#### 2015/16 NHS STANDARD CONTRACT FOR ACUTE, AMBULANCE, COMMUNITY AND MENTAL HEALTH AND LEARNING DISABILITY SERVICES (MULTILATERAL)-

## SECTION B PART 1 - SERVICE SPECIFICATION FOR LUNG CANCER

Service specification No			
Service	Lung Cancer Whole Pathway (commissioned by CCGs and		
	NHSE)		
Commissioner Lead			
Provider Lead			
Period	2015/16		
Date of Review	April 2016		

#### 1.0 Executive summary

Lung cancer is the leading cause of cancer mortality in England and the world. This is because it is common and the majority of people with lung cancer present late when treatment has a limited effect on mortality. Smoking tobacco causes around 85% of lung cancers, people in the most deprived socioeconomic quintile are twice as likely to develop lung cancer as those in the highest and about half of people are ex-smokers or never smokers at presentation. The diagnosis, staging, fitness assessment, treatment and supportive care of lung cancer are complex and require specialist expertise that is not always locally available. There is marked variation in treatment rates in England and marked variation in outcomes. It is important that all people have equal access to the best treatment rates if we are to achieve the outcomes seen in other European countries. The local commissioning structure offers flexibility but has the potential to increase variation if evidence based standards for services are not applied. Thus national guidance should be followed and local flexibility employed to implement the guidance within the local healthcare landscape. Local service planning should involve patient representatives and consideration given to co-commissioning of integral specialist services. This national Service Specification sets out the key evidence based priorities for commissioning high quality, patient-centred services for people wherever they live, taking into account the need to ensure value for money and where possible a reduction in cost. It supports a more integrated approach to commissioning as recommended by the Independent Cancer Taskforce. A nationally agreed optimal clinical care pathway accompanies this Service Specification.

# 1.1 Two page summary of key priorities for commissioning services for people with suspected and confirmed lung cancer

The key priorities concern three broad areas: early diagnosis, reducing variation and living with and beyond cancer. This is because poor patient experience, poor survival, unacceptable variation and high morbidity result from these.

## 1.1.1 Early diagnosis

- Public awareness (section 5.1) Commission local, coordinated campaigns that increase public awareness of the symptoms and signs of lung cancer. Methods should be tailored according to local factors such as sociodemographic profile.
- Recognition and referral (section 5.2) Commission the use of primary care based assessment of the risk of lung cancer, including, where available, the latest decision support tools, so that investigation with chest x-ray or direct referral to secondary care is better targeted to those most at risk. Ensure referral is made within 1 week of presentation to primary care.

# 1.1.2 Reducing variation

 Access to specialist care (section 5.3)
Commission the amount of specialist time as specified in section 5.3 to ensure all patients have access to the most advanced care. Recommendations 4-7 should be a corollary of this recommendation, emphasising its central importance in reducing variation. \* denotes specialist commissioning.

- Diagnosis and stage (section 5.4) Commission services that ensure NICE guidance on diagnosis and staging is followed, specifically:
  - a. People with lung cancer, following initial assessment and computed tomography (CT) scan, are offered investigations that give the most information about diagnosis and staging with the least risk of harm.
  - b. People with lung cancer have adequate tissue samples taken in a suitable form to provide a complete pathological diagnosis including tumour typing and sub-typing, and analysis of predictive genetic profiling that affects treatment options.
- 5. Treatment with curative intent (section 5.5) Commission services that ensure people with lung cancer have the best chance of being cured of their cancer by following NICE guidance, specifically:
  - a. \*People with resectable lung cancer who are of borderline fitness and not initially accepted for surgery are offered the choice of a second surgical opinion, and a multidisciplinary team opinion on non-surgical treatment with curative intent.
  - b. People with higher stage lung cancer are offered assessment for multimodality treatment by a multidisciplinary team comprising all specialist core members.
  - c. \*People with lung cancer stage I–III and good performance status who are unable to undergo surgery are assessed for radiotherapy or chemo-radiotherapy with curative intent by a clinical oncologist specialising in thoracic oncology; those assessed as unsuitable should be offered a second opinion.
  - d. \*People with lung cancer stage I–III and good performance status who are offered radiotherapy with curative intent have access to and receive treatments that optimise the dose to the tumour while minimising the risks of normal tissue damage, including stereotactic ablative radiotherapy (SABR), image-guided radiotherapy (IGRT) and intensity-modulated radiotherapy (IMRT).
- 6. Treatment with palliative intent (section 5.6) Commission services that ensure people with advanced lung cancer have the best chance of treatment that improves survival and overall quality of life, specifically:
  - a. People with stage IIIB or IV non-small-cell lung cancer and eligible performance status are offered systemic therapy (first, second-line and maintenance) in accordance with NICE guidance (including those therapies available through the cancer drugs fund) that is tailored to the pathological sub-type of the tumour and individual predictive factors.
  - b. People with small-cell lung cancer have treatment initiated within 2 weeks of the pathological diagnosis.
  - c. People with lung cancer have access to all appropriate palliative interventions delivered by expert clinicians and teams (see section 2.3.4).

## 1.1.3 Living with and beyond cancer (section 5.7)

- 7. Commission services that ensure people have the same access to care that improves aspects of living with and beyond cancer in line with the National Cancer Survivorship Initiative and underpinned with the Living With and Beyond Cancer agenda, including:
  - a. People with known or suspected lung cancer have access to a named lung cancer clinical nurse specialist who they can contact between scheduled hospital visits.
  - b. People with lung cancer are offered a holistic needs assessment at each key stage of care that informs their care plan and the need for referral to other services.
  - c. People with lung cancer are offered a specialist follow-up appointment within 6 weeks of completing initial treatment and regular specialist follow-up thereafter, which can include protocol-led clinical nurse specialist follow-up.

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d. People with lung cancer are offered care integrated across primary and secondary

#### care with liaison coordinated through specialist nursing teams.

8. Commission services that ensure that people with known or suspected lung cancer have information about their disease and options for treatment presented to them in a format they can understand, to enable them to make an informed choice, and in line with NICE guidance.

#### 2. Population Needs

#### 2.1 National and local context

This national Service Specification sets out the key evidence based priorities for commissioning high quality, patient-centred services for people wherever they live. This evidence based approach will ensure the best value interventions. An effective lung cancer service depends on local services working seamlessly with specialist services that are commissioned directly by NHSE. Specialist services commissioned by NHSE are highlighted in this document with an \*.

The specification covers services for diagnosis of suspected lung cancer and staging and treatment for confirmed lung cancer. Separate specialist service specifications for radiotherapy, thoracic surgery and chemotherapy are being reviewed by NHSE but should not conflict with any of the recommendations in this service specification. Many of the recommendations made here will also ensure high quality care for some non-lung cancers that spread to the lung and malignant mesothelioma.

## 2.2 The Burden of Lung Cancer

Lung cancer is the most common cause of cancer death in men and women accounting for more deaths than breast and bowel cancer combined. The crude incidence rate in England in 2012 was, 74.2 per 100,000 population in males and 60.2 per 100,000 population in females. There were 35,903 newly diagnosed cases of lung cancer in England in 2012, 19,547 in males and 16,356 in females. For the last 5 years, there has been a consistent increase in the crude incidence, with over 1000 extra diagnoses in the UK each year . In England, 28,331 deaths were caused by lung cancer in 2012, over 300 more than in 2010.

One-year relative survival in England is 35.1% for women and 30.4% for men for lung cancers diagnosed in 2009<sup>†</sup>. Five year relative survival is 8.6% in males and 11.6% in females for the period 2005-2009. Recent data has suggested that 5 year survival is improving further, probably explained by higher surgical resection rates. Survival rates in the UK have consistently been shown to be below many other western countries and there is evidence to suggest that this is likely to be the result of both late presentation and/or late referral to specialist care and under treatment. An international study of lung cancer patients based upon tumours diagnosed between 1990 and 2000 showed that a large variation exists in survival for non-small cell lung cancer (NSCLC) by stage. It also showed patients diagnosed with very early stage disease who are surgically treated had overall five year survival of 73%. It has been estimated that at least 1,300 lives could be saved per year if our survival rates were as good as the best in Europe.

Commissioning of services that currently achieve the best outcomes in England would be expected to result in a significant improvement in these survival rates as well as improving symptom control and experience of care for patients. Thus the national emphasis should be to reduce variation by ensuring all services achieve the standards as achieved by the best (and the best improve further).

† survival relative to age and sex matched general population.

## 2.3 The Clinical Problem

## 2.3.1 Types of lung cancer

Lung cancer is classified into non-small cell lung cancer (NSCLC) accounting for the majority of cases, and small cell lung cancer (SCLC) accounting for approximately 10%. NSCLC has two major

sub-types; squamous cell carcinoma and adenocarcinoma. Approximately 6 to 12% of the latter have driver mutations for which targeted biological systemic therapies are currently available. In the future the number of targeted treatments is likely to increase. This classification is important since it has significant implications for treatment. SCLC is generally a more aggressive tumour with NSCLC being more variable. There are a number of other less common types of lung cancer.

## 2.3.2 Prevention of lung cancer

Reducing tobacco smoking has resulted in by far the largest reduction in cancer incidence in the UK and other developed countries. Further reduction of smoking is essential for prevention of many diseases and in lung cancer it is known that people with lung cancer who continue to smoke have worse outcomes at all stages. The well-established smoking cessation services should be recommended to patients on the basis that this would improve survival and mortality. Commissioners should embrace any new tobacco control policy as recommended by the Independent Cancer Taskforce.

#### 2.3.3 Screening for lung cancer

Recent evidence from the US has shown that screening people at risk of lung cancer using computed tomography (CT) reduces mortality. Whilst screening for lung cancer has started in the US, the position in Europe and the UK is that the results of further screening trials are needed to confirm the reduction in mortality and determine the design of cost-effective programmes. The result of one key trial is expected in 2016. Methods other than CT screening have either been shown not to work or are at an early stage of development.

## 2.3.4 Presentation of lung cancer

The commonest presenting symptoms are breathlessness, cough, haemoptysis, chest or shoulder pain and weight loss. All of these symptoms are non-specific and so awareness of combinations of symptoms in conjunction with baseline risk factors is the best way to identify people with lung cancer. Without this approach, it has been shown that simply doing more chest x-rays does not increase the chance of diagnosing patients earlier. As discussed above, the late diagnosis of lung cancer is responsible for a significant proportion (nearly 40%) of patients being diagnosed through the emergency route that is both distressing and associated with a very low 1-year survival of 9%.

## 2.3.5 Diagnosis, staging and fitness assessment

For the most cost-effective treatment to be offered to patients, the diagnosis, stage and fitness assessment has to be accurate. This is complex but is clearly described in NICE CG 121 (<u>http://pathways.nice.org.uk/pathways/lung-cancer</u>). Multiple investigations are often required so it is important to obtain the maximum diagnostic and staging information, with least risk, from each test. Frequently, the requirement for tests is decided on an individual level at a multidisciplinary team (MDT) meeting. All patients must have access to the expertise and technology needed. Many services now run "diagnostic" MDT meetings as a way of focussing expertise on this important aspect of care and this is regarded as good practice.

## 2.3.6 Treatment

# NSCLC

Lung cancer treatment is determined by stage, morphology (cell type of cancer), fitness and patient preference. For early stage disease in fit patients, surgical resection is the treatment recommended. For less fit patients with early stage disease, surgery is preferred but radical radiotherapy (especially SABR) is an option. In patients unsuitable for other curative treatment, radio-frequency ablation (RFA) or microwave ablation can be offered. The treatment of later stage disease (principally stage IIIa) can be with surgery, radiotherapy or chemo-radiotherapy. Following potentially curative treatment, adjuvant chemotherapy improves survival for people with node positive disease and tumours >4cm in diameter. Neo-adjuvant chemotherapy (that is, chemotherapy given pre-operatively in resectable disease) has also shown similar survival improvements since publication of NICE CG 121).

The treatment of advanced NSCLC depends on the sub-type and also, for adenocarcinoma, on whether there is a sensitising mutation. The latter may influence both first and second line treatment options.

There are a number of other palliative treatments that are used. These include palliative radiotherapy (for airway obstruction, chest wall pain, metastases, cough control and haemoptysis), endobronchial tumour treatment (brachytherapy, electrocautery, laser ablation, cryotherapy, stent insertion, photodynamic therapy), pleural procedures (fluid drainage, pleurodesis, indwelling catheter) and supportive care (including a full holistic approach and specialist pain control).

# SCLC

For advanced disease and all except stage I SCLC, chemotherapy or chemo-radiotherapy is the recommended treatment. Treatment of SCLC depends on whether the tumour can be encompassed in a radiotherapy field, in which case intensive concurrent chemo-radiotherapy is generally offered to fitter patients. A very small subpopulation of stage I SCLC patients may be considered for surgical resection. The palliative treatments and supportive care listed above also apply to people with SCLC.

# 2.4 Local context

This is to be determined by local commissioners based on data on the current local outcomes for lung cancer services and the resources available.

Include the following information to establish the extent of the local needs to improve lung cancer outcomes:

## 2.4.1 Infrastructure and resources

For each secondary care provider:

New diagnoses of lung cancer seen in one year.

Number of WTE respiratory physicians with time dedicated to lung cancer. Number of medical oncologists with at least one third of their clinical time dedicated to lung cancer. Number of clinical oncologists with at least one third of their clinical time dedicated to lung cancer. Number of thoracic surgeons with at least one third of their clinical time dedicated to lung cancer. Number of WTE radiologists with time dedicated to lung cancer.

Number of WTE lung cancer specialist nurses by pay band

Number of WTE lung oncology coordinators

The completeness of the COSD data feed to the NCRS and National Lung Cancer Audit There is some evidence from the National Lung Cancer Organisational Audit that the availability of services on site influences how frequently they are used and that they have a positive effect on outcomes. This is particularly notable for thoracic surgery and resection rates.(1) Therefore there should be an assessment of the local availability in order to inform where services, to be delivered locally or centrally, should be commissioned from.

Availability of PET-CT or Ultrasound guided percutaneous biopsy on site.

Availability of endobronchial ultrasound.

Availability of endobronchial palliation on site.

Availability of medical thoracoscopy on site.

Accessibility of result of PET-CT within 7 days of the request.

## 2.4.2 Outcome measures

Crude incidence of lung cancer for last 3 years, and comparison with breast, bowel and prostate cancer.

Crude mortality from lung cancer for last 3 years, and comparison with breast, bowel and prostate cancer.

Age-standardised incidence rate, and comparison with other areas.

Age-standardised mortality, and comparison with other areas.

Proportion of patients diagnosed with stage I and II disease

Proportion of patients alive at one year after diagnosis Proportion of patients who are first seen in secondary care as a result of an emergency or urgent hospital admission

Local resection rate\*\* (as a percentage of all diagnoses of lung cancer).

Local radical radiotherapy rate (including the SABR rate).

Local chemotherapy rate; specify proportion of SCLC patients and NSCLC patients who have stage 4 disease and are performance status 0-1.

Local biological therapy rate as a proportion of all patients and of those with confirmed molecular target (currently EGFR mutation or EML4-ALK rearrangement).

Local overall 'active treatment' rate

Proportion of patients first seen who are alive at 1 year

Proportion of patients with a non-small cell not otherwise specified diagnosis

Proportion of patients with EGFR mutation detected.

Note: further outcomes that may be available include the Key Service Outcomes for thoracic surgery and HQIPs Lung Cancer Consultant Outcomes Project (LCPOP) outcome data on lung cancer surgery. \*\*rates of treatment refer to proportions of all patients with lung cancer unless otherwise specified.

#### 3. Evidence Review

## 3.1 Evidence base

This specification draws its evidence and rationale from a range of documents as listed below:

## 3.1.1 DH

- •Improving Outcomes; a Strategy for Cancer Department of Health (2011) with updates to 2014.
- Cancer Commissioning Guidance Department of Health (2011)

## 3.1.2 NICE

- Improving Supportive and Palliative Care for adults with cancer NICE (2004)
- Improving Outcomes in Lung Cancer NICE (1998)
- Referral guidelines for suspected cancer NICE Clinical Guideline 27 (2005)
- Quality Standard for Lung Cancer NICE (2012)
- Quality Standard for end of life care for adults NICE (2011)
- Lung Cancer: The diagnosis and treatment of Lung Cancer CG121 (2011)
- 3.1.3 National Cancer Peer Review

Manual for Cancer Services: Lung Measures, Version 1.1 April 2013 – National Cancer Peer Review Programme, NHS England.

3.1.4 Peer reviewed publications.

See references.

# 3.2 Why improving early diagnosis is a priority

## 3.2.1 Brief overview of evidence

There is good evidence to show that late diagnosis of lung cancer is a cause of poor outcomes in England and the UK.(2, 3) In international comparisons, the UK lags behind other countries in lung cancer survival and this is mainly explained by differences in the early survival (0 to 1 year). Rates of diagnosis through the emergency route are also high in England at around 40% with only 9% of these people surviving 1 year.(4) There is also evidence that earlier diagnosis may be achieved through awareness campaigns: the Be Clear on Cancer campaign has resulted in a modest increase in earlier stage disease and an increase in resection rates. However, there is also evidence that people who are

diagnosed late with lung cancer have, if anything, more contact with primary care in the weeks and months leading up to the diagnosis.(5) There is also evidence that the targeting of the chest X-ray as a diagnostic tool in primary care is poor(5). Thus there is the potential to improve recognition of people at risk of lung cancer to achieve earlier diagnosis. Secondary care services do not contribute significantly to delay in diagnosis, although reducing variation in pathways will mean better compliance with 62 day waiting time targets. Screening for lung cancer by CT scanning has been shown to reduce mortality in one large trial from the USA and the results of further trials from Europe are awaited before the UK National Screening Committee are prepared to recommend implementation in the UK.(6-8)

## 3.3 Why reducing variation is a priority

## 3.3.1 Brief overview of evidence

Published evidence shows that there is wide variation in treatment rates and that larger centres achieve higher treatment rates and better surgical survival.(9, 10) However, the benefit of higher treatment rates is mostly confined to the patients whose first secondary care appointment is at a centre.(11) Such patients are 37% more likely to receive surgery for their lung cancer after correction for other factors influencing the likelihood of receiving surgery and there are similar findings for chemotherapy treatment rates. Only 30% of lung cancer patients are first referred to a centre so the majority of patients do not benefit from the better outcomes seen at larger centres. Other evidence has demonstrated variation in the pathways of care and functioning of the lung cancer MDT; centres have larger MDTs, more diagnostic services on site and more specialists in lung cancer diagnostics and treatment.(12-14) Recently, the presence of diagnostics on site (e.g. a PET scanner) has been shown to be associated with better surgical resection rates.(1) It is unrealistic for smaller hospitals to develop the same concentration of expertise and specialist equipment. Thus a mechanism is needed to ensure that all patients have access to the expertise that should lead to the same approach seen at centres. Asking patients to travel long distances to centres for their first appointment is unlikely to be a successful strategy as lung cancer patients are elderly (median age 72 years) and probably reluctant to travel. The solution is to provide the same expertise locally from the initial appointment with the respiratory physician and throughout the pathway of care, with travel supported where required for specialist treatment. Where these expert services are commissioned from will depend on local factors. The patient and carers will need holistic support throughout the pathway, especially when considering the option of travelling for treatment.

# 3.4 Why living with and beyond cancer is a priority

## 3.4.1 Brief overview of evidence

Only 30% of people diagnosed with lung cancer survive 1 year and during this time they have distressing symptoms, especially towards the end of life. Treatment for advanced disease causes significant side effects. People are often elderly. There is evidence that early supportive care and continuity of care results in improved quality of life measures (and possibly survival) and for this to be correctly targeted there needs to be early and regular assessment of needs.(15) The lung cancer nurse specialist (LCNS) is best placed to provide the essential holistic and supportive care, as well as an expert view of the individual's position on the pathway from pre-diagnosis to end of treatment. The LCNS will have a close working relationship with specialist palliative care services that are often required to meet the needs of patients. Patient experience is reported in the National Cancer Patient Survey. In this survey, patients with a Clinical Nurse Specialist reported much more favourably than those without on a range of items related to information, choice and care. NICE guidance CG21 and the NICE Quality Standard QS17 recommend, as a priority, that all patients should be seen by a LCNS at all key stages of the pathway and at the end of treatment. Recent research has demonstrated an association between increased treatment rates and being seen by a LCNS and that there is an association between higher salary banded LCNS and the frequency that patients are seen, suggesting that organisation of teams of LCNS may be important. The number of new patients seen annually per LCNS is very variable; median 90 (range 10 to 413). (Khakwani et al, personal communication)

# 4. Scope of the lung cancer service

4.1 Aims and objectives of service

The aim of the lung cancer service is to deliver high quality holistic care for patients with lung cancer so as to increase survival while maximising a patient's functional capability and quality of life and to ensure ready and timely access to appropriate supportive care for patients, their relatives and carers. The service is delivered through primary care (prevention, recognition, referral and supportive and palliative care), and a local lung cancer multi-disciplinary team (MDT), with specialist providers (diagnosis, treatment, supportive and palliative care).

Excellence in outcomes for lung cancer patients is dependent on factors crossing health sector boundaries. These include:

A pro-active approach to prevention of lung cancer through smoking cessation. This is a priority for all smoking related diseases but in lung cancer the effect extends to better outcomes throughout the pathway. Primary, secondary and tertiary providers should include smoking cessation advice and referrals in their management of patients with suspected and diagnosed lung cancer. New tobacco control initiatives, as recommended by the Independent Cancer Taskforce should be supported.

Awareness of the early symptoms of lung cancer and of the benefits of making the diagnosis early within the general population is vital

A high level of awareness and prompt attention to warning symptoms in primary care Access to expert diagnostic and specialist treatment services.

#### 4.2 Service description and care pathway

A service should encourage early referral by primary care through improving awareness and prompt recognition of risk factors and warning symptoms. There should also be prompt referral to the lung cancer service for patients who present though other routes such as emergency admission. All patients in whom lung cancer is suspected should be referred to a Rapid Access Lung Cancer Clinic that is part of an MDT. As this is a common cancer, most acute hospitals have a lung MDT that is regularly reviewed by National Cancer Peer Review. However it is essential to recognise that diagnosis, staging and fitness assessment are complex so that a high degree of commitment from expert clinicians is essential to ensure the correct treatment is given and thus also ensuring cost effectiveness (see 5.3).

The complex nature of the pathway, distressing symptoms from the disease itself, diagnostic investigations and treatment mean that patients often have significant need of a patient advocate, guidance and supportive care whilst they face difficult decisions. The lung cancer nurse specialist (LCNS) provides this element of care. LCNS support patients and carers throughout the whole pathway and provide an essential link between the patient, their carers and the variety of clinicians that are involved in the care pathway and may act as their advocate. LCNS also help with the smooth running of the patient pathway, minimising delays between stages.

The majority of lung cancer patients present with relatively advanced disease where current treatments offer modest survival benefit. For these patients, symptom control and palliation are central to any management plan. Patients who are managed by a lung MDT should be allocated a key worker, usually a LCNS. Specialist palliative care services are often required because of the high level of need of patients with lung cancer; there should be sufficient capacity to ensure all patients have access.

The lung cancer service should have clear pathways agreed for patients requiring care at the end of life. This will include services within hospitals, community services and services in the voluntary sector.

As well as being the most important modifiable factor that can reduce the incidence of lung cancer, smoking cessation is an important consideration throughout the pathway. This is because smoking cessation is associated with better outcomes in both early and later stage disease. Patients diagnosed with lung cancer should be advised to stop smoking, especially if they are to undergo radical treatment, as the evidence for benefit here is strongest. Smoking cessation therapies should be offered to all patients.

Within cancer, the national peer review programme has previously reviewed services annually. It is recommended that commissioners also review the most recent National Cancer Peer Review (or equivalent) report when commissioning this service. There is also a long standing National Lung Cancer Audit (NLCA) that reports activity annually, performance and outcomes by trust and cancer network. The new national Cancer Outcomes and Services Dataset (COSD) is now the main source of data for the NLCA and other cancer intelligence purposes.

A detailed lung cancer pathway is available on the NICE website and is linked to the recommendations in the relevant guidelines and technology appraisals. <u>http://pathways.nice.org.uk/pathways/lung-cancer#content=view-node%3Anodes-symptoms-and-signs-indicating-urgent-chest-x-ray-and-urgent-and-immediate-referral</u> A series of generic lung cancer pathways are appended to this specification that have some flexibility so that they can be adapted according to local circumstances.

#### 5 Essential service specification for commissioning

The service should be commissioned in line with the requirements of the NICE Quality Standard for Lung Cancer. These 15 standards have been incorporated into this document and are annotated (*qs* [number]).

#### 5.1 Public awareness

The service must be supported by local, coordinated campaigns that increase public awareness of the symptoms and signs of lung cancer, and the benefits of making the diagnosis. Methods should be tailored according to local factors such as socio-demographic profile (qs 1).

## 5.2 Recognition and referral

Primary care should support a locally delivered awareness programme that is tailored to the sociodemographics of the local population. Referral to the service must involve the use of primary care based assessment of risk of lung cancer using NICE guidelines, or, where available, the latest decision support tools so that investigation with chest x-ray or direct referral to secondary care is better targeted to those most at risk. Ensure referral is made within 1 week of presentation to primary care (qs 2,3). Secondary care services should expect increases in the number of referrals as the threshold for referral is lowered. Increases in referrals have already been seen following the awareness campaigns. This has resulted in a lowering of the proportion of referrals that have lung cancer. Thus it is necessary for secondary care to have a triage system in place to ensure patients are seen in the appropriate clinic, or discharged back to primary care thereby maximising the use of resources and avoiding the cost of appointments that have little benefit to the patient. Direct referral for CT from primary care supported by an agreed protocol should be considered

## 5.3 Access to specialist care

The service must provide specialist time to ensure all patients have access to the most advanced care. A ime to ensure all patients have access to the most advanced care. on of referrals that have lung cancer. Thus it is necessaring cancer (refer to section 7.2). Treatment that is accurately tailored to the individual will be more cost effective by avoiding inappropriate and unhelpful treatment as well as increasing treatment rates in those patients that will benefit most. Providing adequate specialist time supports recommendations that reduce variation in access to the best and most cost effective care (qs 4-15).

The service must provide the following expert time commitment:

5.3.1 There must be an equivalent of 1 full time respiratory physician with all of their time (10 Pas) spent in lung cancer per 200 new patients per year. This is the approximate expert time currently commissioned from large centres.

5.3.2 There must be local provision of first visits with respiratory physicians, with the above expertise and supportive infrastructure. This may mean commissioning these services from the centre where it may be easier to attract doctors with the necessary specialist interest. These clinicians will need to travel to provide services locally.

5.3.3 There must be access to locally or centrally provided expert diagnostic, staging and fitness assessment including:

- specialist radiological imaging
- bronchoscopy
- endobronchial ultrasound
- thoracoscopy
- radiological biopsy
- thoracic surgical diagnosis and staging\*
- lung function and exercise testing
- specialist diagnostic pathology (see also 5.3.6)

5.3.4 There must be access, through the MDT, to medical and clinical oncologists with at least one third of their job plan devoted to lung cancer. These services are also specified in the specialised commission service specifications for chemotherapy and radiotherapy.

5.3.5 There must be access, through the MDT, to the local thoracic surgical service\*. This service is also described in detail in the Thoracic Surgery service specification for specialised commissioning.

Surgery offers the best hope of long-term survival for lung cancer patients. Resection rates are low in the UK compared to many other countries and there is good evidence that introduction of specialist thoracic surgeons into MDT treatment planning discussions results in significant increases in resection rates.

## NICE Guidance recommends:

- Offer patients with NSCLC who are medically fit and suitable for treatment with curative intent, lobectomy (either open or thoracoscopic) as the treatment of first choice.
- For patients with borderline fitness and smaller tumours (T1a–b, N0, M0), consider lung parenchymal-sparing operations (e.g. segmentectomy or wedge resection) if a complete resection can be achieved.
- Consider surgery in patients with early stage SCLC

5.3.6 There must be access to the centrally provided diagnostic pathology service included molecular diagnostics. The pathology services should operate as per Royal College of Pathologists' guidelines and standards. Laboratories should comply with Clinical Pathology Accreditation (UK) Ltd (CPA) and participate in appropriate NEQAS modules. Where pathology is available, pathologists should complete the Royal College of Pathologists' minimum dataset for lung cancer for discussion at the lung cancer MDT. All non-squamous cancers should be sent for mutation testing where targeted treatment of the mutations would be offered. Mutation testing should not be done for patients who are too unfit for treatment.

5.3.7 There must be a local MDT meeting attended (either in person or via videoconference) by the clinicians specified in 5.3.1 to 5.3.6 above. The features of the MDT should be:

# Membership:

- designated respiratory physician(s)
- designated thoracic surgeon(s)
- clinical oncologist
- medical oncologist (where the responsibility of chemotherapy is not undertaken by the clinical oncologist core member)
- imaging specialist
- histopathologist
- lung cancer nurse specialist
- a core member of the specialist palliative care team
- •MDT co-ordinator/secretary
- •an individual responsible for data collection and audit
- •an NHS-employed member of the core or extended team should be

nominated as having specific responsibility for users' issues and information for patients and carers

• a member of the core team nominated as the person responsible for ensuring recruitment into clinical trials and other well designed studies is integrated into the function of the MDT

The team should have agreed guidelines for the management of lung cancer patients as outlined in the National Cancer Peer Review (NCPR) measures. Further details are available at: <a href="http://www.cquins.nhs.uk/">http://www.cquins.nhs.uk/</a> Teams should as a minimum aim to achieve the median value for compliance with NCPR measures, and if a team had immediate risks or serious concerns identified then remedial action plans should be in place and shared with commissioners in line with the timescales set out in the NCPR handbook.

The MDT should have access to a variety of extended services including dietetics, psychological support, rehabilitation and breathlessness services.

## 5.4 Diagnosis, staging and fitness assessment

Services must ensure NICE guidance on diagnosis and staging is followed, specifically:

5.4.1 People with suspected lung cancer should be offered a contrast-enhanced computed tomography (CT) scan of the neck, chest and upper abdomen to include liver and adrenals. For those on the 2ww pathway, this should be offered prior to their first outpatient appointment

5.4.2 People with lung cancer, following initial assessment and (CT) scan, are offered investigations that give the most information about diagnosis and staging with the least risk of harm (qs 6).

5.4.3 People with lung cancer have adequate tissue samples taken in a suitable form to provide a complete pathological diagnosis including tumour typing and sub-typing, and analysis of predictive markers (qs 7).

5.4.4 Where diagnostic, staging and fitness tests are not available locally, there must be robust referral processes with the timely turnaround of tests.

# 5.5 Treatment with curative intent

Services must ensure that people with lung cancer have the best chance of being cured of their cancer by following NICE guidance, specifically:

5.5.1 Offer patients with NSCLC who are medically fit and suitable for treatment with curative intent, lobectomy (either open or thoracoscopic) as the treatment of first choice (NICE 2011).(Offer more extensive surgery (bronchoangioplastic surgery, bilobectomy, pneumonectomy) only when needed to obtain clear margins.)

5.5.2 People with resectable lung cancer who are of borderline fitness and not initially accepted for surgery are offered the choice of a second surgical opinion\*, and a multidisciplinary team opinion on non-surgical treatment with curative intent (qs 8).

5.5.3 People with lung cancer are offered assessment for multimodality treatment by a multidisciplinary team comprising all specialist core members (qs 9).

5.5.4 People with lung cancer who have had surgery with curative intent who have positive lymph nodes and/or primary tumour size of >4 cm are assessed for post-operative chemotherapy by a thoracic oncologist.

5.5.5 \*People with lung cancer stage I–III and good performance status who are unable to undergo surgery are assessed for radiotherapy (or chemo-radiotherapy, concurrent preferred) with curative intent by a clinical oncologist specialising in thoracic oncology (qs 10). Those assessed as unsuitable should be offered a second opinion\*.

5.5.6 \*People with lung cancer stage I–III and good performance status who are offered radiotherapy

with curative intent have access to and receive treatments that optimise the dose to the tumour while minimising the risks of normal tissue damage, including stereotactic ablative radiotherapy (SABR) and image-guided radiotherapy (IGRT) (qs 11).

5.5.7 People with limited stage SCLC are offered potentially curative chemo-radiotherapy, with concurrent chemo-radiotherapy preferred for patients with good performance status (NICE 2011)

\*A second opinion from a separate MDT or Network is preferred to second opinions from within the same MDT. This avoids institutional commonality of opinion.

## 5.6 Treatment with palliative intent

Services must ensure that people with advanced lung cancer have the best chance of treatment that improves survival and overall quality of life, specifically:

5.6.1 People with stage IIIB or IV non-small-cell lung cancer and eligible performance status are offered systemic therapy (first, second-line and maintenance) in accordance with NICE guidance (including those therapies available through the Cancer Drugs Fund) that is tailored to the pathological sub-type of the tumour and individual predictive factors (qs 12). Systemic therapy must be administered in line with the recommendations of the National Chemotherapy Advisory Group and the NCEPOD (systemic anti-cancer therapy).

5.6.2 People with stage III non-small-cell lung cancer and eligible performance status are offered chemotherapy or sequential chemo-radiotherapy.

5.6.3 People with small-cell lung cancer have treatment initiated within 2 weeks of the pathological diagnosis (qs 13).

5.6.4 People with lung cancer have access to all appropriate palliative interventions delivered by expert clinicians and teams (qs 15). These include:

- palliative radiotherapy (for airway obstruction, metastases, cough control and haemoptysis)
- endobronchial tumour treatment (brachytherapy, electrocautery, laser ablation, cryotherapy, stent insertion, photodynamic therapy)
- pleural procedures (fluid drainage, pleurodesis, indwelling catheter)
- supportive care (including a full holistic approach).
- specialist pain control services.

All patients should have access to treatment centres that allow them to have the choice of cisplatin or carboplatin after an informed discussion with the treating specialist.

# 5.7 Living with and beyond cancer

Services must ensure that people have the same access to care that improves aspects of living with and beyond cancer, specifically:

5.7.1 People with known or suspected lung cancer have access to a named lung cancer nurse specialist who they can contact between scheduled hospital visits (qs 4).

5.7.2 People with lung cancer are offered a holistic needs assessment at each key stage of care that informs their care plan and the need for referral to other services (qs 5).

5.7.3 To ensure that 5.9.1 and 5.9.2 are possible there should be a minimum of 1 WTE LCNS per 80 new patients per year.

5.7.4 People with lung cancer are offered a specialist follow-up appointment within 6 weeks of completing initial treatment and regular specialist follow-up thereafter, which can include protocol-led clinical nurse specialist follow-up (qs 14).

5.7.5 People with lung cancer are offered care integrated across primary and secondary care with liaison coordinated through specialist nursing teams.

5.7.6 Commission services that ensure that people with known or suspected lung cancer have information about their disease and options for treatment presented to them in a format they can understand, to enable them to make an informed choice, and in line with NICE guidance. Excellent communication between professionals and patients is particularly important and can avoid complaints and improve patient satisfaction. The Independent Cancer Taskforce have recommended that all consenting patients be given online access to all test results and communications involving secondary or tertiary providers by 2020.

5.7.7 Rehabilitation is an important aspect of supportive care. There should be appropriate assessment of patients rehabilitative needs across the pathway and the provider must ensure that high quality rehabilitation is provided. This should involve an agreed recovery package and may include:

- Pulmonary rehabilitation delivered pre or post treatment to improve dyspnoea and fatigue
- Nutritional interventions for people at high risk of malnutrition

These commissioning priorities action the key interventions recommended in "Living with and beyond cancer: taking action to improve outcomes", which are:

- Structured Holistic Needs Assessment and care planning;
- Treatment Summaries;
- Patient education and support events (Health and Wellbeing Clinics);
- Advice about, and access to, schemes that support people to undertake physical activity and healthy weight management.

#### 5.8 End of life care

Services must provide end of life care in line with NICE guidance and in particular the markers of high quality care set out in the NICE Quality Standard for end of life care for adults.

- Avoid leaving a discussion about end of life care until the terminal stage of illness
- Document these discussions about end of life care

Services should provide end of life care in line with the principles set out in the NHSE endorsed End of life guidance that can be found at: <u>www.endoflifecareambitions.org.uk</u> An integrated service should be provided that crosses primary and secondary care, that is coordinated

through specialist nursing teams, and includes, where appropriate, use of the Hospice service.

## 5.9 Data collection and audit

Services must comply with the collection of the mandatory Cancer Services and Outcomes Dataset (COSD) and SACT (Systemic Anti-Cancer Therapy) dataset. If the service is a provider of radiotherapy it must also comply with the collection the RTDS (Radiotherapy Dataset). The care of lung patients should be regularly audited locally. The MDT should participate in the National Lung Cancer Audit, network-wide audit of lung services and the National Cancer Peer Review programme.

## 6.1 Cancer Networks

Cancer networks have become part of the Strategic Clinical Networks (SCN) of which there are 12. These will continue to be important in ensuring that the population covered have equal access to care and so provide the necessary reduction in variation and increase in better more cost effective care. Each SCN has an Expert Advisory Group (EAG) covering lung cancer. This group is made up of clinical opinion on issues relating to lung cancer within the cancer network and is an advisor to commissioners locally. Each of these groups is represented on the National Clinical Reference Group for Lung Cancer and so each SCN has contributed to the development of this Service Specification. The EAG has on on-going role in the development and monitoring of the services to ensure that each provider meets the requirements of the Service Specification.

The EAG is responsible for developing referral guidelines, care pathways, standards of care and to share good practice and innovation. They should also collectively implement NICE Improving Outcomes Guidance including the use of new technologies and procedures as appropriate and carry out network and national audits.

Each EAG should agree an up-to-date list of appropriate clinical trials and other well-designed studies for lung cancer patients and record numbers of patients entered into these studies by each MDT. The emergence of the ability to test for a wide range of molecular abnormalities in tumours for the identification of multiple small sub-groups of patients for single centre clinical trials will mean that the cancer networks will need to take an increasingly pro-active role in the promotion of research networks.

## 6.2 Population covered

This is best agreed using the expert knowledge of the Cancer Network Site-Specific Expert Advisory Groups.

In general this service covers patients registered with an English General Practitioner within the CCG and resident in the European Union and eligible for treatment in the NHS under reciprocal arrangements. Patients from Scotland, Wales and Northern Ireland are not part of this commissioned service and the Trust must have separate arrangements in place.

The service is accessible to all patients with a suspected (or confirmed) lung cancer regardless of sex, race, or gender. Providers require staff to attend mandatory training on equality and diversity and the facilities provided offer appropriate disabled access for patients, family and carers. When required the providers will use translators and printed information available in multiple languages.

The provider has a duty to co-operate with the commissioner in undertaking Equality Impact Assessments as a requirement of race, gender, sexual orientation, religion and disability equality legislation

# 6.2 Any acceptance and exclusion criteria

The role of local and specialist services are described in this document. Additional detail is to be found in the relevant service specifications (Thoracic surgery, Radiotherapy and Chemotherapy). Co-commissioning of the whole service should be considered.

# 6.3 Interdependencies with other services

Primary care clinicians need easy and rapid access to chest x-rays with a rapid turn round time of reports. Local arrangements should be in place for the identification of abnormal CXR reports combined with mechanisms for rapid referral to specialist lung cancer clinics. It is considered good practice to offer CT scanning prior to the specialist appointment. CT should usually be offered prior to their first outpatient appointment.

## 6.4 Interdependencies with other organisations

Planning and monitoring of lung cancer services has been shaped by the availability of increasingly more detailed data. New datasets will be able to increase our ability to compare services and to tailor treatment more accurately to those who will benefit. Thus there must be support from the local service for data collection to inform local and national service development. The national Lung Cancer Clinical Reference Group, National Cancer Intelligence Network (part of PHE) and the National Lung Cancer Audit group (part of the Royal College of Physicians) must work closely together to ensure the most indicative data are available.

## 7 Applicable Service Standards

## 7.1 Applicable national standards e.g: NICE, Royal College

Care delivered by the lung cancer service providers must be of a nature and quality to meet the CQC care standards and the relevant NICE quality standards (listed in section 2). The service will also comply with other relevant NICE standards that define clinical best practice.

Imaging and pathology services must be available to the MDT in line with the network agreed guidelines for these services. The pathology services should operate as per Royal College of Pathologists' guidelines and standards. Laboratories should comply with Clinical Pathology Accreditation (UK) Ltd (CPA) and participate in appropriate NEQAS modules. Where pathology is available, pathologists should complete the Royal College of Pathologists' minimum dataset for lung cancer for discussion at the lung cancer MDT.

It is the trust's responsibility to notify the commissioner on an exceptional basis should there be any breaches of the care standards. Where there are breaches any consequences will be deemed as being the trust's responsibility.

Lung cancer services are required to achieve the two-week wait for all patients where lung cancer is suspected. In addition the services are required to meet the following standards for all lung cancer patients:

- 31 day wait from decision to treat to first treatment (96%)
- 31 day wait to subsequent treatment (96%),
- 62 day wait from urgent GP referral or screening referral or consultant upgrade to first treatment (85%).
- Future targets are likely to include a definitive diagnosis in 50% of patients by 2 weeks from referral and in 95% by 4 weeks.

Teams should as a minimum aim to achieve the median value for compliance with the Cancer Peer Review measures, and if a team had immediate risks or serious concerns identified then remedial action plans should be in place and shared with commissioners in line with the timescales set out in the NCPR handbook. Further details are available at www.cquins.nhs.uk

The provider must be able to offer patient choice. This will be both in the context of appointment time and for diagnostic/treatment options, including those not available locally.

## 7.2 Applicable local standards

## Infrastructure

For each secondary care provider there should be access to:

- one WTE respiratory physician per 200 new diagnoses per year.
- a first appointment at the local hospital with a respiratory physician
- medical and clinical oncologists with at least one third of their job plan devoted to lung cancer direct clinical care\*.
- one WTE LCNS per 80 new diagnoses per year
- fast track, pre-clinic CT pathway
- separate diagnostic and treatment MDT meetings (maximum 30 patients per MDT meeting)
- the thoracic surgical service\*.
- specialist radiological imaging
- radiologists with at least a third of their job plan devoted to thoracic imaging direct clinical care
- bronchoscopy
- endobronchial ultrasound
- thoracoscopy
- radiological biopsy
- thoracic surgical diagnosis and staging\*
- lung function and exercise testing
- specialist diagnostic pathology (see also 5.3.6)

\*for tertiary centres this refers to new referrals



8 Key Service C	Dutcomes		-		
Performance indicator	Indicator		Threshold	Method of measureme nt	Consequen ce of breach
Specialist Team	% of new cancer cases discussed at MDT		100%	National Cancer Peer Review	
	Specialist team has full membership		95% quorate, 66% individual attendance	National Cancer Peer Review	
	Proportion of al review indicator	l peer rs met		National Cancer Peer Review	
	Peer review: Im risks	mediate		National Cancer Peer Review	
	Peer Review: S concerns	erious		National Cancer Peer Review	
	Core MDT men have direct clin with patients at advanced com course	bers who cal contact tendance at munications	100%	National Cancer Peer Review	
	Patients reporting good availability of a CNS		90%	Cancer Patient Experience Survey	
Waiting times	TWW referrals seen in 2 weeks		93% <sup>1</sup>		
	Patients treated within 62 days of two week wait referral		85% <sup>1</sup>		
	Patients treated within 31 days of agreeing treatment plan		96%1		
	Patients treated within 62 days of consultant upgrade		96%		
	Patients subsequent treatment within 31 days	Surgery	94% <sup>1</sup>		
		Systemic therapy	98% <sup>1</sup>		
		Radiother apy	96% <sup>1</sup>		
	Diagnostic test result within 10 working days of request		80% <sup>1</sup>		
These operational standards for waiting times are assessed nationally across tumour sites on an					
aggregated basis. However commissioners may want to know performance for each tumour site.					
Audit	Participation in Lung Cancer Au % of expected	Participation in National Lung Cancer Audit % of expected		NLCA	
	cases on whom data is collected CT prior to bronchoscopy				
			95%	NLCA	

	rate				
	The % histological confirmation rate for stage 1 and 2 and performance status 0-1		95%	NLCA	
	The percentage of patients with PS 0-1 having active treatment		80%	NLCA	
	The percentage undergoing surgical resection (all cases excluding Mesothelioma & confirmed Small Cell		15%	NLCA	
	The percentage of small cell cancer patients receiving chemotherapy		65%	NLCA	
Performance indicator	Indicator		Threshold	Method of measurement	Consequence of breach
Outcomes	One year survival by stage			NLCA / ONS	
	Five year survival by stage			NLCA / ONS	
	Proportion of patients diagnosed through the emergency route			ONS	
	Morta Surgi lity and S age, PS	cal 30 10 day by stage and		NLCA / HES / ONS	
	SABI 90 da stage	R 30 and by by age, and PS		NLCA / HES / ONS	
	Radio radio 30 ar by ag and F	al herapy d 90 day e stage 2S		NLCA / HES / ONS	
	Median LOS for surgery			HES	
	Proportion of patients treated by VATS lobectomy by stage			HES	
	Proportion of patients receiving SABR			HES / RAD	
	Proportion of patients receiving radical radiotherapy			HES / RAD	
	Proportion of patients with NSCLC stage IIIb and 4 disease with PS 0- 1 receiving chemotherapy			HES / SACT	
Patient experience	Patients reporting being treated with respect and dignity			Cancer Patient Experience Survey	
	Cancer patient experience survey	Green		Cancer Patient Experience Survey	

	questions scored	Red		Cancer Patient Experience Survey	
Specialist provision	Number of WTE rephysicians with tin dedicated to lung Number of medicated to lung Number of medicated to concologists with a one third of their of time dedicated to cancer. Number of clinical oncologists with a one third of their of time dedicated to cancer. Number of thoraci surgeons with at le third of their clinicated dedicated to lung	espiratory ne cancer. al t least linical lung t least linical lung c east one al time cancer		NLCA organisational audit	
Trial participation	Recruitment into ti	rials	All trials should be offered to eligible people	NIHR	
Cancer registration	DCO rates, Stagir completeness of 0 SACT and RTDS uploads (where applicable)	ng Data, COSD, data		National Cancer Registration Service	

## 9. Location of Provider Premises

The Provider's Premises are located at: *For local agreement* 

Name and address of the Provider's Premises **OR** details of the Provider's Premises **OR** state "Not applicable"

#### 10. Individual Service User Placement

[Insert details including price where appropriate of Individual Service User Placement]

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