

**B10/S/a**

**2013/14 NHS STANDARD CONTRACT  
FOR CANCER: MALIGNANT MESOTHELIOMA (ADULT)**

**SECTION B PART 1 - SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	B10/S/a
<b>Service</b>	Cancer: Malignant Mesothelioma (Adult)
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 months
<b>Date of Review</b>	

**1. Population Needs**

**1.1 National/local context and evidence base**

**National context**

**General overview**

Malignant mesothelioma is an uncommon form of cancer that develops from the protective lining that covers many of the body's internal organs, the mesothelium. It is usually caused by exposure to asbestos.

By far the most common site is the pleura (outer lining of the lungs and internal chest wall), but it may also occur in the peritoneum (the lining of the abdominal cavity), the pericardium (a sac that surrounds the heart) or the tunica vaginalis (a sac that surrounds the testicles).

Mesothelioma that affects the pleura can cause these signs and symptoms:

- Chest wall pain
- Shortness of breath
- Fatigue
- Weight loss
- Excessive sweating
- Wheezing or cough
- Pleural effusion, or fluid surrounding the lung
- Anaemia

Tumours that affect the abdominal cavity often do not cause symptoms until they are at a late stage. Symptoms include:

- Abdominal pain
- Abnormal build up of fluid in the abdomen (ascites)
- Problems with bowel function
- Weight loss
- A mass in the abdomen (rarely)
- Fatigue

The symptoms are steadily progressive and cause a high level of distress in both the patients and their families.

The diagnosis may be suspected with chest x-ray and CT scan and needs to be confirmed with a biopsy using either CT guided needle biopsy of the pleura or thoracoscopy. Thoracoscopy can either be a surgical procedure under general anaesthetic or a 'medical thoracoscopy' under local anaesthetic, this latter usually being carried out by a respiratory physician with a special interest in lung cancer and mesothelioma. Malignant pleural mesothelioma can be subdivided into at least three subtypes: epithelioid, sarcomatous and biphasic. Such sub-classification has important implications for prognosis and treatment.

Most people who develop mesothelioma have worked in occupations where they inhaled asbestos, or they have been exposed to asbestos dust and fibre in other ways. The most common occupational high risk groups currently include those working in the insulation industry, shipbuilding, the building of railway carriages, carpenters, electricians and plumbers. Mesothelioma can develop following para-occupational exposure. This means asbestos being taken outside the workplace and perhaps into the home on the work clothes of someone working with it, or following environmental exposure, for example, having lived near an asbestos factory.

Unlike lung cancer, there is no association between mesothelioma and smoking, but smokers who have also been exposed to asbestos have a significantly increased risk of lung cancer, over and above that related only to their smoking history.

Mesothelioma is considered an industrial injury and as such, victims can receive compensation. Where exposure during the course of an occupation can be established, patients can initiate a civil action against their previous employers (more precisely their insurers). Industrial Injuries Compensation can also be claimed via the government's scheme: Industrial Injuries Disablement Benefit Pneumoconiosis etc. (Workers' Compensation) Act 1979 (Industrial Injuries Lump Sum Payment).

### **Incidence Rates**

There is a long latency period for this disease, with symptoms or signs of

mesothelioma often not appearing until 30 to 40 years (or more) after exposure to asbestos. In 2009 there were around 2,200 newly diagnosed cases of mesothelioma in England, the vast majority of which were malignant pleural mesothelioma. Of these, over 1,800 were in males and nearly 400 in females.

The crude incident rates are 4.3 per 100,000 for all cases, 7.2 per 100,000 in males and 1.4 per 100,000 in females. The incidence rate in males has increased substantially over the last 20 years with the age-standardised rate doubling from 1.6 per 100,000 in 1989 to 3.2 per 100,000 in 2009. Incidence rates continue to increase but are predicted to peak in the UK around 2020 or a little later. The disease is considered almost universally fatal. Nearly 2,000 people died from mesothelioma in England in 2010. Medium-term survival has however been improving and for patients diagnosed in 2005-2009 the one year relative survival estimates were 37% in males and 42% in females.

As there is a strong association of mesothelioma with exposure to asbestos, the incidence rates vary significantly across England with higher rates in areas of heavy industry e.g. the North East and areas of Southern England.

### **Evidence base**

The evidence base for treatment is limited, with very few high quality randomised clinical trials upon which to base firm recommendations. As such, it is all the more important that patients are assessed by specialist clinicians who fully understand the diagnostic and treatment issues and who have access to relevant clinical trials.

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

### **Department of Health**

- Improving Outcomes; a Strategy for Cancer (2011)
- Cancer Commissioning Guidance (2011)
- Mesothelioma Framework(2007)

### **NICE**

- Improving Outcomes (IOG) :Lung Cancer (1998 )
- Pemetrexed disodium for the treatment of mesothelioma: NICE single technology assessment: STA 135, January 2008
- Improving Supportive and Palliative Care for adults with cancer -(2004)
- Quality standard for end of life care for adults (2011)
- Quality standard for patient experience in adult NHS services (2012)

### **National Cancer Peer Review**

- National Cancer Peer Review Handbook – NCPR, National Cancer Action Team (2011)

- Manual for Cancer Services: Lung Measures, Version 2.1 – NCPR, National Cancer Action Team (2011)
- Manual for Cancer Services Acute Oncology Measures (April 2011)
- Manual for Cancer Services Chemotherapy Measures (June 2011)

#### Other

- Statement on Mesothelioma in the UK (British Thoracic Society – 2007)
- Mesothelioma UK (Including: Mesothelioma, a Good Practice Guide) ([www.mesothelioma.uk.com](http://www.mesothelioma.uk.com))
- The National Lung Cancer Audit ([www.ic.nhs.uk](http://www.ic.nhs.uk))
- Chemotherapy Services in England. National Chemotherapy Advisory Group (2009)

## 2. Scope

### 2.1 Aims and objectives of service

The malignant mesothelioma service should be provided by a combination of lung cancer multidisciplinary teams and specialist mesothelioma multidisciplinary teams working in collaboration as agreed with the local cancer network, taking account of the local and regional incidence of the disease and ensuring proper population coverage. Please see below for the different functions of lung cancer and specialist multidisciplinary teams. These teams should work closely with primary care and palliative care services.

Specifically the malignant mesothelioma service aims to provide:

- High quality holistic care delivered through multidisciplinary teams. Patients with mesothelioma will usually be referred to a lung cancer multidisciplinary team, the members of which will all have a specialist interest thoracic oncology, including lung cancer & mesothelioma. Such teams will include: respiratory physician, radiologist with thoracic expertise, histopathologist, and cytologist (this can be one and the same person, depending on skills), clinical nurse specialist, thoracic surgeon, clinical oncologist, medical oncologist (where the responsibility of chemotherapy is not undertaken by the clinical oncologist), and a palliative care specialist.
- Radiological, pathological and diagnostic facilities to effectively diagnose classify and stage the condition prior to planning treatment. This should include timely access to CT guided pleural biopsy and medical or surgical thoracoscopy (will not be available in every trust with a lung cancer multidisciplinary team).
- Expert advice regarding active treatment options, such as chemotherapy, radiotherapy, surgery and specialist palliative interventions where clinically indicated.
- Access to highly specialised surgical treatments appropriate for patients with

mesothelioma.

- Access to all relevant clinical trials.
- Long term surveillance after definitive treatment.
- Since this is an uncommon disease (indeed rare in certain parts of England), the malignant mesothelioma service should ensure that there is appropriate regional provision of more specialised advice and management provided by specialist mesothelioma multidisciplinary teams (MDT). The members of such specialist multidisciplinary teams should have a special interest in mesothelioma. It is recommended that such specialist multidisciplinary teams should be managing a caseload of 25 or more patients per year. A specialist multidisciplinary team would usually be a lung cancer multidisciplinary team that is designated as a mesothelioma specialist multidisciplinary team on the basis of the special expertise of its members. It may meet separately or include this specialist work as a part of its regular multidisciplinary team meetings.
- Continuous audit of services, this should be based on the National Lung Cancer Audit, though more detailed audit of mesothelioma should be considered at a local and network level.
- Because of the relative rarity of mesothelioma, not all diagnostic investigations, treatments and clinical trials will be available in all trusts. Therefore, robust management protocols and referral pathways to specialist mesothelioma multidisciplinary teams and centres need to be established and monitored.
- An integrated local and regional service with agreed care pathways based on clinical protocols (including the management of pleural effusion), referral criteria, network diagnostic and treatment policies (including access to highly specialised surgical services) and access to clinical trials.
- All relevant members of the multidisciplinary teams should be actively engaged with the local network tumour group and participate in peer review for lung tumours.

The overall aims and objectives of the services are:

- To provide an exemplary and comprehensive service for all patients referred with malignant mesothelioma that are delivered in line with the Department of Health Mesothelioma Framework (2007), Cancer Waiting Times and professional guidance such as the British Thoracic Society's 'Statement on Mesothelioma in the UK' (2007).
- To provide expert diagnosis of malignant mesothelioma utilising the most up-to-date validated diagnostic tools and knowledge.
- To provide expert assessment and management of patients with confirmed malignant mesothelioma through the use of the most up-to-date clinical protocols agreed with local Cancer Network.
- To ensure that there is clinically appropriate consideration and provision of specialist surgery, chemotherapy and palliative interventions for patients with malignant mesothelioma along their whole care pathway.
- To provide effective monitoring of patients with malignant mesothelioma to ensure that they experience the best possible level of symptom control and quality of life.
- To ensure that all patients have access to a clinical nurse specialist with experience of mesothelioma along the whole care pathway.

- To ensure that all aspects of the service are delivered as safely as possible, conform to national standards and published clinical guidelines and are monitored by objective audit.
- To ensure that structures are in place to allow patients access to all relevant clinical trials.
- To provide care with a patient and family centred focus to ensure high quality patient experience.
- Provide high quality information for patients, families and carers in appropriate and accessible formats and mediums. This should cover information about access to industrial injuries compensation.
- To ensure that there is involvement of service users and carers in service development and review.
- To ensure compliance with peer review measures.

The malignant mesothelioma service should work closely with primary care and palliative care services and be provided, as agreed by the local cancer network, either from:

- A lung cancer multidisciplinary team:
  - Manage patients with advanced mesothelioma who are unfit for active treatment and/or clinical trials.
  - Patient with supportive and palliative needs only.
- and/or
- A specialist mesothelioma multidisciplinary team:
  - Manage patients where there are difficulties with diagnosis (or staging where surgery is being considered).
  - Advice on the management of patients with a performance status of 0-2 where chemotherapy, radical treatment or clinical trial entry may be an option.
  - Advice and, where appropriate, management of patients who are fit for consideration of radical surgical or multimodality treatment.

## 2.2 Service description/care pathway

The service for patients with malignant mesothelioma should be commissioned to provide and deliver high quality clinical care to patients with suspected mesothelioma tumours and be able to offer and provide them with appropriate specialist treatment.

The managing multidisciplinary team should include medical and nursing staff with specialised knowledge of diagnosis and treatment, both curative and palliative, of malignant mesothelioma. A lead clinician - normally a respiratory physician - should take managerial responsibility for the service as a whole.

### Membership of the malignant mesothelioma specialist multidisciplinary team

Members of the specialist mesothelioma multidisciplinary team would include the same range of professionals as the lung cancer multidisciplinary team, however all

core members should have a clear specialist interest in and experience of the management of malignant mesothelioma:

- Respiratory physician with a special interest in lung cancer and mesothelioma.
- Radiologist with thoracic expertise. The radiologist has a local co-ordinating role, ensuring that patients whose chest x-rays show possible mesothelioma are referred to the Lung Cancer Team.
- Histopathologist & cytologist (can be one and the same person, depending on skills) with wide experience in mesothelioma.
- Clinical nurse specialist. A nominated individual with specialised knowledge of lung cancer and mesothelioma should be available to provide patient support and advocacy, to facilitate communication and the flow of information, and to liaise with other services.
- Oncologists with a special interest in thoracic oncology and wide experience in mesothelioma: either a clinical oncologist who can offer both radio- and chemotherapy, or a medical oncologist working closely with a clinical oncologist from the centre to which patients are referred for radiotherapy.
- Palliative care specialist. Because of the nature of the disease, close links with the palliative care team are essential.
- Thoracic surgeon with wide experience in the management of pleural disease including mesothelioma.
- Sufficient administrative support to provide co-ordination of the work of the multidisciplinary team and to collect data for the purposes of clinical audit.

**Note:** The specialist multidisciplinary team is expected to see a minimum of 25 new patients per year.

There should be a single named lead clinician for each the malignant mesothelioma service who should also be a core team member.

### **Patient information**

Every patient and family / carer must receive information about their condition in an appropriate format. The information must cover:

- Description of the disease
- Management of the disease within the scope of the commissioned service as described in the specification, clinical pathways and service standards
- Treatment and medication (including their side effects) commissioned in the clinical pathway
- Pain control
- Social support
- Psychological support
- Advice on available benefits
- Self-management and care
- Local NHS service and care/treatment options
- Contact details of the patient's allocated named nurse
- Possible industrial injuries benefits and compensation

The service must also provide education to patients and carers on:

- Symptoms of infection and management of neutropenic sepsis and prophylaxis
- Out of hours advice/support
- Contact in case of concern or emergency
- Other sources of information regarding malignant mesothelioma (e.g. mesothelioma UK)

### **Diagnosis and staging**

The service should work to network agreed assessment and referral guidelines that have been developed with the lead clinicians of the malignant mesothelioma service (local and specialist) multidisciplinary teams.

Diagnosing mesothelioma is often difficult, because the symptoms are similar to those of a number of other conditions. Patients with a suspected diagnosis of malignant mesothelioma should be referred promptly to specialist rapid access lung cancer clinics. The service should have access to appropriate diagnostic tests and investigations, carried out by clinicians with expertise in mesothelioma. The elements of diagnosis include:

- Medical history: A history of exposure to asbestos may increase clinical suspicion for mesothelioma.
- Physical examination (including lung function)
- Imaging: chest x-ray and then a contrast-enhanced CT scan of the thorax and upper abdomen. In some patients a PET-CT scan may be required to provide more staging information.
- Ultrasound guided diagnostic sampling of pleural effusions for biochemical and cytological examination.
- Biopsy: Image-guided percutaneous pleural biopsy including CT (or ultrasound) guided biopsy, medical or surgical thoracoscopy is needed to confirm a diagnosis of malignant mesothelioma. Not all these investigations are expected to be available in every trust.

### **Imaging**

The service should ensure that all appropriate imaging and image-guided biopsy modalities are available to patients in a timely manner. The service should agree imaging modalities and their specific indications. Where specific investigations are not available in a particular trust, clear and timely arrangements should be made for them to be carried out in other centres as agreed by the cancer network.

### **Pathology**

Histological confirmation of tumour is required before treatment with chemotherapy or radiotherapy. The pathology team should have access to a full range of appropriate immunohistochemical stains and, in difficult cases, advice



from a panel of highly specialist pathologists.

The pathology services should comply with Clinical Pathology Accreditation (UK) Ltd (CPA)<sup>1</sup> and the Human Tissue Authority (HTA)<sup>2</sup>

## **Treatment**

The prognosis for malignant mesothelioma remains disappointing, although there have been some modest improvements in prognosis from newer chemotherapy regimens and multimodality treatments. It is a highly symptomatic cancer and access to specialist palliative interventions will form an important part of any high quality service. The service should have agreed protocols for the diagnosis, staging, management and clinical trial entry of patients with malignant mesothelioma. Such protocols should be developed by cancer networks in association with lung cancer and specialist mesothelioma multidisciplinary teams.

The outcomes of treatment of malignant mesothelioma are better if the disease can be diagnosed at an earlier stage, but it almost universally recurs and so called 'cures' are exceedingly rare.

## **Surgery**

Pleurodesis and radical decortication are currently the most common surgical procedures in these patients. Radical decortication requires a high level of surgical expertise and has the intent of resecting all visible tumour, leaving the underlying lung in situ. Although it has not been shown in a randomised trial to prolong life, there are a number of case series which report promising results. It is very shortly (2012) to be the subject of a major UK clinical trial (MARS 2). Less common now, is extrapleural pneumonectomy (EPP), in which as well as the pleura, the lung, the hemi-diaphragm and the pericardium are removed;

Not all thoracic surgical centres have wide experience or the local expertise to carry out all these surgical procedures. Whilst there are no published guidelines on minimum numbers, commissioners should consider stipulating a minimum number of such procedures that centres providing this service carry out per year.

## **Chemotherapy and radiotherapy**

- Chemotherapy is the only treatment for mesothelioma that has been proven to improve survival.
- Chemo-radiotherapy is sometimes given as part of a multi-modality approach in combination with surgery in very fit patients with limited disease.
- Chemotherapy should be carried out at designated centres by appropriate specialists as recommended by the malignant mesothelioma service. Such centres should be compliant with peer review measures for chemotherapy and acute oncology.

<sup>1</sup> CPA, the principle accrediting body of clinical pathology services and External Quality Assessment (EQA) Schemes in the UK. Modernising Pathology Services. Department of Health (2004)

<sup>2</sup> HTA Regulatory body for all matters concerning the removal, storage, use and disposal of human tissue. [www.hta.gov.uk](http://www.hta.gov.uk)

- Radiotherapy is also used to palliate chest wall pain and to treat chest wall nodules that can result from tumour seeding.
- There should be a formal relationship between the malignant mesothelioma service and the providers of non-surgical oncology services that is characterised by agreed network protocols, good communication, and well-defined referral pathways. This relationship should be defined in writing and approved by the cancer network director and the lead clinician for the malignant mesothelioma service.
- Auditing of compliance with these protocols will need to be demonstrated.

### **Palliative Care**

The provider shall give high quality supportive and palliative care in line with NICE guidance. The extended team for the multidisciplinary team includes additional specialists to achieve this requirement. Patients who are managed by a malignant mesothelioma multidisciplinary team will be allocated a key worker.

- Palliative care and symptom control should be central to any management plan.
- Specialist palliative care including specific interventions such as radiotherapy to site of chest drainage/biopsy, the insertion of tunnelled in-dwelling pleural catheters, nerve blocks and cordotomy are important to provide symptom relief in specific patient groups.
- Patients who require palliative care will be referred to a palliative care team in the hospital and the team will be involved early to liaise directly with the community services.
- All patients will be allocated a key worker who will usually be a clinical nurse specialist with expertise and experience in lung cancer and mesothelioma. Patients will be provided with their key worker's name and contact details.
- Specialist palliative care advice will be available on a 24 hour, seven days a week basis.

### **Rehabilitation**

It is important that patients are supported from diagnosis through the entire pathway with appropriate rehabilitation support. The rehabilitation care pathways provide a model for this support and cover the acute, community and primary care settings. There should be appropriate assessment of patients' rehabilitative needs across the pathway and the provider must ensure that high quality rehabilitation is provided in line with the network agreed lung rehab pathway at: [www.ncat.nhs.uk/our-work/living-with-beyond-cancer/cancer-rehabilitation](http://www.ncat.nhs.uk/our-work/living-with-beyond-cancer/cancer-rehabilitation)

### **Supportive care**

Each patient should be offered an holistic needs assessment at key points in their cancer pathway including at the end of primary treatment and the beginning of the end of life. A formal care plan should be developed. The nurse specialist(s) should ensure the results of patients' holistic needs assessment

are taken into account in the multidisciplinary team decision making.

## **Survivorship**

The National Cancer Survivorship Initiative (NCSI) is testing new models of care aimed at improving the health and well being of cancer survivors. The new model stratifies patients on the basis of need including a shift towards supported self management where appropriate. In some circumstances traditional outpatient follow-up may be replaced by remote monitoring. The model also incorporates care coordination through a treatment summary and written plan of care.

It will be important for commissioners to ensure that work from this programme is included and developed locally to support patients whose care will return to their more local health providers once specialist care is no longer required.

## **End of life care**

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

## **Acute oncology service**

All hospitals with an Accident and Emergency (A&E) department should have an “acute oncology service” (AOS), bringing together relevant staff from A&E, general medicine, haematology and clinical/medical oncology, oncology nursing and oncology pharmacy. This will provide emergency care not only for cancer patients who develop complications following chemotherapy, but also for patients admitted suffering from the consequences of their cancer. For full details on AOS please refer to the service specification for chemotherapy referred to above.

## **2.3 Population covered**

### **Accessibility**

### **Geographic coverage/boundaries**

The service outlined in this specification is for patients ordinarily resident in England<sup>3</sup>; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt

<sup>3</sup> Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England

from charges).

The service is accessible to all patients with a suspected malignant mesothelioma regardless of age, sex or race. 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 is 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.

The malignant mesothelioma service is to be delivered in the model outlined in the Department of Health Mesothelioma Framework, and the National Cancer Peer Review Programme Manual for Cancer Services (2011): Lung Cancer measures.

The malignant mesothelioma service should be provided by a planned collaboration between local lung cancer multidisciplinary teams and specialist mesothelioma multidisciplinary teams. Management and referral will depend on the characteristics of each particular patient but all patients with malignant mesothelioma should at least be registered by the regional specialist multidisciplinary team. The configuration of the service is to be agreed with local networks based on caseload volume (minimum of 25 cases a year) and availability of appropriate clinical expertise for specialist teams. The management of mesothelioma cancer involves four cross-linked teams:

- Primary health care team,
- Local lung cancer team,
- Specialist mesothelioma team
- Palliative care team

### **Care pathways**

A sequential flow diagram of the integrated service user pathway(s) showing access, transfer and exit points, potential routes and relationships with other health and/or social care providers is set out in *Appendix 1 – Clinical Management Pathway for Malignant Mesothelioma*

### **Location(s) of Service Delivery**

The service is delivered across England by most hospitals with a lung multidisciplinary team and by specialist mesothelioma multidisciplinary team services.

### **Days/hours of operation**

24 hours a day, 365 days a year.

## 2.4 Any acceptance and exclusion criteria

### Referral criteria & sources

GP urgent referral for patients for a chest x-ray with:

- History of employment in high risk industries; including 'casual' exposure (recognising that such a history is not always present).
- Clinical signs of a pleural effusion, unexplained chest pain, breathlessness or weight loss.

GPs should have a low threshold for requesting repeat x-rays if symptoms persist and employment history is high risk.

Referrals are accepted by any qualified doctor from the malignant mesothelioma service where the patient has confirmed or suspected malignant mesothelioma. The receiving clinician at one of the providers may request the referrer to carry out further investigations to aid the proper diagnosis of the patient's condition.

### Referral route

Referrals to the service will come from either primary care or a local multidisciplinary team. Steps prior to referral to the specialist team include:

- The local team will already have made a diagnosis, confirmed by ultrasound, CT or biopsy.
- The patient will have been informed of the diagnosis and given the date of a CT scan.
- The patient will have had staging investigations.
- The patient will have been discussed at their local multidisciplinary team.
- The patient will have been referred to a specialist multidisciplinary team.

### Response time & detail and prioritisation

Patients identified in primary care with suspected malignant mesothelioma should usually be referred to a rapid access lung cancer clinic under the '2 week wait' referral route.

Patients with large pleural effusion or who are very breathless are likely to need more urgent attention, which may include hospital admission. For such patients initial telephone contacts from referrers are to be dealt with immediately by the respiratory consultant on duty. Advice on optimal management should be given and on-going support will be provided until the patient is transferred.

Transfer of patients to the malignant mesothelioma service will be prioritised according to the needs of individual patients but in all cases where a transfer to the malignant mesothelioma service has been agreed, that transfer will take place as soon as is practicable and the urgency will depend on this clinical condition of the patient.

## 2.5 Interdependencies with other services

For patients who have received inpatient care it is important that:

- No adverse outcomes are anticipated.
- Where surgical procedures have been carried out, discharge is safe.
- Clinically appropriate arrangements for local care and local or specialist mesothelioma multidisciplinary team service follow-up have been discussed and agreed by all relevant parties.
- Parents/carers have demonstrated competence in any care they will be required to provide in relation to malignant mesothelioma.
- Parents/carers understand and have the necessary information to contact their local or specialist mesothelioma multidisciplinary team service provider, including the name and contact details of a key worker.

All discharge planning will be managed by the lead clinician (physician or surgeon) in charge of the case with local health and social care providers being fully informed of the patient's condition and any responsibilities they will have to assume. This will be formalised in written communication to the patient's GP and all other relevant parties.

Strategic clinical networks will be in place from April 2013 located in 12 areas across England. They will be established in areas of major healthcare challenge where a whole system, integrated approach is needed to achieve a real change in quality and outcomes of care for patients. Cancer has been identified as one of the conditions that will be within this new framework. Strategic clinical networks will help commissioners reduce unwarranted variation in services and will encourage innovation. They will use the NHS single change model as the framework for their improvement activities.

## 3. Applicable Service Standards

### 3.1 Applicable national standards e.g. NICE, Royal College

Care delivered by the specialist MDT for mesothelioma must be of a nature and quality to meet the Care Quality Commission (CQC) care standards and relevant parts of the Improving Outcomes guidance (IOG) / peer review measures for lung cancers. It is the Trust's responsibility to notify the commissioner should there be any breaches of the care standards. Where there are breaches any consequences will be the Trust's responsibility to address.

Mesothelioma cancer services are required to achieve the two week wait for all patients where cancer is suspected. In addition the services are required to meet the following standards for all such cancer patients,

- 31 day wait from diagnosis to first treatment,
- 31 day wait to subsequent treatment,
- 62 day wait from urgent GP referral or screening referral or consultant

upgrade to first treatment.

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. Further details are available at [www.cquins.nhs.uk](http://www.cquins.nhs.uk)

The provider must be able to offer patient choice. This will be both in the context of appointment time and of treatment options and facilities including treatments not available locally.

The service will comply with the relevant NICE quality standards which defines clinical best practice.

#### 4. Key Service Outcomes

The NCIN Tumour specific group are currently developing Clinical Lines of Enquiry and providers will be expected to record the following:

- The % of expected cases on whom data is recorded
- The % histological confirmation rate
- The % having active treatment (active defined here as surgery, chemotherapy and/or radiotherapy)

#### Quality & Performance Standards

Performance Indicator Quality	Indicator	Threshold	Method of Measurement	Consequence of breach
	% of cases discussed at multidisciplinary team	100%	Reported within national audit reports but not reported regularly to Board	
	Follow Up Ratios		Not regularly reported	
	Other Quality Measures	TBC	TBC	
	Percentage attendance by individual core members or their agreed cover at multidisciplinary team	67%	Reported in Peer Review Submissions	
	Attendance at	100%.	Peer Review	

	advanced communications course Links to specification point 3.1.10			
Compliance with Peer Review	Compliance with all other peer review measures (other than where agreed with commissioners when the provider should have an action plan in place that has been agreed with the commissioner)	Minimum of 70%	National reports / regular verbal feedback to Board	
Performance & Productivity	The Provider should ensure that these targets are achieved for the part of the patient pathway that it delivers and that when the patient pathway crosses outside the locality border, appropriate scheduling of patients/activity supports achievement of the target by other providers in the pathway wherever possible, except when informed patient choice or clinical appropriateness mitigate against this.			
Waiting Time Compliance	62 day wait - % treated in 62 days from GP referral, consultant referral and referral from screening programme	>~86%		
Aggregate Measures	14 day suspected cancer referral standard performance (A20)	93%		
	31 day first treatment standard performance (A15)	96%	Regularly reported to Board	
	31 day subsequent treatment (Surgery) standard performance (A16)	94%	Regularly reported to Board	



	31 day subsequent treatment (Drugs) standard performance (A16)	98%	Regularly reported to Board	
	31 day subsequent treatment (Radiotherapy) standard performance (A17)	94%	Live from 1st January 2011 and regularly reported to Board	
	31 day subsequent treatment (Other Treatments) standard performance Links to specification point 2.2.2	TBC	Live from 1st January 2011 and regularly reported to Board	
	31 day subsequent treatment (Palliative) standard performance	TBC	Live from 1st January 2011 and regularly reported to Board	
	62 day standard from 14 day referral performance (A18)	85%	Regularly reported to Board	
	62 day standard from screening referral performance (A19)	90%	Regularly reported to Board	
	62 day standard from consultant upgrade performance (A19)	TBC	Live from December 2008 and regularly reported to Board	
	Diagnostic Test Waiting Times	TBC	Not regularly reported to Board, no longer a CQC target	

## Activity Performance Indicators

Activity Performance Indicators		Threshold	Method of measurement	Consequence of breach
Audits (Specification Point 2.3.4)	Annual review conducted		NSSG	
	Participation in National Audits	100%	Part of Network Performance Report but only in terms of submission not in terms of data quality	
	Additional Audits undertaken	N/A	Reported at NSSGs but not Board unless specific service change	
Activity (Specification Point 3.1.4)	Threshold for number of procedures	Establish baseline cancer activity data for :- number of procedures for elective, day case , non elective non emergency, non elective emergency, outpatient FA, outpatient FU, outpatient procedures all by speciality	Not currently regularly reported to Board	
	Length of stay benchmarking			
	Level of admissions			
	Choice			
Service User Experience	National Cancer Patient Experience survey (ref A46 main contract)	National survey report when published	National findings reported to Board. Currently establishing a baseline.	If the provider does not take part they will be required to meet with the commissioners to explain reasons for not doing so

				and activity planned to enable the information to be captured through alternative mechanisms
	Improving Service User Experience	Of responses received 75% should express overall satisfaction with the service. Trust to evidence the measures it has taken to improve service user experience and outcomes achieved and numbers / percentages stratified		
	Addressing Complaints	Trust to evidence the measures it has taken to address complaints and outcomes achieved		
	Patient involvement	Trust to evidence the actions it has taken to engage with patients and demonstrate where this has impacted		
Staff survey	Staff survey results			

Trial Activity (Specification Point 8.2.8)	Recruitment into trials	Patients eligible for an existing clinical trial should be offered to the chance to be treated in a clinical trial	Reported to Board on a regular basis but not part of the performance report	
Outcomes (Specification Point 8.2.6)	30 day mortality		Registry data	
	1 yr survival		Part of Network Performance Report	
	5 yr survival			
	30 day readmission rates for cancer patients	Numbers and percentage baseline to be set in year	Not currently reported to Board	
Data Submission (Specification Point 8.2.6)	Registry dataset submission status	As required by Registry	Not currently regularly reported to Board	
	Death Certificate Only (DCO)		Regular updates to Network	
	Staging data (Specification Point 2.3.4)	As required by Registry	Not currently regularly reported to Board	

### Additional information

Mesothelioma is classified using the International classification of diseases version 10 (ICD10) as:

C45: Mesothelioma. There are around 2,200 newly diagnosed cases of mesothelioma in England

Incidence data are for patients diagnosed in England, 2009. Source: UKCIS, accessed August 2012.

### Cancer Waiting Times

Mesothelioma is included within the category of lung for cancer waiting times.