



Royal College
of Physicians

National
Mesothelioma Audit



MESOTHELIOMA UK
Supporting People With This Asbestos Cancer

National Mesothelioma Audit report 2018

(for the audit period 2014–16)





Royal College of Physicians

The Royal College of Physicians (RCP) plays a leading role in the delivery of high-quality patient care by setting standards of medical practice and promoting clinical excellence. We provide physicians in over 30 medical specialties with education, training and support

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The Care Quality Improvement Department (CQID) of the RCP delivers projects that aim to improve healthcare in line with the best evidence for clinical practice: guideline development, national comparative clinical audit, the measurement of clinical and patient outcomes, and change management. All of our work is carried out in collaboration with relevant specialist societies, patient groups and NHS bodies.



MESOTHELIOMA UK

Supporting People With This Asbestos Cancer

The charity Mesothelioma UK is a national specialist resource centre dedicated to all matters related to mesothelioma. The charity provides specialist mesothelioma information, support and

education and seeks to improve care, treatment and outcomes for all UK mesothelioma patients and their carers.

The charity integrates into NHS front-line services to ensure specialist mesothelioma nursing is available at the point of need. This is achieved through a growing network of specialist mesothelioma nurses, regionally based in NHS hospitals but funded by Mesothelioma UK. The charity relies entirely on donations, grants, legacies and fundraising to ensure all services are provided free of charge across the UK.

Visit www.mesothelioma.uk.com

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Thank you to all the mesothelioma teams that have contributed data to the audit; without your considerable efforts, this report would not be possible.

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Wales Cancer Network

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Thank you to Tom Cecil, consultant peritoneal surgeon at Basingstoke Hospital and his team for guidance on surgery for peritoneal mesothelioma and the national peritoneal mesothelioma multidisciplinary team (MDT).

The National Lung Cancer Audit team is funded by the Healthcare Quality Improvement Partnership (HQIP) which holds the contract to manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP). Data for this report is based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE).

Document Purpose	To disseminate results on the quality of care for patients in England and Wales diagnosed with malignant pleural mesothelioma and for patients in England diagnosed with peritoneal mesothelioma in the audit period between 1 January 2014 and 31 December 2016
Title	National Mesothelioma Audit report 2018 (for the audit period 2014–16)
Author	Royal College of Physicians, Care Quality Improvement Department
Publication	June 2018
Target audience	NHS staff in mesothelioma multidisciplinary teams; hospital managers and chief executives; commissioners; mesothelioma researchers; mesothelioma patients, their families and their carers
Description	This is the third publication on malignant mesothelioma from the National Lung Cancer Audit. It publishes organisational, national and network-level results on the quality of mesothelioma care for patients diagnosed between 1 January 2014 and 31 December 2016. It covers many processes of care across the entire patient pathway.
Related publications	National Lung Cancer Audit pleural mesothelioma report 2016 (audit period 2014) National Lung Cancer Audit report 2014 Mesothelioma (audit period 2008–2012) National Lung Cancer Audit annual report 2017 www.nlcaudit.co.uk/Home/Data
Contact	NLCA@rcplondon.ac.uk

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Contents

Foreword	5
Purpose and background	7
Key findings	
Number of cases and demographics	8
Performance against audit standards	9
Data completeness	9
Pathological confirmation	10
Active anti-cancer treatment	11
Chemotherapy/SACT	11
Surgery	12
Radiotherapy	12
Other key measures	13
Specialist nurse story	13
Survival	14
Network performance	15
Is the standard of care improving?	16
Patient story	17
Peritoneal mesothelioma	18
Key recommendations for 2018 onwards	20
Glossary of terms and abbreviations	21
References	23

Foreword



We are delighted to publish the third National Mesothelioma Audit report in collaboration with Mesothelioma UK.

Results are presented for over 7,000 patients from England and Wales, for the first time also including people with peritoneal mesothelioma. It is pleasing to see a further rise in the use of chemotherapy for patients of good performance status and this is the first report in which we have been able to use our linkage to the Systemic Anti-Cancer Therapy (SACT) dataset to obtain details of first and second-line treatments used. The results also show encouraging trends towards higher active treatment rates, staging

and mesothelioma subtyping, although for some of our other audit measures national performance remains similar to previous years.

The persisting variation in active treatment and outcomes across cancer networks and individual organisations demands improvements in the care and outcomes for mesothelioma patients in accordance with the recently published British Thoracic Society (BTS) guidelines.

Dr Susan Harden – Clinical lead, National Mesothelioma Audit

‘I very much hope that those responsible for providing and commissioning the services for patients suffering from mesothelioma will look at this report and seriously consider what implications it has for their own responsibilities for providing high–quality care for all.’



I am delighted to see the publication of this, the third report of the National Mesothelioma Audit in the UK. This is the work of the excellent National Lung Cancer Audit (NLCA) team, commissioned and funded by Mesothelioma UK. The NLCA has evolved in recent years, in particular working in direct partnership with the National Cancer Registration and Analysis Service (NCRAS) in Public Health England, a collaboration which has meant greater access to a wider range of data sources, enhancing the value of the work greatly. We also believe that access to the NCRAS data means that the audit has captured the entire population of patients who were diagnosed with pleural mesothelioma in England and Wales. Unfortunately we are not

yet able to include detailed data from Scotland and Northern Ireland, though it is hoped that will be possible in future. For the first time we are also reporting on mesothelioma of the peritoneum, a rare but devastating disease which is almost certainly under-reported. Specialist services for patients suffering from peritoneal mesothelioma are now emerging and I hope their inclusion here is a small step towards an increasing recognition of the disease.

There is evidence of some improvements since the first report particularly in the pathological diagnosis of pleural mesothelioma and the proportion of patients receiving chemotherapy, but wide variations remain between cancer alliances and it is clear that many lung cancer MDTs are managing very small numbers of cases each year. Pathological subtyping of pleural mesothelioma is of great importance, but in terms of prognosis and as a criterion for the increasing number of clinical trials now opening for recruitment. I very much hope that those responsible for providing and commissioning the services for patients suffering from mesothelioma will look at this report and seriously consider what implications it has for their own responsibilities for providing high–quality care for all.

I would finally like to thank all those who give so generously of their time and money to make it possible for Mesothelioma UK to commission work of this sort and strive towards the day when ‘Mesothelioma is history’.

Professor Mick Peake – Chair of the Board of Trustees, Mesothelioma UK

National Mesothelioma Audit

Mesothelioma UK and the Royal College of Physicians

Results from 2014–16

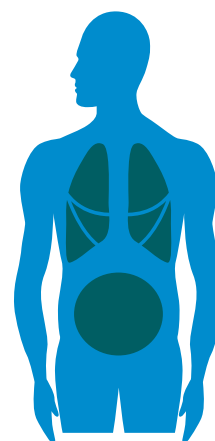
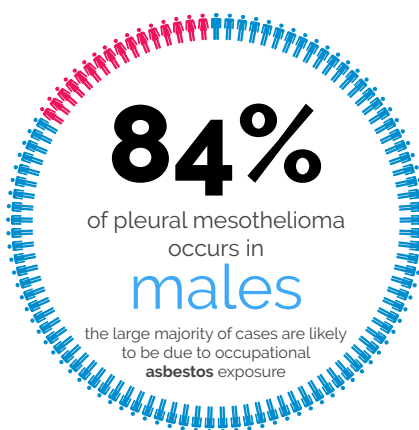
Demographics

153 

organisations
across England and Wales
submitted data that
contributed to this report

7,192 

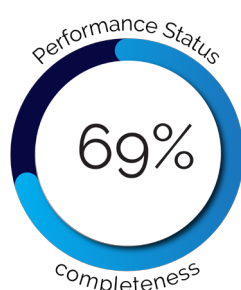
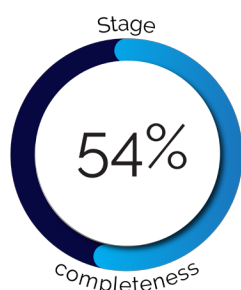
individual patients
were diagnosed with
mesothelioma during
the audit period



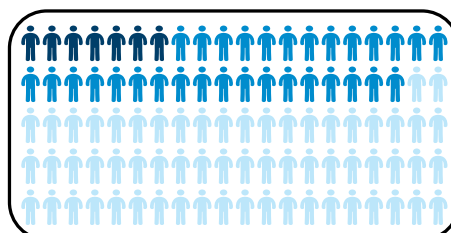
6,932
pleural
cases

260
peritoneal
cases

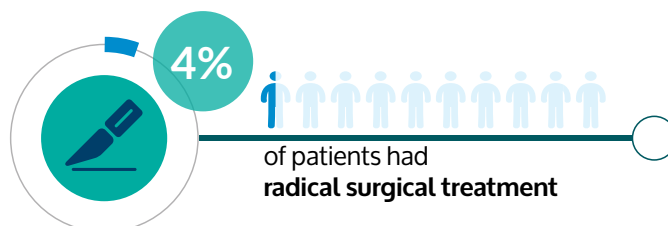
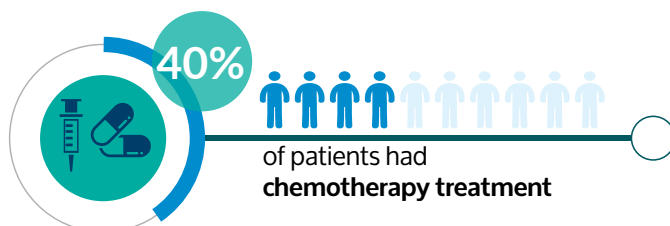
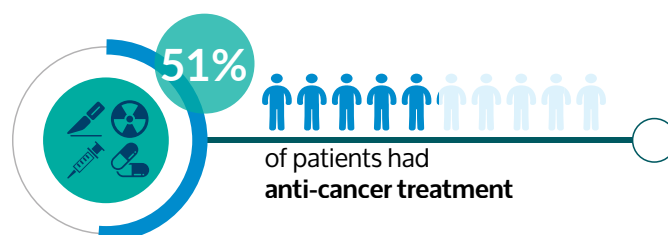
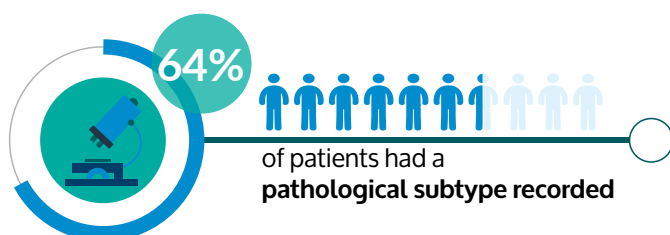
Data completeness



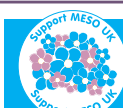
Survival



Treatment



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Purpose and background

Malignant mesothelioma (MM) is a type of cancer that develops over a long period of time, but once clinically apparent is often rapidly progressive. The cancer commonly originates in mesothelial cells found in the thin membrane (pleura) that lines the lungs and the inside of the chest wall (malignant pleural mesothelioma – MPM). Mesothelioma can also affect the similar peritoneal membrane within the abdominal cavity (peritoneal mesothelioma – PM). Approximately 90 % of cases of MPM are linked to asbestos exposure, and so a number of occupations, notably shipbuilding, railway engineering, insulation, plumbing, electrical installation and asbestos product manufacturing, are associated with an increased risk of the disease.¹ With the 20–50 year lag between exposure to asbestos and the development of MM, estimates of the likely burden of disease suggest that numbers of cases in the UK are likely to peak between 2020 and 2025.

The National Lung Cancer Audit (NLCA) is an audit commissioned by the Healthcare Quality Improvement Partnership (HQIP) and has collected data on people with lung cancer and MPM since 2005. The database includes a large amount of information on mesothelioma patients, including demographics, referral pathways, investigation, treatment and outcome.

In late 2014, the contract for the NLCA was awarded to the Royal College of Physicians. However, the contract did not include an audit for mesothelioma. Funding for an ongoing national mesothelioma audit from 2014 onwards has been provided by Mesothelioma UK. The charity and NLCA team hope that this collaboration can increase quality improvement initiatives that will directly improve mesothelioma services. This year the report also includes patient-level data from Wales and a separate section reporting on peritoneal mesothelioma for the first time. Data flows to the NLCA team for mesothelioma patients in Scotland and Northern Ireland are not established yet and so these cases were not available for inclusion in this report.

Data collection

The report covers patients in England and Wales with a diagnosis of mesothelioma in the years 2014–16 classified with code C45 of the tenth edition of the World Health Organization International Classification of Disease (ICD-10) and Morphology M905.

Since the numbers of annual cases of mesothelioma are relatively small (approximately 2,300), this report has combined 3 years of data to give more reliability to the results. This enables reporting of activity and performance at a regional level. This regional grouping is based on the historic cancer networks which were in operation in the period 2014–16, although more recently their role has been superseded by cancer alliances. Despite this, the number of cases for each individual provider of care is still small and so the report itself does not include any detail at this level. A more granular analysis down to provider-level is available online but should be interpreted with caution.

NHS hospitals in England submit the details for all mesothelioma patients via the Cancer Outcomes and Services Dataset (COSD) to the NLCA through

the National Cancer Registration and Analysis Service (NCRAS). The data are linked to other datasets, including Hospital Episode Statistics (HES), the National Radiotherapy Dataset (RTDS), the Systemic Anti-Cancer Dataset (SACT), pathology reports and death certificate data.

In Wales, data are collected through the Cancer Network Information System Cymru (CANISC) and a pseudo-anonymised extract of patient-level data is submitted to the NLCA.

Standards and guidelines

The first British Thoracic Society (BTS) guidelines for pleural mesothelioma were published in 2018.² The recommendations in this audit report for MPM are chosen to reflect these recent guidelines.

All the results in this report as well as further detailed analyses are available online at:

www.nlcaudit.co.uk/Mesothelioma

Key findings

The National Mesothelioma Audit (NMA) collects a large amount of data from a variety of sources and can report on a wide range of process and outcome measures. This report provides a national picture for England and Wales. Provider-level data can be viewed and downloaded at www.nlcaudit.co.uk/Mesothelioma



Number of cases and demographics

6,932 cases of malignant pleural mesothelioma were recorded in England (6,642) and Wales (290) between 2014–16. The number of cases diagnosed in each cancer network is shown in Table 2, and a more detailed analysis down to individual secondary care provider is available on our website. A further 260 cases of malignant peritoneal mesothelioma were recorded in England.

For pleural mesothelioma, 84 % of cases occur in males with a large majority of these likely being related to occupational asbestos exposure. Peritoneal mesothelioma is also more common in males, although the proportion of 66 % is less striking.

The following summaries and commentary focus on the pleural mesothelioma cases, while the peritoneal cases are discussed in a separate section.

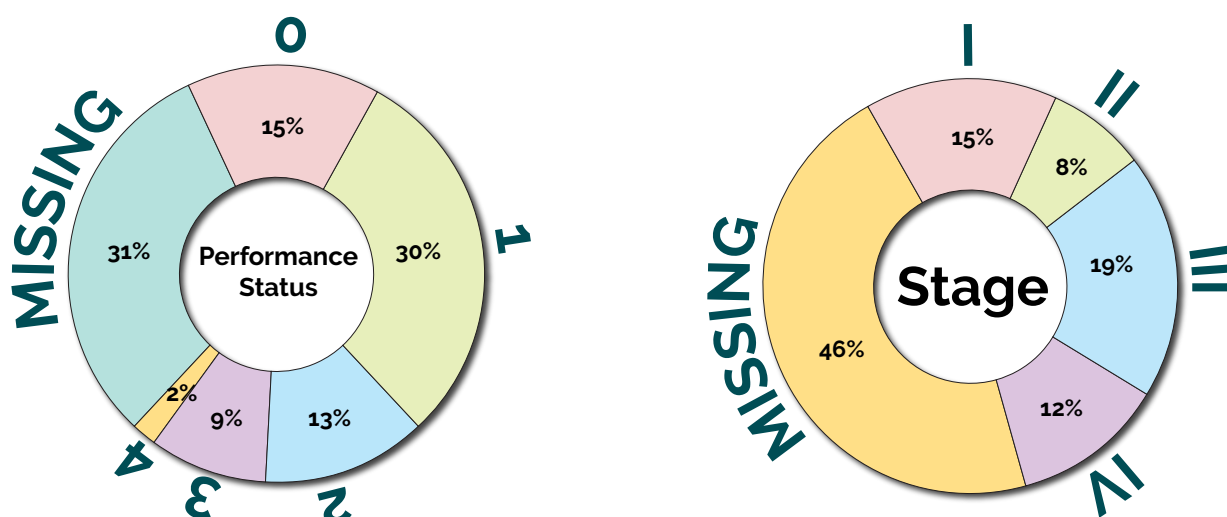


Figure 1: Distribution of performance status and stage in pleural mesothelioma

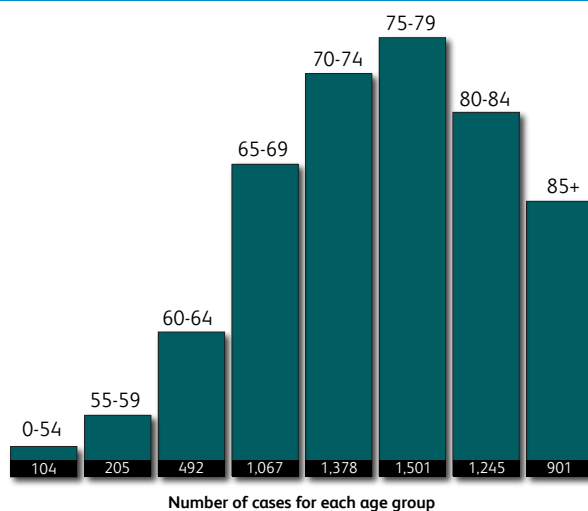


Figure 2: Distribution of age at diagnosis in pleural mesothelioma

Performance against audit standards

In our previous report, we made a number of recommendations and set challenging audit standards in order to push teams to achieve excellence. Of those recommendations that can be audited with the available data, unfortunately none have been achieved on a national level, although some networks have done so, as shown in Figure 3. Further details of provider results are available at www.nlcaudit.co.uk/Mesothelioma

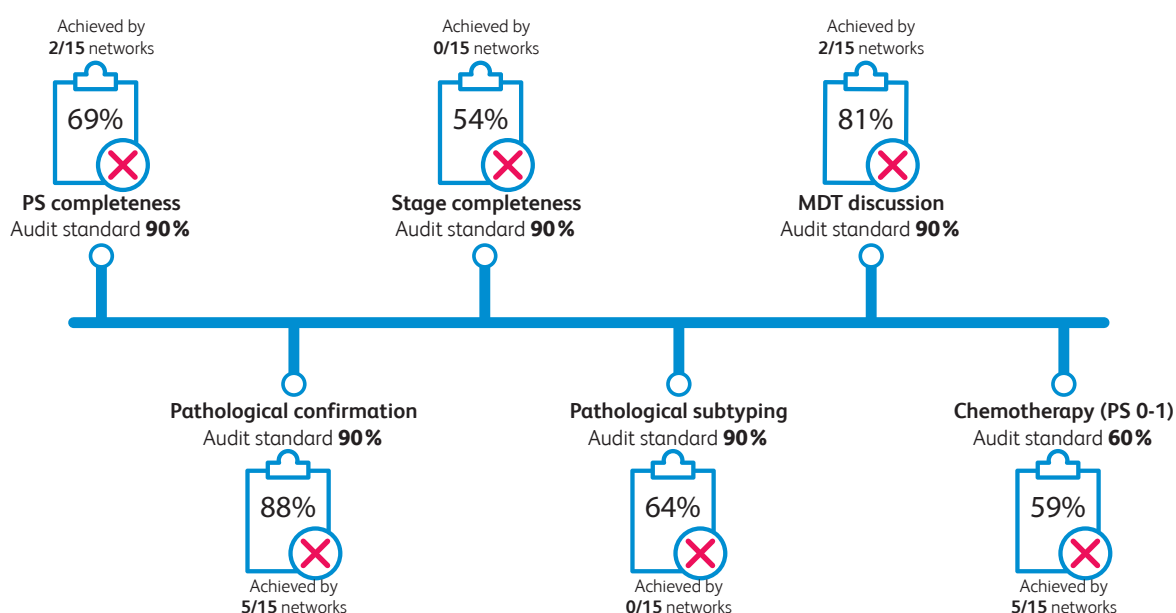
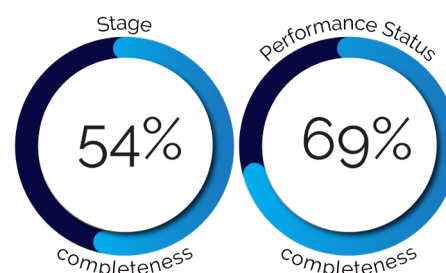


Figure 3: Performance against audit standards

Data completeness (MPM)

It is important to maintain or improve the quality of data submitted to the NMA, including detailed clinical data, to allow the most accurate risk adjustment to be carried out. Performance status (PS) describes a patient's level of functioning in terms of their ability to care for themselves, daily activity and physical ability. Stage refers to the extent of the cancer, such as how large the tumour is and whether it has spread.



Commentary

Data completeness for PS in Wales is around 99%, and while improving in England, is considerably lower at 68%. There is an unacceptably wide variation in recording of PS across English networks ranging from 48% to 83% (details available online).

Stage for MPM was recorded in 54% of all cases. It is welcome that this has increased from 42% in our previous report, but again there is unacceptable variation across all the cancer networks from 26% to 76% (details available online). The new BTS guidelines recommend that all cases of diagnosed MPM are staged using the new IASLC/IMIG TNM 8 clinical staging system.^{2,3}



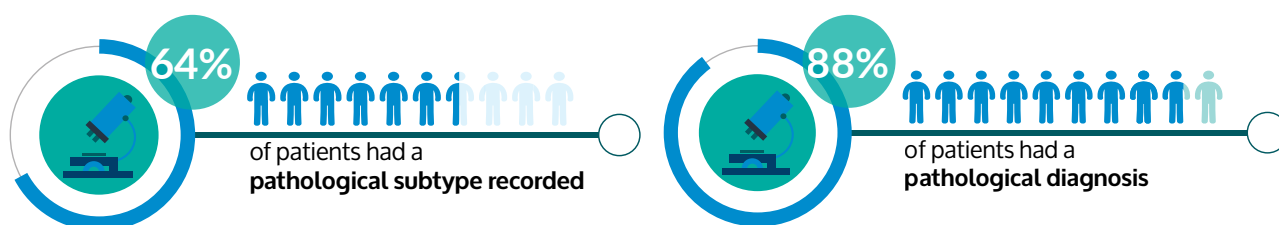
RECOMMENDATION

- ✓ **Data completeness for PS and stage (using the proposed TNM 8 system) should each exceed 90%.**
- ✓ **All MDTs should appoint a 'clinical data lead' with protected time to allow promotion of data quality, governance and quality improvement.**



Pathological confirmation

A high proportion of MPM patients (88 %) had pathological confirmation of diagnosis, varying across networks from 81 % to 95 %. Reporting of histological subtype is improving and was reported for 64 % of cases. However, 36 % of cases are still recorded as unspecified mesothelioma without a histological subtype, varying across networks from 22 % to 63 % (see Table 3).



Commentary

The BTS guidelines recommend that pathologists should report histological subtype of MPM in all cases. MPM subtyping correlates with prognosis and may also guide treatment options and influence stratification into clinical trials.

Table 1: MPM pathology in 2014–16

Pathology	Number of histology confirmed cases	% of cases subtyped
M9050/3 Unspecified	2,221	36.3
M9051/3 Sarcomatoid	671	11.0
M9052/3 Epithelioid	2,701	44.2
M9053/3 Biphasic	520	8.5



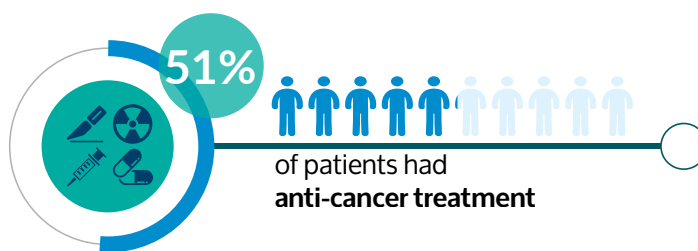
RECOMMENDATION

- ✓ **Pathological confirmation should be over 95%, and where the proportion of cases of unspecified MPM is above 10%, review of diagnostic procedures and pathological processing is recommended.**

Active anti-cancer treatment

Palliative chemotherapy, debulking surgery and palliative radiotherapy are commonly included as active anti-cancer treatments for MPM patients and are reported separately below. In total 51 % of cases received such treatment and the variation by cancer network is shown in Table 3. It is harder to collect data

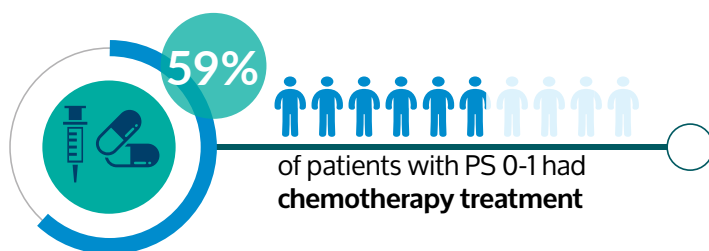
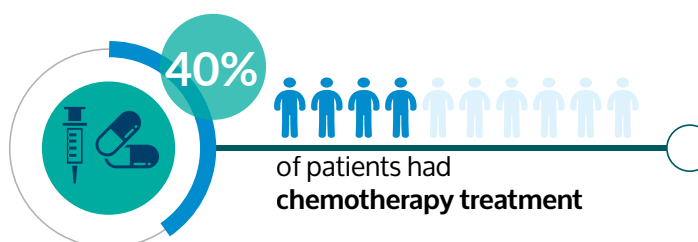
on other palliative treatment measures such as fluid management and pain control which may also impact on quality of life and patient outcome. There is increasing use of medical rather than surgical pleurodesis for fluid control and the insertion of indwelling pleural catheters (IPCs). These data are not collected via COSD, although fluid control is viewed as a standard of care within BTS MPM guidelines. Pain control is also essential for optimising quality of life. However, data on the use of opiates, nerve blocks and cordotomies are not currently collected via COSD.



Chemotherapy/SACT

The BTS MPM guidelines recommend the use of first-line pemetrexed platinum chemotherapy in patients with good performance status based on high-quality randomised controlled trials. In this patient cohort, 40 % of MPM patients received chemotherapy, an increase compared with previous audits. For patients with PS 0–1,

use of chemotherapy has also increased compared with earlier audits with 59 % receiving chemotherapy, but a network variation ranging from 49 % up to 78 % as shown in Table 3.



The most commonly used first-line regimen was pemetrexed/carboplatin, closely followed by pemetrexed/cisplatin with treatments reported to SACT simply as 'Trial' the third most frequent. Bevacizumab and pembrolizumab were rarely used. At national level, for all MPM patients receiving chemotherapy, only 15 % received a second-line treatment.

Commentary

After first-line chemotherapy, there is still no established second-line treatment for MPM and BTS guidelines recommend second-line clinical trials for all patients with good PS above any other option.

Fit patients should be offered referral to specialist centres if they wish, for consideration of systemic treatment within clinical trials, even if this involves travelling.



RECOMMENDATION

- ✓ **Patients with adequate performance status should be offered active anti-cancer treatment, including palliative chemotherapy. MDTs with chemotherapy rates (in good PS patients) below 60% should perform detailed case note review to ascertain why. High-quality patient information should be available to guide treatment decisions.**



Surgery

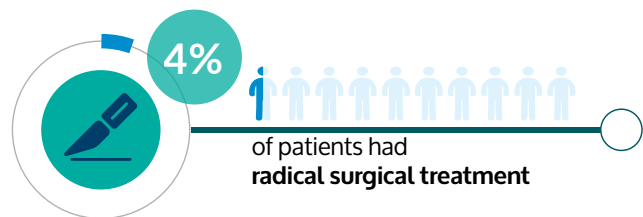
The role of radical debulking surgery for MPM remains controversial and is only offered to a small sub-group of selected patients. During the financial year 2014–15, the Society of Cardiothoracic Surgeons (SCTS) internal audit records just two people who underwent extrapleural pneumonectomy (EPP – resection of pleura, lung, diaphragm and pericardium) in England while 77 underwent radical/extended decortication (EPD – resection of pleura, diaphragm and/or pericardium); 108 underwent pleurectomy decortication (PD – pleura), over half by a VATS approach.

This audit uses surgical procedure OPCS-4 codes that correlate with the SCTS data for reporting radical debulking surgical treatments but which cannot distinguish between the three SCTS definitions of surgical extent above.

Of the patients diagnosed in 2014–16, 4.3 % received radical debulking surgery although many people received other palliative or diagnostic surgical procedures – primarily pleurodesis. In view of the debate as to the clinical benefit of radical debulking surgery, variation across networks should be interpreted with caution. It can be viewed in Table 3.

Commentary

BTS guidelines recommend that extended pleurectomy decortication (P/D) is not offered outside of a clinical trial (MARS2) and based on previous reported trials do not advise either EPP⁴ or VATS-partial pleurectomy over talc pleurodesis.⁵



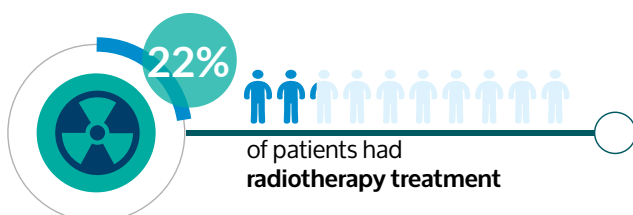
RECOMMENDATION

- ✓ **For patients undergoing surgical treatment, every effort should be made to accurately record the OPCS-4 code of the procedure undertaken.**

Radiotherapy

During 2014–16, 22 % of patients received radiotherapy. This ranged from 14 % to 31 % by network and can be viewed in Table 3. The use of radiotherapy has been reducing, in part because routine prophylactic intervention site irradiation is no longer recommended, although two clinical trials were still ongoing during the audit period.⁶⁻⁸

Similarly, with the decline in extrapleural pneumonectomy (EPP), hemithoracic irradiation is no longer delivered. However, the use of palliative radiotherapy for symptom control remains very important with an ongoing clinical trial investigating optimal dose and fractionation (<http://www.systems-2.co.uk>). The most commonly used radiotherapy fractionations were 21Gy/3# and 20Gy/5#.



Commentary

Consider palliative radiotherapy for localised pain in MPM where the pain distribution matches areas of underlying disease.

Other key measures



Patients discussed at MDT meetings

Of the patients diagnosed in 2014–16, 81 % were documented as having been discussed at MDT meetings. This has improved since the previous audit. There was variation in MDT discussion by network, ranging from 53 % to 100 % (details available online).



Patients seen by a cancer nurse specialist

In Wales, 93 % of patients were documented as having been assessed by a cancer nurse specialist (CNS). For England, where data completeness for this item was low (66 %), 54 % of patients were recorded as being assessed by a CNS, with variation from 28 % to 62 % by English network (details available online).



RECOMMENDATION

- ✓ **All mesothelioma cases should be discussed in a timely fashion by an MDT that reviews a sufficient number of cases to maintain expertise and competence in the diagnosis and treatment of MPM.**
- ✓ **At least 90 % of patients should be seen by a cancer nurse specialist (CNS) and signposted to MesoUK resources including the mesothelioma CNS helpline if there is not a locally available mesothelioma CNS; at least 80 % of patients should have a CNS present at the time of diagnosis.**

Nurse story: Simon Bolton, mesothelioma specialist nurse

The North and West Yorkshire region of the UK has a high incidence of mesothelioma and a Mesothelioma UK Cancer Nurse Specialist (CNS) in post is vital to support patients and carers affected by the disease.

My role commenced in September 2016 and has focused on establishing a regional patient/carers support group, which has continued to grow, bringing people affected by mesothelioma closer together. Many frustrations highlighted within the group revolved around a lack of geographical equity when attempting to access clinical trials. I was able to use this feedback as a driver to open two drug trials in the region with the support of my medical oncology colleagues.

Ensuring that every patient is discussed by a panel of experts is something I am passionate about. Specialist regional mesothelioma multidisciplinary teams (MDTs) are perhaps the only forums where this can be guaranteed and fortunately are being established in more regions across the UK. My next major challenge will involve working with the individual lung cancer MDTs to make this happen.



Survival

Survival of patients has been calculated from the date of diagnosis to the date of death. For this audit period 2014–16 the percentage of patients surviving to 1 year after diagnosis was 38 %, and patients surviving to 3 years after diagnosis was 7 %.

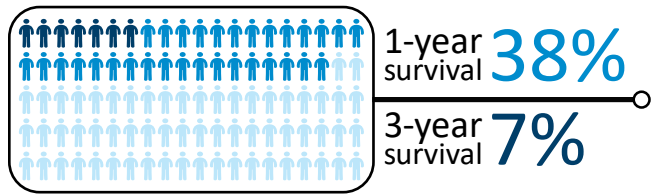


Figure 4 and Table 2 give further details of the 1-year, 3-year and median survival by pathological subtype.

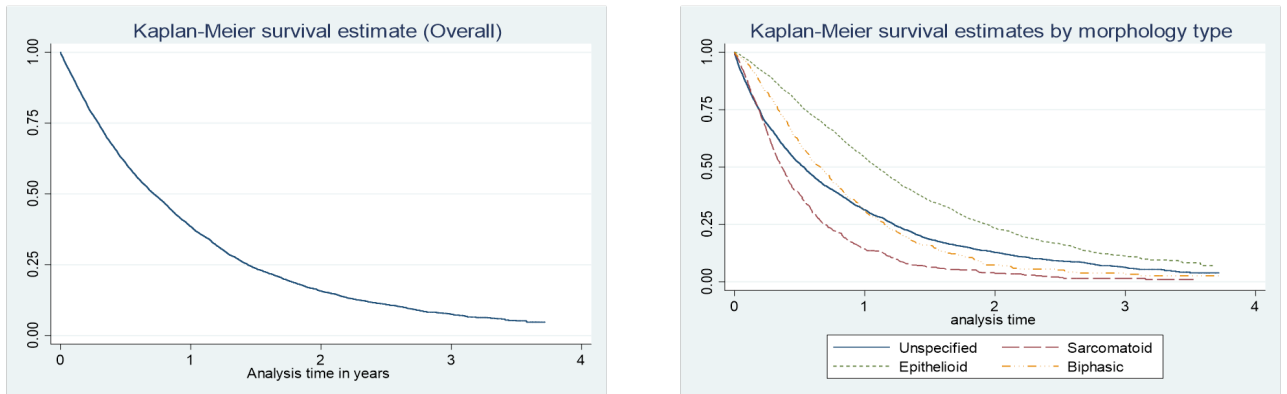


Figure 4: Kaplan-Meier survival curves for patients with pleural mesothelioma

Table 2: One-year and 3-year survival according to pathological subtype

Pathology	1-year survival	3-year survival	Median survival days (IQR)
M9050/3 Unspecified	29 %	2 %	195 (69 – 447)
M9051/3 Sarcomatoid	14 %	1 %	133 (69 – 249)
M9052/3 Epithelioid	51 %	3 %	400 (198 – 710)
M9053/3 Biphasic	28 %	1 %	243 (122 – 420)

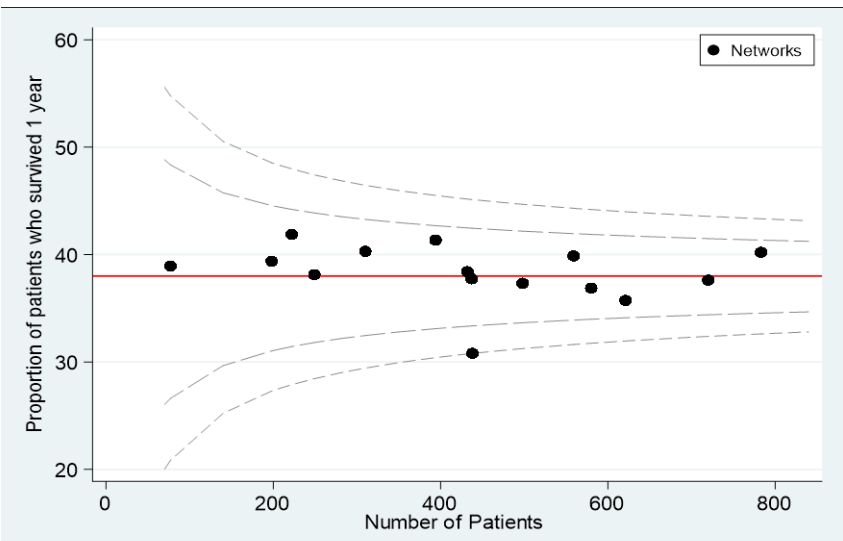


Figure 5: Funnel plot of 1-year survival in pleural mesothelioma for each cancer network (specific results can be found in Table 3).

Unadjusted 1-year survival for mesothelioma patients in each cancer network is shown in Figure 5.

The specific results for each network are given in Table 3, and further details are available online.

In the funnel plot, the dashed lines represent 2 and 3 standard deviations from the mean which give an indication of the statistical significance of the variation.

Table 3: Main performance measures by Cancer Network (pleural mesothelioma)

Cancer Network	No. of cases	Pathological subtyping ¹	Anti-cancer treatment ²	Chemo-therapy ³	Surgery ⁴	Radiotherapy ⁵	One-year survival ⁶
London Cancer Alliance (N44)	436	70.3	56.0	78.3	5.0	20.9	41.4
Cheshire and Merseyside (N50)	259	69.2	45.9	50.8	1.9	26.6	38.2
Greater Manchester, Lancs and S. Cumbria (N51)	616	37.1	55.2	70.7	1.3	20.6	36.9
Northern England (N52)	528	74.9	50.4	69.4	0.8	20.3	37.3
Yorkshire and the Humber (N53)	772	49.6	46.4	54.7	3.0	18.3	37.6
East of England (N54)	827	73.3	49.7	56.3	7.5	18.0	40.2
East Midlands (N55)	466	71.9	51.7	53.3	14.4	13.7	38.4
West Midlands (N56)	466	52.8	51.1	52.3	6.0	28.5	30.8
South West (N57)	586	73.8	48.0	51.1	1.4	26.1	39.8
South East Coast (N58)	661	61.6	54.3	62.7	5.4	22.7	35.7
Thames Valley (N59)	238	52.7	56.7	58.6	7.1	30.7	41.9
Wessex (N60)	462	73.5	50.2	48.6	1.7	28.8	37.8
London Cancer (N61)	325	66.8	58.2	59.3	3.1	24.6	40.3
North Wales (NWW)	78	60.0	42.3	54.1	3.8	16.7	39.0
South Wales (SWCN)	212	77.7	53.8	60.5	0.0	23.6	39.4

¹ Proportion of patients where mesothelioma histological subtype is recorded² Proportion of patients receiving one of surgery, radiotherapy or chemotherapy³ Proportion of patients with PS 0-1 who received chemotherapy as treatment for their mesothelioma⁴ Proportion of patients undergoing radical surgery as treatment for their mesothelioma⁵ Proportion of patients receiving radiotherapy as treatment for their mesothelioma

⁶ Proportion of patients with mesothelioma who survive at least 1 year following diagnosis

Is the standard of care improving?

The previous two national mesothelioma reports have used different methodologies and datasets to derive their results and so it is difficult to make direct comparisons. For example, the first report included England, Wales and Scotland, the second report was for England only, and this report covers England and Wales. Likewise, this report is based on cancer registration data, and includes some patients who would not have been included in previous datasets derived by different methods – we know from similar work on the lung cancer data that these extra patients are likely to be older, with poorer performance status and less likely to have active anti-cancer treatment.

Despite these caveats, the graphics in Figure 6 below give some sense of the variation in key performance indicators over time.



Figure 6: Change in key performance indicators across the three previous National Mesothelioma Audits

Patient story

My story begins in the summer of 2015, although I didn't quite realise it at that point! I had intermittent pains in my chest, but thought they were muscular, due to heaving my bike on and off the train as a commuter. The following year, I had a cough, nothing unusual in a household with young children, but, my cough didn't settle, and I became anxious. By the time I saw my GP, she asked if I had been short of breath, and worryingly, I realised that I had.

In January 2017, following a CT scan, I was told I had pleural cancer. This turned out to be mesothelioma. I found it very difficult to make treatment decisions, but with the guidance of my oncologist, I decided to go for chemotherapy. Luckily for me, I had an incredible response, with most of the tumour shrinking away, allowing me to have a wonderful summer with my family.

Things have changed for me since then; the disease progressed again fairly quickly. I am now on my third line of treatment but have my eye on the numerous clinical trials currently open in the UK.

In this era of social media, patients are increasingly well informed and connected. They understandably question the differences between treatment options in different centres. Audit of care can drive up standards, giving both treatment centres targets to aim for, and something for patients to benchmark their care against.

Dr Mags Portman, genitourinary medicine consultant and mesothelioma patient.



Peritoneal mesothelioma

Peritoneal mesothelioma is rare and may not always be associated with a definite history of asbestos exposure. In this audit cohort, it accounted for 4 % of mesothelioma cases diagnosed in England, with 260 cases of peritoneal mesothelioma identified during 2014–16, two-thirds in men and one-third in women with a mean age of 67 and median age of 71.

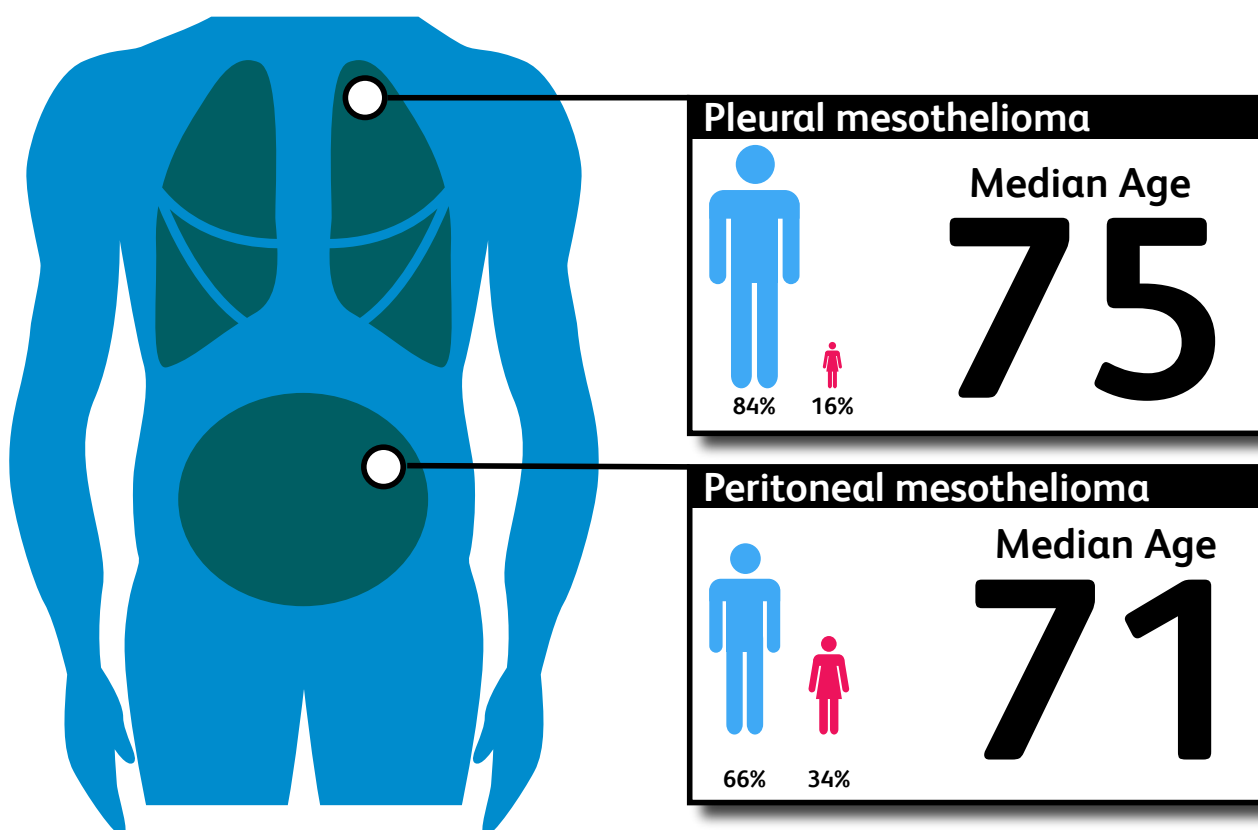
Clinical presentation is often with non-specific abdominal symptoms of bloating, distension, pain and ascites (an accumulation of fluid in the abdomen) and diagnosis with advanced disease is often made via a colorectal or gynaecologic MDT after a surgical procedure.

There are two main types:

- low-grade peritoneal mesothelioma which includes multicystic mesothelioma and well-differentiated papillary mesothelioma
- diffuse malignant peritoneal mesothelioma which includes epithelioid, biphasic and sarcomatoid subtypes.

Perhaps because these cases have not previously been reported or validated via the NLCA, COSD data is less complete than for pleural mesothelioma cases; 65 % of malignant peritoneal mesothelioma cases were discussed at an MDT, 43 % had a documented PS and 29 % were documented as assessed by a cancer nurse specialist.

There is no formal staging system for peritoneal mesothelioma. A high proportion (94 %) of malignant peritoneal mesothelioma cases had histological confirmation of their diagnosis although 56 % of these cases were not subtyped further.



Palliative chemotherapy was given to 41 % of all peritoneal mesothelioma cases, rising to 65 % for those with a documented PS 0–1. Pemetrexed with carboplatin/cisplatin was the most commonly used regimen with some patients also receiving carboplatin/cisplatin with paclitaxel. A small number (3 %) received radiotherapy.

‘A national peritoneal mesothelioma MDT has been running since March 2016, co-ordinated from the Peritoneal Malignancy Institute Basingstoke....’

Surgery in peritoneal mesothelioma

Mr Tom Cecil, consultant surgeon in Basingstoke Hospital, explains the role of surgery in peritoneal mesothelioma and the role of the national peritoneal mesothelioma MDT:

Surgery may benefit a subgroup of selected peritoneal mesothelioma patients with good performance status where complete tumour removal can be achieved by cytoreductive surgery, using peritonectomies and multi-visceral resection combined with hyperthermic intraperitoneal chemotherapy (HIPEC). A further small subgroup may benefit from tumour debulking (with

omentectomy) to help suppress recurrent ascites. In the majority of patients however, the presence and extent of mesothelioma at crucial anatomical sites, limits the ability to achieve complete cytoreduction and surgery with HIPEC is unlikely to be of benefit.

A national peritoneal mesothelioma MDT has been running since March 2016, coordinated from the Peritoneal Malignancy Institute Basingstoke, where both low and high grade peritoneal mesothelioma cases can be referred and reviewed ([bnh-ft. PeritonealNMDT@nhs.net](mailto:bnh-ft.PeritonealNMDT@nhs.net)). Recently a dedicated peritoneal mesothelioma CNS has been appointed by MesoUK to support peritoneal patients across the country.

36 cases (13.8 %) from this 3-year patient cohort were referred and discussed at the national peritoneal mesothelioma MDT with 7 patients (2.7 %) undergoing cytoreductive surgery and HIPEC at Basingstoke Hospital after national peritoneal MDT review. A further 11 patients underwent some form of debulking surgery (including omentectomy by OPCS code) at other surgical trusts.

One-year survival was 38 % and 3-year survival 15 % for the 3-year cohort of peritoneal mesothelioma.



RECOMMENDATION

- ✓ **All patients should be referred for discussion at a mesothelioma MDT and signposted to MesoUK resources; patients with good PS should be considered for treatment with palliative chemotherapy.**
- ✓ **For patients with good PS and epithelioid subtype refer to the national peritoneal mesothelioma MDT for consideration of cytoreductive surgery.**

Key recommendations for 2018 onwards

This report makes specific recommendations against which we will audit, analyse and report in the next full mesothelioma report of 2016–18 data due to be published in 2020. Our recommendations require change, as is true for all clinical quality improvement (QI). The NLCA can give support to organisations to develop, implement and evaluate QI strategies for MPM using this audit data.

01

Data – PS

Data completeness for the performance status field should exceed 90 %.

02

Data – staging

In accordance with TNM8, clinical teams are encouraged to record clinical TNM staging at multidisciplinary team meetings for MPM patients. Hospital trusts should aim for an overall recording of stage in at least 90 % of cases.

03

MDT

At least 95 % of patients submitted to the audit should be discussed at a mesothelioma multidisciplinary team (MDT) meeting.

04

Data lead

All MDTs should appoint a ‘clinical data lead’ with protected time to allow promotion of data quality, governance and quality improvement.

05

Pathology

Pathological confirmation should be over 95 %, and where the proportion of cases of unspecified MPM is above 10 %, review of diagnostic procedures and pathological processing is recommended.

06

Nursing

At least 90 % of patients should be seen by a CNS and signposted to MesoUK resources including the mesothelioma CNS helpline if there is not a locally available mesothelioma CNS; at least 80 % of patients should have a CNS present at the time of diagnosis.

07

Treatment

Patients with adequate performance status should be offered active anti-cancer treatment, including palliative chemotherapy. MDTs with chemotherapy rates (in good PS patients) below 60 % should perform detailed case note review to ascertain why. High-quality patient information should be available to guide treatment decisions.

08

Surgery

For patients undergoing surgical treatment, every effort should be made to accurately record the OPCS-4 code of the procedure undertaken.

09

Clinical trials

All patients should be offered access to relevant clinical trials even if this requires referral outside of their network.

10

Survival

Where survival is below national average, an in-depth local audit is recommended, including analysis of active anti-cancer treatment rates and length of the diagnostic pathway.

11

Peritoneal

All patients should be referred for discussion at a mesothelioma MDT and signposted to MesoUK resources; patients of good PS should be considered for treatment with palliative chemotherapy.

12

Peritoneal

For patients of good PS and epithelioid subtype refer to the national peritoneal mesothelioma MDT for consideration of cytoreductive surgery.

Glossary of terms and abbreviations

Active anti-cancer treatment: a term used to define treatments that have an effect on the tumour itself, not just on symptoms. In MPM patients, these are most often palliative chemotherapy, radiotherapy, surgery or a combination of these.

Asbestos: the commercial product, after mining and processing, obtained from a family of fibrous hydrated silicates divided mineralogically into amphiboles (amosite, anthophyllite, and crocidolite) and serpentines (chrysotile). Inhalation of asbestos particles can cause asbestosis, pleural plaques, pleural fibrosis, pleural effusion, mesothelioma, and lung cancer.

Biopsy: removal and examination of tissue, usually microscopic, to establish a precise (pathological) diagnosis.

Cancer nurse specialist (CNS): a nurse specialising in care of people diagnosed with cancer.

Chemotherapy/SACT (systemic anti-cancer therapy): medicines used in the treatment of cancer that can be given by mouth or by injection. First-line therapy is the first treatment given for a disease.

COSD: the Cancer Outcomes and Services Dataset (COSD) is the national standard for reporting on cancer in the NHS in England. Trusts submit a data file to the National Cancer Registration and Analysis Service (NCRAS) every month.

CT scan: the abbreviated term for computerised tomography. These tests produce detailed images of the body using X-ray images that are enhanced by a computer.

Cytoreduction: another term for debulking.

Data completeness: a measure of the standard of data submitted to the audit, in terms of both the number of cases submitted and the data on each individual case.

Debulking surgical procedures: surgical removal of as much of a tumour as possible. Tumour debulking in combination with other anti-cancer treatments may help eradicate tumour cells, relieve symptoms or help the patient live longer.

Decortication: removal of portions of the cortex of a structure or organ, such as of the pleura or lung.

Diagnosis: confirming the presence of the disease (see pathological diagnosis).

Histological subtype: groupings of mesothelioma tumours with characteristic microscopic appearance and biological behaviours.

Holistic Needs Assessment: a discussion with your doctor or nurse to talk about your physical, emotional and social needs.

Hospital trust: an organisation providing secondary healthcare services in England. A hospital trust may be made up of one or several hospitals within a region.

IASLC: International Association for the Study of Lung Cancer

IMIG: International Mesothelioma Interest Group

Interquartile range: the range of a particular variable excluding the highest quarter and lowest quarter of the values recorded. Can be useful to give a sense of the spread of a set of data without being affected by very high or very low results.

IPC: indwelling pleural catheter

Irradiation: The use of high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumours. Radiation may come from a machine outside the body (external beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy or brachytherapy). Systemic irradiation uses a radioactive substance, such as a radiolabelled monoclonal antibody that travels in the blood to tissues throughout the body. Also called radiation therapy and radiotherapy.

MDT: multidisciplinary team; a group of healthcare professionals working in a coordinated manner for patient care.

MPM: malignant pleural mesothelioma – cancer of the lining of the lung (pleura) caused by exposure to asbestos.

NCRAS: the National Cancer Registration and Analysis Service (NCRAS) is part of Public Health England and is responsible for all cancer registration in England. There are eight regional offices.

NICE guidelines: National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.

NLCA: National Lung Cancer Audit

NMA: National Mesothelioma Audit

Omentectomy: excision of the omentum (a fold of peritoneal tissue in the abdomen).

OPCS-4: an NHS Fundamental Information Standard that supports various forms of data collection, such as Central Returns and Commissioning Data Sets, as well as other secondary uses of information essential to planning and improving healthcare.

Pathological diagnosis: a diagnosis of cancer based on pathological examination of a tissue (histology) or fluid (cytology), as opposed to a diagnosis based on clinical assessment or non-pathological investigation (eg CT scan).

Performance status (PS): a systematic method of recording the ability of an individual to undertake the tasks of normal daily life compared with that of a healthy person.

Peritoneal mesothelioma: a type of mesothelioma that originates in the peritoneum (a serous membrane that lines the walls of the abdominal cavity and folds inward to enclose the viscera).

Pleural mesothelioma: a type of mesothelioma that originates in the pleura (a membrane that enfolds the lungs).

Pleurectomy: excision of part of the pleura.

Peritonectomy: excision of the peritoneal membrane in the abdomen.

Pleurodesis: the creation of a fibrous adhesion between the visceral and parietal layers of the pleura, thus obliterating the pleural cavity.

Radiotherapy: the treatment of cancer using radiation, most often external beam radiotherapy.

RCP: Royal College of Physicians

Registry dataset: processed data produced by the NCRAS. The NCRAS has access to cancer data from a variety of sources including pathology, radiology, Office for National Statistics (ONS), Hospital Episode Statistics (HES), Cancer Waiting Times (CWT) and Patient Administration Systems (PAS), as well as the information submitted via COSD.

Secondary care: care provided by a hospital, as opposed to that provided in the community by a GP and allied staff (primary care).

SCTS: Society for Cardiothoracic Surgery

Staging/stage: the anatomical extent of a cancer.

Strategic Clinical Network (SCN): a system within the NHS to organise the integrated care of patients across a geographical region.

Tertiary centres: hospitals that specialise in diagnosis and treatment of specific conditions, often handling very complex cases. Other hospitals may refer patients to these centres for specialist treatment.

Thoracoscopy: the insertion of an endoscope, a narrow-diameter tube with a viewing mirror or camera attachment, through a very small incision (cut) in the chest wall.

TIPC: tunnelled intrapleural catheter

TNM: tumour-nodes-metastasis staging system

VATS: video-assisted thoracic surgery

References

1. Rake C, Gilham C, Hatch J et al. Occupational, domestic and environmental mesothelioma risks in the British population: a case-control study. *Br J Cancer* 2009 Apr 7;100(7):1175–83 www.ncbi.nlm.nih.gov/pubmed/19259084 [Accessed 17 October 2016]
2. Woolhouse I et al. British Thoracic Society Guideline for the investigation and management of malignant pleural mesothelioma. *Thorax* 2018;73:i1–i30.
3. Rusch VW et al. The IASLC Mesothelioma Staging Project: Proposals for the M Descriptors and for Revision of the TNM Stage Groupings in the Forthcoming (Eighth) Edition of the TNM Classification for Mesothelioma. *J Thorac Oncol* 2016;11:2112–2119.
4. Treasure T et al. Extra-pleural pneumonectomy versus no extra-pleural pneumonectomy for patients with malignant pleural mesothelioma: clinical outcomes of the Mesothelioma and Radical Surgery (MARS) randomised feasibility study. *Lancet Oncol* 2011; doi:10.1016/S1470-2045(11)70149-8.
5. Rintoul RC et al. Efficacy and cost of video-assisted thoracoscopic partial pleurectomy versus talc pleurodesis in patients with malignant pleural mesothelioma (MesoVATS): an open-label, randomised, controlled trial. *Lancet* 2014; doi:10.1016/S0140-6736(14)60418-9
6. O'Rourke N et al. A randomised controlled trial of intervention site radiotherapy in malignant pleural mesothelioma. *Radiother Oncol* 2007;84:18–22.
7. Bayman N et al. Protocol for PIT: a phase III trial of prophylactic irradiation of tracts in patients with malignant pleural mesothelioma following invasive chest wall intervention. *BMJ Open* 2016;6:e010589.
8. Clive, AO et al. Prophylactic radiotherapy for the prevention of procedure-tract metastases after surgical and large-bore pleural procedures in malignant pleural mesothelioma (SMART): a multicentre, open-label, phase 3, randomised controlled trial. *Lancet Oncol* 2016;17:1094–1104.

National Mesothelioma Audit

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