

National Institute for Health and Clinical Excellence

**Lung cancer
Quality Standard Consultation Comments Table**
28 October – 25 November 2011

PLEASE NOTE: Consultation comments have been grouped for analysis purposes, potentially resulting in some reordering and duplication of comments. Responses are provided in relation to the statement number allocated in the table.

ID	Stakeholder	Statement No	Comments	Responses
001	Medicines and Healthcare Products Regulatory Agency	General	We do not have any comments to make on the below consultation.	Thank you.
002	National Lung Cancer Forum for Nurses	General	We would want to see a greater emphasis on communication, provision of information and decision making , MDT working, access to Clinical Trials, key Audit questions, integration of the Key Worker concept.	Communication, provision of information and decision making are important themes for all NHS care. The NICE quality standard on 'patient experience in adult NHS services' (please see statements 5 and 6), which is cross-cutting and referenced in this quality standard, covers this area in more detail. MDT working and the key worker concept are key themes throughout the final quality standard. Please see statements 2, 3, 4, 9 and 10 for examples of this. Access to clinical trials is outside the scope of this quality standard.
003	National Lung Cancer Forum for Nurses	General	Should the standards become more generic? e.g. 'All patients to be considered for treatment appropriate to their stage of disease in a timely fashion and in accordance with NICE guidance'. 'All patients with Stage I and II lung cancer should be reviewed by a Thoracic Surgeon'.	NICE quality standards are a set of specific, concise statements that cover a single concept or aspect of care that can be measured. Each statement focuses on one area of care where practice is variable, or when implementation can have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.
004	British Lung	General	The British Lung Foundation recommends that the Quality statements are	Thank you for your comment. We believe the

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	Foundation		organised to follow the typical lung cancer patient journey and two additional statements have been included to reflect this.	quality standard reflects the typical lung cancer patient journey.
005	Kent and Medway Cancer Network	General	This document is a collaboration of comments based upon 2 Trust Lung MDM's within Kent & Medway	Thank you.
006	Roche Products Ltd	General	Roche believes this is a valuable and essential quality standard and welcome the opportunity to respond to the consultation process. We feel this quality standard appropriately covers a wide range of topics from prevention to end-of life care. In particular we whole-heartedly support quality statement 5, which addresses the important role of the lung cancer clinical nurse specialist; and quality statement 12, which addresses the importance of specialist assessment to ensure effective diagnoses and appropriate treatment. Based on Roche's areas of expertise and experience we have chosen to specifically comment on those quality statements relating to tissue diagnosis (QS 10), access and choice of systemic therapy (QS15) and follow up regime after therapy (QS17). We have where possible also addressed the specific questions put forward by NICE.	Thank you for your support. These statements appear as statements 4, 9 and 10 in the final quality standard.
007	British Thoracic Society	General	The development of quality standards in lung cancer care is welcomed. However, the burden on lung cancer teams to collect data and evidence to support these standards should not be underestimated. These standards should be incorporated into/replace Peer Review so as to maximise the benefit and minimise the bureaucracy. It is important that teams are adequately resourced so that clinical time is maximised for the benefit of patient care. Local arrangements for agreeing targets are welcomed, but must not be determined by commissioners alone, but through dialogue with clinical teams, and based on both past performance and national data/trends.	Where possible, measurement of the quality standard should be, at least in part, supported by data that is already available or could be available utilising existing data collection processes. Relevant measures from the National Cancer Peer Review Programme and the National Lung Cancer Data Audit are highlighted in the final quality standard to support services in measuring achievement of the statements.
008	Lilly UK	General	We note that TA190 (Pemetrexed for the maintenance treatment of non-small-cell lung cancer) is not included as a development source – we would like to ensure all aspects of treatment have been considered in the development of this quality standard, including maintenance therapy.	The final quality standard includes reference to maintenance therapy in statement 12, and the evidence sources section has been updated accordingly.
009	Department of Health	General	The above rankings of the Qs are an illustration; the LCAMAG group believes there are sufficient opportunities to merge Qs to keep the number down to 15. Key generic statements would be: All patients to be considered for treatment appropriate to their stage of disease in a timely fashion and in accordance with NICE guidance.	Thank you for your suggestion. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement; please see statements 9, 10, 11 and 12 which cover

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			All patients with Stage I and II lung cancer should be reviewed by a Thoracic Surgeon.	appropriate treatment and involvement of specialists.
010	RCGP and the Primary Care Respiratory Society	General	<p>Will the quality standard improve early detection and management of lung cancer in primary care? If not – what changes or additions would you suggest so that it does?</p> <p>Please see response to Q1, above (marked *). Common symptoms of lung cancer tend to be non-specific. We also know that many early lung cancer symptoms are normalised by patients and not presented to GPs (Corner et al, 2005; 2006), even though this group make greater than average use of GP services in the year before diagnosis (Hamilton, 2005). Early symptoms are likely to be missed by GPs, or explained in other ways and not lead to urgent referrals. Clinical decision support aids are required that can assist GPs to elicit a full range of potentially relevant symptoms, and then provide predictive values for Lung Cancer, thereby supporting GPs faced with non-specific symptoms. Research is on-going to develop and evaluate clinical prediction tools. The quality standard needs to recommend the systematic use of evaluated clinical decision support aids for patients presenting with potential lung cancer symptoms (explained or not) in primary care.</p> <p>As stated earlier, having clear clinical guidelines of when to suspect lung cancer even with normal CXR are very important.</p> <p>We need GP open access to CT/MRI scanning nationally with guidelines on how often to screen high risk patients with asbestos exposure/high risk etc. Referring everyone with possible lung cancer symptoms would overwhelm our respiratory services to beyond breaking point, national open access scanning would prioritise those who need to be seen within 2 weeks with definite tumours.</p> <p>Hertfordshire has been running projects on screening patients in primary care, supermarkets etc to pick up at risk patients for COPD and stop smoking projects – it needs proper funding but can be done successfully in primary care but has to be flexible to accommodate different populations – inner city to rural for example and use new technology – new spirometers, text messaging for stop smoking etc – keep guideline simple and allow flexibility on what you provide.</p> <p>Why not ban smoking — we would see the benefits within 40 years easily.</p> <p>Reductions in myocardial infarctions already seen since ban of smoking in public.</p>	<p>Thank you for your comments. The topic expert group identified the development sources they felt were most relevant to developing the standard, within the framework of the quality standards development process. The quality standards are based on evidence-based recommendations from national accredited guidance, i.e. the NICE Lung Cancer clinical guideline. The quality standards do not seek to reassess or redefine the evidence base.</p> <p>Promoting a ban on smoking is outside the remit of NICE quality standards.</p> <p>The topic expert group are aware of both ongoing and published work on predictive models. However, while such tools could support measurement, at present it is difficult to sign-post a specific tool where there has been no systematic evaluation of the evidence that meets NICE standards.</p> <p>Your comments on GP open access to CT scanning have been noted. However, for the reasons stated above it is outside of the remit of the quality standard to consider additional evidence beyond that which was assessed in the development of the source guideline. Please refer to the full clinical guideline for detailed summary of the underpinning evidence base for the clinical recommendations on which the quality standard is based.</p>
011	RCGP and the Primary Care Respiratory Society	General	<p>Statements recommend losing, or which could be combined in order to reduce total to 15?</p> <p>Incorporate statement 11 into 13 and 10 into 9?</p>	<p>Thank you for your suggestions. The final quality standard has been revised down to 15 statements. All suggestions for additional</p>

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			<p>Smoking standard not appropriate for all and should be combined into others especially if surgical or curative treatment. Standard 2 this has been already done and warnings on cigarette packets etc. 1 5 and 6 can be combined in 2 and 4 and throughout the pathway.</p> <p>The diagnostics statements could be put together in one statement re appropriate tests and samples.</p> <p>Care re specialist nurse important but could be amalgamated with holistic assessment.</p> <p>Other possible statements: Ban smoking, screen patients in primary care by whatever means successfully works in your practice population and is legally and ethically sound, open access CT scanning with guidelines on how often screen at risk, see consultant team within 2 weeks where possible, MDT approach where possible, lung cancer support team by most suitable provider available for that population of patients where possible, use latest research to provide most up to date treatments to improve cure rates and ethically approved, audit results and compare nationally and internationally, national fund for cancer treatment costs, palliative care - either funded by NHS totally or separate guidelines to cover all providers.</p>	<p>statements were discussed by the topic expert group who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements.</p>
012	RCGP and the Primary Care Respiratory Society	General	<p>Primary care is being overwhelmed with an aging population requiring palliative care services not fully funded on the NHS – its taking up a lot of time in GP to manage patients to die at home. There are not enough hospice beds for those that need them GPs know how to do it –but have limited time and staff to provide the service and no control on what the charitable based services provide. They are very good mostly but if they can't provide something you can't do anything about it. – if you raise an expectation for something that cannot be provided on the NHS then why have it in the NHS guidelines – should be a separate guideline for all providers on palliative care services and therefore not NHS based.</p> <p>The thing about guidelines is that they are a guide only but they do go out of date quickly – keep short, to the point and allow innovation and flexibility.</p>	<p>Thank you for your comments. NICE quality standards define what high quality care should look like in the NHS, and apply to all providers of care to NHS patients.</p> <p>The topic expert group identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process.</p>
013	Teenagers and Young Adults with Cancer	General	<p>TYAC would support the draft quality standard but would like to emphasise that all young people (16-24) are also linked in with their local teenage and young adult services, this includes ensuring that all 16-24 year olds are discussed at a TYA MDT as well as the site specific MDT. Young people need the best medical management as with all lung cancer patients and their families, but they also have specific psychosocial needs related to their age that need support.</p>	<p>Thank you for your comment. The scope of the quality standard includes all adults (16 years and over), but it is not expected that each statement would apply to all age groups.</p>
014	Royal College of	General	The draft statements seem comprehensive	Thank you for your comment.

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015	Nursing Royal College of Nursing	General	If using the National Lung Cancer Audit as the main source of data, then data set should be modified to include reasons for exceptions (for example, draft quality statement 16 - reason patient with small cell lung cancer not assessed by thoracic oncologist within one week). This will reduce the need for local audit for the proposed eighteen quality measures, which would be a burden on already stretched resources.	Suggested data sources are not definitive sources of data to support quality measures but are examples of existing national data collection which may be relevant, in part at least, to the quality measure. The topic expert group prioritised measures they considered most important for measuring the quality statements. Relevant existing measures are highlighted in the final quality standard but it is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full. The quality standard will also be reviewed for the development of potential indicators for both the Quality and Outcomes Framework and the Commissioning Outcomes Framework. For the Commissioning Outcomes Framework this will involve testing of potential indicators and full public consultation.
016	Macmillan Cancer Support	General	<p>Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care.</p> <p>Macmillan Cancer Support is a member of the United Kingdom Lung Cancer Coalition (UKLCC). The UKLCC is a partnership of the leading charities with an interest in lung cancer, clinicians and healthcare companies and believes it is vital that the lung cancer quality standard sets out clearly what constitutes good clinical practice, enabling services to improve lung cancer outcomes and patients' experience care.</p> <p>The UKLCC has published its own quality standard, which is endorsed by Macmillan Cancer Support. This quality standard is a set of 20 quality statements setting out what UKLCC professionals believe should be the standards reached by every lung cancer service. The UKLCC's quality standard has been drafted by an expert group of leading physicians and nurses, based on their practical expertise and the latest clinical evidence. It covers the whole patient pathway, from diagnosis and confirmation, through treatment and care, along with support for</p>	<p>Thank you for your comments.</p> <p>The quality standards are based on evidence-based recommendations from national accredited guidance, i.e. the NICE Lung Cancer clinical guideline. The topic expert group use this guidance to identify and prioritise areas where quality improvement is required, which are then developed into quality statements.</p>

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			<p>patients at every stage.</p> <p>In addition to the UKLCC's quality standard, Macmillan welcomes the opportunity to additional comment on the draft Lung Cancer Quality Standard. We believe some amendments need to be made to it to ensure that it guides commissioners and providers to provide high-quality care and support for lung cancer patients.</p>	
017	Macmillan Cancer Support	General	<p>Key points</p> <ul style="list-style-type: none"> • We strongly support the inclusion of quality statements on opportunities to discuss treatment options and access to a clinical nurse specialist. • We believe that Quality Statement 6 could be improved by including financial support as part of holistic needs assessment and ensuring all information is provided in a tailored, timely and accessible way. • We believe Quality Statement 19 should be more explicit about end of life care and out-of-hours support and ensuring that patients preferred place of death at the end of life. We believe there should be signposting within the quality standard to other relevant quality standards, such as those on end of life and patient experience. 	<p>Thank you for your comments. Financial support has been incorporated into the definition of what a holistic needs assessment should include.</p> <p>The scope of the quality standard for lung cancer covers adults receiving supportive and palliative care, but there is a separate NICE quality standard on end of life care which addresses areas of care important for those people approaching end of life in more detail. This has now been explicitly referenced as a related NICE quality standard.</p>
018	Royal Brompton & Harefield NHS Foundation Trust	General	2 Standards particularly relevant for Pal Care	Thank you.
019	The National Council for Palliative Care	General	The Lung Cancer Quality Standard should be linked explicitly to the End of Life Care Quality Standard, shortly to be published. There needs to be consistency across all of the Quality Standards produced by NICE in order to be of maximum use to the NHS Commissioning Board.	Thank you for your comment. The end of life care quality standard has now been explicitly referenced as a related NICE quality standard.
020	Merck Sharp & Dohme UK Ltd	General	MSD Ltd is supportive of the quality standards for lung cancer and, in particular, we welcome the inclusion of quality standards which cover supportive care for cancer patients. Ensuring appropriate supportive care is offered to patients at the right time is important for patients to have a positive experience of care, which is listed as one of the outcomes the quality standards intend to deliver. In some cases supportive care measures are also required to allow patients to complete potentially life-saving treatment courses.	Thank you for your comments.
021	Merck Sharp & Dohme UK Ltd	General	<p>MSD Ltd would only suggest that the final 15 quality standards evenly represent the three main outcomes listed on page 1 of the draft quality standards consultation document:</p> <ul style="list-style-type: none"> • Preventing people from dying prematurely. 	Thank you for your comment. We believe the quality standard, when delivered collectively, should contribute to improving the effectiveness, safety and experience of care

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			<ul style="list-style-type: none"> • Enhancing quality of life for people with long-term conditions. • Helping people to recover from episodes of ill health or following injury. • Ensuring that people have a positive experience of care. • Treating and caring for people in a safe environment and protecting them from avoidable harm. 	for people with lung cancer in terms of the domains within the NHS Outcomes Framework.
022	Pfizer	General	We welcome the early prioritisation of this NICE quality standard as lung cancer accounts for the largest number of cancer deaths in the UK. A concerted effort will be required to reduce the inequalities associated with this cancer and achieve a better standard of treatment and care for all. A NICE quality standard for lung cancer that is genuinely fit for the future can play a vital role in promoting clarity on best practice to make a difference to lung cancer patient outcomes.	Thank you for your support.
023	Pierre Fabre Ltd	General	These quality standards are a very clever way to recognise the importance of teamwork in the management of the patient pathway and will encourage the flow of administrative and practical skills between the centres and units in a structured way. This is still a complex task and some leadership and structure will be required to collect core materials and recognise skills that enhance management. If we can apply what we already know more uniformly across the NHS we will enhance outcomes and provide a process to share and coach Good Practice throughout the NHS. This does require some resource and leadership. The Cancer Collaborative was a very strong model for this need – allowing units and teams to demonstrate excellence and define or adapt new procedures that others can use and creating a culture of improvement.	Thank you for your support.
024	Royal College of Physicians	General	The NCRI/RCP/RCR Faculty of clinical oncology/ACP/JCCO are pleased to offer the following joint response to this quality standard consultation. Overall, our experts believe that these standards are of a high level and reflect the expertise and sensible approach of the group appointed to progress the work.	Thank you for your support.
025	Royal College of Physicians	General	As outlined in response to question one above, some of the quality statements will be difficult to measure. A number also overlap eg statements 6 and 19. Referring to holistic needs assessments and counting how many patients have satisfied this risks becoming an exercise in which local management tick boxes. In 2001-2002 Scotland undertook a national exercise of inspections of clinical standards for common tumour sites. The reports produced suggested differences between the hospitals surveyed when it was clear in some cases that these differences reflected how the local teams had interpreted or counted up how well they matched the standards rather than true differences in service quality. For	Thank you for your comments. The topic expert group reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. In addition, the quality standard will be reviewed for the development of potential indicators for both the Quality and Outcomes

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			example the individual hospital definition of what constituted a lung cancer CNS service varied widely. Without very clear and objective measures the quality statements might produce unhelpful results.	Framework and the Commissioning Outcomes Framework. For the Commissioning Outcomes Framework this will involve testing of potential indicators and full public consultation.
026	NICE Implementation Team	General	It would be useful if some indication was given about how the quality measures should be assessed – for example through case note audit or patient survey.	NICE quality standards are not prescriptive about how the statements should be implemented and measured. Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. The expectation is that quality statements and measures will be used and adapted at a local level.
027	NICE Implementation Team	General	It is not clear what the list in the ‘outcome’ sections are referring to and how the things in this list relate to the related quality statement.	Overarching outcomes are referenced when the topic expert group believe that a statement will contribute to them.
028	NICE Implementation Team	General	It is not always clear how the ‘relevant existing indicators’ and the ‘other possible national data sources’ for some of the quality statements should be used and this needs to be explicitly stated.	Suggested data sources are not definitive sources of data to support quality measures but are examples of existing national data collection which may be relevant, in part at least, to the quality measure. The paragraph in the preamble section of the quality standard on ‘quality measures’ explains this. The relevant existing indicators and data sources section is also particularly useful when the quality standard is reviewed for the development of potential indicators for both the Quality Outcomes Framework and the Commissioning Outcomes Framework.
029	NICE Implementation Team	General	Where links are included to other data sources they should go straight to the resource, rather than to the home page of the website.	It is NICE style (as advised by Editorial team) to link to the home page of a website to ensure that the link continues to work even if the site owner restructures the website. If a resource is particularly difficult to find we can provide additional guidance. Editorial usually test

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030	NICE Implementation Team	General	Some of the quality standards refer to the NICE audit tools under the 'other possible national data sources' section and we are not sure this is the most appropriate place as they aren't data items – they are audit tools for local use which organisations do not have to complete.	these out as part of their review. We agree that audit tools are not data sources but understand that this was agreed to be the most appropriate place to reference the tools. We have since agreed to merge the 'other possible national data sources' and 'relevant existing indicators' rows and use them to signpost users of the quality standard to any useful sources of information that will assist them in measuring achievement against each statement, although we appreciate that 'data source' may not be the most appropriate 'catch all' phrase.
031	Royal College of Radiologists	General	General Comments: 1. These are well thought out Quality Standards that encompass the vast majority of all aspects of care in patients with lung cancer. 2. Whilst it is correct to state that there is limited evidence available on outcome data, the expert panel are probably able to provide informed comment on percentages achievable and consequent benefit. This would enable more measurable standards, that might always be changed later ie remain aspirational. The phrase as a minimum may always be used to allow for over achievement.	Thank you for your comments. Quality measures should form the basis for audit criteria developed and used locally to improve the quality of healthcare. As part of developing these audit criteria the audit standards or levels of expected achievement should, unless otherwise stated, be decided locally. While typical aspirational achievement is likely to be 100% or 0%, realistic standards should take account of patient safety, patient choice and clinical judgement. The topic expert group reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
032	Roche Products Ltd	Question 1	Response to Q. 1. Have we identified all appropriate healthcare outcomes for each individual quality statement? We would like to suggest the following outcomes for the quality statements below and highlight in bold those that we believe are the most important: QS 1: Prevalence, age-standardised incidence, actual incidence, 2 and 3 year survival rates, 5-year survival QS 2: Stage at diagnosis, Proportion of patients with suspected cancer detected	Thank you for your suggestions. The TEG considered all suggestions for suitable outcome measures and prioritised the measures they considered most important for measuring the quality statements, and specified outcomes directly where they felt able to define these.

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			<p>through national screening programmes or by hospital specialists who wait fewer than 62 days from referral to treatment</p> <p>QS 7: Prevalence, age-standardised incidence, actual incidence</p> <p>QS 8. Proportion of patients with suspected cancer detected through national screening programmes or by hospital specialists who wait fewer than 62 days from referral to treatment</p> <p>QS 9: Patient experience, Patient satisfaction – we suggest experience from lung cancer patients are more specifically drawn out from the national cancer patient experience survey and included as a process measure.</p> <p>QS 10: Stage at diagnosis, proportion of patients receiving their first definitive treatment within 31 days of diagnosis</p> <p>QS 13: 1-year survival rates, 5-year survival rates, mortality, adherence to guidelines and guidance</p> <p>QS 14: 1-year survival rates, 5-year survival rates, mortality, adherence to guidelines and guidance</p> <p>QS 15: 1-year survival rates, 5-year survival rates, mortality, adherence to guidelines and guidance</p> <p>QS 16: 1-year survival rates, 5-year survival rates</p> <p>QS 17: cancer readmissions (i.e. primary diagnosis code of cancer), patient experience, patient satisfaction</p> <p>QS 19: Place of death</p>	
033	Amgen	Question 1	<p>This draft quality standard for lung cancer looks at the diagnosis and management of lung cancer, and the supportive care provided to people with lung cancer, to achieve the following outcomes as set out in the NHS Outcomes Framework:</p> <ul style="list-style-type: none"> • Preventing people from dying prematurely. • Enhancing quality of life for people with long-term conditions. • Helping people to recover from episodes of ill health or following injury. • Ensuring that people have a positive experience of care. • Treating and caring for people in a safe environment and protecting them from avoidable harm. <p>It is noteworthy that this quality standard does not include quality statements around mortality outcomes. The NHS vision for cancer in 'Improving Outcomes: A Strategy for Cancer' focuses on the importance of improving survival (with a key focus on treating people in a safe environment and protecting them from avoidable harm) and includes possible indicators such as 30-day mortality following</p>	<p>The TEG considered all suggestions for suitable outcomes and prioritised the measures they considered most important for measuring the quality statements. Mortality is an important measure but as lung cancer survival is short and most treatment is palliative, it was felt that a major impact of the quality standard should be to improve access to treatments that improve quality of life and length of life. This includes active treatment rates, correct treatment and treatment with curative intent (see statements 8, 9, 10, and 11 in the final quality standard).</p>

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			<p>chemotherapy. Reducing avoidable mortality is a key facet of lung cancer care and an integral marker of high-quality care for patients. For example, chemotherapy-induced febrile neutropenia (FN) is recognised as one of the most serious complications of cancer treatment. As well as having an impact on quality of life, chemotherapy-induced FN predisposes patients with cancer to serious and often life-threatening infections with overall mortality for patients hospitalised due to FN at 9.5%.</p> <p>Consequently, in order to improve survival outcomes for lung cancer patients as well as reduce inequalities in the management of chemotherapy-induced FN, we would like to request that indicators linked to mortality particularly avoidable mortality such as reducing chemotherapy-induced FN be given further consideration for inclusion in the quality statements contained in this draft quality standard.</p>	
034	Lilly UK	Question 1	Please see above for additional suggestions (QS4)	Thank you.
035	RCGP and the Primary Care Respiratory Society	Question 1	<p>Comments for Question 1: Have we identified all appropriate healthcare outcomes for each individual quality statement?</p> <p>*Referral quality statement: the denominator for the process measure is the number of people visiting their GP with symptoms or signs suggestive of lung cancer. This is an inadequate measure for a number of reasons. Firstly symptom recording in GP notes is unsystematic and influenced by how significant the GP thinks the symptom is. Furthermore, NICE referral criteria recommend referral for unexplained symptoms. In those at increased risk of lung cancer (e.g. smokers and x-smokers), symptoms can often be explained in other ways. Involvement of PHCT would be paramount and this is something easily measured.</p> <p>Effect of banning smoking not mentioned.</p> <p>Consideration should be given to the issue of CT scanning instead CXR first line – since this is more effective picking up early lung cancer. There may be room for saying that in patients with symptoms clearly suggestive of lung cancer and a normal CXR a CT scan should be ordered and/or urgent referral arranged.</p> <p>Palliative care is not funded fully by NHS but by charitable organisations so we do not have control over what they provide.</p>	<p>Quality measures should form the basis for audit criteria developed and used locally to improve the quality of healthcare. The topic expert group prioritised the measures they felt were most important in measuring the quality statements. Promoting a ban on smoking is outside the remit of this NICE quality standard. The topic expert group identified the development sources they felt were most relevant to developing the standard and within the framework of the quality standards development process. Please see 'process guide for healthcare quality standards' on the NICE website for further information.</p>
036	Royal College of Nursing	Question 1	Yes, however, there is no mention of key worker, entry to clinical trials and little emphasis on provision of patient information.	Please see statement 4 in the final quality standard which relates to the key worker concept (in terms of the lung cancer clinical nurse specialist).

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				<p>Provision of patient information is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in all quality standards (for adults), covers this area in more detail. Access to clinical trials is outside the scope of this quality standard.</p>
037	Royal Brompton & Harefield NHS Foundation Trust	Question 1	Have we identified all appropriate healthcare outcomes for each individual quality statement? Yes.	Thank you for your comment.
038	Royal College of Physicians	Question 1	<p>It is understandable that the focus of the statements is process rather than outcome - although specific outcome measures are referred to in at least some of the individual statements. However, from the perspective of the public (and the government in funding the NHS), the priority is to ensure that the service achieves measurable benefit for the treated population. For an individual patient it is certainly much more important to have a service achieving high survival rates, than one which delivers all the investigations within a two week timescale. So as a general principle some believe that if substantial time and resource are to be invested in the statements and their measurement, then they should include as many objective measures of outcome as possible. As stands, this is not the case for many of the statements.</p>	<p>Thank you for your comments. The quality standard as a whole aims to describe high quality care across the care pathway and is expected to improve care for people with lung cancer. Outcome measures are stated where the topic expert group felt these were appropriate, which include patient-reported outcomes. As lung cancer survival is short and most treatment is palliative it was felt that a major impact of the quality standard should be to improve access to treatments that improve quality of life and length of life, which includes active treatment rates, correct treatment and treatment with curative intent, as well as timeliness of investigations and treatment.</p>
039	Astra Zenica	Question 1	Yes	Thank you.
040	Roche Products Ltd	Question 2	<p>Response to Q. 2. What are the key priority areas that you would want to see covered by this quality standard? We acknowledge that prevention, early diagnosis, and radical treatment of limited stage disease, have a very important role to play in reducing lung cancer morbidity and mortality and therefore support the quality statements relating to these aspects of care. Unfortunately, however successful initiatives in these area are there will continue to be a large number of people requiring treatment for advanced disease for many years to come. This is because not all patients with</p>	<p>Thank you for your comments. The quality standard as a whole aims to describe high quality care across the care pathway and is expected to improve care for people with advanced lung cancer as well as improve survival rates. We agree that many patients will not be suitable for treatment with curative intent, and many of the statements are</p>

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			lung cancer are non-smokers or ex-smokers, there is a large group of people whose smoking history is such that they are already destined to develop cancer and because the lack of a reliable screening tool means that people with lung cancer will continue to present with advanced disease. Under these circumstances it will remain important that optimal diagnostics and treatments, as well as follow up services are available to people with advanced lung cancer in this country are world class and are reflected within this quality standard.	directed towards palliative care (please see statements 5 and 15 for examples). By raising the standard of care generally it is hoped that more patients will be offered active treatments.
041	Amgen	Question 2	We believe that quality statements 6, 15 and 19 around provision of holistic needs assessment at each key stage of care, offering chemotherapy tailored to tumour type and individual factors for patients with advanced stage lung cancer treatment and ensuring access to appropriate palliative treatments to improve patients' quality of life, are key to ensure that patients have a positive experience of care and are treated in a safe environment and protected from avoidable harm, all fundamental aims of the NHS Outcomes Framework.	Thank you for your comments. This comment is in line with the discussions of the topic expert group during development of the quality standard. Please see statements 5, 12 and 15 in the final quality standard.
042	Lilly UK	Question 2	Please see the prioritisation piece below (1, 2, 15, 5, 3, 10, 9, 14, 4, 13, 19, 12, 16, 17, 6)	Thank you. The final quality standard has been revised down to 15 statements.
043	Lilly UK	Question 2	This was an extremely difficult task; our priorities are based on the view that these areas are where the most impact could be had in terms of improving diagnosis and management of lung cancer in the UK. While not wanting to end up with extensive statements we felt some could be combined. We felt QS11 could be covered within QS13 without overburdening QS13. We also felt QS7 could and should be addressed in other areas.	Thank you for your suggestions. The final quality standard has been revised down to 15 statements.
044	Department of Health	Question 2	<ul style="list-style-type: none"> • The standard should state that all patients with a lung cancer diagnosis need to be assessed for suitability for resection (current drafting assumes all patients are re-sectable). • The standard should include a statement that following resection of a lung cancer, patients have the opportunity to discuss adjuvant treatments with a medical or clinical oncologist. • We would want to see a greater emphasis on communication, provision of information and decision making , MDT working, access to Clinical Trials, key Audit questions, integration of the Key Worker concept. • There is no mention of: EGFR testing, Prophylactic cranial irradiation or Prophylactic Thoracic irradiation in small cell lung cancer. 	Thank you for your suggestions. The final quality standard has been revised down to 15 statements. All suggestions for additional statements were discussed by the topic expert group who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.

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				<p>Please see statements 4 and 10 in the final quality standard for reference to the key worker concept (in terms of the lung cancer clinical nurse specialist) and patients who are unable to undergo surgery.</p> <p>Provision of patient information is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail.</p> <p>Access to clinical trials is outside the scope of this quality standard.</p>
045	RCGP and the Primary Care Respiratory Society	Question 2	<p>Comments Question 2</p> <p>What are the key priority areas that you would want to see covered by this quality standard?</p> <p>Referral times, Chest x-ray, communication, access to tests and tissue diagnosis, access to surgery, access to radiotherapy are all key priority areas if lung cancer survival is to be improved. None that are missing but the key priority should be around the 2 week referral to chest team</p> <p>Would like to see more in the quality statements about accurate diagnosis, i.e. not being falsely reassured by normal CXR and those patients with cough and weight loss, haemoptysis are investigated appropriately. Would like to see that in the quality statements family support and also liaison with primary health care team as these are the people who will be with the patient most of the time so information is needed to be shared with patient consent. Ban smoking.</p> <p>CXR does not pick up early lung cancer – promote more open access CT scanning and ensure this is properly funded. Survival rates are much better if early surgery removes tumour – CXR are just not good enough to do this and miss a lot of cancers.</p> <p>How often should you screen people at risk of cancer of the lung with PH of asbestos exposure confirmed on CXR?</p> <p>Allow clinical freedom in innovation and development for new cancer treatments with proper funding and quick response time to new developments from start to implementation in practice – the process takes too long</p> <p>Promote research for lung cancers with low survival rates and stop blocking use</p>	<p>Thank you for your comments. Please see statements 2, 3, 7, 8, and 10 in the final quality standard.</p> <p>Communication is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and is referenced in this quality standard, covers this area in more detail.</p> <p>The NICE Quality Standards programme is unable to make research recommendations as this would be the role of a Guideline Development Group. The topic expert group prioritised the areas of care they felt were most important for patients based on the development sources listed in appendix 1.</p> <p>Endorsing a smoking ban or commenting on funding arrangements is outside the remit of this NICE quality standard.</p> <p>Your comments on GP open access to CT scanning have been noted. However, for the reasons stated above it is outside of the remit of the quality standard to consider additional</p>

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			expensive cancer drugs by PCTs – should be a separate national fund for this.	evidence beyond that which was assessed in the development of the source guideline. Please refer to the full clinical guideline for detailed summary of the underpinning evidence base for the clinical recommendations on which the quality standard is based.
046	Royal College of Nursing	Question 2	Key priority areas are: Draft Quality Statement1 Draft Quality Statement1 2 Draft Quality Statement1 5	Thank you for your comment. Please see statements 1, 2 and 4 in the final quality standard.
047	Royal Brompton & Harefield NHS Foundation Trust	Question 2	What are the key priority areas that you would want to see covered by this quality standard? It is important that teams demonstrate appropriate referral to specialist services not just 'access to'.	The topic expert group prioritised the measures they felt were most important in measuring the quality statements. Please see the measures in statement 5 as an example.
048	Royal College of Physicians	Question 2	Key priority areas for quality of service which can be objectively measured include histological diagnosis rate, surgical resection rate, rates of palliative and radical radiotherapy as proportion of NSCLC and SCLC populations, chemotherapy treatment rates for palliative intent in stage IIIb/IV NSCLC, chemotherapy treatment rates for SCLC and for adjuvant postop populations and obviously median and overall survivals as well as death rates within 30 days of treatment (surgery, radiotherapy or chemotherapy). A further measure in national lung cancer audit has been proportion of patients who do not receive specific anti-cancer therapy.	Please see statements 6, 8, and 9 in the final quality standard for examples of where these outcomes have been included.
049	Astra Zeneca	Question 2	AstraZeneca is keen to ensure that patients have easy and prompt access to diagnostic tests as well as appropriate licensed therapies to treat their condition.	Access to diagnostic tests and appropriate treatment are themes through the quality standard. Please see statements 2 and 12 for examples of this.
050	North Trent Cancer Network	General	People with known or suspected lung cancer are discussed at a formally constituted multidisciplinary team meeting (MDT) where the full range of treatments are available, and the resulting diagnostic, staging and treatment recommendations are recorded in the clinical notes.	Thank you for this suggestion. We believe the final quality standard promotes these aspects of care.
051	North Trent Cancer Network	General	Following resection of a lung cancer, patients have the opportunity to discuss adjuvant treatments with a medical or clinical oncologist.	Thank you for this suggestion. The topic expert group prioritised statements that they felt were key markers of clinical and cost

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				effective care that had a significant impact on outcomes, addressed variations in delivery of care and had the potential to generate measurable indicators.
052	British Lung Foundation	General	<p>There are two key areas where quality statements have not as yet been drafted but which the British Lung Foundation would be pleased to see the quality standard development team actively consider:</p> <p>Support for carers: Carers play an essential role in supporting patients, but their information and support needs may differ from those of the patient. While it is understandable that clinicians may focus on meeting the needs of the patient first and foremost, the needs of carers should not be neglected, especially given the frequently rapid trajectory of disease progression in lung cancer. Lung cancer specialist nurses and supporting social workers and allied health professionals have important roles here. We therefore propose the following quality statement for consideration:</p> <p><i>Carers of patients with lung cancer are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.</i></p> <p>Access to clinical trials: Improvements in future treatment and care will be hampered without active participation of patients in research and clinical trials. All MDTs should have available a list of all trials that are open for recruitment and consider whether trial entry is an option that can be offered to every lung cancer patient that is discussed. Links with translational and more basic research are to be encouraged and it is important that links are established between units which carry out such research and those which are more clinically oriented. In this area, we propose the following quality statement for consideration:</p> <p><i>Every lung cancer patient has the opportunity to enrol into appropriate clinical trials at all stages of their patient pathway.</i></p>	<p>Thank you for your comments.</p> <p>Support for carers is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail.</p> <p>The topic expert group noted that holistic needs assessments are not yet in place for most patients and as such prioritised the statement for progression to the final quality standard. The definition of what should be included in a holistic needs assessment refers to the preferences of both patients and carers. Access to clinical trials is outside the scope of this quality standard.</p>
053	Department of Health	General	<p>People with known or suspected lung cancer are discussed at a formally constituted multidisciplinary team meeting (MDT) where the full range of treatments are available, and the resulting diagnostic, staging and treatment recommendations are recorded in the clinical notes.</p>	<p>Thank you for this suggestion. We believe the quality standard promotes these aspects of care.</p>
054	United Kingdom Lung Cancer Coalition	General	<p>There are two key areas where quality statements have not as yet been drafted but which the UKLCC would be pleased to see the quality standard development team actively consider:</p> <p>Support for carers: Carers play an essential role in supporting patients, but their</p>	<p>Thank you for your comments.</p> <p>Support for carers is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services',</p>

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			<p>information and support needs may differ from those of the patient. While it is understandable that clinicians may focus on meeting the needs of the patient first and foremost, the needs of carers should not be neglected, especially given the frequently rapid trajectory of disease progression in lung cancer. Lung cancer specialist nurses and supporting social workers and allied health professionals have important roles here. We therefore propose the following quality statement for consideration:</p> <p><i>Carers of patients with lung cancer are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.</i></p> <p>Access to clinical trials: Improvements in future treatment and care will be hampered without active participation of patients in research and clinical trials. All MDTs should have available a list of all trials that are open for recruitment and consider whether trial entry is an option that can be offered to every lung cancer patient that is discussed. Links with translational and more basic research are to be encouraged and it is important that links are established between units which carry out such research and those which are more clinically oriented. We note that there is evidence that patients treated in research-active environments receive better quality of care and may experience improved outcomes (International Journal of Gynaecological Cancer 2005, <i>Pattern of care and impact of participation in clinical studies on the outcomes in ovarian cancer</i>).</p> <p>In this area, we propose the following quality statement for consideration:</p> <p><i>Every patient has the opportunity to enrol into appropriate clinical trials at all stages of their patient pathway.</i></p>	<p>which is cross-cutting and referenced in this quality standard, covers this area in more detail.</p> <p>The topic expert group noted that holistic needs assessments are not yet in place for most patients and as such prioritised statement 5 for progression to the final quality standard. The definition of what should be included in a holistic needs assessment refers to the preferences of both patients and carers. Access to clinical trials is outside the scope of this quality standard.</p>
055	British Lung Foundation	S1	<p>The British Lung Foundation supports the statement recommending that “people are made aware of the symptoms and signs of lung cancer public awareness campaigns that result in early presentation.”</p> <p>Patients with lung cancer often fail to identify or ignore symptoms, meaning that they present late, with an average of three months’ delay before seeking help. In the UK, each GP sees on average fewer than 2 patients with a new presentation of lung cancer each year. They may confuse lung cancer symptoms with more common conditions, which present in a similar way such as COPD, persistent wheeze, or cough, or fail to connect less common symptoms (e.g. fatigue or weight loss) with the disease.</p> <p>The British Lung Foundation therefore recommends that action is needed to improve both patient and GP awareness of the symptoms of lung cancer. Any</p>	<p>Thank you for your comments. Statement 1 promotes public awareness campaigns to encourage early presentation.</p>

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			<p>public awareness campaign about the symptoms of lung cancer to encourage early presentation to primary care should be sustained and targeted. At risk groups which need to be targeted include current smokers, ex-smokers or those with conditions which are make them more prone to lung cancer such as Chronic Obstructive Pulmonary Disease. New risk assessment tools may help to trigger alerts and speed early referral.</p> <p>In order to improve and reinforce GP awareness of lung cancer signs and symptoms, and to aid their continuing professional development, the British Lung Foundation advocates that all diagnosed cases of lung cancer are reviewed in general practice significant event reviews.</p>	
056	Lilly UK	S1	<p>This draft statement is phrased as follows: <i>“People are made aware of the symptoms and signs of lung cancer through coordinated public awareness campaigns that result in early presentation.”</i> While we fully support a statement that results in early presentation, we feel the signs and symptoms listed as suggestive of lung cancer are symptoms of severe or advanced disease and we question whether this would ultimately result in early presentation.</p> <p>We believe this list should be revised to include signs and symptoms that would enable GPs to potentially identify people with early lung cancer. While we are cognisant that this is difficult for lung cancer, we feel this is an important area to explore and may include signs such as unexplained breathlessness at night, repeat prescriptions for antibiotics or wheezing diagnosed as asthma that is refractory to an inhaler. We would also suggest including in the statement the proactive identification of high risk patients, such as smokers with other signs of early lung cancer.</p> <p>Our concern is that currently QS1 is not aspirational enough and will continue to bring in patients with advanced disease and will not support the goal of early diagnosis.</p>	<p>Thank you for your comments. The definition of symptoms and signs is taken from NICE clinical guideline 121, the key NHS Evidence accredited development source.</p> <p>The topic expert group noted the difficulties for the guideline developers in making a strong recommendation in this area, in which there is little scientific evidence.</p>
057	Teenagers and Young Adults with Cancer	S1	<p>TYAC is concerned with cancer in teenagers and young adults, therefore lung cancer is a disease that is very rare for this age group, but awareness could be further raised in this group by ensuring that education programmes for this group contain information about lung cancer. Two examples of good education are the Sometimes its Cancer education package (devised by the Lorraine Wright and Sam Smith at the Christie Hospital in Manchester, currently with the DoH) and the education package devised by the Teenage Cancer Trust.</p>	<p>Thank you for this information. We anticipate that public awareness campaigns will be developed locally and utilise existing sources of relevant public information where possible.</p>
058	Macmillan Cancer	S1	<p>Macmillan believes it is important that patients receive information and support</p>	<p>Thank you for your comments.</p>

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	Support		throughout their cancer journey, and that the information and support they receive is relevant for them at that time in the journey. We welcome Quality Statement 1 on raising awareness of the symptoms of lung cancer, as low awareness of the symptoms is such a critical factor in late diagnosis and poor prognosis	
059	NCL and West Essex Lung Cancer Network	S1	Whilst agree with the sentiment it would be helpful to provide evidence of the cost effectiveness of these programmes.	The source clinical guideline acknowledges the difficulty in assessing the effectiveness of such initiatives, however NICE has produced a support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard.
060	United Kingdom Lung Cancer Coalition	S1	<p>The UKLCC supports the statement recommending that <i>“people are made aware of the symptoms and signs of lung cancer public awareness campaigns that result in early presentation.”</i></p> <p>Patients with lung cancer often fail to identify or ignore symptoms, meaning that they present late, with an average of three months’ delay before seeking help. In the UK, each GP sees on average fewer than 2 patients with a new presentation of lung cancer each year. They may confuse lung cancer symptoms with much commoner conditions with a similar presentation such as COPD, persistent wheeze, or cough, or fail to connect less common symptoms (e.g. fatigue or weight loss) with the disease.</p> <p>Action is therefore needed to improve both patient and GP awareness of the symptoms of lung cancer. Any public awareness campaign about the symptoms of lung cancer to encourage early presentation to primary care should be both targeted and sustained. New risk assessment tools may help to trigger alerts and speed early referral.</p> <p>In order to improve and reinforce GP awareness of lung cancer signs and symptoms, and to aid their continuing professional development, the UKLCC advocates that all diagnosed cases of lung cancer are reviewed in general practice significant event reviews.</p>	Thank you for your comments. Statement 1 promotes public awareness campaigns to encourage early presentation.
061	Royal College of Radiologists	S1	This should presumably include medical healthcare professionals, rather than be exclusively aimed at the public.	We believe the quality standard promotes greater awareness of symptoms and signs of lung cancer amongst all audiences (see statements 1 and 2 in the final quality standard).
062	British Thoracic	S1	We agree with the sentiment of encouraging earlier diagnosis, but are concerned	Thank you for your comments. The measures

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	Society		<p>about specific metrics for outcomes that are sometimes difficult to precisely define, measure, and are of no proven benefit in altering outcome. For example, what is the difference between 1a) and 1b) in the “Process” section. The former refers to those who self-present as a result of a public awareness campaign, the latter to those who are identified - presumably as a result of GP education. This is a very worthwhile point to try to dissect, and has been looked at in some detail in Leeds. However, we would question whether or not collection of these data are possible – the Leeds study has used surrogates by intervening with public health awareness in some parts of the city, and GPs in others. However, to attempt to discriminate 1a) from 1b) outside of a research study I think would be almost impossible. Similarly, for 1c) it would be very difficult to take 200 lung cancers a year (for example) and work out what motivated their presentation. By ‘early diagnosis intervention’ I presume this means both public and GP interventions, but how do you tell GP-directed CXRs that resulted from any intervention and those that did not?</p> <p>Regarding outcomes, we think there will have been data on outcome c) showing a change following early detection campaigns, there has certainly been no convincing evidence of a change in any of the other outcome parameters. Our concern would be holding PCTs/GP commissioners/NHS trusts to account over parameters that it maybe cannot be influenced by any early diagnosis campaign. Existing research may be showing an effect on emergency admission rates (further data awaited) following and increase in CXRs from 20,000 per year to 30,000 per year. However, they have shown no effect at all on outcomes b), d) and e).</p>	<p>have been revised for the final quality standard to improve clarity. Outcome measures are stated where the topic expert group felt these were appropriate.</p>
063	Lilly UK	S1	<p>In addition, while the outcomes relate to capturing patients with less advanced disease, the measures themselves do not relate strongly to early diagnosis but to people self presenting or identified as part of a public awareness campaign (be that an ‘early diagnosis intervention’).</p>	<p>Thank you. Statement 1 promotes public awareness campaigns to encourage early presentation and therefore earlier detection of disease.</p>
064	NICE Implementation Team	S1	<p>Some of the process measures do not match the quality statement. The quality statement is ‘People are made aware of the symptoms and signs of lung cancer through coordinated public awareness campaigns that result in early presentation’. However two of the quality measures refer to people being identified ‘as part of an early diagnosis intervention’ and people who present with symptoms being ‘referred for further assessment’.</p>	<p>Thank you for your comments. The measures have been revised for the final quality standard to improve clarity.</p>
065	NICE	S1	<p>For process measure a – how will users know that a person has presented as a</p>	<p>The measures will be adapted for local use.</p>

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	Implementation Team		result of the public awareness campaign?	The topic expert group anticipated that patients could be asked about what prompted their decision to access services once they have been assessed and put on a treatment pathway.
066	United Kingdom Lung Cancer Coalition	S1	<p>Our members note that it may be valuable to distinguish between 1a) proportion of people with symptoms suggestive of lung cancer who present as a result of a public awareness campaign and 1b) proportion of people with symptoms suggestive of lung cancer who are identified as part of other early diagnosis interventions e.g. open access to chest x-rays, primary care engagement, use of decision support tools, etc). Colleagues from the British Thoracic Society have drawn our attention to relevant work being carried out in Leeds, where researchers are exploring whether or not wholesale collection of these data are possible, using surrogates by intervening with public health awareness in some parts of the city and GPs in others.</p> <p>We also question how easy it might be to retrospectively work out which factors, or combination of factors, motivated presentation. We would value greater clarity over what is meant by an 'early diagnosis intervention' and whether this means both public and GP interventions. We note that it could be difficult to differentiate between chest x-rays that resulted from a GP intervention and those that did not. It is important that commissioners and providers are encouraged to enable early presentation and detection, but held to account using parameters over which early diagnosis campaigns can be realistically expected to have some influence.</p>	Thank you for your comments. The measures have been revised for the final quality standard to improve clarity. Outcome measures are stated where the topic expert group felt these were appropriate.
067	National Lung Cancer Forum for Nurses	S2	Could be merged with QS3 to make 1 standard. Q3 can be implemented with no additional resource implication and offers a failsafe approach.	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
068	North Trent Cancer Network	S2	In the interest of distilling the number of indicators into a few key indicators QS2 and QS3 could usefully be merged.	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the

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				individual statements as both elements are key markers of quality that will have an impact on outcomes.
069	British Lung Foundation	S2	<p>The British Lung Foundation supports inclusion of the statement that <i>“people presenting with symptoms suggestive of lung cancer are referred urgently for a chest X-ray or directly to a chest physician who is a core member of the lung cancer multidisciplinary team.”</i></p> <p>Symptomatic patients should have rapid access to a chest x-ray and if clinical concerns remain they should be referred directly for a CT scan or to a chest physician who is a core member of the lung cancer multidisciplinary team (MDT). NICE recommends urgent referral for a chest x-ray (CXR) if a patient has persistent symptoms for 3 weeks. Even then not all chest x-rays are abnormal, since small tumours or those in upper zones or positioned behind overlying structures can be easily missed on chest x-rays. Whilst chest x-ray may be an acceptable first test it should not be relied upon to exclude a diagnosis of lung cancer and therefore the threshold for having access to a CT scan should be significantly lower than at present in the UK.</p> <p>We advocate that every patient where lung cancer is suspected following a chest x-ray or CT scan should be referred to a rapid access clinic. Reports of all chest x-rays and CT scans where the possibility of a lung cancer diagnosis is raised should be sent urgently both to the referring clinician and to the lung cancer team, or should automatically trigger a referral. Where the chest x-ray is suspicious of a lung tumour, a contrast-enhanced CT scan of the chest, neck and upper abdomen should be carried out and be available at the first clinic visit.</p> <p>Therefore the British Lung Foundation recommends that statement 2 and 3 are combined. The suggested revised statement is recommended:</p> <p><i>People presenting with symptoms suggestive of lung cancer are referred urgently (within 2 weeks) for a chest X-ray and if clinical concern remains directly for a CT scan. Results of chest X-ray and scans are reported rapidly by the radiologist and the results assessed by a lung cancer multidisciplinary team.</i></p>	Thank you. The final quality standard has been revised down to 15 statements. The topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
070	Lilly UK	S2	<p>As above for QS1 we believe the impact of this statement is limited by the signs and symptoms listed, which we feel are suggestive of advanced disease and would inadequately lead to the referral of patients with early lung cancer.</p> <p>We suggest the criteria to be expanded to allow GPs to refer patients for X-ray more freely if lung cancer is suspected.</p>	Thank you for your comments. Statement 2 promotes rapid referral of people with symptoms of lung cancer. The symptoms and signs described in the definition section do not preclude GPs from referring in all circumstances where lung cancer is

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				suspected.
071	Department of Health	S2	<p>Could usefully be merged with QS 3, Q3 can be implemented with no additional resource implication and offers a failsafe approach.</p> <p>Incorporate the need for a CT study and for that study to be considered by a radiologist and other members of the multidisciplinary team. (The CT scan is one of the most important and pivotal points on the patient journey. There is little point in a patient with an abnormal CXR seeing a chest physician quickly if that is not done in association with a contemporaneous CT study).</p>	<p>Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.</p> <p>The topic expert group prioritised statements that they felt were key markers of clinical and cost effective care that had a significant impact on outcomes, addressed variations in delivery of care and had the potential to generate measurable indicators.</p>
072	RCGP and the Primary Care Respiratory Society	S2	<p>Comment about QS2:</p> <p>Happy with the standard, though difficult to measure the denominator.</p> <p>See further comments below about concerns re lack of reliability of CXR and that a clear CXR can give false reassurance – CT is considered more reliable.</p>	<p>The topic expert group identified the development sources they felt were most relevant to developing the standard and within the framework of the quality standards development process - see appendix 1 for listed development sources.</p>
073	NCL and West Essex Lung Cancer Network	S2	<p>Patients should not need to make an appointment for a CXR there should be a walk-in service at radiology departments for this test.</p>	<p>We do not believe that statement 2 implies this. It is acknowledged that different areas will have different arrangements for chest X-rays.</p>
074	United Kingdom Lung Cancer Coalition	S2	<p>The UKLCC supports inclusion of the statement that <i>“people presenting with symptoms suggestive of lung cancer are referred urgently for a chest X-ray or directly to a chest physician who is a core member of the lung cancer multidisciplinary team.”</i></p> <p>Symptomatic patients should have rapid access to a chest x-ray and if clinical concerns remain they should be referred directly for a CT scan or to a chest physician who is a core member of the lung cancer multidisciplinary team (MDT).</p> <p>NICE recommends urgent referral for a chest x-ray (CXR) if a patient has persistent symptoms for 3 weeks. Even then not all CXRs are abnormal, since small tumours or those in upper zones or positioned behind overlying structures</p>	<p>The topic expert group prioritised the areas of care they felt were most important for patients based on the development sources listed – see appendix 1 for listed development sources.</p> <p>The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.</p>

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			<p>can be easily missed on CXRs. Whilst CXR may be an acceptable first test it should not be relied upon to exclude a diagnosis of lung cancer and therefore the threshold for having access to a CT scan should be significantly lower than at present in the UK.</p> <p>CT scans should be available early in the pathway and be reported on by a specialist radiologist for consideration by the members of the MDT. We encourage the Committee to reflect on this when revisiting this standard to ensure that patients are able to access CT scans as well as CXRs early in the patient journey.</p>	
075	United Kingdom Lung Cancer Coalition	S2	<p>We note that there is no standard for patients who present to either medical assessment units or emergency assessment units with a definite or suspicious clinical picture or with complications during treatment. We would urge the Committee to consider these patients' needs and in particular the importance of:</p> <ul style="list-style-type: none"> • The explicit timeframe for seeing a respiratory team member • Not being sent home with an insecure 'follow up by / referral to chest team' <p>Not being followed up in a MAU-based non-specialist clinic or a non-specialist ambulatory care setting (increasingly common with pressure on beds etc)</p>	Please see statements 2 and 3 in the final quality standard which include people reporting symptoms suggesting lung cancer in any setting, and people with incidental chest X-ray findings.
076	British Thoracic Society	S2	<p>There is a difference between process a) and process b) in that the former measures those referred for CXR or direct to lung cancer clinician, whereas the latter just measures clinician referral. The problem comes with which symptoms are classed as 'suggestive of lung cancer'. Cough is listed on the form, so presumably the inference is that anyone presenting twice with a cough should be referred irrespective of CXR findings - the risk of lung cancer in patients presenting twice to GP with cough is 0.6% for non-smokers and 1.2% for smokers. This will fill up a lot of our clinics if GPs work strictly to this target. The term "suggestive of lung cancer" is rather vague and open to interpretation which is never good when trying to collect data.</p> <p>The standard does not mention patients who come to attention through non-GP pathways e.g medical assessment units (approx 25%). These patients need to be included because otherwise they get an insecure "follow up by / referral to chest team", or follow up in a non-specialist clinic/non-specialist ambulatory care setting.</p>	<p>Thank you for your comments. The measures have been revised for the final quality standard to improve clarity. The aim of statement 2 is increased numbers of chest X-rays and referrals and therefore earlier lung cancer diagnoses.</p> <p>Please see statements 2 and 3 in the final quality standard which include people reporting symptoms suggesting lung cancer in any setting, and people with incidental chest X-ray findings.</p>
077	RCGP and the Primary Care Respiratory Society	S2	The proposed indicator is flawed, since it measures the number of consultations for all patients with the symptoms defined as being suggestive. Furthermore, doubts about the validity of applying a threshold for number of consultations equally across cancers where a test is commonly undertaken (e.g. lung) and one	Thank you for your comments. The topic expert group agreed that measurement is difficult in this area and revised the measures for the final quality standard to improve clarity.

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			<p>where it isn't (breast, melanoma). Even in a perfect world, someone with lung cancer will rack up two consultations (one for presentation and one to get the result of the CXR). Lastly, this is confounded by standard 3, which would take the second consultation out of the count.</p> <p>Agree we need to be able to measure timeliness of diagnosis in primary care. Also agree that twice should generally be enough attendances to trigger consideration of a CXR. However, the measure as written has considerable difficulties. Many lung cancers do not present within the current NICE guidance – for example those just with a cough. It is unreasonable to expect a GP to act on the second attendance (though they should ensure adequate follow-up to be certain of investigating should the symptoms persist). Many criteria use time rather than a number of GP attendances. So, would three weeks be better?</p> <p>Concerned that patient surveys are the possible instrument of choice. The problem is not that the replies are unreliable, but that it is very difficult for the patient to know what their first experience of the cancer symptom was, and whether they brought it to medical attention. It's easy for 'red-flag' symptoms like haemoptysis (and investigation should be done on the FIRST attendance for this) but only 40% of lung cancers experience haemoptysis. It's much harder for the patient with cough and insidious dyspnoea to count the number of attendances before investigation was undertaken. There is a risk that we'll just get another 'GP-bashing' report – look at the recent pancreas report, and previous ovarian reports. This is not to say GPs get it right (we don't) but we need a credible instrument for measuring it.</p>	
078	RCGP and the Primary Care Respiratory Society	S2	There is a key problem. The standard lacks a clear definition of "symptoms suggestive of lung cancer". Cough persisting for 3 weeks or more is an extremely common symptom and the size of the denominator varies hugely as to whether or not this on its own were considered "suggestive of lung cancer".	The definition of symptoms and signs suggestive of lung cancer is taken from NICE clinical guideline 121. The topic expert group revised the measures for the final quality standard to improve clarity.
079	National Lung Cancer Forum for Nurses	S3	Could be merged with QS2 to make 1 standard. Q3 can be implemented with no additional resource implication and offers a failsafe approach.	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on

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				outcomes.
080	North Trent Cancer Network	S3	In the interest of distilling the number of indicators into a few key indicators QS3 and QS2 could usefully be merged.	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
081	British Lung Foundation	S3	<p>The British Lung Foundation supports inclusion of the statement that <i>“people presenting with symptoms suggestive of lung cancer are referred urgently for a chest X-ray or directly to a chest physician who is a core member of the lung cancer multidisciplinary team.”</i></p> <p>Symptomatic patients should have rapid access to a chest x-ray and if clinical concerns remain they should be referred directly for a CT scan or to a chest physician who is a core member of the lung cancer multidisciplinary team (MDT). NICE recommends urgent referral for a chest x-ray (CXR) if a patient has persistent symptoms for 3 weeks. Even then not all chest x-rays are abnormal, since small tumours or those in upper zones or positioned behind overlying structures can be easily missed on chest x-rays. Whilst chest x-ray may be an acceptable first test it should not be relied upon to exclude a diagnosis of lung cancer and therefore the threshold for having access to a CT scan should be significantly lower than at present in the UK.</p> <p>We advocate that every patient where lung cancer is suspected following a chest x-ray or CT scan should be referred to a rapid access clinic. Reports of all chest x-rays and CT scans where the possibility of a lung cancer diagnosis is raised should be sent urgently both to the referring clinician and to the lung cancer team, or should automatically trigger a referral. Where the chest x-ray is suspicious of a lung tumour, a contrast-enhanced CT scan of the chest, neck and upper abdomen should be carried out and be available at the first clinic visit.</p> <p>Therefore the British Lung Foundation recommends that statement 2 and 3 are combined. The suggested revised statement is recommended: <i>People presenting with symptoms suggestive of lung cancer are referred urgently (within 2 weeks) for a chest X-ray and if clinical concern remains directly for a CT scan. Results of chest X-ray and scans are reported rapidly by the radiologist and</i></p>	Thank you. The final quality standard has been revised down to 15 statements. The topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.

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			<i>the results assessed by a lung cancer multidisciplinary team.</i>	
082	Kent and Medway Cancer Network	S3	GPs are the gatekeepers, not the Trust lung cancer team. Patients have choice about where to be referred and may have reasons why they would wish to be followed in the Trust in which the initial CXR was done. In our area many GPs use a neighbouring imaging service yet refer to Trusts when the CXR is positive, this would not occur in this situation. A better option would be if the Lung specialist receives the report and has a duty to chase the GP (not the patient) to get them to refer to the appropriate service. The hospital directly contacting patients would cause patient shock and for co-morbidity reasons may not be appropriate.	Please see statement 3 in the final quality standard. A definition is included clarifying that the statement does not detract from the principle of responsibility for follow-up resting with the clinician who ordered the test.
083	Department of Health	S3	Could usefully be merged with QS 2 Incorporate the need for a CT study and for that study to be considered by a radiologist and other members of the multidisciplinary team.	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
084	RCGP and the Primary Care Respiratory Society	S3	Comments about QS3 Happy with the standard, though it raises questions of the level of patient information we would have to give prior to a CXR request where the level of suspicion is low or where it is done for some other clinical indication. Don't know how this would be dealt with in the context of 2 week rule – whether this pickup process would count for Cancer Waiting Times purposes. There is no timescale described. The patient surely has to be seen within 2 weeks for it to be consistent with 2 week rule. It is very important for there to be absolute clarity as to whose responsibility it is to follow up abnormal results: this should primarily rest with the clinician who ordered the test. Hence any system for a different arrangement should not detract from this principle and there should be immediate clear communication with primary care if the result is being communicated and subsequent action undertaken by the hospital team.	Please see statement 3 in the final quality standard. We believe the statement does not impact upon the usual arrangements for urgent suspected cancer referrals. A definition is included clarifying that the statement does not detract from the principle of responsibility for follow up resting with the clinician who ordered the test.
085	Central South Coast Cancer Network	S3	In our area & I am sure other areas in the UK. Our Trust performs CXRs on several different sites & although reported by radiologists locally the pt/GP may prefer to refer geographically (i.e. closer to home) to another Lung cancer team. Equally CXRs taken in locality hospitals and are reported & visible only in one trust but the GP often refers to another where the x-ray cannot be visualised. If abnormal CXRs are to be reported to an MDT to which MDT are they to be	It is acknowledged that different areas will have different arrangements for chest X-rays and expected that quality statements and measures will be used and adapted at a local level, appropriate to local circumstances. Please see statement 3 in the final quality

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			<p>reported to? There is a danger of great confusion around who is the clinician responsible for acting on an abnormal result, (i.e. in medicine this has always been the clinician ordering the test) & who the patient is to be referred to? Currently the radiologists, suggest to the GP on the CXR report (which they receive electronically the moment the report is verified) that the patients is referred urgently to the Lung Team, the GP can then discuss the results of the CXR & the choice of hospital that they want to attend with the patient. This system works well for the patients and GP's.</p>	<p>standard. We believe the statement does not impact upon the usual arrangements for urgent suspected cancer referrals. A definition is included clarifying that the statement does not detract from the principle of responsibility for follow up resting with the clinician who ordered the test.</p>
086	United Kingdom Lung Cancer Coalition	S3	<p>The UKLCC supports the statement that <i>“people with a chest X-ray result suggestive of lung cancer have a copy of the radiologist’s report sent to and followed up by the lung cancer multidisciplinary team.”</i></p> <p>We advocate that every patient where lung cancer is suspected following a chest x-ray or CT scan should be referred to a rapid access clinic. Reports of all chest x-rays and CT scans where the possibility of a lung cancer diagnosis is raised should be sent urgently both to the referring clinician and to the lung cancer team, or should automatically trigger a referral. Where the chest x-ray is suspicious of a lung tumour, a contrast-enhanced CT scan of the chest, neck and upper abdomen should be carried out and be available at the first clinic visit.</p>	<p>Thank you for your comments.</p>
087	British Thoracic Society	S3	<p>This maybe a bit pedantic, but don't processes b) and c) refer to the same thing. In some areas, GPs have refused to let this process happen as they want to choose what happens to their patient. Overall, however, we agree with the sentiment however of chasing up CXRs.</p>	<p>Thank you for your comments. The measures have been revised for the final quality standard to improve clarity.</p>
088	Royal College of Radiologists	S3	<p>As a variety of reporters may report the CXR – chest physicians – consultants and SpRs – Radiologists – General, Specialist, Consultants and SpRs, and increasingly outsourced Radiology Private Providers – Quality reporting is paramount. Including report quality audit measures would be an excellent addition here. Particularly as the aim is to try and detect earlier disease which may be more subtle radiographically.</p>	<p>Thank you for your comments. The quality of chest X-ray reporting is outside the scope of this quality standard. The topic expert group reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.</p>
089	North Trent Cancer Network	S4	<p>In the interest of distilling the number of indicators into a few key indicators QS4 and QS5 could usefully be merged.</p>	<p>Thank you. The final quality standard has been revised down to 15 statements. Communication is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this</p>

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				quality standard, covers this area in more detail. Please also see revised statement 4 in the final quality standard.
090	British Lung Foundation	S4	<p>The British Lung Foundation supports the statement 4 that <i>“people with known or suspected lung cancer are provided with opportunities to discuss tests and the risks and benefits of treatment options in a private environment, and are offered information that supports them to make informed choices.”</i></p> <p>The British Lung Foundation also supports the statement 5 that <i>“people with known or suspected lung cancer have access to a lung cancer clinical nurse specialist who they can contact between scheduled hospital visits for continuing support, and people with lung cancer are subsequently offered the option of protocol-driven follow-up”</i>.</p> <p>Accurate, tailored, timely and accessible information should be provided to people at key points along the care pathway. Alongside this, people with known or suspected lung cancer will require support to navigate the different sources of information available, assistance to understand the content of information materials, emotional support to cope with any difficult implications and advice on how to access and use information materials.</p> <p>The lung cancer clinical nurse specialist provides essential support for lung cancer patients and their families throughout the cancer journey. They are important advocates for the patient in the MDT meeting and, ideally, should be present to work with the patient from as early as possible in the journey – and ideally from the time of diagnosis. We advocate that each lung cancer nurse specialist has a workload which does not exceed 80 new lung cancer patients a year.</p> <p>The British Lung Foundation therefore recommends that statements 4 and 5 are combined. The British Lung Foundations recommends the following revised statement: <i>“People with known or suspected lung cancer are provided with opportunities to discuss tests and the risks and benefits of treatment options in a private environment, and given access to a named lung cancer clinical nurse specialist who they can contact for continuing support and to help them make informed choices”</i>.</p>	<p>Accurate, tailored, timely and accessible information is an important theme for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail (please see statements 5 and 6).</p> <p>Please see statement 4 in the final quality standard which covers the lung cancer clinical nurse specialist.</p>
091	Lilly UK	S4	<p>We would like to go further with the outcome of this measure and see included that the patient feels their wishes and concerns are addressed. It is too easy to provide an opportunity to discuss tests and the risks of treatment in a private environment – it is essential healthcare professionals also first look to understand</p>	<p>Thank you for your comment. Communication and providing patients with opportunities to participate in shared decision making are important themes for all NHS care. The NICE</p>

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			<p>the goals of each patient, what they want from treatment and why. We suggest a change to the wording to reflect this along the lines of: <i>“People with known or suspected lung cancer are provided with the opportunity to express their wishes with regard to outcomes and to discuss tests and the risks and benefits.[.]..to make informed choices.”</i></p>	<p>quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail (please see statements 5 and 6 in the NICE quality standard on ‘patient experience in adult NHS services’).</p>
092	Department of Health	S4	<p>Could usefully be merged with QS 5</p>	<p>Thank you. The final quality standard has been revised down to 15 statements. Communication is an important theme for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail. Please also see revised statement 4 in the final quality standard.</p>
093	Macmillan Cancer Support	S4	<p>We also strongly support the inclusion of Statement 4 which provides the opportunity for patients to discuss the risks and benefits of treatment options. Quality Statement 4 also references the importance of ‘a private environment’. Macmillan recognises the contribution the physical environment can provide in providing quality cancer care, and has developed the Macmillan Quality Environment Mark. The Quality Environment Mark is the first assessment framework to recognise excellence in physical environments designed and built for cancer care, and has been is designed to support and complement work that’s being planned for the future by the NHS. Further information on improving cancer environments is available from http://www.macmillan.org.uk/HowWeCanHelp/CancerEnvironments/CancerEnvironments.aspx</p>	<p>Thank you for your comments. Communication is an important theme for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail.</p>
094	Merck Sharp & Dohme UK Ltd	S4	<p>As well as being informed about the benefits and risks of treatment options, we believe that it is important that patients are aware of the supportive care measures available to them, to allow them to make an informed choice about their treatment plan. For this reason we would kindly suggest that the statement of QS 4 is expanded to the following: <i>“People with known or suspected lung cancer are provided with opportunities to discuss tests and the risks and benefits of treatment options, and the available supportive care, in a private environment, and are offered information that supports them to make informed choices.”</i></p>	<p>Thank you for your comments. Communication and information provision are important themes for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail.</p>

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			It may also be relevant to define what should be included in the information offered to patients. This could be done in a similar manner as in QS 6, where a list of topics to include in the holistic assessment is provided in the 'Definitions' section of the QS.	
095	Pierre Fabre Ltd	S4	This is brilliant. The only thing to mention is the consistency and accuracy of the information and centres will need a core set of materials that they can adapt for local use. This also helps structured staff training and supports the flow of skills and knowledge throughout the team. Roy Castle and CancerBackup (Macmillan) have great experience in this field.	Thank you for your comments. Information is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail.
096	United Kingdom Lung Cancer Coalition	S4	<p>The UKLCC supports the statement that <i>“people with known or suspected lung cancer are provided with opportunities to discuss tests and the risks and benefits of treatment options in a private environment, and are offered information that supports them to make informed choices.”</i></p> <p>Accurate, tailored, timely and accessible information should be provided to people at key points along the care pathway. Alongside this, people with known or suspected lung cancer will require support to navigate the different sources of information available, assistance to understand the content of information materials, emotional support to cope with any difficult implications and advice on how to access and use information materials. It is imperative that efforts are made to create the right setting for a full discussion with patients, enabling them to ask the questions they want supported with clear information and input from a lung cancer specialist nurse.</p> <p>Privacy is essential, and this is particularly important in the in-patient setting where privacy is often at a premium. There should be a requirement to ensure that patients are offered the opportunity to have someone with them when difficult news is going to be imparted.</p>	Thank you for your comments. Communication and information are important themes for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail (please see statements 5 and 6 in the NICE quality standard on 'patient experience in adult NHS services').
097	British Thoracic Society	S4	<p>We think that the comment about privacy should apply 'whether in an inpatient or outpatient setting'.</p> <p>Demonstrating good communication is much more than showing that you have appropriate written information. The style and mode of delivery is very important and so patient satisfaction is, as indicated, the appropriate measure. Attendance on an “Advanced Communication Skills” course might be a useful process measure.</p>	The quality standard applies to all relevant settings and services. Communication and information are important themes for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail.

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098	National Lung Cancer Forum for Nurses	S5	Could be merged with QS6 to make 1 standard: 'people with.....for continuing support and should be offered a holistic needs assessment at each key stage of care.'	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
099	North Trent Cancer Network	S5	In the interest of distilling the number of indicators into a few key indicators QS5 and QS4 could usefully be merged.	Thank you. The final quality standard has been revised down to 15 statements. Communication is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail. Please also see revised statement 4 in the final quality standard.
100	British Lung Foundation	S5	<p>The British Lung Foundation supports the statement 4 that <i>“people with known or suspected lung cancer are provided with opportunities to discuss tests and the risks and benefits of treatment options in a private environment, and are offered information that supports them to make informed choices.”</i></p> <p>The British Lung Foundation also supports the statement 5 that <i>“people with known or suspected lung cancer have access to a lung cancer clinical nurse specialist who they can contact between scheduled hospital visits for continuing support, and people with lung cancer are subsequently offered the option of protocol-driven follow-up”</i>.</p> <p>Accurate, tailored, timely and accessible information should be provided to people at key points along the care pathway. Alongside this, people with known or suspected lung cancer will require support to navigate the different sources of information available, assistance to understand the content of information materials, emotional support to cope with any difficult implications and advice on how to access and use information materials.</p> <p>The lung cancer clinical nurse specialist provides essential support for lung cancer patients and their families throughout the cancer journey. They are important advocates for the patient in the MDT meeting and, ideally, should be present to</p>	<p>Thank you. The final quality standard has been revised down to 15 statements. The topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.</p> <p>Communication and information are important themes for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail.</p>

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			<p>work with the patient from as early as possible in the journey – and ideally from the time of diagnosis. We advocate that each lung cancer nurse specialist has a workload which does not exceed 80 new lung cancer patients a year.</p> <p>The British Lung Foundation therefore recommends that statements 4 and 5 are combined. The British Lung Foundations recommends the following revised statement:</p> <p><i>“People with known or suspected lung cancer are provided with opportunities to discuss tests and the risks and benefits of treatment options in a private environment, and given access to a named lung cancer clinical nurse specialist who they can contact for continuing support and to help them make informed choices”.</i></p>	
101	Lilly UK	S5	The impact of the lung cancer clinical nurse has been widely demonstrated and we strongly support their involvement in providing quality care for patients with lung cancer.	Thank you. Please see statement 4 in the final quality standard.
102	Department of Health	S5	Could usefully be merged with QS 4	Thank you. The final quality standard has been revised down to 15 statements. Communication and information are important themes for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail, therefore draft statement 4 did not progress to the final quality standard. Please also see revised statement 4 in the final quality standard.
103	Department of Health	S5	Also potential to merge QS 6 with QS 5 “people with.....for continuing support and should be offered a holistic needs assessment at each key stage of care.”	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
104	Macmillan Cancer Support	S5	We also welcome the recognition in Quality Statement 5 of the importance have access to a lung cancer clinical nurse specialist who patients can contact between scheduled hospital visits for continuing support.	Thank you. Please see statement 4 in the final quality standard.

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105	Royal College of Physicians	S5	Follow-up can be by LCNS or medic. This will depend on the future therapeutic options when seen by the latter rather than the former. Lung CNS - this is really important. However, the reality is that a CNS is not always available in all areas (some areas have none). Also trusts are scrutinising CNS's and down banding many of them so that CNS led follow up may not be possible (eg for band 6 nurses). Also, many patients decline stand alone nurse follow up making it difficult to encourage trusts to support it.	Thank you. The quality standard has been revised to clarify this. Please see statement 14 in the final quality standard.
106	NICE Implementation Team	S5	This statement is looking at more than one idea and if it's left in, these should be split up.	Thank you. The quality standard has been revised to take this into account. Please see statements 4 and 14 in the final quality standard.
107	United Kingdom Lung Cancer Coalition	S5	The UKLCC supports the statement that <i>“people with known or suspected lung cancer have access to a lung cancer clinical nurse specialist who they can contact between scheduled hospital visits for continuing support, and people with lung cancer are subsequently offered the option of protocol-driven follow-up.”</i> The lung cancer clinical nurse specialist provides essential support for lung cancer patients and their families throughout the cancer journey. They are important advocates for the patient in the MDT meeting and, ideally, should be present to work with the patient from as early as possible in the journey – and ideally from the time of diagnosis. We advocate each lung cancer nurse specialist has a workload which does not exceed 80 new lung cancer patients a year. High quality, protocol-driven follow up is essential to enable the patient to feel supported, self-manage where possible, and identify potential problems early so they can be dealt with effectively and efficiently.	Thank you. Please see statement 4 in the final quality standard.
108	Royal College of Radiologists	S5	Agree	Thank you.
109	The National Council for Palliative Care	S5	The statements need a specific method of measuring outcomes. Statements are almost entirely structure and process focused, which risks encouraging a tick box approach.	The quality standard as a whole aims to describe high quality care across the care pathway. It is expected to improve care for people with lung cancer. Outcome measures are stated where the topic expert group felt these were appropriate, which include patient and carer-reported outcomes. The quality measures aim to improve the structures and processes of care that are considered to be linked to outcomes, as well

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				as specifying outcomes directly where the TEG felt able to define these.
110	Merck Sharp & Dohme UK Ltd	S5	In addition to the measures already listed for QS 5, we would suggest that it is also important to measure evidence of local arrangements for educating clinical nurse specialists and other healthcare professionals on the follow-up protocols, and for ensuring that systems and processes are in place which support the protocols. Inclusion of these measures in QS 5 would ensure that people are aware of the protocols and that they can be followed effectively.	Thank you. The quality standard has been revised to clarify this. Please see statement 14 in the final quality standard.
111	National Lung Cancer Forum for Nurses	S6	Yes. 2 weeks is a reasonable timeframe to set.	Thank you. Please see statement 5 in the final quality standard.
112	British Thoracic Society	S6	Providing appropriate referrals to specialist services (for example clinical psychology) may be very difficult within a two week-time frame, unless adequately resourced through commissioning.	Thank you. Please see statement 5 in the final quality standard.
113	Lilly UK	S6	Yes, we believe this is correct	Thank you. Please see statement 5 in the final quality standard.
114	Department of Health	S6	Yes, 2 weeks is a reasonable timeframe	Thank you. Please see statement 5 in the final quality standard.
115	RCGP and the Primary Care Respiratory Society	S6	Comments for Question 3 Very definitely. Most are seen < 2 weeks, there should be flexibility on this and not judged on this, some patients take time to decide to see a specialist, may be too ill to get there or want their holiday first.	Thank you. All quality statements take into account patient choice and clinical judgement.
116	Royal College of Nursing	S6	For draft quality statement 6: Yes. However, some specialist services in some areas may be funded by charities and donations for example local hospices/community palliative care teams. Is this standard of two weeks applicable to voluntary/charitable organisations and what will happen if services providing NHS funded care are not able to meet this state Quality Statement?	The final quality standard uses the 'Notes on the scope' section to make clear that the quality standard applies to all relevant NHS settings and services. We expect that further advice about how quality standards should be used by the NHS will come from the National Quality Board and, when it is established, from the NHS Commissioning Board.
117	Royal Brompton & Harefield NHS Foundation Trust	S6	For draft quality statement 6: Is it correct to say that people referred for specialist services should receive them within a timeframe that does not cause avoidable physiological or psychological distress and should not exceed 2 weeks? For specialist palliative care we would anticipate that this should be less - ? 1wk –	Thank you. Please see statement 5 in the final quality standard.

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			after timely referral made as in statement 6.	
118	Royal College of Physicians	S6	Yes.	Thank you. Please see statement 5 in the final quality standard.
119	Astra Zenica	S6	Yes	Thank you. Please see statement 5 in the final quality standard.
120	Chartered Society of Physiotherapy	S6	For draft quality statement 6: Is it correct to say that people referred for specialist services should receive them within a timeframe that does not cause avoidable physiological or psychological distress and should not exceed 2 weeks? This is a reasonable statement to make especially with the rapid nature of symptoms that lung patients can present with.	Thank you. Please see statement 5 in the final quality standard.
121	National Lung Cancer Forum for Nurses	S6	Could be merged with QS5 to make 1 standard: 'people with.....for continuing support and should be offered a holistic needs assessment at each key stage of care.'	Thank you. The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
122	British Lung Foundation	S6	The British Lung Foundation supports the statement that <i>“people with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services when necessary.”</i> We recommend that every patient with lung cancer should have a current and agreed care plan, which should be based on a holistic, structured assessment of their needs. This should be prepared following their diagnosis and be updated as and when appropriate at key points along their care pathway. The assessment should cover their information, physical, psychosocial, spiritual, financial and rehabilitation needs, and they should receive tailored interventions based on the needs identified. With regard to the specific question, the British Lung Foundation supports the additional recommendation that people referred to specialist services should receive them in a timeframe that does not cause avoidable distress and should not exceed 2 weeks. The British Lung Foundation also supports the statement that <i>“people with known or suspected lung cancer who are current smokers are offered smoking cessation</i>	Thank you. Please see statement 5 in the final quality standard, which has been amended to strengthen the link to the care plan and now incorporates smoking cessation advice as part of the definition of holistic needs.

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			<p><i>advice and therapies to help them stop smoking”.</i></p> <p>However the British Lung Foundation recommends that this advice should be tailored and sensitive to reflect the fact that in addition to the challenge of giving up smoking the patients will also be coping with a lung cancer diagnosis. Therefore the British Lung Foundation suggests that statement 6 and 7 are combined. The following statement is recommended:</p> <p><i>“People with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services including smoking cessation advice for those who are current smokers”.</i></p>	
123	Amgen	S6	<p>QS 6 and 15 (listed below) emphasize key aspects of high quality lung cancer care such as providing holistic needs assessment at each key stage of care and offering chemotherapy tailored to tumour type and individual factors for patients with advanced stage lung cancer. We are of the view that these quality statements are highly significant as they focus on patient-centred aspects and are critical in ensuring that patients have a positive experience of care, a central tenet of the NHS Outcomes Framework. We are also of the opinion that in addition to ensuring that patients have a positive experience of care, it is of utmost importance that they are treated in a safe environment and protected from avoidable harm (a fundamental aim of the NHS Outcomes Framework). It is therefore important that as part of the holistic needs assessment at each key stage of care and in offering chemotherapy tailored to tumour type, patients have timely access to information in an accessible format, appropriate to their individual needs and preferences that would help patients make better informed decisions around their care taking into account a broad range of factors such as efficacy, safety, tolerability etc. This would be especially important for patients receiving anticancer therapy and exposed to (avoidable) mortality risk from toxicities related to their anticancer therapy.</p> <p>QS 6 – People with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services when necessary.</p> <p>QS 15 – People with advanced stage IIIB or IV non-small-cell lung cancer and performance status 0-1 are offered systemic therapy, in accordance with NICE guidance, that is tailored to the histological type and sub-type of the tumour, and individual predictive factor.</p>	<p>Thank you for your comments. Please see quality statements 5 and 12 in the final quality standard.</p> <p>Information provision and shared decision making are important themes for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more detail (please see statements 5 and 6).</p>
124	Department of Health	S6	<p>Also potential to merge QS 6 with QS 5 “people with.....for continuing support and should be offered a holistic needs assessment at each key stage of care.”</p>	<p>Thank you. The final quality standard has been revised down to 15 statements. It is</p>

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				important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality that will have an impact on outcomes.
125	Macmillan Cancer Support	S6	<p>We are pleased that the Quality Statement 6 refers to a holistic needs assessment, but believe it also needs to make reference to the need to offer support at key points in each patient's journey.</p> <p>In Quality Statement 6, we would like to see that lung cancer patients receive <u>individualised agreed care plans</u> based on a holistic structured assessment of their needs (i.e. not just clinical needs, but also psychosocial, practical and financial needs). This would help to identify which care pathway is most suitable for each patient, based on the treatment and the patient's ability to manage, and therefore what level of professional involvement will be required. This was recommended as part of the UKLCC Draft Quality Statements 8. (People with cancer have a current agreed care plan, based on a holistic, structured assessment of their needs, which is first done following their diagnosis and is updated as and when appropriate at key points along their care pathway. The assessment covers their information, physical, psychosocial, spiritual, financial and rehabilitation needs, and they receive tailored interventions based on the needs identified.)</p> <p>We welcome the current inclusion of a detailed definition under this quality statement of what holistic should entail, but we would like to see that information is provided on gaining financial support. This is especially important since the 2010 National Cancer Patient Experience Survey showed only 50% of those who wanted financial information were given any.</p>	Thank you. Please see statement 5 in the final quality standard, which has been amended to strengthen the link to the care plan. We have also included additional aspects of holistic needs in the definition section.
126	Macmillan Cancer Support	S6	<p>It is also critically important that there is recognition in the Quality Standard on the importance of <u>patients receiving tailored, timely and accessible information throughout their cancer journey</u>, and that the information and support they receive is relevant for them at that time in the journey. This was recommended as part of the UKLCC Draft Quality Statements 9. (People with cancer receive accurate, tailored, timely and accessible information at key points along their care pathway, alongside support to navigate the different sources of information available, assistance to understand the content of information materials, emotional support to cope with any difficult implications and advice on how to access and use</p>	Information provision is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail (please see statements 5 and 6).

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			information materials.) Cancer Information Prescriptions, which are currently being rolled out across England, provide a solution for providers in offering this continual support.	
127	Royal Brompton & Harefield NHS Foundation Trust	S6	People with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services when necessary.	Thank you.
128	College of Occupational Therapists	S6	It may be a bit more directive if it mentioned the National Cancer Rehab Pathways as a suggestion of the evidence based practice that the four main AHPs carry out?	The definitions section is used to broadly define or clarify particular terms used in the quality statement. The topic expert group are unable to provide supporting information or additional detail about terms not included in the quality statement where this can be found elsewhere.
129	United Kingdom Lung Cancer Coalition	S6	<p>The UKLCC supports the statement that <i>“people with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services when necessary.”</i></p> <p>We recommend that every patient with lung cancer should have a current and agreed care plan, which should be based on a holistic, structured assessment of their need. This should be prepared following their diagnosis and be updated as and when appropriate at key points along their care pathway. The assessment should cover their information, physical, psychosocial, spiritual, financial and rehabilitation needs, and they should receive tailored interventions based on the needs identified.</p> <p>With regard to the specific question, the UKLCC supports the additional recommendation that people referred to specialist services should receive them in a timeframe that does not cause avoidable distress and should not exceed 2 weeks.</p> <p>We also note the importance of General Practice being kept in the loop, particularly given that they are likely to be called on for matters of symptom control and to support the patient’s family (alongside the lung cancer specialist nurse).</p> <p>We urge the Committee to consider inserting a standard which contains an explicit contact between the patient and their GP after initial diagnosis and treatment to at least ‘touch base’.</p> <p>Many units have an open access policy for their clinics through secretaries or lung cancer nurses – providing an important trouble-shooting mechanism. However, these can inadvertently lead to the GP being excluded from the information loop.</p>	<p>Thank you. Please see statement 5 in the final quality standard, which has been amended to strengthen the link to the care plan. We have also included additional aspects of holistic needs in the definition section.</p> <p>Please see statement 14 in the final quality standard which addresses follow-up. Liaison with the patient’s GP was considered by the topic expert group to be implicitly included within the concept of follow-up.</p>

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			We ask the Committee to consider whether immediate access to such services – which should include primary care – should be referenced in the standards.	
130	Royal College of Radiologists	S6	Agree	Thank you.
131	Chartered Society of Physiotherapy	S6	It is vital that patients are not just referred to specialist service ie at one off HNA assessments in their pathway and that the HNA can be used not just at key points but also at any time including self referral options.	Thank you for your comments. Please see statement 5 in the final quality standard. The statement does not preclude holistic needs assessments being undertaken in all circumstances where appropriate.
132	The National Council for Palliative Care	S6	The statements need a specific method of measuring outcomes. Statements are almost entirely structure and process focused, which risks encouraging a tick box approach.	The quality standard as a whole aims to describe high quality care across the care pathway. It is expected to improve care for people with lung cancer. Outcome measures are stated where the topic expert group felt these were appropriate, which include patient and carer-reported outcomes. The quality measures aim to improve the structures and processes of care that are considered to be linked to outcomes, as well as specifying outcomes directly where the TEG felt able to define these.
133	Chartered Society of Physiotherapy	S6	Draft Quality measure Heading: Points for consideration are typed in blue: Structure: Evidence of local arrangements, staff education and written clinical protocols to ensure that people with lung cancer are offered a holistic needs assessment at each key stage of care, including on the emergence of symptoms, and are offered prompt referral to specialist services when necessary.	Thank you for your comments. Please see statement 5 in the final quality standard. The statement does not preclude holistic needs assessments being undertaken in all circumstances where appropriate.
134	Chartered Society of Physiotherapy	S6	Please see addition to sentence (typed in blue): If this point is added it will need to added throughout QS6 People with lung cancer are offered a holistic needs assessment at each key stage of care and on the emergence of symptoms, and are offered prompt referral to specialist services when necessary.	Thank you for your comments. Please see statement 5 in the final quality standard. The statement does not preclude holistic needs assessments being undertaken in all circumstances where appropriate.
135	Chartered Society of Physiotherapy	S6	Section: Description of what the quality statement means for each audience: See addition to sentence typed in blue: Service providers ensure there are systems in place for people with lung cancer to	Thank you for your comments. Please see statement 5 in the final quality standard. The statement does not preclude holistic needs

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			<p>be offered a holistic needs assessment at each key stage of care and on emergence of symptoms. This should include self referral pathways and prompt referral to specialist services when necessary.</p> <p>Healthcare professionals offer people with lung cancer a holistic needs assessment at each key stage of care and on emergence of symptoms, and are offered prompt referral to specialist services when necessary.</p> <p>Commissioners ensure they commission services for people with lung cancer to be offered a holistic needs assessment at each key stage of care and on emergence of symptoms, and are offered prompt referral to specialist services when necessary.</p>	assessments being undertaken in all circumstances where appropriate.
136	Merck Sharp & Dohme UK Ltd	S6	We support the inclusion of the list of topics that should be covered in the holistic needs assessment, however we would suggest that clarification is provided that 'control of physical symptoms' applies to both symptoms of the cancer and symptoms caused by therapy-related toxicities. This will ensure that the holistic needs assessment captures both of these important aspects of a patient's physical symptoms. For example, the wording could be updated to: "control of physical symptoms of the cancer and of therapy-related toxicities".	Thank you for your comments. We believe the control of physical symptoms included in the definitions section includes all symptoms without reference to the exact cause.
137	Chartered Society of Physiotherapy	S6	Due to differences in knowledge between members of the MDT, Rehabilitation should be defined (i.e. Physiotherapy/Occupational Therapy/Dietetics/Speech and language/Physical activity programmes/vocational rehab programmes)	The definitions section is used to broadly define or clarify particular terms used in the quality statement. The topic expert group are unable to provide supporting information or additional detail about terms not included in the quality statement where this can be found elsewhere.
138	Chartered Society of Physiotherapy	S6	Under Definition heading and bullet point Rehabilitation: - ? add as per NCAT Rehabilitation pathways	The definitions section is used to broadly define or clarify particular terms used in the quality statement. The topic expert group are unable to provide supporting information or additional detail about terms not included in the quality statement where this can be found elsewhere.
139	British Lung Foundation	S7	<p>The British Lung Foundation supports the statement that <i>“people with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services when necessary.”</i></p> <p>We recommend that every patient with lung cancer should have a current and agreed care plan, which should be based on a holistic, structured assessment of</p>	Thank you. This statement was not progressed to the final quality standard. Please see statement 5, which has been amended to strengthen the link to the care plan. We have also included additional

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			<p>their needs. This should be prepared following their diagnosis and be updated as and when appropriate at key points along their care pathway. The assessment should cover their information, physical, psychosocial, spiritual, financial and rehabilitation needs, and they should receive tailored interventions based on the needs identified.</p> <p>With regard to the specific question, the British Lung Foundation supports the additional recommendation that people referred to specialist services should receive them in a timeframe that does not cause avoidable distress and should not exceed 2 weeks.</p> <p>The British Lung Foundation also supports the statement that <i>“people with known or suspected lung cancer who are current smokers are offered smoking cessation advice and therapies to help them stop smoking”</i>.</p> <p>However the British Lung Foundation recommends that this advice should be tailored and sensitive to reflect the fact that in addition to the challenge of giving up smoking the patients will also be coping with a lung cancer diagnosis. Therefore the British Lung Foundation suggests that statement 6 and 7 are combined. The following statement is recommended: <i>“People with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services including smoking cessation advice for those who are current smokers”</i>.</p>	<p>aspects of holistic needs in the definition section, which incorporates smoking cessation advice.</p>
140	The National Council for Palliative Care	S7	<p>There should be recognition that it may not be appropriate to prioritise smoking cessation in people who are close to the end of life. For people in this group to be told to suddenly stop smoking may not carry significant benefit and might impact considerably on their quality of life.</p>	<p>Thank you. This statement was not progressed to the final quality standard. Please see statement 5, which now includes smoking cessation advice as part of the definition of holistic needs.</p>
141	United Kingdom Lung Cancer Coalition	S7	<p>The UKLCC supports the statement that <i>“people with known or suspected lung cancer who are current smokers are offered smoking cessation advice and therapies to help them stop smoking.”</i></p> <p>The advice they receive should be tailored and sensitive to reflect the fact that in addition to the challenge of giving up smoking they will also be coping with a lung cancer diagnosis.</p>	<p>Thank you. This statement was not progressed to the final quality standard. Please see statement 5 in the final quality standard where we have incorporated smoking cessation as part of the definition of holistic needs.</p>
142	Royal College of Radiologists	S7	<p>Agree</p>	<p>Thank you.</p>
143	National Lung Cancer Forum for Nurses	S8	<p>Could be merged with QS9 to make 1 standard.</p>	<p>Thank you. The final quality standard has been revised down to 15 statements. Please see revised statement 6 in the final quality</p>

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				standard. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
144	North Trent Cancer Network	S8	In the interest of distilling the number of indicators into a few key indicators QS8 and QS9 could usefully be merged.	Thank you. The final quality standard has been revised down to 15 statements. Please see revised statement 6 in the final quality standard. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
145	British Lung Foundation	S8	<p>The British Lung Foundation supports the statement that <i>“people with suspected lung cancer following initial assessment and CT scan are offered diagnostic and staging tests that give the most information with the least risk, in accordance with NICE guidance.”</i></p> <p>The diagnostic and staging pathway should be planned at the earliest possible time within the referral pathway to allow timely access to appropriate diagnostics. This pathway must be designed to allow the safest and most informative diagnosis, including the type and extent of the cancer, with the fewest tests. The British Lung Foundation also supports the statement that <i>“people with suspected lung cancer have comprehensive diagnostic and staging tests completed within 2 weeks of their first lung cancer clinic outpatient appointment or first contact with the lung cancer multidisciplinary team as an inpatient.”</i></p> <p>We believe that the timeframe recommended is appropriate. However the British Lung Foundation recommends that statements 8 and 9 are combined. The following revised statement is suggested: <i>“People with suspected lung cancer following initial assessment and CT scan should be offered diagnostic and staging tests which give the most information with the least risk, accordance with NICE guidance. These tests should be given within 2 weeks of the person’s first lung cancer clinic outpatient appointment or first contact with the lung cancer multidisciplinary team as an inpatient”.</i></p>	Thank you. These comments are in line with the discussions of the topic expert group during development of the quality standard. Please see revised statement 6 in the final quality standard.
146	Department of Health	S8	<p>Could usefully be merged with QS 9.</p> <p>Quality measure, process a) is rather woolly with no easily measurable outcome.</p>	Thank you. The final quality standard has been revised down to 15 statements. The measures for this statement have been revised

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				to improve clarity and incorporated into statement 6. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
147	United Kingdom Lung Cancer Coalition	S8	<p>The UKLCC supports the statement that <i>“people with suspected lung cancer following initial assessment and CT scan are offered diagnostic and staging tests that give the most information with the least risk, in accordance with NICE guidance.”</i></p> <p>The diagnostic and staging pathway should be planned at the earliest possible time within the referral pathway to allow timely access to appropriate diagnostics. This pathway must be designed to allow the safest and most informative diagnosis, including the type and extent of the cancer, without putting the patient through unnecessary or repetitive tests.</p>	Thank you. These comments are in line with the discussions of the topic expert group during development of the quality standard. Please see revised statement 6 in the final quality standard.
148	British Thoracic Society	S8	The sentiments outlined here are entirely appropriate, but in practice, this is a complex area, and process measures 1a) and 1b) are probably not going to be measurable in the real world.	Thank you. Please see statement 6 in the final quality standard. The measures for this draft statement have been revised to improve clarity and incorporated into statement 6.
149	NCL and West Essex Lung Cancer Network	S8	Patients should have a diagnostic test that yields the most information about stage and cell type, however, sometimes appropriate diagnostic tests will be negative and they will need more than one diagnostic test. Hence 8c will capture 2 groups of people – those where the first biopsy did not give staging information and also patients who have a difficult diagnostic pathway.	Thank you for your comments. Please see revised statement 6 in the final quality standard. Levels of expected achievement should be decided locally. While typical aspirational achievements are likely to be 100% or 0%, realistic standards should take account of patient safety, patient choice and clinical judgement.
150	United Kingdom Lung Cancer Coalition	S8	<p>We ask the Committee to revisit the wording around process a), since we cannot see that as currently drafted it lends itself to an easily measurable outcome:</p> <p><i>a) Proportion of people with suspected lung cancer following initial assessment and CT scan who receive diagnostic and staging tests that give the most information with the least risk, in accordance with NICE guidance.</i></p> <p><i>Numerator – the number of people in the denominator who receive diagnostic and staging tests that give the most information with the least risk, in accordance with NICE guidance.</i></p> <p><i>Denominator – the number of people with suspected lung cancer following initial</i></p>	Thank you. The measures for this statement have been revised to improve clarity and incorporated into statement 6.

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			<i>assessment and CT scan.</i>	
151	Royal College of Radiologists	S9	This is potentially from the radiology services viewpoint, the most challenging Quality Standard. The committee are correct to address this component of care. At present, it may be 1 to 2 weeks from CXR report to clinic appointment, then 2 weeks to CT scan, a week for MDT discussion, 2 weeks to biopsy and potentially a further 2 weeks for PET-CT. This process clearly needs shortening. As written, the QS separate 8 and 9, but in practice they are a continuum of investigations, decision-making, OP appointments and MDTs. As written the patient should have an urgent CXR – presumably within 24 hours – then may wait 2 weeks for a 2 week referral, then 2 weeks for a CT scan after being seen in Chest clinic, then the following has to occur within 2 weeks - MDT discussion, PET-CT, percutaneous needle biopsy and/or bronchoscopy, and/or EBUS. It would probably be better to suggest that from the time of the CXR report identifying suspected lung cancer, to a definitive treatment decision being made in those patients eventually proven to have lung cancer a maximum time period of 3 weeks is permissible. This would encourage protocol driven CT scanning alongside chest clinic referral, the performance of EBUS upfront rather than following conventional bronchoscopy, percutaneous nodal or lung biopsy discussed / arranged and performed prior to MDT discussion, early referral for PET-CT etc	Thank you for your comments. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
152	National Lung Cancer Forum for Nurses	S9	2 weeks is unachievable for some centres/units mainly due to pressures in Radiology Departments.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
153	Lilly UK	S9	We believe this is a reasonable goal; however, we have some concerns around the impact of tight timelines on the quality of care. Does the pressure of completing diagnosis and staging tests within 2 weeks mean that in some cases the quality of samples, for example, are compromised? We would prefer a target for ~80% of patients to complete their diagnosis and staging tests within 2 weeks; this would allow clinicians to make prompt but quality decisions as they would be able to undertake additional tests or assessments <u>if</u> the diagnosis was difficult and these were required.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
154	Department of Health	S9	2 weeks is unachievable for some centres/ units mainly due to pressures in Radiology Departments	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national

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ID	Stakeholder	Statement No	Comments	Responses
				cancer waiting times targets have not been included.
155	Royal College of Nursing	S9	<p>For draft quality statement 9: No. Within two weeks of first consultant appointment is not a realistic quality marker for a number of reasons including the following:</p> <ol style="list-style-type: none"> If initial biopsy is non-diagnostic or inadequate to provide a complete pathological diagnosis, patients may need a repeat biopsy. Co-morbidities may lead to delays in investigations for example if patient is receiving anti-coagulation therapy this may need to be discontinued prior to a procedure. The time needed for a complete pathological diagnosis analysis (as samples may need to be sent to specialist laboratories for analysis of predictive markers). Patient choice to delay investigations (especially over holiday periods and religious events). Staging investigations for example PET/CT scan may demonstrate the possibility/probability of site of disease which may affect management (which would require further investigation for example colonoscopy which requires patient preparation). Patient may need time to recover from investigations especially if travelling long distances. 	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
156	British Nuclear Medicine Society	S9	<p>Draft quality statement 9 access to tests, specific question posed by NICE Is within 2 weeks of first consultant appointment a realistic quality marker for completion of comprehensive diagnosis and staging tests? Please remember that statements should be 'aspirational but achievable'. Answer This might be difficult to achieve within 2 weeks for some patients the following investigations which would be typical for a patient considered for surgery or radical chemoradiotherapy : CT, PET-CT, cardiorespiratory exercise testing, biopsy (TBNA or percutaneous) and possibly endobronchial ultrasound. A period of 2-4 weeks might be more achievable and possibly desirable for some patients who might find this number of investigations difficult to cope with on days close together especially if elderly and symptomatic.</p>	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
157	Royal College of Physicians	S9	A proportion of patients need more time. Hence, 2 weeks may be achievable for the majority but not all. It probably fulfils the aspirational and (usually) achievable	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes

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			point.	additional to those covered by the national cancer waiting times targets have not been included.
158	Royal College of Physicians	S9	Defined two week limit on referral to specialist service and further two weeks to achieve diagnosis are worthy targets in terms of timely interventions. However there is not an evidence base to support this arbitrary timescale and it is important to recognise the heterogeneous natural history and pathology of lung cancer. Clearly a patient presenting with SVCO requires much faster diagnosis and treatment than two weeks and the patient with slowly enlarging pulmonary nodule over a period of years does not. The difficulty with setting these timescales and setting targets to achieve on these, risks losing sight of clinical prioritisation.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
159	Astra Zenica	S9	Yes	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
160	National Lung Cancer Forum for Nurses	S9	Could be merged with QS8 to make 1 standard.	Thank you. The final quality standard has been revised down to 15 statements. Please see revised statement 6 in the final quality standard. Draft statement 9 did not progress to the final quality standard.
161	North Trent Cancer Network	S9	In the interest of distilling the number of indicators into a few key indicators QS9 and QS8 could usefully be merged.	Thank you. The final quality standard has been revised down to 15 statements. Please see revised statement 6 in the final quality standard. Draft statement 9 did not progress to the final quality standard.
162	British Lung Foundation	S9	The British Lung Foundation supports the statement that <i>“people with suspected lung cancer following initial assessment and CT scan are offered diagnostic and staging tests that give the most information with the least risk, in accordance with NICE guidance.”</i> The diagnostic and staging pathway should be planned at the earliest possible time within the referral pathway to allow timely access to appropriate diagnostics. This pathway must be designed to allow the safest and most informative diagnosis, including the type and extent of the cancer, with the fewest tests. The British Lung Foundation also supports the statement that <i>“people with</i>	Thank you. These comments are in line with the discussions of the topic expert group during development of the quality standard. Draft statement 9 did not progress to the final quality standard. Timeframes additional to those covered by the national cancer waiting times targets have not been included.

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			<p><i>suspected lung cancer have comprehensive diagnostic and staging tests completed within 2 weeks of their first lung cancer clinic outpatient appointment or first contact with the lung cancer multidisciplinary team as an inpatient.”</i></p> <p>We believe that the timeframe recommended is appropriate. However the British Lung Foundation recommends that statements 8 and 9 are combined. The following revised statement is suggested:</p> <p><i>“People with suspected lung cancer following initial assessment and CT scan should be offered diagnostic and staging tests which give the most information with the least risk, accordance with NICE guidance. These tests should be given within 2 weeks of the person’s first lung cancer clinic outpatient appointment or first contact with the lung cancer multidisciplinary team as an inpatient”.</i></p>	
163	Kent and Medway Cancer Network	S9	<p>This is unreasonable and unrealistic. Define ‘comprehensive’? Diagnostic and staging tests could involve CT, lung function, CT/PET, EBUS, histology (including molecular tests such as EGFR or ALK). 2w is beyond aspirational as patients need counselling before each test and many tests requests are iterative, depending on the result of a previous investigation.</p> <p>Agree in an ideal situation the patient should be completed in 2 weeks, however for patient choice reasons, need to stop anticoagulants etc, and those that are difficult to biopsy (ie may require more than one attempt) a certain percentage will never be diagnosed within 2 weeks. Therefore making this a mandatory standard will cause the need for many breach reports. Better if a standard eg 80% are diagnosed within this time frame is far better.</p>	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
164	British Thoracic Society	S9	<p>This is a major challenge for many units particularly when sequential tests are required, and where a malignant diagnosis is confirmed, but more tissue is required to refine diagnosis and treatment. There is a danger that undue haste will prevent this refinement (although dealt with in Standard 10). Changes to the patient pathway by arranging a CT-scan prior to the out-patient appointment is probably the simplest way of speeding things up and could easily become a measure in this standard.</p> <p>Delays in pathology reporting can be an issue – NICE should consider an explicit standard for turn round times.</p>	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
165	Department of Health	S9	<p>Could usefully be merged with QS 8.</p> <p>Trying to get all diagnostic and staging tests within 2 weeks will prove well nigh impossible given the increasing complexity of the lung diagnostic and staging pathway and not all of these test are necessary e.g. Mediastinoscopy following a PET scan if the nodes do not light up. Many tests can only be planned once a</p>	Thank you. Please see revised statement 6 in the final quality standard. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have

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			preceding test is negative. Rather than doing this what we need is for all patients to have an investigations plan decided at first MDT which includes the sequence of tests and which ones need doing if initial tests are negative rather than bringing them back to the MDT each time.	not been included.
166	Pierre Fabre Ltd	S9	This is very important as this is a surrogate measure for many core team skills that are essential for an efficient service, such as good administration, understanding of the process by all and a clear sense of urgency. The MDT is a critical Team and adequate time and leadership is required for audit, training and communication with other departments is required. Time is very important "Rapid disease progression with delay in treatment of NSCLC. Int J.Radiation Oncology. 2011, vol 79; 466. A 2 week time frame is already routine for some. Aspirational should alert us to the need to share good practice. We have seen that "Telling" centres how to do things is not the same as "showing" them – a structure similar to the Cancer Collaborative could showcase Good Practice and provide a mechanism for coaching these standards.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
167	Royal College of Physicians	S9	See answer to question 4. Staging tests within 2 weeks - This is a laudable aim, however we suspect that for patients who need staging mediastinoscopies this will not be achievable in the majority of cases.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
168	NCL and West Essex Lung Cancer Network	S9	The two week time frame proposed is not possible in this day and age when all samples should have immunohistochemistry performed and all non-squamous cancers not suitable for radical treatment should have mutation testing performed. It also does not take into account patients whose first appropriate biopsy proves non-diagnostic.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
169	Central South Coast Cancer Network	S9	Diagnostic and staging tests completed within 2/52 of initial appt seem rather optimistic.	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
170	Central South Coast Cancer Network	S9	Realistically only a small proportion of patients are able to have all investigations and a diagnosis in 2 weeks	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.

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ID	Stakeholder	Statement No	Comments	Responses
171	United Kingdom Lung Cancer Coalition	S9	<p>The UKLCC supports the statement that <i>“people with suspected lung cancer have comprehensive diagnostic and staging tests completed within 2 weeks of their first lung cancer clinic outpatient appointment or first contact with the lung cancer multidisciplinary team as an inpatient.”</i></p> <p>We believe that the timeframe recommended is appropriate but that it will never be possible (or appropriate) to meet such a ‘target’ in every patient.</p>	Thank you. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
172	Royal College of Radiologists	S9	<p>This is potentially from the radiology services viewpoint, the most challenging Quality Standard. The committee are correct to address this component of care. At present, it may be 1 to 2 weeks from CXR report to clinic appointment, then 2 weeks to CT scan, a week for MDT discussion, 2 weeks to biopsy and potentially a further 2 weeks for PET-CT. This process clearly needs shortening. As written, the QS separate 8 and 9, but in practice they are a continuum of investigations, decision-making, OP appointments and MDTs. As written the patient should have an urgent CXR – presumably within 24 hours – then may wait 2 weeks for a 2 week referral, then 2 weeks for a CT scan after being seen in Chest clinic, then the following has to occur within 2 weeks - MDT discussion, PET-CT, percutaneous needle biopsy and/or bronchoscopy, and/or EBUS. It would probably be better to suggest that from the time of the CXR report identifying suspected lung cancer, to a definitive treatment decision being made in those patients eventually proven to have lung cancer a maximum time period of 3 weeks is permissible. This would encourage protocol driven CT scanning alongside chest clinic referral, the performance of EBUS upfront rather than following conventional bronchoscopy, percutaneous nodal or lung biopsy discussed / arranged and performed prior to MDT discussion, early referral for PET-CT etc</p>	Thank you for your comments. Draft statement 9 did not progress to the final quality standard, and timeframes additional to those covered by the national cancer waiting times targets have not been included.
173	British Lung Foundation	S10	<p>The British Lung Foundation supports the statement that <i>“people with suspected lung cancer have adequate tissue samples taken in a suitable form to provide a complete pathological diagnosis. Pathologists provide a complete diagnosis including tumour sub-typing and analysis of necessary predictive markers.”</i></p> <p>According to the National Lung Cancer Audit 2010, histological confirmation rates are still low in some areas, and we believe that every Trust should be able to achieve a proven histological confirmation of lung cancer of at least 75%. Rapid developments in technologies and therapies mean that sub-typing and analysis of predictive markers will become increasingly important to enable access to the most effective treatments.</p>	Thank you. This comment is in line with the discussions of the topic expert group during development of the quality standard. Please see statement 7 in the final quality standard.
174	Lilly UK	S10	We would like to suggest a change to the wording of this statement to reflect that	Thank you. Please see statement 7 in the final

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			<p>tissue samples should be sufficiently large to not impact upon tests that are required: <i>“People with suspected lung cancer have adequate tissue samples taken, <u>that are sufficiently large to not impact upon tests and in suitable form to provide a complete.[.]..analysis of predictive markers.”</u></i></p>	<p>quality standard. We believe the statement supports this concept.</p>
175	Pfizer	S10	<p>Given the potential of lung cancer patients to receive unprecedented benefit from the introduction of new targeted pharmaceutical therapies, we welcome the recommendation in QS10 that analysis of predictive molecular markers be delivered to all patients with suspected lung cancer.</p> <p>In order to allow patients full benefit from these treatments as they are introduced, the NHS should ensure that testing for new predictive molecular markers is planned for and implemented in advance of the introduction of these therapies. Next-generation targeted therapies have the potential to revolutionise treatment for certain lung cancer patients, resulting in unprecedented clinical benefit and substantially improved likelihood of response. As new targeted therapies are developed, ensuring timely access to the molecular diagnostics required for their use is imperative.</p>	<p>Thank you. Please see statement 7 in the final quality standard.</p>
176	Royal College of Physicians	S10	<p>This is an important standard. It is good to have adequacy of tissue at first procedure documented.</p>	<p>Thank you. Please see statement 7 in the final quality standard.</p>
177	United Kingdom Lung Cancer Coalition	S10	<p>The UKLCC supports the statement that <i>“people with suspected lung cancer have adequate tissue samples taken in a suitable form to provide a complete pathological diagnosis. Pathologists provide a complete diagnosis including tumour sub-typing and analysis of necessary predictive markers.”</i></p> <p>According to the National Lung Cancer Audit 2010, histological confirmation rates are still low in some areas, and we believe that every Trust should be able to achieve a proven histological confirmation of lung cancer of at least 75%. Rapid developments in technologies and therapies mean that sub-typing and analysis of predictive markers will become increasingly important to enable access to the most effective treatments.</p>	<p>Thank you. This comment is in line with the discussions of the topic expert group during development of the quality standard. Please see statement 7 in the final quality standard.</p>
178	Royal College of Radiologists	S10	<p>Agree</p>	<p>Thank you.</p>
179	Kent and Medway Cancer Network	S10	<p>The problem with the 1st measure Numerator – the number of people in the denominator who have a second diagnostic test in order to obtain histological information. Denominator – the number of people with suspected lung cancer.</p>	<p>Thank you. Please see statement 7 in the final quality standard. The measures have been revised for the final quality standard to improve clarity.</p>

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			<p>The denominator here should really be 'the number of pts who have had a biopsy for lung cancer'. Just using the pts with suspected lung cancer is too broad. Given the current issues in histology for lung cancer it is felt a more useful benchmark might be to ask MDM's to report the % with histology, % cytology, %EGFR mutation, %NOS etc</p> <p>An increasing number of patients are very elderly, very frail and have late stage disease. There are no treatment options and therefore subjecting them to biopsy procedures is dangerous costly and of no benefit to the patient. This standard seems to suggest all patients will have a diagnosis. It is felt it would be better if another standard stated that a MDT made a histological diagnosis in 75% or had an option to explain why a biopsy was not performed</p> <p>Standard stating tests are not done simply for achieving a standard but are done because they will alter or enable management. For many old frail people making a confirmed diagnosis whilst good for statistics/data is not in their best interest.</p>	<p>Quality measures should form the basis for audit criteria developed and used locally to improve the quality of health and social care. As part of developing these audit criteria the audit standards or levels of expected achievement should, unless otherwise stated, be decided locally. While typical aspirational achievement is likely to be 100% or 0%, realistic standards should take account of patient safety, patient choice and clinical judgement.</p>
180	Roche Products Ltd	S10	<p>Roche welcomes this recognition that as systemic treatments become more sophisticated it is important that clinicians have available sufficient information on patient's tumours to select the right treatment. We feel that although the spirit of the quality measure is good, it could be made more effective by giving some definition of what information should be available to clinicians and the timeliness expected.</p> <p>Since the treatment of lung cancer is rapidly evolving, pathology tests of little clinical relevance today may be vitally important in the future. In order to future proof this quality standard we do not recommend a list of required tests are included, however it would be helpful if the last sentence of the "Structure" for this quality measure were amended to read "<i>Pathologists provide a complete diagnosis of histology, tumour sub-typing, and analysis of predictive markers including, as a minimum, those required to determine the suitability of patients for NICE recommended treatments</i>"</p> <p>With a disease such as lung cancer where patients can decline very rapidly once their disease becomes symptomatic delays in starting treatment are likely to be prejudicial to patient outcome. Therefore timeliness of the availability of tissue diagnostic information should be included as a process measure. Since the MDT meeting is where initial treatment decisions are made an appropriate outcome would be the "Proportion of people with lung cancer who have a tumour sub-type identified at the time of the first MDT at which their case is discussed".</p>	<p>Thank you. The topic expert group prioritised the measures they felt were most important in measuring the quality statement, and acknowledged that although timeliness is important, the aspiration of this statement is that sufficient information is available to select the right treatment. Please see revised statement 7 in the final quality standard where the measures have been revised to improve clarity, and definitions expanded. All quality standards will be reviewed regularly to determine whether they need to be updated.</p>
181	British Thoracic	S10	Process measure 1c) – should this refer only to non-small cell cancers – otherwise	Thank you. The measures have been revised

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	Society		you'll get 100% just by differentiating small cell from non-small cell. Process measure 1d) – this seems too vague to be a useful measure, unless you add “as determined by the local cancer network”.	for the final quality standard to improve clarity (please see statement 7).
182	Lilly UK	S10	We would suggest an additional measure around the percentage of Not Otherwise Specified (NOS) tumours. We believe the measure should be that <10% of tumours are classified as NOS. This is in accordance with international guidance, is currently reflected in the Lung cancer audit and is key to ensuring adequate tissue samples are taken.	Thank you. The measures have been revised for the final quality standard to improve clarity (please see statement 7).
183	Merck Serono	S10	Merck Serono supports the tissue sub-typing and analysis of predictive markers as these processes are crucial steps in the management of lung cancer patients. In the LUCADA 2010 audit, the histological sub-typing is reported but it is not possible from the published report to identify the processes a) to d) and their associated performance/uptake in the NHS. Consequently, we feel that the outcomes of processes a) to d) should be clearly reported in future audits.	Thank you. We envisage that inclusion of these measures in the quality standard will ensure that they are measured at a local level, and may in time influence any national data collections.
184	NCL and West Essex Lung Cancer Network	S10	a) will not be 0% but should be as low as possible. b) should read pathological not histological as some cytology preparations are suitable for full analysis including EGFR. For d) the denominator should be the number of people with the type of lung cancer where a predictive marker is available – at present non-squamous NSCLC, otherwise this measure will promote mutation testing in inappropriate patients which would not be cost effective.	Thank you. The measures have been revised for the final quality standard to improve clarity (please see statement 7).
185	North Trent Cancer Network	S11	In the interest of distilling the number of indicators into a few key indicators QS11 and QS13 could usefully be merged.	The final quality standard has been revised down to 15 statements. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).
186	British Lung Foundation	S11	The British Lung Foundation supports the statement that “ <i>people with resectable lung cancer are offered an assessment of risk of a perioperative cardiac event, perioperative mortality and postoperative dyspnoea and mortality (including an increased risk for people who smoke).</i> ” Surgery is the main curative treatment for lung cancer and the optimum treatment for early stage patients provided they are medically fit. If mortality and survival rates from lung cancer are to improve then increasing access to surgical resection is essential. Access to specialist thoracic surgical opinion within the MDT (and ideally opinion from two thoracic surgeons on operability) is important to ensure that patients who may be older or borderline medical fitness are not excluded from	The final quality standard has been revised down to 15 statements. These comments are in line with the discussions of the topic expert group during development of the quality standard. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).

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			<p>being considered for surgery. The MDT also has an important role here in supporting patients to prepare and enhance their fitness ahead of surgery, as well as taking actions to enhance recovery in the period immediately after surgery and into the longer term.</p> <p>Therefore the British Lung Foundation recommends that Quality Statement 11 and 13 are combined. The British lung Foundation recommends the following revised statement to reflect the importance of borderline patients being considered for treatment to help improve survival outcomes for lung cancer:</p> <p><i>“All patients with lung cancer should be considered for resection against NICE clinical guidelines and assessed by at least two specialist thoracic surgeons within the lung cancer multidisciplinary team. All lung cancer patients should be offered an assessment of risk of a perioperative cardiac event, perioperative mortality and postoperative dyspnoea and mortality (including an increased risk for people who smoke).”</i></p>	
187	Department of Health	S11	Could usefully be merged with QS 13.	The final quality standard has been revised down to 15 statements. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).
188	United Kingdom Lung Cancer Coalition	S11	<p>The UKLCC supports the statement that <i>“people with resectable lung cancer are offered an assessment of risk of a perioperative cardiac event, perioperative mortality and postoperative dyspnoea and mortality (including an increased risk for people who smoke).”</i></p> <p>Surgery is the main curative treatment for lung cancer and the optimum treatment for early stage patients provided they are medically fit. If mortality and survival rates from lung cancer are to improve then increasing access to surgical resection is essential. Access to specialist thoracic surgical opinion within the MDT (and ideally opinion from two thoracic surgeons on operability) is important to ensure that patients who may be older or borderline medical fitness are not excluded from being considered for surgery. The MDT also has an important role here in supporting patients to prepare and enhance their fitness ahead of surgery, as well as taking actions to enhance recovery in the period immediately after surgery and into the longer term.</p>	These comments are in line with the discussions of the topic expert group during development of the quality standard. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).
189	Royal College of Radiologists	S11	Agree	Thank you. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).
190	British Thoracic	S11	We are not sure that 30/60 day mortality rates are the best measure of whether	Thank you. Please see revised statement 8 in

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	Society		fitness assessment has been carried out, nor of the quality of that assessment. You can achieve a 0% mortality by operating on no-one because their risk is quantifiable.	the final quality standard.
191	Royal College of Physicians	S11	What about the morbidity/complication rate of surgery being measured eg b-p fistula, cavity infection?	Thank you. Draft statement 11 did not progress to the final quality standard (please see revised statement 8 in the final quality standard).
192	British Lung Foundation	S12	The British Lung Foundation supports the statement that <i>“people with lung cancer being considered for multimodality treatment are assessed by a thoracic oncologist and a thoracic surgeon, and those with lung cancer potentially suitable for radiotherapy with curative intent are assessed by a clinical oncologist specialising in thoracic oncology.”</i> It is vital that every patient has their case discussed by a specialist lung cancer MDT which has a membership that is representative of every relevant discipline and that every healthcare professional in the MDT is a thoracic specialist.	Thank you. Please see revised statement 9 in the final quality standard.
193	United Kingdom Lung Cancer Coalition	S12	The UKLCC supports the statement that <i>“people with lung cancer being considered for multimodality treatment are assessed by a thoracic oncologist and a thoracic surgeon, and those with lung cancer potentially suitable for radiotherapy with curative intent are assessed by a clinical oncologist specialising in thoracic oncology.”</i> It is vital that every patient has their case discussed by a specialist lung cancer MDT which has a membership that is representative of every relevant discipline and that every healthcare professional in the MDT has a specialism in thoracic oncology.	Thank you. Please see revised statement 9 in the final quality standard.
194	Royal College of Radiologists	S12	Agree	Thank you.
195	Pierre Fabre Ltd	S12	You should also consider measures to encourage consistency in these assessments between centres. Subsequent analysis could then identify administrative, procedural or communication needs for the team/network. The Lung Cancer Core Data set and LUCADA have helped transform access to surgery in the last 10 years. Concurrent chemo-radiotherapy is pushing the stage limits for curative treatment but requires new standards of precision for assessment of PS. Many centres have developed these skills but some leadership is required to coach all centres to the same standard. Do you need a quality measure for the whole data set? Multimodality rates may be an adequate	Thank you. The topic expert group prioritised the measures they felt were most important in measuring the quality statements. Please see the revised statement 9 in the final quality standard.

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ID	Stakeholder	Statement No	Comments	Responses
			surrogate but training should cover all aspects of data management.	
196	National Lung Cancer Forum for Nurses	S13	Some MDTs still only have access to 1 Thoracic Surgeon therefore this standard is unachievable although aspirational.	Please see revised statement 8 in the final quality standard. It is acknowledged that different areas will have different arrangements for accessing a second surgical opinion.
197	North Trent Cancer Network	S13	In the interest of distilling the number of indicators into a few key indicators QS13 and QS11 could usefully be merged.	The final quality standard has been revised down to 15 statements. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).
198	British Lung Foundation	S13	<p>The British Lung Foundation supports the statement that <i>“people with resectable lung cancer are offered an assessment of risk of a perioperative cardiac event, perioperative mortality and postoperative dyspnoea and mortality (including an increased risk for people who smoke).”</i></p> <p>Surgery is the main curative treatment for lung cancer and the optimum treatment for early stage patients provided they are medically fit. If mortality and survival rates from lung cancer are to improve then increasing access to surgical resection is essential. Access to specialist thoracic surgical opinion within the MDT (and ideally opinion from two thoracic surgeons on operability) is important to ensure that patients who may be older or borderline medical fitness are not excluded from being considered for surgery. The MDT also has an important role here in supporting patients to prepare and enhance their fitness ahead of surgery, as well as taking actions to enhance recovery in the period immediately after surgery and into the longer term.</p> <p>Therefore the British Lung Foundation recommends that Quality Statement 11 and 13 are combined. The British lung Foundation recommends the following revised statement to reflect the importance of borderline patients being considered for treatment to help improve survival outcomes for lung cancer:</p> <p><i>“All patients with lung cancer should be considered for resection against NICE clinical guidelines and assessed by at least two specialist thoracic surgeons within the lung cancer multidisciplinary team. All lung cancer patients should be offered an assessment of risk of a perioperative cardiac event, perioperative mortality and postoperative dyspnoea and mortality (including an increased risk for people who smoke).”</i></p>	The final quality standard has been revised down to 15 statements. These comments are in line with the discussions of the topic expert group during development of the quality standard. Draft statement 11 did not progress to the final quality standard (please see revised statement 8).
199	British Thoracic Society	S13	Although defined in the standard, we think that the term “borderline fitness” is vague and unworkable. Access to a second surgical opinion is likely to be more useful.	Thank you. Please see revised statement 8 in the final quality standard. A definition of borderline fitness has been included.

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ID	Stakeholder	Statement No	Comments	Responses
200	Department of Health	S13	Could usefully be merged with QS 11. Some MDTs still only have access to 1 Thoracic surgeon therefore, although aspirational, this standard is unachievable.	Draft statement 11 did not progress to the final quality standard (please see revised statement 8). It is acknowledged that different areas will have different arrangements for accessing a second surgical opinion.
201	Royal College of Nursing	S13	The Lung Cancer MDT already suggest referral to thoracic surgeon so this quality statement should read "... or a second option from another thoracic surgeon"	Please see revised statement 8 in the final quality standard.
202	Pierre Fabre Ltd	S13	If radical chemo-radiotherapy is a viable option for these patients and should the team also be alerted to these patients for a second opinion? Effectively combining QS 13 with QS 14 would create an assessment for curative treatment that could add urgency or minimise delay (see "Rapid disease progression with delay in treatment of NSCLC. Int J.Radiation Oncology. 2011, vol 79; 466.) . If these patients are borderline for surgery it may be because they have an increased systemic element for their disease and may require systemic treatment. Should this QS include a thoracic oncology opinion within the cure channel?	Please see revised statement 8 in the final quality standard, which includes options for non-surgical treatment with curative intent.
203	Royal College of Physicians	S13	Should age for surgery appear here or is that an audit issue? There is a need to somehow achieve less ageism in resections	The underpinning guidance does not include age as a factor that should be considered when assessing fitness for surgery and the quality statement reflects that, so we believe the statement supports the achievement of less ageism in resections. The topic expert group prioritised the measures they felt were most important in measuring the quality statements. Quality measures should form the basis for audit criteria developed and used locally to improve the quality of health and social care. If there was concern about ageism in local decision-making then local audit teams could consider including age of the patient as part of the audit measures. It is also anticipated that this information will be monitored through the national audit.
204	NCL and West Essex Lung Cancer Network	S13	This will be hard to deliver in some areas as most MDTs only have one thoracic surgeon and may delay alternative treatment for these patients.	Please see revised statement 8 in the final quality standard. It is acknowledged that different areas will have different arrangements for accessing a second surgical opinion.

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205	Central South Coast Cancer Network	S13	There needs to be more clarity around the statement 'Patients with borderline fitness for surgery are given surgery or a 2 nd opinion from another surgeon'.	Please see revised statement 8 in the final quality standard.
206	United Kingdom Lung Cancer Coalition	S13	The UKLCC supports the statement that <i>"people with resectable lung cancer who are of borderline fitness are offered surgery or a second opinion on their fitness for surgery from the lung cancer multidisciplinary team including another thoracic surgeon."</i> As set out in our response to QS11, if mortality and survival rates from lung cancer are to improve then increasing access to surgical resection is essential. Access to specialist thoracic surgical opinion within the MDT (and ideally opinion from two thoracic surgeons on operability) is important to ensure that patients who may be older or borderline medical fitness are not excluded from being considered for surgery. Surgeons should have a true thoracic interest, defined as a minimum one full day thoracic operating per week, minimum one full MDT per week and a thoracic surgical outpatient clinic with lung nurse specialist support present at clinic. They should be able to provide the full range of surgical techniques.	Thank you. Please see revised statement 8 in the final quality standard.
207	Royal College of Radiologists	S13	This QS implies that some patients of borderline fitness are declined by Thoracic surgeons. This may be correct, but it may also be the case that the MDT or chest physicians are less enthusiastic about surgery. Perhaps this may be measured specifically – number of patients of borderline fitness with reason for non-surgical choice of treatment specifically recorded over the number of patients of borderline fitness for surgery in total. This might highlight why some MDTs decline some groups of patients whilst others offer surgery. It may also help when reviewing outcomes across MDTs.	Thank you. The topic expert group prioritised the measures they felt were most important in measuring the quality statements. Please see revised statement 8 in the final quality standard.
208	National Lung Cancer Forum for Nurses	S14	Could be merged with QS15 to make 1 standard.	The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality. Please see statements 11 and 12 in the final quality standard.
209	British Lung Foundation	S14	The British Lung Foundation supports the statement that <i>"people with lung cancer stage I-III and good performance status who are unable to undergo surgery are offered radiotherapy with curative intent, using planning and treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue</i>	Thank you. Please see statement 9 in the final quality standard which addresses MDT composition and revised statement 11 which addresses optimal radiotherapy.

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			<p><i>damage.”</i></p> <p>Specialism in thoracic oncology is a requirement for any high quality service and the British Lung Foundation believes that there should be at least two oncologists per MDT – one medical and one clinical. In order to optimise and personalise radiotherapy, wider access should be given to PET-CT, stereotactic targeted therapies and other recent or more advanced techniques.</p>	
210	Kent and Medway Cancer Network	S14	<p>Why not mention the ideal of being offered radical concurrent chemo-radiation. This is superior to sequential or just radical RT but we know offering of concurrent is variable in UK.</p> <p>‘Using planning and treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue damage.’ This statement is too broad as any RT can be said to be delivered in a way that minimises normal tissue damage while optimising dose to tumour.</p> <p>Why not recommend SBRT for early stage peripheral and inoperable lesions.</p>	A definition of treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue damage has been included in the final quality standard (see revised statement 11), which lists the relevant examples.
211	Department of Health	S14	<p>Needs to be split into 2: Stage I/II should be offered stereotactic radiotherapy or conventional radical radiotherapy.</p> <p>Stage III chemoradiotherapy.</p>	It is acknowledged that not all statements will be appropriate for all patients. As quality measures form the basis for audit criteria developed and used locally, realistic standards should take account of patient safety, patient choice and clinical judgement.
212	The Society and College of Radiographers	S14	<p>Stereotactic radiotherapy can reduce treatment costs while improving overall survival and local control in comparison to standard fractionated radiation therapy in patients with medically inoperable non-small-cell lung cancer. That is the message from American researchers who monitored the responses of 86 patients with the disease. The former treatment was found to be less expensive and improved survival rates, with 71% of patients surviving for 36 months, as opposed to 42%.</p> <p>Nursing Times</p>	Thank you. A definition of treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue damage has been included for revised statement 11 in the final quality standard, which lists the relevant examples.
213	Pierre Fabre Ltd	S14	<p>Patients outside stage 1 have an increasing systemic element to their disease and will require some systemic treatment to minimise relapse and improve outcomes (adjuvant or concurrent chemotherapy +/- biological enhancement). Would inclusion of a chemotherapy assessment in this QS improve communication between radiographer and chemo suite?</p>	The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.
214	Royal College of	S14	No mention of concurrent chemoradiotherapy.	The topic expert group prioritised areas of care

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	Physicians			where practice is variable, or where implementation could have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.
215	United Kingdom Lung Cancer Coalition	S14	<p>The UKLCC supports the statement that <i>“people with lung cancer stage I–III and good performance status who are unable to undergo surgery are offered radiotherapy with curative intent, using planning and treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue damage.”</i></p> <p>Specialism in thoracic oncology is a requirement for any high quality service and the UKLCC believes that there should be at least two oncologists per MDT – one medical and one clinical. In order to optimise and personalise radiotherapy, wider access should be given to PET-CT, stereotactic targeted therapies and other recent or more advanced techniques.</p>	Thank you. Please see statement 9 in the final quality standard which addresses MDT composition and revised statement 11 which addresses optimal radiotherapy.
216	Royal College of Radiologists	S14	Agree	Thank you.
217	The Society and College of Radiographers	S14	In the section that describes how to measure the outcome, the numerator in “b” is any patient who has received optimal radiotherapy. Does this mean that they can have received a combination of the techniques described in the definition or do they need to have had 4D planned IMRT SBRT with IGRT. The abstracts of recent papers (i.e. Karolinska Institute) appear to have been 3D planned.	A definition of planning and treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue damage has been included for revised statement 11 in the final quality standard, which lists the relevant examples.
218	National Lung Cancer Forum for Nurses	S15	Could be merged with QS14 to make 1 standard.	The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality. Please see statements 11 and 12 in the final quality standard.
219	British Lung Foundation	S15	The British Lung Foundation supports the statement that <i>“people with advanced stage IIIB or IV non-small-cell lung cancer and performance status 0-1 are offered systemic therapy, in accordance with NICE guidance, that is tailored to the histological type and sub-type of the tumour, and individual predictive factors.”</i>	Thank you. Please see revised statement 12 in the final quality standard.

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			All patients with advanced (stage IIIB/IV) NSCLC of good performance status (PS 0/1) should be considered for systemic therapy and all treatments recommended in NICE technology appraisals should be available to them as options. All suitable patients should have access to second line treatment and maintenance.	
220	Roche Products Ltd	S15	<p>Although Roche partly agrees that “people with stage IIIB or IV NSCLC and PS 0-1 should be offered systemic therapy” we are concerned that this draft quality statement implies that no other patients with advanced disease should receive systemic therapy.</p> <p>The restriction to people of PS 0-1 (in other words, the fittest) appears to stem from evidence informing the original NICE Clinical Guideline on lung cancer (CG 24, 2005) that demonstrated a lack of overall survival benefit from platinum-based first-line chemotherapy in less fit patients. There is now evidence that some less aggressive systemic treatments offer good clinical benefits to less fit patients as well as those of the highest performance status and there is no reason to exclude them from systemic therapy (see evidence for this in paragraphs below). This is particularly true when low PS is a result of lung cancer, rather than comorbidities. In such cases effective lung-cancer treatment can improve PS with obvious benefits to the patient. We therefore recommend that the restriction of systemic therapy to people with PS 0-1 only is removed from the statement but is retained as a process measure.</p> <p>For example, both of the Phase III studies comparing first-line treatment with the EGFR tyrosine kinase inhibitor (TKI) Tarceva with conventional platinum-doublet chemotherapy (OPTIMAL and EURTAC) included PS 2 patients and showed reductions in the risk of disease progression of 79% and 52% respectively for these poor performance status patients (similar to the benefit seen in the study group as a whole). Although the confidence intervals around these point estimates were wide, this is a manifestation of the small numbers in these patient subgroups and there is nothing to indicate that poor PS patients do not benefit from first-line Tarceva to a similar extent to PS 0-1 patients. Similarly in the BR21 study of second-line Tarceva, the drug produced a similar response rate in PS 2-3 patients as in PS 0-1’s (11.7% versus 7.7%).</p>	Thank you. Please see the revised statement 12 in the final quality standard, and the definitions section which describes eligible performance status.
221	Amgen	S15	QS 6 and 15 (listed below) emphasize key aspects of high quality lung cancer care such as providing holistic needs assessment at each key stage of care and offering chemotherapy tailored to tumour type and individual factors for patients with advanced stage lung cancer. We are of the view that these quality statements are highly significant as they focus on patient-centred aspects and are critical in	Thank you. Information is an important theme for all NHS care. The NICE quality standard on ‘patient experience in adult NHS services’, which is cross-cutting and referenced in this quality standard, covers this area in more

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			<p>ensuring that patients have a positive experience of care, a central tenet of the NHS Outcomes Framework. We are also of the opinion that in addition to ensuring that patients have a positive experience of care, it is of utmost importance that they are treated in a safe environment and protected from avoidable harm (a fundamental aim of the NHS Outcomes Framework). It is therefore important that as part of the holistic needs assessment at each key stage of care and in offering chemotherapy tailored to tumour type, patients have timely access to information in an accessible format, appropriate to their individual needs and preferences that would help patients make better informed decisions around their care taking into account a broad range of factors such as efficacy, safety, tolerability etc. This would be especially important for patients receiving anticancer therapy and exposed to (avoidable) mortality risk from toxicities related to their anticancer therapy.</p> <p>QS 6 – People with lung cancer are offered a holistic needs assessment at each key stage of care, and are offered prompt referral to specialist services when necessary.</p> <p>QS 15 – People with advanced stage IIIB or IV non-small-cell lung cancer and performance status 0-1 are offered systemic therapy, in accordance with NICE guidance, that is tailored to the histological type and sub-type of the tumour, and individual predictive factor.</p>	<p>detail (please see statements 5 and 6).</p>
222	Department of Health	S15	<p>Could be merged with standard 14.</p>	<p>The final quality standard has been revised down to 15 statements. It is important that each statement covers just one concept or requirement, and the topic expert group felt it was important to retain the individual statements as both elements are key markers of quality. Please see statements 11 and 12 in the final quality standard.</p>
223	Pfizer	S15	<p>We have concerns regarding limiting systemic therapy for stage IIIB and IV lung cancer to patients with PS 0 – 1. The introduction of targeted medicines may provide less toxic, more effective treatments which could lead to benefit in patients with poorer performance status. We acknowledge that obtaining biopsy material from less fit patients may limit the ability to deliver treatment with such agents, but many patients will be sufficiently fit for biopsy (perhaps from accessible nodal disease) or will be considered for such targeted therapy in the second line following chemotherapy when PS has deteriorated and where biopsy material has</p>	<p>Thank you. Please see the revised statement 12 in the final quality standard, and the definitions section which describes eligible performance status.</p>

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			been banked. This is especially true for near-to-launch new medicines.	
224	Pierre Fabre Ltd	S15	Histological type and biomarkers will become increasingly important in planning treatment and auditing outcomes as a basis for further research. The accurate measurement and recording of these data must be recognised as Good Practice – accuracy should be celebrated and not simplified. For example, terms such as “Non-squamous” should not be allowed to include “unknown” as around half of these may be expected to be squamous cell and be exposed to potentially harmful treatments. Recognising people who are good at this will encourage others and drive increasing standards.	Thank you.
225	Merck Serono	S15	With regard to the “systemic therapy for advanced NSCLC”, the draft quality statement 15 identifies stage III or IV patients with a performance status 0-1 as per most NICE technology guidances. More recently, NICE clinical guideline CG121 (April 2011) suggests that single agent therapy can be offered to patients intolerant to the “systemic therapy” and additionally considered as treatment for patients with co-morbidities. Therefore it seems that reference to the NICE CG121 is probably more appropriate than NICE guidance.	Thank you. Please see statement 12 in the final quality standard, where the definition section makes clear that the guidance referred to in the statement is NICE clinical guideline 121.
226	Merck Serono	S15	In relation to patients with performance status 2, Merck Serono understands from clinical experts that chemotherapy should be available. It would be helpful to understand how this category of patients is generally treated in the NHS.	Thank you. Please see the revised statement 12 in the final quality standard, and the definitions section which describes eligible performance status.
227	United Kingdom Lung Cancer Coalition	S15	The UKLCC supports the statement that <i>“people with advanced stage IIIB or IV non-small-cell lung cancer and performance status 0-1 are offered systemic therapy, in accordance with NICE guidance, that is tailored to the histological type and sub-type of the tumour, and individual predictive factors.”</i> All patients with advanced (stage IIIB/IV) NSCLC of good performance status (PS 0-1) should be considered for systemic therapy and all treatments recommended in NICE technology appraisals should be available to them as options. It may be possible that patients with poorer performance status could also benefit from systemic therapy and these patients’ test results and preferences should be considered by the MDT. All suitable patients should have access to second line treatment and maintenance. In addition, the term ‘individual predictive factors’ could benefit from improved clarity. We refer the Committee to the definition in QS10 which considers predictive markers as <i>“molecular characteristics of the tumour that may predict response to systemic therapy,”</i> and provides a sufficiently helpful level of detail.	Thank you. Please see the revised statement 12 in the final quality standard, and the definitions section which describes eligible performance status.

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228	Royal College of Radiologists	S15	Agree	Thank you.
229	Roche Products Ltd	S15	We suggest an additional outcome measure should be introduced for the proportion of PS 2-3 patients receiving first-line systemic therapy, although this is likely to be fairly low, it will make it clear that there is an expectation that this option will be considered for patients where appropriate.	Thank you. Please see the revised statement 12 in the final quality standard, and the definitions section which describes eligible performance status. The topic expert group prioritised the measures they felt were most important in measuring the quality statements.
230	Roche Products Ltd	S15	<p>Although not explicitly stated this quality statement appears to have evolved from CG24 and there is an implication that it is referring to first-line systemic therapy. It is likely also to have been influenced by the National Lung Cancer Audit which reports the proportion of PS 0-1 patients receiving first-line chemotherapy. However, there are now four systemic therapies with regulatory approval for use after the failure of first-line systemic treatment for NSCLC (Tarceva (erlotinib), Iressa (gefitinib), docetaxel and pemetrexed). Roche's market research (<i>Kantar Health, Patient case record study 2010-2011</i>) suggests that 33-47% of patients get second-line therapy, though this proportion is very variable according to treatment centre.</p> <p>Since there are a range of globally utilised and effective treatments it seems appropriate to measure their utilisation in UK treatment centres as part of this quality statement. Although, to our knowledge there are no published audit data on second-line treatment rates, we believe that data is being collected now within the National Lung Cancer Audit (NLCA), which should facilitate calculation of this figure, however there is a lack of consistency in 2nd line treatment rates being submitted by Trusts to NLCA and would suggest this is include as a process measure within this statement.</p>	Thank you. Please see revised statement 12 in the final quality standard, which makes clear that it refers to both first and second line treatment.
231	Lilly UK	S15	<p>Because of the subjective nature of the assessment of performance statuses we believe the process should include mention that there are systems in place to ensure performance status ratings are undertaken effectively, taking into account a range of relevant measures, and based on consideration of a patient's history, not limited to presentation on the day of the assessment. For example, poor mobility on the day of assessment may be due to acute back pain or a recent sprain due to an accident.</p> <p>Because of the importance of performance status on treatment decisions, the subjective nature of the assessment and the dynamic nature of conditions that relate to the analysis of performance status, we would welcome discussion around</p>	The topic expert group prioritised the areas of care they felt were most important for patients based on the recommendations within the key development sources listed.

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			an additional measure that challenges healthcare professionals to correct reversible symptoms that would enable performance status to change, if to the benefit of the patient in terms of treatment options available.	
232	Pfizer	S15	We feel the statement made in QS15 around tailoring of treatment to individual predictive factors could benefit from clarification. QS 10 defines predictive markers as “molecular characteristics of the tumour that may predict response to systemic therapy”. However in QS15 the term “individual predictive factors” is unclear. In addition to ensuring that treatment is tailored to individual patient characteristics and preferences, treatment should be targeted to the molecular characteristics of the individual tumour to ensure the best possible efficacy. We suggest clarifying the definition of “individual predictive factors” to include patient characteristics and preferences, as well as predictive markers, specifically defined as molecular characteristics of the tumour that may predict response to systemic therapy.”	All quality statements and measures are applied locally and take into account patient safety, patient choice and clinical judgement.
233	Galil Medical	S16	No account seems to have been taken of the work of ablation in the area of small cell lung cancer. Cryotherapy has shown great potential for such treatments.	The topic expert group identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process.
234	Galil Medical	S16	No mention of the work of Interventional Radiologists in delivering above treatment.	The quality standards are based on evidence-based recommendations from national accredited guidance, i.e. the NICE Lung Cancer clinical guideline. It is outside the remit of the quality standard to consider additional evidence beyond that which was assessed in the development of the source guideline. Please refer to the full clinical guideline for detailed summary of the underpinning evidence base for the clinical recommendations on which the quality standard is based.
235	British Lung Foundation	S16	The British Lung Foundation supports the statement that <i>“people with small-cell lung cancer are assessed by a thoracic oncologist within 1 week of the decision to recommend treatment, and are offered chemotherapy and radiotherapy in accordance with NICE guidance.”</i> The National Lung Cancer Audit 2010 indicates variations between Trusts in the	Thank you. Please see revised statement 13 in the final quality standard which focuses on timeliness of treatment.

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			proportions of patients with small-cell lung cancer accessing chemotherapy. We believe that more patients with small-cell lung cancer should be able to access therapy and that this would be enhanced by rapid availability of assessment by a thoracic oncologist. We advocate that patients with small-cell lung cancer should be treated within 2 weeks of the date of their tissue diagnosis.	
236	Royal College of Physicians	S16	1 week to see a small cell patient should be achievable.	Thank you. Please see revised statement 13 in the final quality standard which focuses on timeliness of treatment.
237	United Kingdom Lung Cancer Coalition	S16	The UKLCC supports the statement that <i>“people with small-cell lung cancer are assessed by a thoracic oncologist within 1 week of the decision to recommend treatment, and are offered chemotherapy and radiotherapy in accordance with NICE guidance.”</i> The National Lung Cancer Audit 2010 indicates variations between Trusts in the proportions of patients with small-cell lung cancer accessing chemotherapy. We believe that more patients with small-cell lung cancer should be able to access therapy and that this would be enhanced by rapid availability of assessment by a thoracic oncologist. We advocate that patients with small-cell lung cancer should be treated within 2 weeks of the date of their tissue diagnosis.	Thank you. Please see revised statement 13 in the final quality standard which focuses on timeliness of treatment.
238	Royal College of Radiologists	S16	This does not seem aspirational enough. Using the QS as written at present a patient with SCLC may have a diagnostic CXR then wait two weeks for referral, 2 weeks for CT, then other investigations lasting 2 weeks, then an MDT, then 1 week for an Oncology appointment. Up to 7 weeks may have gone by, before treatment. It must be possible to truncate these timeframes in patients with suspected SCLC/rapidly progressive symptoms.	Thank you. Please see revised statement 13 in the final quality standard which focuses on timeliness of treatment.
239	British Thoracic Society	S16	Whilst aiming for rapid treatment is appropriate, a measurement of early death (30/60 day mortality) after starting treatment would also be a good marker of a quality service.	The topic expert group prioritised the measures they felt were most important in measuring the quality statements.
240	National Lung Cancer Forum for Nurses	S17	The follow up should be carried out where the greatest concentration of lung cancer expertise and resource is based to ensure timely and appropriate investigation and treatment in the event of recurrence. Currently this is with the lung cancer services. If this is to be devolved to community based services it may be prudent to consider utilising current nursing resources to run community based satellite nurse led clinics rather than expect GP colleagues to become experts in the management of lung cancer.	Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.
241	Lilly UK	S17	We strongly support specialist follow up and would stipulate that follow up should	Thank you. Please see revised statement 14

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			be at least with secondary care.	in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.
242	Department of Health	S17	<p>There is no evidence that regular follow up benefits patients really one needs to follow up according to patients needs.</p> <p>Some sick patients may well benefit from regular follow up, some may well prefer self referral for follow up or telephone follow up.</p> <p>However, where there is follow up, it should be carried out where the greatest concentration of lung cancer expertise and resource is based to ensure timely and appropriate investigation and treatment in the event of recurrence. Currently this is with the lung cancer services. If this is to be devolved to community based services it may be prudent to consider utilising current nursing resources to run community based satellite nurse led clinics rather than expect GP colleagues to become experts in the management of lung cancer.</p>	<p>Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.</p> <p>The topic expert group identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process – see appendix 1 for development sources used.</p> <p>A definition has been included to make clear that regularity of follow-up will be determined by the preferences of the patient.</p>
243	Royal College of Nursing	S17	<p>For draft quality statement 17:</p> <p>Yes.</p> <p>However, it may be more appropriate for the patient to be followed-up by community team for example GP/Palliative Care Team depending on treatment options/distance to specialist lung cancer service.</p> <p>If this is the case, then there should be easy access back in to the specialist lung cancer service either giving the patient an 'open' appointment and /or via the lung cancer clinical nurse specialist.</p>	<p>Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.</p>
244	Royal College of Physicians	S17	<p>The issue of who and how should lung cancer follow-up be done is topical. Most important is that it should be individualised according to needs of patient. Some patients with advanced disease and short prognosis, with effective community primary and palliative care would not choose or need hospital follow-up. For many palliative patients however the disease course may be short but punctuated by increasing and changing needs in terms of symptom control. Some of these patients might benefit from oncology intervention and many will benefit from respiratory and palliative care input so there is a need for a team based accessible follow-up. For radically treated patients there is a real need to follow-up as new and more intensive therapies are used. We need to monitor acute and late toxicity of therapy as well as assessing time to and sites of relapse and considering</p>	<p>Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.</p>

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			further second line therapies.	
245	Astra Zenica	S17	Yes	Thank you.
246	National Lung Cancer Forum for Nurses	S17	This could include protocol nurse led follow up.	Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.
247	British Lung Foundation	S17	<p>The British Lung Foundation supports the principle of the statement that “people with lung cancer are offered a specialist follow-up appointment within 6 weeks of completing initial treatment(s) to discuss ongoing care, and offered regular specialist follow-up thereafter.”</p> <p>However patients may easily feel ‘abandoned’ after the initial period of intensive investigation and first line treatment, with little understanding of what the future holds. Therefore the British Lung Foundation recommends that the follow up appointment takes place within one month of the end of treatment. The patient and a close carer should be invited to attend a ‘stock-take’ clinic to assess their current problems, their understanding of what has happened to them to date, what to look for in the future and to be given a clear and single point of contact if problems arise. We believe that the lung cancer service should lead follow-up and that the lung cancer clinical nurse specialist is well placed to carry this out, recognising that they may require support from allied health care professionals, social workers and psychologists. Patients should never be unclear about what the next step is in their cancer journey.</p> <p>Therefore the British Lung Foundation recommends that the QS 17 be revised as follows: “People with lung cancer are offered a specialist follow-up appointment within a month of completing initial treatment(s) to discuss ongoing care, and offered regular specialist follow-up thereafter.”</p>	<p>Thank you. Please see revised statement 14 in the final quality standard, which makes clear that follow-up can be specialist or protocol-led clinical nurse specialist.</p> <p>A definition has also been included to make clear that regularity of follow-up will be determined by the preferences of the patient.</p>
248	Kent and Medway Cancer Network	S17	There is no evidence that being seen 6w post initial therapy has any impact on outcomes. Objections were raised at Trusts level towards the randomness of such a guideline. For example in local Trusts current practice is to see patients completing 1 st line chemotherapy at about 8w post chemo with a CT done at 4-6w. This is entirely justifiable as it takes lung patients this long to get over their first line treatment.	<p>The topic expert group identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process – see appendix 1 for development sources used.</p> <p>A definition has been included to make clear that regularity of follow-up will be determined by the preferences of the patient.</p>

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249	Roche Products Ltd	S17	<p>Response to Q.5. Do you agree that regular specialist follow up should be carried out by the lung cancer service?</p> <p>Yes, however there is no definition of what comprises a “specialist” appropriate for follow-up in the quality statement as currently drafted. Given the increasing flexibility of the NHS workforce it is probably difficult to define a particular type of specialist as the one most appropriate to carry out follow-up. However, it seems appropriate to indicate that the specialists should be one qualified and empowered to institute new treatments as appropriate. This could be made clear as a definition within this statement.</p>	<p>Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.</p>
250	British Thoracic Society	S17	<p>We agree that follow-up should be with by the lung cancer service. This standard will help as many commissioners are pushing to reduce follow-up appointments. There has been some debate about the role of the GP who may be called upon at the time symptom control becomes an issue and also in dealing with the “lung cancer family”. However, there is concern about the quality of care provided by some GPs.</p> <p>Whilst many units have an open access policy for their clinics through their secretaries or lung cancer nurses, we felt there might need to be some sort of standard to aim for, like the 2 week wait for initial referral. We know needs change rapidly in lung cancer and often have to be addressed urgently.</p>	<p>Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.</p> <p>A definition has also been included to make clear that regularity of follow-up will be determined by the preferences of the patient.</p>
251	Lilly UK	S17	<p>We suggest a revision of the wording to reflect the importance of assessments of responses to treatment as per the following:</p> <p><i>“People[..].are offered specialist follow-up[..].to discuss ongoing care, objective and subjective assessment of response to treatment and offered specialist follow-up thereafter.”</i></p>	<p>Thank you for your suggestion. It is expected that the assessment of response to treatment is implicitly included within the concept of follow-up.</p>
252	Department of Health	S17	<p>Optimal follow up. There is no evidence that regular follow up benefits patients really one needs to follow up according to patients needs. Some sick patients may well benefit from regular follow up, some may well prefer self referral for follow up or telephone follow up.</p> <p>Could include protocol nurse led follow up.</p>	<p>The topic expert group identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process - please see appendix 1 for development sources used.</p> <p>Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.</p> <p>A definition has also been included to make clear that regularity of follow-up will be</p>

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				determined by the preferences of the patient.
253	RCGP and the Primary Care Respiratory Society	S17	Comments on QS17: As there is a growing population of lung cancer survivors its vital follow-up regimes address psychosocial needs and the substantial co-morbidities of these patients Ideally, models which integrate specialist nurse, primary care and consultant follow-up should be encouraged. Health outcomes: should include psychological well-being and QOL Others might include fear of recurrence and perceived co-ordination of care received.	Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist. Outcome measures are stated where the topic expert group felt these were appropriate, which include patient-reported outcomes in this case.
254	Pierre Fabre Ltd	S17	These quality standards will further encourage communication to enhance the flow of awareness and skill from the centre to primary care. This is desirable but it should be recognised that the average GP will see 1 new lung cancer per year. As the early recognition of signs and symptoms of relapse can improve outcomes, is it reasonable for GPs to develop and maintain such high skill levels for such occasional use? Is it not more sensible to maintain this skill within the core team and encourage communication on areas where the GP can have greater impact, eg smoking cessation.	Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist.
255	Royal College of Physicians	S17	What about adequate imaging post treatment at 6/52 follow-up? They should have CTscan post chemo; also CXR at each FU thereafter which should be minimum 3-monthly in the first year (but more evidence required). The point of offering everyone specialist follow-up appears somewhat different to the proposed national risk stratified lung cancer pathway of 'self-management' 'shared care' or 'complex care'. NICE should factor this.	The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.
256	United Kingdom Lung Cancer Coalition	S17	The UKLCC supports the statement that " <i>people with lung cancer are offered a specialist follow-up appointment within 6 weeks of completing initial treatment(s) to discuss ongoing care, and offered regular specialist follow-up thereafter.</i> " However we recommend extending this as follows: "People with lung cancer are offered a specialist follow-up appointment within 6 weeks of completing initial treatment(s) to discuss ongoing care, and offered regular specialist follow-up thereafter. They should also have access to high quality protocol-driven follow up including lung cancer nurse specialist follow up to enable the patient to feel supported, self-manage where possible, and identify problems early so they can be dealt with effectively and efficiently." Patient may easily feel 'abandoned' after the initial period of intensive investigation and first line treatment, with little understanding of what the future holds. Within one month of the end of treatment the patient and a close carer should be invited to attend a 'stock-take' clinic to assess their current problems, their understanding	Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist. A definition has also been included to make clear that regularity of follow-up will be determined by the preferences of the patient.

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			of what has happened to them to date, what to look for in the future and to be given a clear and single point of contact if problems arise. We believe that the lung cancer service should lead follow-up and that the lung cancer clinical nurse specialist is well placed to carry this out, recognising that they may require support from allied health care professionals, social workers and psychologists. Patients should never be unclear about what the next step is in their cancer journey.	
257	Royal College of Radiologists	S17	It may be helpful for radiology departments to be encouraged to fax reports back to the referring oncologist or lung cancer MDT co-ordinator – who may then forward them to the appropriate oncologist, if disease relapse is suspected, and specifically if this is associated with disease that may benefit from intervention ie stenting SVC or bronchial.	The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.
258	Roche Products Ltd	S17	Again Roche wholeheartedly endorses the idea that lung cancer patients should be regularly followed up by specialists in order that an early intervention can be made to deal with relapsing disease or worsening symptoms. Early intervention is likely to be synonymous with effective intervention in a disease where deterioration can be rapid. However we feel that to be maximally useful the draft quality measure needs to be more specific with regard to timing of follow-up and who does it. The draft quality measure process (b) measures the proportion of people with lung cancer who receive regular specialist follow-up. An annual appointment could be described as “regular” follow up but would clearly be of minimal value for patients with advanced disease where survival is measured in months. The quality measure should propose target follow-up intervals appropriate to particular patient groups (at minimum patients treated with curative and palliative intent)	Thank you. Please see revised statement 14 in the final quality standard, which clarifies that follow-up can be specialist or protocol-led clinical nurse specialist. A definition has also been included to make clear that regularity of follow-up will be determined by the preferences of the patient.
259	National Lung Cancer Forum for Nurses	S18	This could be incorporated into statement 19 as a specific inclusion.	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.
260	North Trent Cancer Network	S18	In the interest of distilling the number of indicators into a few key indicators QS18 and QS19 could usefully be merged.	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.
261	British Lung Foundation	S18	The British Lung Foundation supports the statement that <i>“people with lung cancer are monitored for endobronchial obstruction and offered prompt treatment when obstruction is identified.”</i> Patients should be made aware of the symptoms of endobronchial obstruction as	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.

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			<p>part of their care discussions, and encouraged to report symptoms about which they are concerned to their lung cancer specialist nurse for rapid assessment. The British Lung Foundation supports the statement that “people with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinicians and teams.”</p> <p>Providing effective supportive and palliative care requires both patients and their carer’s holistic needs to be identified, including for rehabilitation. We advocate use of the SPARC questionnaire, or an equivalent tool, to assess these needs. These should form the basis for care plans and referral to other services for specialist palliative and supportive care. Specialist palliative care professionals should also be active participants in and contributors to the MDT meeting.</p> <p>However the British Lung Foundation recommends that QS 18 (statement) and QS19 (statement) are combined as NICE guidance states that the treatment of endobronchial obstruction tends to be mainly palliative. Therefore British Lung Foundation recommends the following revised statement: <i>“People with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinical teams and are carefully monitored for endobronchial obstruction and offered prompt treatment when obstruction is identified.”</i></p>	
262	Kent and Medway Cancer Network	S18	‘Monitored for endobronchial obstruction’ is very vague. Suggest recommending that those with EBO are referred promptly for endobronchial therapy. Monitoring is not really possible unless you are saying that regular CT scanning or FOB should be done during follow up. Additionally many oncologists would consider external beam RT for 1 st presentation of progressive endobronchial obstruction reserving stents/brachy etc for relapse within a previously irradiated field.	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.
263	British Thoracic Society	S18	Endobronchial treatments aren’t an absolute priority and this standard could potentially be dropped.	Thank you. Please see revised statement 15 in the final quality standard which includes endobronchial treatments as a specific measure.
264	Department of Health	S18	Could usefully be merged with QS 19.	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.
265	United Kingdom Lung Cancer Coalition	S18	<p>The UKLCC supports the statement that <i>“people with lung cancer are monitored for endobronchial obstruction and offered prompt treatment when obstruction is identified.”</i></p> <p>Patients should be made aware of the symptoms of endobronchial obstruction as</p>	Thank you. Please see revised statement 15 in the final quality standard which includes endobronchial treatments as a specific measure.

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			part of their care discussions, and encouraged to report symptoms about which they are concerned to their lung cancer specialist nurse for rapid assessment.	
266	Royal College of Radiologists	S18	It may be helpful for radiology departments to be encouraged to fax reports back to the referring oncologist or lung cancer MDT co-ordinator – who may then forward them to the appropriate oncologist, if disease relapse is suspected, and specifically if this is associated with disease that may benefit from intervention ie stenting SVC or bronchial.	The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improve outcomes, and where there is potential to generate measurable indicators.
267	Galil Medical	S19	No account seems to have been taken of the work of ablation (Cryotherapy, RFA and Microwave) in the area of Palliative Interventions.	The quality standards are based on evidence-based recommendations from national accredited guidance, i.e. the NICE Lung Cancer clinical guideline. It is outside the remit of the quality standard to consider additional evidence beyond that which was assessed in the development of the source guideline. Please refer to the full clinical guideline for detailed summary of the underpinning evidence base for the clinical recommendations on which the quality standard is based.
268	Galil Medical	S19	No mention of the work of Interventional Radiologists in delivering above treatments.	The quality standards are based on evidence-based recommendations from national accredited guidance, i.e. the NICE Lung Cancer clinical guideline. It is outside the remit of the quality standard to consider additional evidence beyond that which was assessed in the development of the source guideline. Please refer to the full clinical guideline for detailed summary of the underpinning evidence base for the clinical recommendations on which the quality standard is based.
269	North Trent Cancer Network	S19	In the interest of distilling the number of indicators into a few key indicators QS19 and QS18 could usefully be merged.	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.

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ID	Stakeholder	Statement No	Comments	Responses
270	British Lung Foundation	S19	<p>The British Lung Foundation supports the statement that <i>“people with lung cancer are monitored for endobronchial obstruction and offered prompt treatment when obstruction is identified.”</i></p> <p>Patients should be made aware of the symptoms of endobronchial obstruction as part of their care discussions, and encouraged to report symptoms about which they are concerned to their lung cancer specialist nurse for rapid assessment.</p> <p>The British Lung Foundation supports the statement that <i>“people with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinicians and teams.”</i></p> <p>Providing effective supportive and palliative care requires both patients and their carer’s holistic needs to be identified, including for rehabilitation. We advocate use of the SPARC questionnaire, or an equivalent tool, to assess these needs. These should form the basis for care plans and referral to other services for specialist palliative and supportive care. Specialist palliative care professionals should also be active participants in and contributors to the MDT meeting.</p> <p>However the British Lung Foundation recommends that QS 18 (statement) and QS19 (statement) are combined as NICE guidance states that the treatment of endobronchial obstruction tends to be mainly palliative. Therefore British Lung Foundation recommends the following revised statement: <i>“People with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinical teams and are carefully monitored for endobronchial obstruction and offered prompt treatment when obstruction is identified.”</i></p>	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.
271	Kent and Medway Cancer Network	S19	Given the Mass General data on improved survival (Temel et al NEJM) with early palliative care, this is an area that needs to be highlighted more. It is felt you should push for more structured and regular symptom bases palliative care assessment through the course of an illness.	Thank you for your comment. Please see statement 5 on holistic needs assessment, which is intended to address the point of early planning and regular assessment.
272	British Thoracic Society	S19	“Access” to appropriate palliative interventions/care is rather vague. A unit may be able to access something 100 miles away but never do so because it is too much hassle!	Please see revised statement 15 in the final quality standard. It is acknowledged that providing access to treatments is difficult to measure, and the process measures have therefore been amended to take account of this, by measuring receipt of treatments.
273	Amgen	S19	QS 19 which states that “People with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinicians and teams” is highly significant as it focuses on aspects that are important for lung	Thank you. These comments are in line with the discussions of the topic expert group during development of the quality standard.

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			cancer patients especially those with metastatic disease (i.e. whose cancer has spread to other sites) for whom morbidity outcomes become as important, if not more important, as mortality outcomes. For example, for lung cancer patients with metastatic disease and whose cancer has spread to bone, liver and brain (the most common sites for lung cancer metastasis) and who experience significant symptoms such as pain, it is key to ensure that they have a positive experience of care with access to treatments that improve their quality of life, and are treated in a safe environment and protected from avoidable harm (all of which are fundamental aims of the NHS Outcomes Framework).	
274	Lilly UK	S19	<p>In line with NICE guidance, we believe it is important to discuss palliative care and end of life pathways early on. As such we would suggest a revision to the statement as follows:</p> <p><i>“People[..].have access to[..].care delivered by expert clinicians and teams early in the care pathway.”</i></p> <p>This could be reflected by an additional measure around the proportion of patients who have this discussion early in treatment, or prior to the terminal stages of illness.</p>	Thank you. This comment is in line with the discussions of the topic expert group during development of the quality standard. Please see revised statement 15 in the final quality standard, and also statement 5 on holistic needs assessment, which is intended to address this point.
275	Department of Health	S19	Could usefully be merged with QS 18 (incorporate into QS 19 as a specific inclusion).	Thank you. Please see revised statement 15 in the final quality standard which has taken this approach.
276	Macmillan Cancer Support	S19	<p>We also welcome the recognition in Statement 19 of access to appropriate palliative care interventions and specialist palliative care. However, we think this statement should also explicitly reference the delivery of end of life care, and what needs to happen outside of normal working hours. This is especially important in palliative and end of life care, and indeed the NICE Supportive and Palliative Care Guidance notes that a reduction in out-of-hours support is probably to blame for people not dying in their place of choice.</p> <p>Most people would prefer to die at home and not in a hospital – between 56% and 74% according to different sources. However, recent statistics show that only 25% of people diagnosed with cancer die at home. Macmillan believes that the provision of out-of-hours support could help a greater people to die in their place of choice and has been campaigning for all people with cancer nearing the end of life to have access to 24/7 community nursing so that they are able to die at home if they wish to do so.</p> <p>Therefore, we propose that Quality Statement 19 could include the following:</p> <p><i>People approaching the end of life who experience an unexpected crisis at any</i></p>	Thank you. The scope of the quality standard for lung cancer covers adults receiving supportive and palliative care, but there is a separate NICE quality standard on end of life care which addresses areas of care important for those people approaching end of life in more detail. This has now been explicitly referenced as a related NICE quality standard – see section ‘Related NICE quality standards’ in final standard.

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			<p><i>time of day or night, receive prompt, safe and effective urgent care appropriate to their needs in all settings. They are also offered details of how to contact a named healthcare professional, and what to do if they need urgent support out-of-hours.</i></p> <p>Statement 19 should also make specific reference the soon to be released NICE End of Life Care Quality Standard, to ensure there is consistency in the outcomes sought across all the quality standards.</p>	
277	Royal Brompton & Harefield NHS Foundation Trust	S19	People with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinicians and teams.	Thank you.
278	The National Council for Palliative Care	S19	<p>We welcome this statement but urge that it be included higher up in the list. Palliative care, which is about maximising quality of life throughout the cancer journey, should not be seen as an “add on”. That it is the last statement of 19 tends to imply palliative care is a last consideration.</p> <p>There is evidence that “Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival.” (Temel et al N Engl J Med 2010;363:733-42). The 2004 NICE guidance on supportive and palliative care stated that “It is now widely recognised that palliative care has a crucial role in the care received by patients and carers throughout the course of the disease and should be delivered in conjunction with anticancer and other treatments.”</p> <p>The statement should also be more explicit about end of life care. People do die from the condition and ensuring people with lung cancer experience a “good death” is extremely important. As above, the lung cancer quality standard needs to link with the end of life care standard, for example, the “existing indicators” needs to be populated with the indicators included in the latter.</p> <p>The importance of early discussion and planning soon after diagnosis should be included. The guidance should signpost to materials produced by the Dying Matters coalition, established as part of the Department of Health End of Life Care Strategy (2008), as these can be used by professionals to open up conversations about dying, death and bereavement with people with lung cancer.</p> <p>The importance of support “at any time of day and night” (to use the language of NICE’s imminent Quality Standard on End of Life Care) should be emphasised throughout, and especially as the person approaches the end of life. Ensuring that people can access the care and support they need when they need it, and</p>	<p>Quality statements are intended to be presented in a logical order of the clinical pathway, as agreed by the topic expert group. Please also see statement 5 on holistic needs assessment in the final quality standard, which we believe addresses the importance of early discussion and planning.</p> <p>The scope of the quality standard for lung cancer covers adults receiving supportive and palliative care, but there is a separate NICE quality standard on end of life care which addresses areas of care important for those people approaching end of life in more detail. This has now been explicitly referenced as a related NICE quality standard - see section ‘Related NICE quality standards’ in final standard.</p>

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			<p>enabling the person to be cared for and die in their preferred place of care wherever possible, should be prioritised. This is one of the key objectives of the End of Life Care Strategy.</p> <p>We support the thrust of Macmillan Cancer Support’s recommendation that Statement 19 includes the following:</p> <p><i>People approaching the end of life who experience an unexpected crisis at any time of day or night, receive prompt, safe and effective urgent care appropriate to their needs in all settings. They are also offered details of how to contact a named healthcare professional, and what to do if they need urgent support out-of-hours.</i>(With the suggestion that “at any time of day or night” used in the end of life care standard, be adopted in place of “out of hours” which is very provider focused).</p>	
279	College of Occupational Therapists	S19	It may be a bit more directive if it mentioned the National Cancer Rehab Pathways as a suggestion of the evidence based practice that the four main AHPs carry out?	The definitions section is used to broadly define or clarify particular terms used in the quality statement. The topic expert group are unable to provide supporting information or additional detail about terms not included in the quality statement where this can be found elsewhere.
280	United Kingdom Lung Cancer Coalition	S19	<p>The UKLCC supports the statement that “people with lung cancer have access to all appropriate palliative interventions and specialist palliative care delivered by expert clinicians and teams.”</p> <p>Providing effective supportive and palliative care requires both patients and their carer’s holistic needs to be identified, including for rehabilitation. We advocate use of the SPARC questionnaire, or an equivalent tool, to assess these needs. These should form the basis for care plans and referral to other services for specialist palliative and supportive care. Specialist palliative care professionals should also be active participants in and contributors to the MDT meeting.</p>	Thank you. This comment is in line with the discussions of the topic expert group during development of the quality standard. Please see statement 5 in the final quality standard which addresses holistic needs assessment.
281	Royal College of Radiologists	S19	Agree.	Thank you.

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These organisations were approached but did not respond:

Abbott GmbH & Co KG
Abbott Laboratories
Action on Smoking and Health
African HIV Policy Network
Air Products PLC
Airedale NHS Trust
Almac Diagnostics
Anglia cancer network
Arden Cancer Network
Association for Palliative Medicine of Great Britain
Association for Respiratory Technology and Physiology
Association of British Insurers
Association of Cancer Physicians
Association of Chartered Physiotherapists in Oncology and Palliative Care
Association of Chartered Physiotherapists in Respiratory Care
Association of Clinical Pathologists
BOC Healthcare
Boehringer Ingelheim
Boston Scientific
Bradford District Care Trust
Brighton and Sussex University Hospital NHS Trust
Bristol and Avon Chinese Women's Group
Bristol-Myers Squibb Pharmaceuticals Ltd
British Association of Otorhinolaryngologists, Head and Neck Surgeons
British Dietetic Association
British Geriatrics Society
British Medical Association
British Medical Journal
British National Formulary
British Pain Society
British Psychological Society
British Society for Immunology
British Thoracic Oncology Group
BUPA Foundation

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Calderdale and Huddersfield NHS Trust
Cambridge University Hospitals NHS Foundation Trust
Camden Link
Cancer Network User Partnership
Cancer Research UK
Cancer Services Co-ordinating Group
Cancer Voices
Capsulation PPS
Care Quality Commission (CQC)
Central & North West London NHS Foundation Trust
Central Manchester and Manchester Children's Hospital NHS Trust
Clatterbridge Centre for Oncology
CLIC Sargent
Cochrane Pain, Palliative Care and Supportive Care Group
College of Emergency Medicine
County Durham Primary Care Trust
Covidien Ltd.
Department for Communities and Local Government
Derby-Burton Cancer Network
Derbyshire Asbestos Support Team
Derbyshire Mental Health Services NHS Trust
Dorset Cancer Network
Dorset Primary Care Trust
Dudley PACT Patient Advisory Cancer Team
East Lancashire Hospitals NHS Trust
East Midlands Cancer Network
Energy Therapy World-Wide Net
Essex Cancer Network
Eusapharma
GE Healthcare
George Eliot Hospital NHS Trust
GlaxoSmithKline
Gloucestershire Hospitals NHS Foundation Trust
Gloucestershire LINK
Great Western Hospitals NHS Foundation Trust
Greater Manchester and Cheshire Cancer Network

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Greater Manchester and Cheshire Cardiac and Stroke Network
Greater Midlands Cancer Network
Grunenthal Ltd
Harrogate and District NHS Foundation Trust
Health Protection Agency
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Heart of England NHS Foundation Trust
Hospira UK Limited
Hull and East Yorkshire Hospitals NHS Trust
Humber and Yorkshire Coast Cancer Network
Imperial College Healthcare NHS Trust
Institute of Biomedical Science
Johnson & Johnson
Joint Collegiate Council for Oncology
karimahs cucina
KCARE
Knowsley Primary Care Trust
Lancashire Care NHS Foundation Trust
Leeds Irish Health and Homes
Leeds Primary Care Trust (aka NHS Leeds)
Leicestershire, Northamptonshire and Rutland Cancer Network
Liverpool Community Health
Lothian University Hospitals Trust
Luton and Dunstable Hospital NHS Trust
Manchester Metropolitan University
Marie Curie Cancer Care
Ministry of Defence
MRC Clinical Trials Unit
National Cancer Action Team
National Cancer Research Institute
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Institute for Health Research Health Technology Assessment Programme

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National Patient Safety Agency
National Public Health Service for Wales
National Treatment Agency for Substance Misuse
Newham Primary Care Trust
NHS Bournemouth and Poole
NHS Clinical Knowledge Summaries
NHS Connecting for Health
NHS Direct
NHS Improvement
NHS Kirklees
NHS National Programmes
NHS North Central London
NHS Plus
NHS Sefton
NHS Sheffield
NICE - CPHE
NICE - CPHE Methodology - Simon for info
NICE - Guidelines Coordinator - for info
NICE - Guidelines HE for info
NICE - IMPLEMENTATION CONSULTANT Region - East
NICE - IMPLEMENTATION CO-ORDINATION for info
NICE - PPIP
NICE - R&D for info
NICE - Technical Appraisals
North East London Cancer Network
North of England Cancer Network
North Yorkshire & York Primary Care Trust
Northern Ireland Cancer Network
Nottingham City Hospital
Novartis Pharmaceuticals
Nucletron
Nutricia Clinical Care
OSI Pharmaceuticals
Oxfordshire Primary Care Trust
Pan Birmingham Cancer Network
Patient Assembly

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Patients Watchdog
PERIGON Healthcare Ltd
Pharmacosmos
Philips Healthcare
Pilgrims Hospices in East Kent
Pnn Medical
Roche Diagnostics
Rowcroft Hospice
Royal Berkshire NHS Foundation Trust
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Psychiatrists
Royal College of Surgeons of England
Royal Free Hampstead NHS Trust
Royal Marsden NHS Foundation Trust
Royal Pharmaceutical Society
Royal Society of Medicine
Sandwell Primary Care Trust
Sanofi
Sarcoma Information Services Ltd.
Scarborough and North Yorkshire Healthcare NHS Trust
Scottish Intercollegiate Guidelines Network
Sheffield Primary Care Trust
Sheffield Teaching Hospitals NHS Foundation Trust
Shropshire & Mid Wales Cancer Forum
Smokefree North West
SNDRi
Social Care Institute for Excellence
Society for Acute Medicine
Society for Cardiothoracic Surgery of Great Britain and Ireland
Society of British Neurological Surgeons
South Asian Health Foundation
South Staffordshire Primary Care Trust

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South Wales Cancer Network
Southport and Ormskirk Hospital NHS Trust
St Ann's Hospital
St Helens and Knowsley Teaching Hospitals NHS Trust
Step4Ward Adult Mental Health
Sue Ryder Care
Sussex Cancer Network
Takeda UK Ltd
Teva UK
Thames Valley Cancer Network
The British In Vitro Diagnostics Association
The National LGB&T Partnership
The Rotherham NHS Foundation Trust
UCB Pharma Ltd
UCL Partners
UK Clinical Pharmacy Association
UK National Screening Committee
UK NEQAS for Immunology and Immunochemistry
University College London
University College London Hospital NHS Foundation Trust
University Hospital Birmingham NHS Foundation Trust
Welsh Cancer Services Coordinating Group
Welsh Government
Welsh Scientific Advisory Committee
West Midlands Ambulance Service NHS Trust
Western Cheshire Primary Care Trust
Western Health and Social Care Trust
Wye Valley NHS Trust
York Hospitals NHS Foundation Trust

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