | Statement 4- Question 4 | We believe that most people in whom a PET-CT scan is required are getting it, but in many cases, there are delays of up to a month between requesting the scan and receiving the report.The use of routine brain imaging as part of the work up prior to curative therapy probably varies widely across the country and access to brain imaging with MRI (the gold standard when looking for cerebral metastases) is severely limited in some areas, meaning that brain CT is being carried out instead which is less than ideal. Full lung function is available everywhere, thought timeliness is an issue in many areas. |
| 73 | Astrazeneca | Statement 5 | top of page 25We recommend amending the following statement ‘support immunohistochemical and/or genetic analysis to detect specific biomarkers that predict whether targeted treatments are likely to be effective, for example, epidermal growth factor receptor (EGFR) mutations, anaplastic lymphoma kinase (ALK) gene rearrangement, or programmed death-ligand 1 (PDL-1) expression’ to read as:Support reflex immunohistochemical testing and/or genetic analysis to reduce delays in detecting specific biomarkers that predict whether targeted treatments, for example epidermal growth factor receptor (EGFR) mutations, anaplastic lymphoma kinase (ALK) gene rearrangement, or programmed death-ligand 1 (PDL-1) expression, are likely to be effective and enable better and more accurate clinical decision making.  |
| 74 | Astrazeneca | Statement 5 | top of page 25We would suggest further strengthening the language in this section to support the case for targeted treatments prior to IO use and the importance of waiting for test results before making a decision on treatment options. |
| 75 | British Society of Thoracic Imaging | Statement 5 | My only comment would be that we welcome the recognition of the importance of access to thoracic radiologists with skills in image guided lung biopsy Should benign resection rate should be a quality standard? I may be wrong, but I don’t think it is in the 2012 statement? With screening being rolled out, this will become a more important quality metric, and is another driver to ensure appropriate skills for image guided biopsy are available. |
| 76 | British Society of Thoracic Imaging | Statement 5 | QS5-tissue sampling in advanced stage disease.  This is more likely to take the form of neck node or metastases sampling, rather than biopsy of the lung primary, despite the emphasis on thoracic radiologists and lung biopsy.  Quality measure 5c) states Evidence of audit of the local test performance of endobronchial ultrasound-guided transbronchial needle aspiration (EBUS-TBNA) and endoscopic ultrasound guided fine-needle aspiration (EUS-FNA), whereas 5a) states Evidence of the availability of thoracic radiologists experienced in performing lung biopsies for adults with lung cancer. I agree with Anand about the importance of thoracic radiologists for lung biopsy and so local test performance should also be undertaken for lung biopsy, not just EBUS and EUSUnless I have missed it, there is no comment on image guided lung biopsy for lung cancer with curative intent. |
| 77 | British Society of Thoracic Imaging | Statement 5 | “Providing there is no risk to the person, tissue samples of sufficient size and quality should be taken to support pathological diagnosis”There is always a risk, so I think this should be amended to reflect this. |
| 78 | Clinical Expert Group for Lung Cancer NHSE | Statement 5 | Is it helpful to focus this statement on adults with advanced non-small-cell lung cancer or should it focus on a wider population? No This should be applied to a wider group because treatment initially intended is not always that eventually delivered and targeted treatment is given to other stages |
| 79 | Clinical Expert Group for Lung Cancer NHSE | Statement 5 | Although other (earlier) stages of NSCLC may be tested for molecular markers, for patients with earlier stage disease, the full range of markers is not an assessment of quality, as EGFR, ALK and ROS-1 do not influence patient treatment, as they do in patients with advanced disease. It can be argued that PD-L1 assessment is relevant, due to Durvalumab availability post CTRT in PD-L1 positive patients, and so this may be a quality standard in this particular group.  I note that ROS-1 assessment is not included, presumably as Crizotinib in this indication is available via the CDF rather than standard commissioning, however, it should be included as this is an internationally accepted standard treatment. |
| 80 | EGFR POSITIVE UK (Patient Group) | Statement 5 | It is helpful to focus this statement on adults with NSCLC if there remains too much local variation in way tissue samples are taken. However, where possible patients should be offered less invasive liquid biopsy as a first option for molecular testing in advanced NSCLC. We are puzzled this is not mentioned in these quality standards. More widespread use of blood biopsy is less invasive, provides accurate results and could improve the numbers of patients eligible for targeted therapies – currently too many patients eligible for targeted therapies are not being assessed for them. |
| 81 | MSD | Statement 5 | Structure (b)According to the UK Lung Cancer Coalition’s (UKLCC) January 2019 report – Molecules Matter - there is a lack of a coordinated strategy to ensure that there is a common approach to testing across the country and currently there are no data available on activity, performance or the link between testing, treatment and outcomes. Therefore, it may be challenging to evidence local processes which ensure adults with NSCLC are having samples taken in a suitable form which allows assessment of biomarkers. In October 2018 NHS England launched a network of seven national genomic laboratory hubs (GLHs) which will organise genomic testing in defined geographical areas across England. The GLHs will support the delivery of the Genomic Medicine Service (GMS) which should provide a world class resource for the NHS. Despite these steps forward rolling out the GMS, which will be of huge benefit to lung cancer patients, there is much which needs to be done to ensure that the service is optimised to deliver current and emerging molecular diagnostic tests in lung cancer in the next 2-5 years which could support achievement of this QS [[29]](#endnote-28). |
| 82 | Pfizer | Statement 5 | Under page 25 (Definitions of terms used in this quality statement; samples taken in suitable form) – bullet point 2 should also include ROS1 gene mutations as part of their example (i.e – in addition to ALK, EGFR and PDL1 listed by NICE).Reason: ALK, EGFR and ROS1 are recommended for reflex (routine) testing by various guidelines including ESMO.  Despite this, our own data indicates that ROS1 testing is still sub-optimally performed in the UK.  It is important therefore that clinicians are aware that adequate tissue sampling is of critical importance to facilitate the testing of these various predictive biomarkers (e.g. EGFR, ALK, ROS1 and PDL1) to be performed in a timely and adequate manner.   |
| 83 | Royal College of Pathologists | Statement 5 | This statement is in line with existing best practice. Measuring these standards should be feasible with existing lung cancer audits returns. Measurement is also feasible through the Cancer Outcomes Services and Dataset (COSD) reporting standards which should be adopted by all UK pathology laboratories. However take up has been slower than anticipated and may not be fully complete across the UK yet.  |
| 84 | Royal College of Physicians (RCP) | Statement 5 | * Although measuring the performance of EBUS/EUS is a good idea, the QS does not give any indication of how this should be measured, and how it should differentiate diagnostic from staging procedures; neither is there any indication of a standard for such test performance that can be audited against to determine quality.
* Measuring the proportion of patients with stage III/IV lung cancer who have a pathological diagnosis is a good measure, but depends on case-mix. We would suggest limiting this measure to patients with ‘good’ performance status 0-1 where the standard can be set very high since it is this patient group that actually benefit form pathological confirmation.
 |
| 85 | University Hospital Birmingham | Statement 5 | The data is available – requires specific retrospective audit data collection. Agree focus on advanced NSCLC rather than early stage disease |
| 86 | UK Lung Cancer Coalition | Statement 5 - Question 2 | There is no way currently that the appropriateness and quality of tissue samples that relate to molecular testing is measured. It is our belief that, at least for EBUS, every provider should be required to produce data on QA for this investigation.  |
| 87 | UK Lung Cancer Coalition | Statement 5- Question 3 | The appropriateness and quality of biopsy for molecular diagnostic purposes varies a great deal around the country and QA metrics need to be put in place to ensure best practice.  |
| 88 | The Society and College of Radiographers | Statement 5- Question 5 | Taking the information contained in the briefing paper into account, yes The Society and College of Radiographers feels it is reasonable to focus on this group related to poor outcomes. |
| 89 | Astrazeneca | Statement 5 – Question 5 | In order to contribute to improvements in lung cancer diagnoses at stages I or II and 1-year and 5-year lung cancer survival rate, we would recommend the focus of the statement be extended to all lung cancer patients, rather than restricted to adults with advanced non-small-cell lung cancer.  |
| 90 | British Thoracic Society | Statement 5- Question 5 | This should apply to a wider population of lung cancer patients, and apply to all relevant cases where at all possible |
| 91 | MSD | Statement 5 – Question 5 | Current immunotherapies are relevant to the treatment of non-small cell lung cancer. Please see comments in table below. |
| 92 | UK Lung Cancer Coalition | Statement 5 -Question 5 | It is our view that there is a great deal of overlap between the issues covered in statements 4 and 5 and that the recommendation should be that all patients have a full diagnostic, staging and biomarker work up appropriate to their stage. So we would ask that statement 4 applies to all patients and to statement 5 should also apply to all patients since all it is suggesting is that tissue samples of sufficient quality for molecular testing are taken, not that all patients have those tests carried out. Also, patients with stage IIIa should be specifically included in any stage-specific statement.  |
| 93 | Clinical Expert Group for Lung Cancer NHSE | Statement 6 | All patients in this group should be assessed, but the key here is how. Most patients in this group who are fit enough should be assessed for potentially curative treatment if they are poor PS (3/4) it may not be appropriate to put the patient through assessment for a treatment that they are not going to be well enough to receive |
| 94 | MSD | Statement 6 | RationaleAs mentioned above, this quality statement (QS) should not be limited to adults with stage I-II NSCLC with a good performance status, nor should it focus solely on treatment with curative intent. This QS should be broader in its focus to include all NSCLC stages in addition to SACT. This suggestion is in light of the large proportion of lung cancer patients diagnosed at stage III-IV i in addition to the number of immunotherapies featuring in the NICE treatment pathway which have shown improved overall survival ii. It should not just be adults with NSCLC stage I-II and a good performance status whom are involved in their treatment decision this precedent should apply to all NSCLC cancer patients.  |
| 95 | Royal College of Physicians (RCP) | Statement 6  | * ‘Proportion of adults with non-small-cell lung cancer stage I or II and good performance status who are satisfied that treatment options were explained to them.’ - although NCPES asks about explanation of treatment options, it does not differentiate by stage or PS and so cannot be used to derive this measure.
* Our experts are not sure that measuring quality of life, whilst very important, is actually relevant to the quality statement of offering curative treatment.
 |
| 96 | University Hospital Birmingham | Statement 6 | The data is available. the pathways are in place in our organisation to routinely assess stage 3a for curative intent |
| 97 | UK Lung Cancer Coalition | Statement 6 - Question 2 | This is currently available via the NLCA.  |
| 98 | British Thoracic Society | Statement 6 – Question 6 | Patients with Stage IIIA should certainly be considered for treatment with curative intent – and we would expect this to occur at every MDT. |
| 99 | The Society and College of Radiographers | Statement 6 – Question 6 | The complete implementation of SABR should be a requirement in relation to curative treatment, especially in this site and should be a strong recommendation in these guidelines |

## Registered stakeholders who submitted comments at consultation

* Action on Smoking and Health (ASH)
* Alliance Medical Ltd
* AstraZeneca
* British HIV Association (BHIVA)
* British Society of Thoracic Imaging
* British Thoracic Society
* EGFR Positive UK
* MSD
* NHS England – Clinical Expert Group for Lung Cancer
* Pfizer
* Primary Care Respiratory Society
* Public Health England - Tobacco Control Team
* Roche Products and Roche Diagnostics UK
* Royal College of General Practitioners
* Royal College of Nursing
* Royal College of Pathologists
* Royal College of Physicians
* Roy Castle Lung Foundation
* The Society and College of Radiographers
* UK Lung Cancer Coalition (including Society for Cardiothoracic Surgery)
* University Hospital Birmingham
1. PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees. [↑](#footnote-ref-1)
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