Royal College of Physicians | National Lung Cancer Audit | MESOTHELIOMA UK CHARITABLE TRUST - 1126083

Supporting People With This Asbestos Cancer

National Lung Cancer Audit pleural mesothelioma report 2016

(for the audit period 2014)

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Mesothelioma UK is a national specialist resource centre, specifically for the asbestos-related cancer, mesothelioma. The charity is dedicated to providing specialist mesothelioma information, support and education, and to improving care and treatment 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.

Mesothelioma UK is based at the University Hospitals of Leicester NHS Trust Glenfield site.

The charity relies entirely on donations, legacies, fundraising and sponsorship to ensure all services provided free of charge across the UK. Visit **www.mesothelioma.uk.com**

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Author	Royal College of Physicians, Clinical Effectiveness and Evaluation Unit
Publication date	December 2016
Target audience	NHS staff in lung cancer multidisciplinary teams; hospital managers and chief executives; commissioners; lung cancer researchers; mesothelioma patients, their families and their carers
Description	This is the second publication on malignant pleural mesothelioma from the National Lung Cancer Audit. It publishes national- and network-level results on the quality of mesothelioma care for patients diagnosed in 2014. It covers many processes of care across the entire patient pathway.
Related publications	National Lung Cancer Audit report 2014 Mesothelioma (Report for the period 2008–2012) **www.rcplondon.ac.uk/projects/outputs/lung-cancer-audit-report-2014-mesothelioma** National Lung Cancer Audit annual report 2015 **www.rcplondon.ac.uk/projects/outputs/nlca-annual-report-2015**
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Contents

Foreword

We are delighted to publish the second national pleural mesothelioma audit report in collaboration with Mesothelioma UK.

Results are presented for over 2,000 patients using, for the first time, two sources of data – the LUCADA submissions via the National Lung Cancer Audit (NLCA), and the National Cancer Registration and Analysis Service (NCRAS) dataset. The results show reassuringly high levels of pathological confirmation of mesothelioma and encouraging trends towards higher treatment rates and survival. The proportion of patients with good performance status receiving chemotherapy has increased from 41% to 54%. The proportion of patients surviving to 1 year after diagnosis has improved from 40% to 43%.

While these results are promising, there remains significant variation in treatment and outcomes across cancer networks in England that is not wholly explained by differences in casemix. The patient stories included within this report highlight the importance of equitable access for all patients to hospitals providing the full range of mesothelioma diagnostic and treatment services, as well as the latest clinical trials. We encourage all clinical teams involved in caring for patients with mesothelioma to critically review these results and identify areas where further improvements could be made. Mesothelioma UK will continue to do all it can to promote efforts to ensure that every patient has access to the best standard of care available and these data will support such work.

The NLCA quality improvement leads are available to provide support and advice for clinical teams. We are also working towards producing a 3-year mesothelioma audit report in 2018.

Dr Ian Woolhouse
Senior clinical lead, National Lung Cancer Audit

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

Executive summary

The purpose of this document, the second mesothelioma report of the National Lung Cancer Audit (NLCA), is to summarise the key findings of the audit for patients in England who were diagnosed with malignant pleural mesothelioma (MPM) in 2014.

MPM is a type of cancer that develops over a long period of time, but once clinically apparent is often rapidly progressive. The cancer originates in mesothelial cells found in the thin membrane (pleura) that line the lungs and the inside of the chest wall. Approximately 90% of cases of MPM are linked to asbestos exposure. With the 20–50 year lag between exposure to asbestos and the development of MPM, estimates of the likely burden of disease suggest that numbers of cases in the UK are likely to peak between 2020 and 2025.[1,2]

In late 2014, the contract for the NLCA was awarded to the Royal College of Physicians by the Healthcare Quality Improvement Partnership for 3 to 5 years. The contract did not include an audit for mesothelioma, and this audit is now being independently funded by Mesothelioma UK.

Overview of the results

The audit collected data on 2,179 patients who were diagnosed with MPM in England in 2014, with a median of 13 cases per year for secondary care hospital trusts. This is the first national cancer audit to use Cancer Outcomes and Services Data (COSD) and cancer registry data directly to identify patients, which has enabled all cases of pleural MPM diagnosed in 2014 to be included in the audit.

The cancer registry data was supplemented with some data submitted using the bespoke lung cancer dataset known as LUCADA. In view of the fact that a minority of hospital trusts submitted data solely via COSD and are thus not directly comparable, this 1-year interim report summarises results at national and strategic clinical network (SCN) level only.

Recording of key audit data is good, but variation exists in the data completeness of stage, performance status, multidisciplinary team (MDT) discussion and access to lung cancer nurse specialists (LCNS) across networks.

Although the overall pathological confirmation (following analysis of a tissue or fluid sample) of MPM is excellent (100% of cases), nearly half of MPM patients still receive an unspecified MPM diagnosis with no pathological subtyping. It is important that hospital trusts seek to improve this, since pathological subtype influences prognosis, and may affect eligibility or stratification for entry into clinical trials and response to systemic treatment.

In general, anti-cancer treatment and use of palliative chemotherapy has increased since the previous audit with 36.5% of all patients receiving it compared with 34% in the first report. In particular, for patients with good general health (performance status 0–1), chemotherapy delivery has increased to 53.5% cases compared with 41% previously. However, there is marked network variation ranging from 42.2% to 77.4%, which should be addressed.

Use of radiotherapy for MPM appears to have reduced since the last audit and was received by 16.5% of patients compared with 29% in the 2014 report.

Although the use of radical surgical treatment is extremely low in England, debulking surgical procedures (surgical removal of as much of a tumour as possible) in general do appear to have increased since the previous audit from 2.3% to 5.2%.

Overall, survival rates for patients with MPM are also gradually improving over time but still remain poor with 43% surviving 1 year compared with 40% in 2008–2012. Variation by network ranged from 37.5% to 55.6% 1 year overall survival.

Although the low number of cases means that data must be interpreted with caution, there appears to be significant variation in the approach to diagnosis and treatment and survival between networks. This should form the basis for service improvement.

A full mesothelioma-specific audit report of cases from 2014, 2015 and 2016 is planned for publication in 2018. It is intended to include hospital-level data and a special focus on the rare peritoneal mesothelioma (cases that arise in the abdomen).

All the results in this report as well as further detailed analyses are available online at: **www.rcplondon.ac.uk/Meso2016**.

Key recommendations

This report makes specific recommendations against which we will audit, analyse and report in the next full mesothelioma report of 2014, 2015 and 2016 data due to be published in 2018. 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.

Data completeness

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

2. In anticipation of a validated International Mesothelioma Interest Group (IMIG) staging system planned for publication in 2017, clinical teams are encouraged to record the current non-validated IMIG tumour-nodes-metastasis (TNM) staging system at multidisciplinary team meetings for MPM patients. Once a validated staging system is available, hospital trusts should aim for an overall recording of stage in at least 90% of cases.

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

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

Process of care

5. Pathological confirmation in life should be over 95%, as there are no specific clinico-radiological features for diagnosing mesothelioma. In view of its prognostic value, every effort should be made to pathologically subtype the MPM, and where the proportion of cases of unspecified MPM is above 10%, review of diagnostic procedures and pathological processing is recommended.

6. At least 90% of patients should be seen by a lung cancer nurse specialist (LCNS); at least 80% of patients should have an LNCS present at the time of diagnosis.

Treatment and outcomes

7. Patients with adequate performance status should be offered active treatment, including palliative chemotherapy. MDTs with lower than expected chemotherapy rates (below 60%) or with low risk-adjusted odds ratio (statistical adjustment to reflect different patient characteristics) should perform detailed case note review to ascertain why. High-quality patient information should be available to guide treatment decisions.

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

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

10. Survival: Where risk-adjusted odds ratios are low, an in-depth local audit is recommended, including analysis of active treatment rates and length of the diagnostic pathway.

Purpose and background

Background to the audit

Malignant pleural mesothelioma (MPM) is a type of cancer that develops over a long period of time, but once clinically apparent is often rapidly progressive. The cancer originates in mesothelial cells found in the thin membrane (pleura) that lines the lungs and the inside of the chest wall. Mesothelioma can also affect the similar peritoneal membrane within the abdominal cavity. 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.[3] With the 20–50 year lag between exposure to asbestos and the development of MPM, 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. The first mesothelioma specific audit report covering cases diagnosed from 2008 to 2012 was published in 2014.[4]

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. Losing the national audit for mesothelioma following the success of the first report, particularly as the UK has the highest incidence of mesothelioma in the world, would have been a significant loss. Recognising this, funding from Mesothelioma UK has been forthcoming for 2014 data onwards, and the charity and audit team are now optimistic about the benefits of working collaboratively and hope that together they can increase the quality improvement initiatives that will directly improve mesothelioma services.

The purpose of this document, the second mesothelioma report of the NLCA, is to summarise the key findings of the audit for the 2,179 patients in England who were diagnosed with MPM in 2014, in order to assess current practice and to highlight regional variation, which if addressed may lead to better outcomes for patients. Data for MPM patients diagnosed during 2014 in Wales (115 cases), Scotland (175 cases) and Northern Ireland (33 cases) were not available for this audit.[5]

Table 1: Number of cases of pleural mesothelioma throughout the UK in 2014	
England	2,179
Scotland	175
Wales	115
Northern Ireland	33
Total	**2,502**

At present, there are no British guidelines for the management of MPM. The International Mesothelioma Interest Group (IMIG) has recommended the use of the 2010 guidelines of the European Respiratory Society and the European Society of Thoracic Surgeons for the management of MPM.[6] Last year, the European Society of Medical Oncology (ESMO) published updated European guidelines for mesothelioma.[7] The first British Thoracic Society (BTS) guidelines will be published in 2017. The recommendations within this audit report are chosen to reflect the most recent guidelines.

Methodology

Since 2014, the NLCA in England uses the Cancer Outcomes and Services Dataset (COSD)[8] as its primary data source. The COSD is a revised generic cancer registration dataset with additional clinical and pathology site-specific data items relevant to different tumour types. It specifies the items to be submitted electronically by service providers to the National Cancer Registration and Analysis Service (NCRAS) on a monthly basis. The COSD also identifies the items that the NCRAS will obtain from other sources, such as cancer waiting times and data from the Office for National Statistics. COSD replaces the previous NLCA bespoke dataset submitted through a web portal (known as LUCADA – LUng CAncer DAta). In contrast to LUCADA (where patients were assigned to a cohort based on the year in which they were first seen in secondary care), the COSD cohort assigns patients based on the year of diagnosis.

All registry identified cases of MPM diagnosed in England during 2014 are included in this report. The use of the registry dataset for 2014 means that every hospital trust in England has submitted patients and participated in this audit. For this transition year audit report, with the majority of hospital trusts still using LUCADA as their primary submission route to the NLCA, additional LUCADA-submitted data has been merged with the registry dataset to optimise data completeness. In view of the fact that a minority of hospital trusts submitted data solely via COSD and are thus not directly comparable, this 1-year interim report, summarises results at national and strategic clinical network (SCN) level only.

A full mesothelioma audit report of patients from 2014, 2015 and 2016 is planned for publication in 2018 and is intended to include hospital-level data and a special focus on patients with peritoneal mesothelioma.

Since a diagnosis of MPM may be inferred from several of the audit data fields, a hierarchy of diagnosis was used to ensure appropriate patient selection. Thus, we included patients with MPM confirmed on pathological samples taken at the time of surgery; or if no surgery was undertaken, we included patients with MPM confirmed on other pathological samples taken pre-treatment. Finally, if no pathological sample was taken, we included those patients where MPM was diagnosed on the basis of a clinico-radiological picture (ICD-10 code of C45/C45.0).

All the results in this report as well as further detailed analyses are available online at: **www.rcplondon.ac.uk/Meso2016**.

Results

The number of patients diagnosed with MPM in 2014 was 2,179 (Fig 1). This is an increase from the previous report where the annualised rate of MPM diagnoses was 1,748 patients. This may reflect the additional use of the cancer registration dataset to identify patients. The breakdown of patients by cancer network is shown in Fig 2.

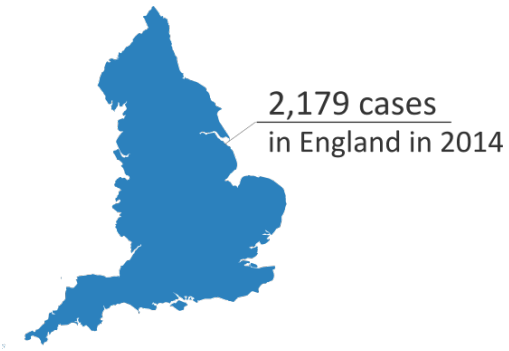
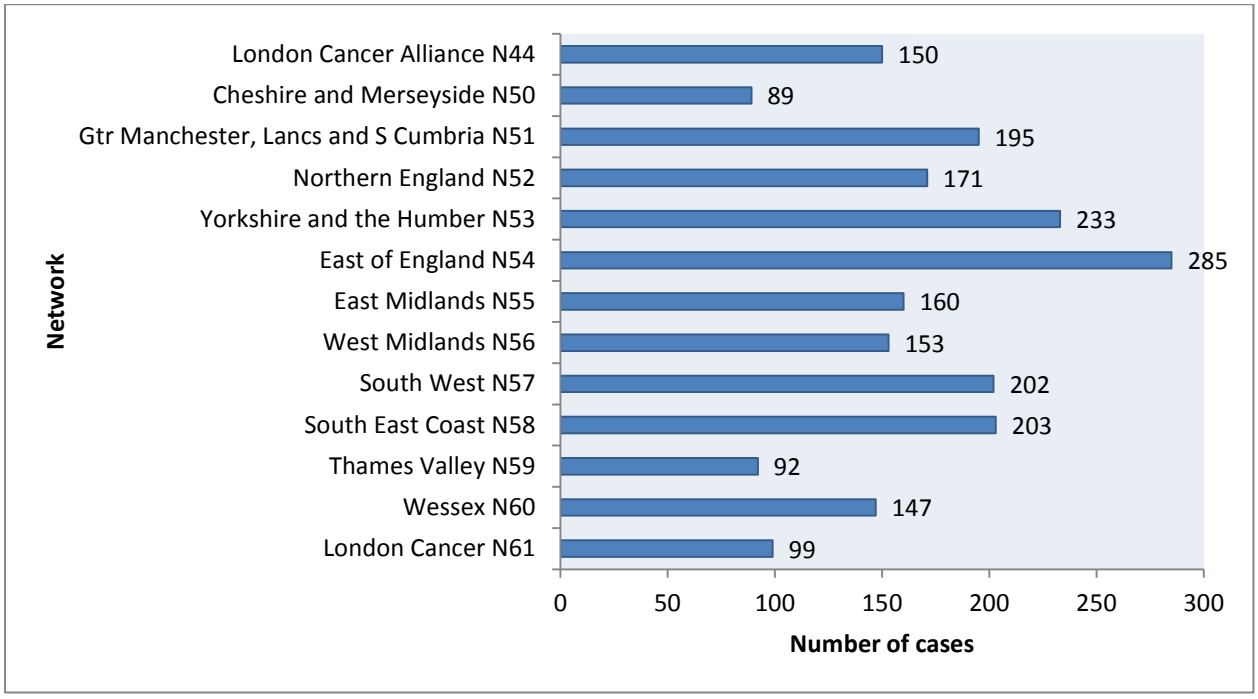


Fig 1: Total number of submitted MPM cases in 2014

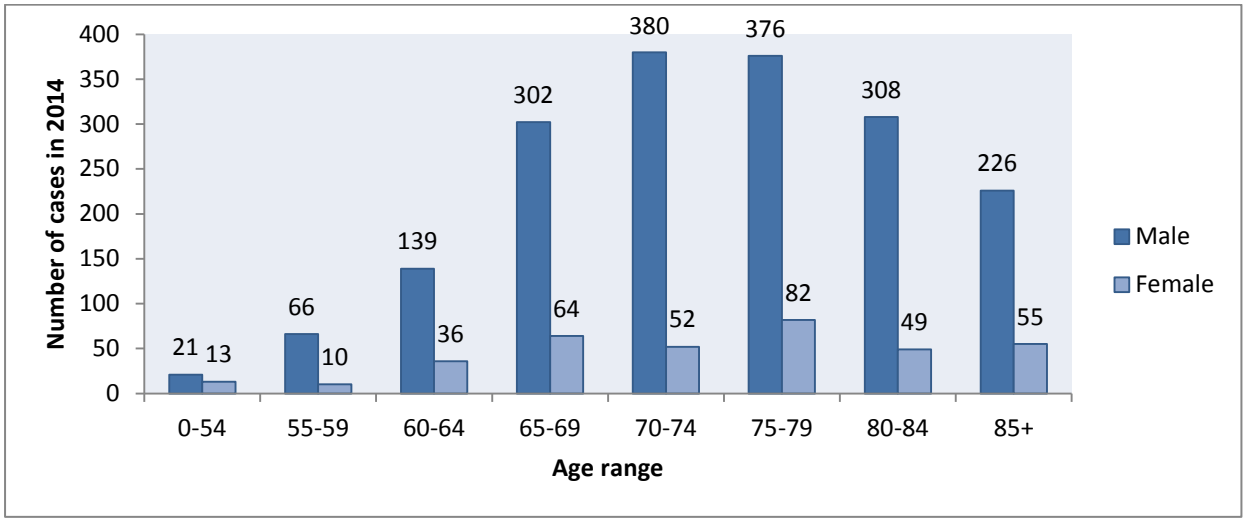
Fig 2: Number of submitted MPM cases per network in 2014



Age

Age at the time of diagnosis was recorded in 100% of patients in 2014. MPM is a disease affecting adults, with age at diagnosis ranging from 35 to 98 years in this dataset. The median age was 75 years. This has increased from the first report where the median age was 73, and the range 21 to 100 years.

Fig 3: Analysis of the age of MPM patients in 2014



Sex

Sex was recorded in 100% of patients diagnosed with MPM in 2014. MPM predominantly affects men – 83.4% of patients were male compared with 16.6% female. In 2014, there were 1,818 men diagnosed with MPM compared with 361 women.

These results are very similar to the data in the first MPM report covering 2008–2012, which also recorded sex in 100% of MPM patients with 83% men and 17% women. Between 2008 and 2012, a total of 7,266 patients with MPM were male and 1,474 were female.

Fig 4: Sex of MPM cases in 2014

Patient story: Mavis Nye, aged 74

I was exposed to asbestos through washing my husband's work clothes when I was just married in 1960…I was 68 years old when first diagnosed with mesothelioma. Finding centres of excellence, clinical trials and generally active clinicians has been a continuous self-investigated job!

Initially I couldn't breathe and luckily enough I had an X-ray as my arms were numb and hands were twisting. A bed was arranged by the GP who had me booked into A&E to have my lung drained of 7 litres of fluid, which when tested had MPM cells showing. So therefore I was diagnosed 4 June 2009, on our wedding anniversary. I was booked in for the talc op and then chemo.

After 15 months a scan showed growth so I was entered into a trial but I might have had the placebo as my meso kept growing. I had cisplatin and pemetrexed again, which held the disease back for a while and then I had Gem/Carbo but that failed after 2 months.

Faced with no more treatment I had to research trials and managed to find a phase I trial available in London. This has turned my life around; well, it has actually saved my life. I have had complete response and I'm in remission. I dread to think how it would have all turned out if I wasn't computer literate.

The 2014 audit report provided the first details about the standard of care across our country and the variation that we, the patients, know exists.

Thank you Mesothelioma UK for investing in this excellent initiative that is the first step along the road to making sure we know what is happening and where. Perhaps we can then start to encourage improvement in those areas most needing it.

Stage

Stage is a measure of the extent of disease and is important as it helps to determine prognosis, treatment options and entry into clinical trials. Historically, there has been no validated staging system for the clinical assessment of MPM stage (although lung cancer staging TNM was sometimes used), and it was only possible to define stage in patients undergoing surgery. The International Mesothelioma Interest Group (IMIG) TNM system is now recommended for both clinical and pathological staging, and organisations are encouraged to use this system for recording of stage wherever possible (Appendix 2). A validated clinical International Association for the Study of Lung Cancer (IASLC) / IMIG TNM staging for MPM is planned to be published in early 2017.

For patients diagnosed in 2014, stage was recorded in 42% of all cases. This has increased compared with earlier years (36% cases in the first report), but is still low, in part due to the fact that there isn't a validated clinical staging system for MPM (see Fig 5). The ESMO guidelines recommend that all cases of diagnosed MPM are staged using the current non-validated IMIG TNM staging.

In anticipation of the publication of a validated IASLC/IMIG TNM staging system in 2017, all hospital trusts are encouraged to include staging as a standard part of MDT discussion. Variation in recording of staging is seen at network level from 24.7% to 64.2% (see Table 2 and Fig 6).

Fig 5: Analysis of disease stage and performance status (PS) of MPM cases in 2014

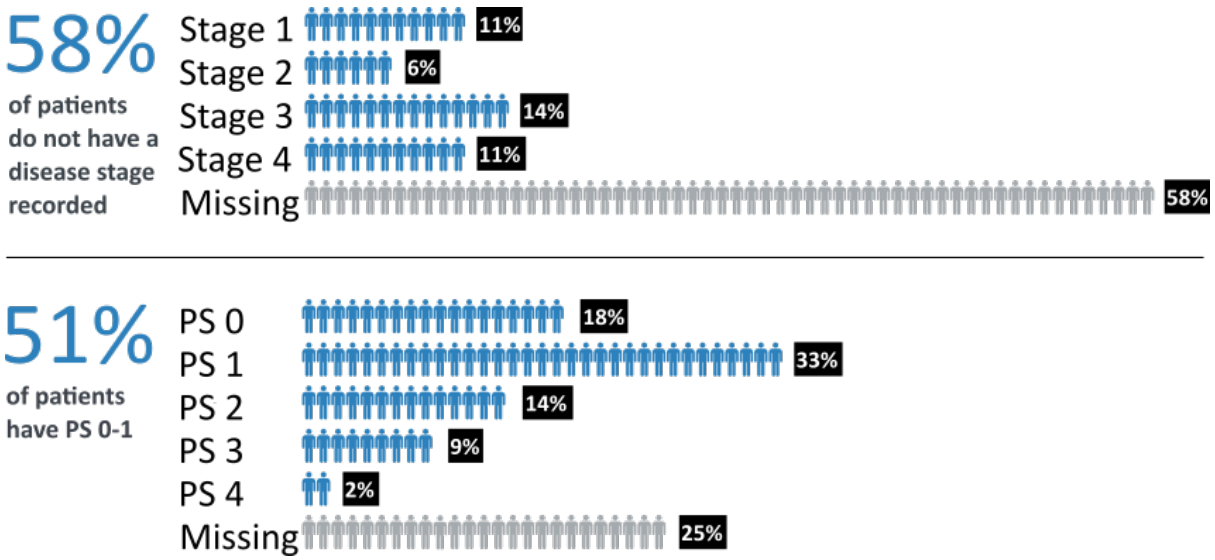


Table 2: Data completeness for key fields by network

Network first seen	Performance status (%)	Stage (%)
N44 London Cancer Alliance	45.3	24.7
N50 Cheshire and Merseyside	80.9	49.4
N51 Greater Manchester, Lancashire and South Cumbria	88.2	61.0
N52 Northern England	81.9	26.9
N53 Yorkshire and the Humber	83.7	34.8
N54 East of England	83.2	64.2
N55 East Midlands	52.5	36.3
N56 West Midlands	79.1	36.6
N57 South West	75.7	36.6
N58 South East Coast	78.8	48.8
N59 Thames Valley	77.2	32.6
N60 Wessex	78.2	37.4
N61 London Cancer	53.5	26.3

Fig 6: Data completeness for performance status and disease stage

Performance status

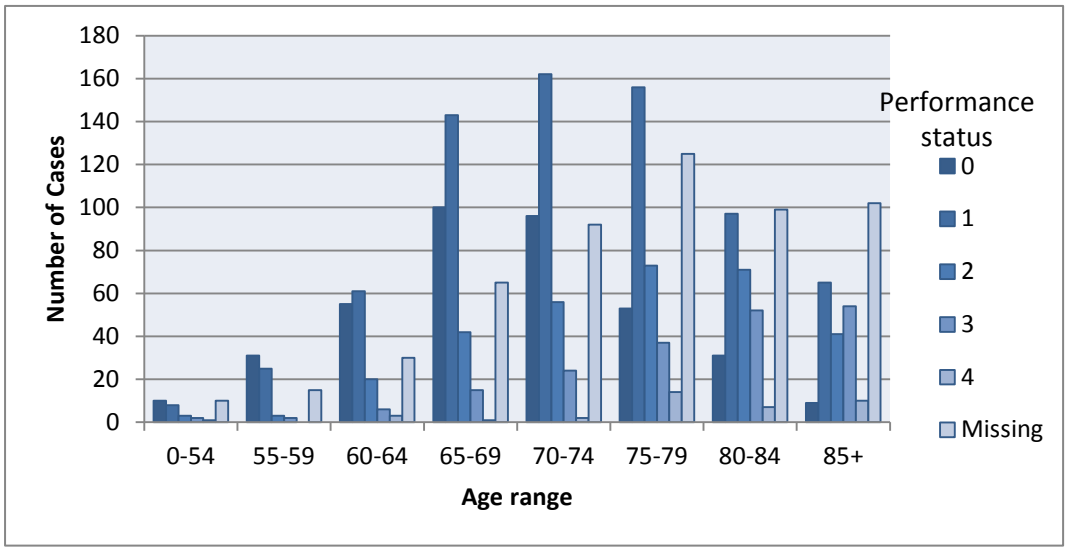
Performance status is a standardised method of assessing a patient's overall fitness. Performance status was recorded in 75% of patients diagnosed in 2014. Table 3 shows the numbers and percentage of performance status recorded. Performance status completeness has dropped for this audit compared with the first report (82%), in part due to the transition nature of data collection and submission for 2014 with variation in performance status completeness by network ranging from 45.3% to 88.2% (see Table 2). Analysis of performance status by age range is shown in Fig 7.

Table 3: Analysis of performance status for MPM cases in 2014

Performance status	Cases (n)	%
0	385	18%
1	717	33%
2	309	14%
3	192	9%
4	38	2%
Missing	538	25%
Total	**2,179**	**100.0**

Patients with performance status 0–1 will often be fit enough to be offered and receive anti-cancer treatment for their disease, whereas patients with performance status 3–4 will not. Patients with performance status 2 require individualised assessment for anti-cancer treatment. Many patients may require active treatment for symptoms such as pain, for example with radiotherapy. Table 3 indicates that 65% of patients had performance status 0–2 recorded at the time of diagnosis and so might be suitable for anti-cancer treatment, and 51% of patients had performance status 0–1.

Fig 7: Analysis of performance status by age range in 2014

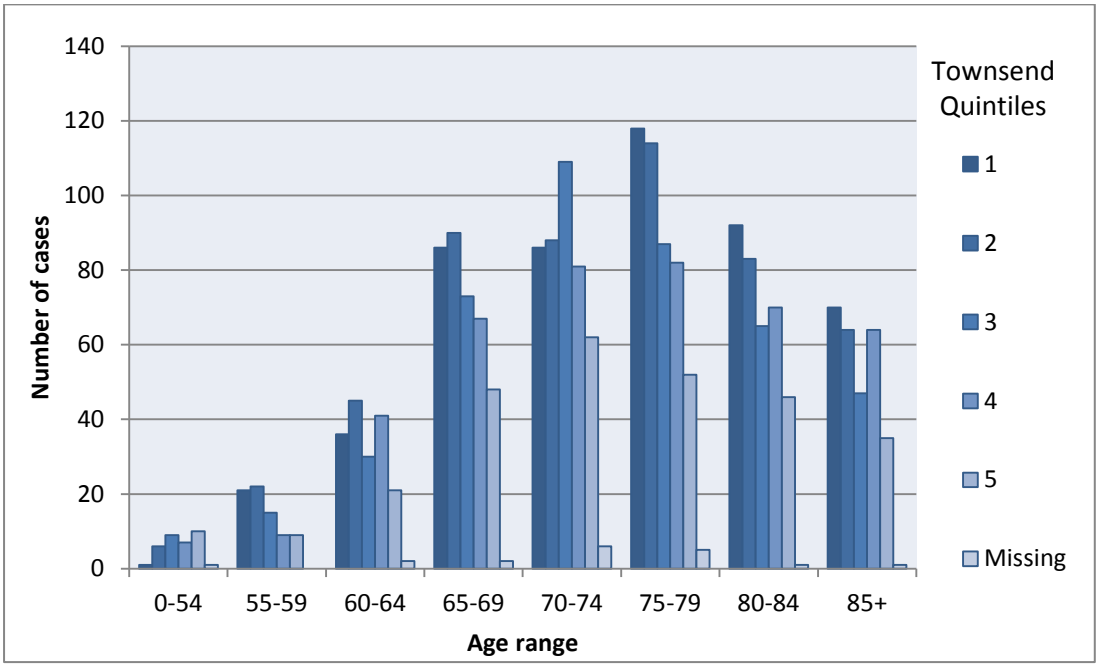


Socio-economic status

The Townsend Index is a measure of socio-economic deprivation and is derived from a patient's postcode. It can be a useful way to measure health inequalities. A greater Townsend Index score implies a greater degree of deprivation (a score of 1 is least deprived).

Analysis of the Townsend Index of patients with MPM shows that there is a trend for more cases to be found in less deprived communities and this is unchanged from the previous report. This is likely to be due to the fact that MPM is an occupational disease and being in paid work is one of the variables that gives people a better Townsend Index score.

Fig 8: Analysis of socio-economic status for MPM cases in 2014



Most cases of MPM are believed to be caused by occupational asbestos exposure and so the demographics are strongly influenced by this.

Patients discussed at MDT meetings

Of the patients diagnosed in 2014, 80% (1,736 cases) were discussed at MDT meetings. This is lower than the 94% discussion rate reported in the first audit and may be due to a drop in data quality seen with the implementation of the new data collection and data analysis methodologies in 2014.

There was variation by network, ranging from 37.5% to 91.5% (see Table 4) although some of this variation will again be due to differences in data completeness during the transition to the new data collection process at hospital trust level.

It is not currently possible to distinguish whether MDT discussion is at a lung MDT or a mesothelioma MDT, as recommended by current guidelines.

Table 4: Analysis of MPM cases discussed at MDT in 2014		
Network	**Number of cases**	**% discussed at MDT meeting**
N44 London Cancer Alliance	150	62.7
N50 Cheshire and Merseyside	89	82.0
N51 Greater Manchester, Lancashire and South Cumbria	195	88.7
N52 Northern England	171	83.6
N53 Yorkshire and the Humber	233	86.7
N54 East of England	285	87.4
N55 East Midlands	160	37.5
N56 West Midlands	153	91.5
N57 South West	202	78.7
N58 South East Coast	203	84.7
N59 Thames Valley	92	78.3
N60 Wessex	147	85.0
N61 London Cancer	99	74.7

Patients seen by a lung cancer nurse specialist

Overall, 66% of MPM cases were documented as being assessed by a lung cancer nurse specialist (LCNS). However, data completeness for this item was only 71%. It is recognised that this data item can be difficult to document as patients may not have been given their diagnosis or been seen by an LCNS prior to the MDT discussion where most data items are recorded. The data presented for 2014 patients show variation by network in the percentage of patients assessed by an LCNS in England (31.3% to 78.9%), although some of this variation will be due to the differences in transition from LUCADA to COSD data submission between hospital trusts. A key recommendation is that at least 90% of patients are seen by an LCNS, and hospitals with low data completeness for this item will need to work on a strategy to improve this for future years.

Table 5: Analysis of MPM cases seen by an LCNS in 2014			
Network	**Number of cases**	**% of patients assessed by LCNS**	**% of complete LCNS assessed**
N44 London Cancer Alliance	150	34.7	36.0
N50 Cheshire and Merseyside	89	68.5	74.2
N51 Greater Manchester, Lancashire and South Cumbria	195	67.2	68.7
N52 Northern England	171	78.9	82.5
N53 Yorkshire and the Humber	233	78.1	81.5
N54 East of England	285	72.6	80.4
N55 East Midlands	160	46.9	50.0
N56 West Midlands	153	71.9	76.5
N57 South West	202	66.8	71.3
N58 South East Coast	203	74.4	83.7
N59 Thames Valley	92	72.8	81.5
N60 Wessex	147	67.3	71.4
N61 London Cancer	99	31.3	32.3

It was extremely useful to receive the NLCA MPM Report 2014. Having this data of what we believe to be the largest case series of its kind in the world gave a baseline for key messages and recommendations. In my opinion, the data demonstrated a clear need for the setting up of a Regional MPM MDT meeting in order to drive forward improved diagnosis, treatment, care and clinical trials for patients with MPM.
Lorraine Creech, senior clinical nurse specialist for MPM, The Neil Cliffe Centre, University Hospital of South Manchester

Pathological confirmation

Pathological confirmation of diagnosis is strongly recommended, particularly as it is difficult to radiologically distinguish between carcinoma metastatic to pleura and MPM. Furthermore, subtyping of MPM has implications for prognosis and may impact on entry into clinical trials and response to active cancer treatments.

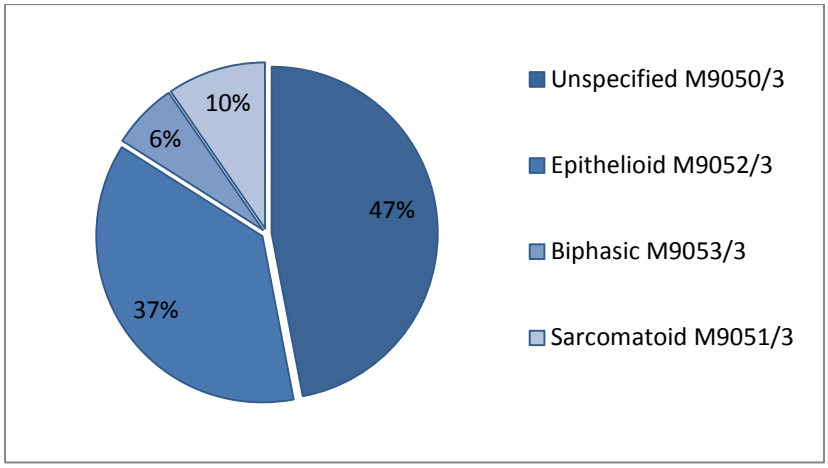
All cases of MPM in 2014 were recorded as confirmed pathologically. This may reflect the fact that registry data includes all post-mortem diagnoses. Pathological confirmation was recorded at 90% for the previous audit, which used LUCADA data alone.

Table 6 and Fig 9 show the proportion of pathological confirmed cases that are sub-classified. The percentage of unspecified MPM (M9050) is 46.9% with 36.9% epithelioid, 9.6% sarcomatoid and 6.4% biphasic. There is also variation by network in the proportion of cases with a non-specified MPM diagnosis ranging from 32.6% to 74.4% (see Table 7). Compared with the first audit, the proportion of MPM cases without subtyping has improved, reducing from 50.9% to 46.9%, but still remains very high.

Table 6: MPM pathology in 2014

Pathology	Number of cases	% of cases subtyped
M9050/3 Unspecified	1,024	46.9
M9051/3 Sarcomatoid	209	9.6
M9052/3 Epithelioid	806	36.9
M9053/3 Biphasic	140	6.4

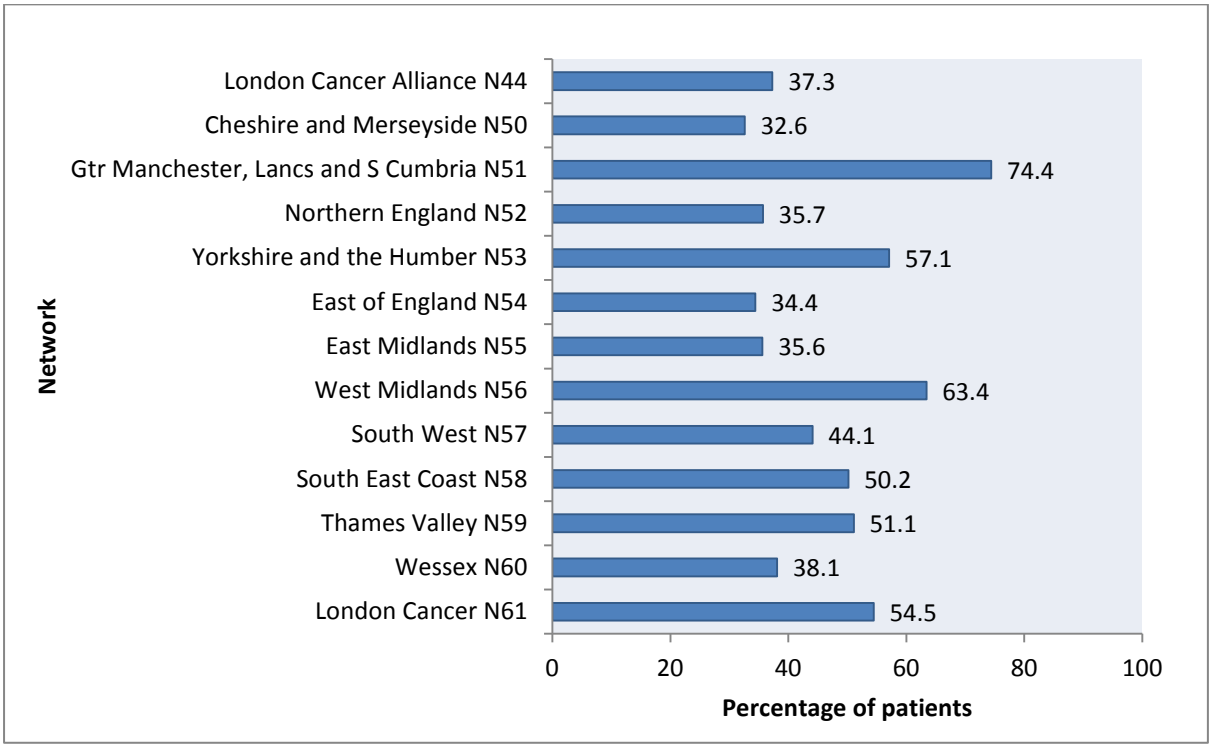
Fig 9: Proportion of pathological confirmed cases that are sub-classified



The European ESMO guidelines recommend that all cases of MPM diagnosed on tissue biopsy should be given a major subtype diagnosis. MPM subtyping influences prognosis and may also guide active treatment options and influence stratification into clinical trials. Therefore, a key recommendation from this report is that hospital trusts with a greater than 10% non-specified MPM rate should review their pathology processes.

Table 7: Analysis per network of patients with unspecified morphology M9050/3		
Network	**Number of cases**	**Patients with unspecified morphology M9050/3 (%)**
N44 London Cancer Alliance	150	37.3
N50 Cheshire and Merseyside	89	32.6
N51 Greater Manchester, Lancashire and South Cumbria	195	74.4
N52 Northern England	171	35.7
N53 Yorkshire and the Humber	233	57.1
N54 East of England	285	34.4
N55 East Midlands	160	35.6
N56 West Midlands	153	63.4
N57 South West	202	44.1
N58 South East Coast	203	50.2
N59 Thames Valley	92	51.1
N60 Wessex	147	38.1
N61 London Cancer	99	54.5

Fig 10: Patients with unspecified morphology M9050/3



Non-pleural mesothelioma

Pleural mesothelioma accounts for 97% of all mesothelioma cases. Although not discussed in this interim audit covering a single year, it should be noted that 70 cases of peritoneal mesothelioma were diagnosed in 2014, constituting 3% of the total number of mesothelioma cases (see Table 8). There will be a special focus on peritoneal mesothelioma with multi-year data available to increase numbers, in the full 2018 report.

Table 8: Non-pleural MPM in 2014		
Primary diagnosis	**Number of cases**	**Percentage**
C384 Malignant neoplasm of pleura	1	0
C450 Mesothelioma of pleura	2,179	96.7
C451 Mesothelioma of peritoneum	70	3.1
C457 Mesothelioma of other sites	3	0.1

Active treatment

Palliative chemotherapy, debulking surgery and palliative radiotherapy are commonly included as active treatments for MPM patients and are reported separately below. 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. In the first audit, simple surgical pleurodesis was counted as an active treatment, but medical pleurodesis was not. 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 MPM guidelines.

For this audit, only surgical procedures viewed as active debulking treatment and collected as such by the Society for Cardiothoracic Surgery (SCTS) have been counted as active surgical treatment (see Appendix 3). This means that figures are not directly comparable to the previous audit, but do more accurately reflect surgical practice in 2014. 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. Clinical trial data was also not available for this report.

Chemotherapy in mesothelioma

High-quality randomised controlled trial data supports the use of palliative chemotherapy in patients of good performance status, as it provides an approximately 2 to 3 month survival advantage and is approved by NICE.[9,10]

In 2014, 36.5% (795 cases) of MPM patients received chemotherapy. There was network variation for delivery of palliative chemotherapy ranging from 26.8% up to 55.4%. For patients of PS 0–1, overall 53.5% received chemotherapy, with network variation ranging from 42.2% up to 77.4%, shown in Fig 11 and Table 9.

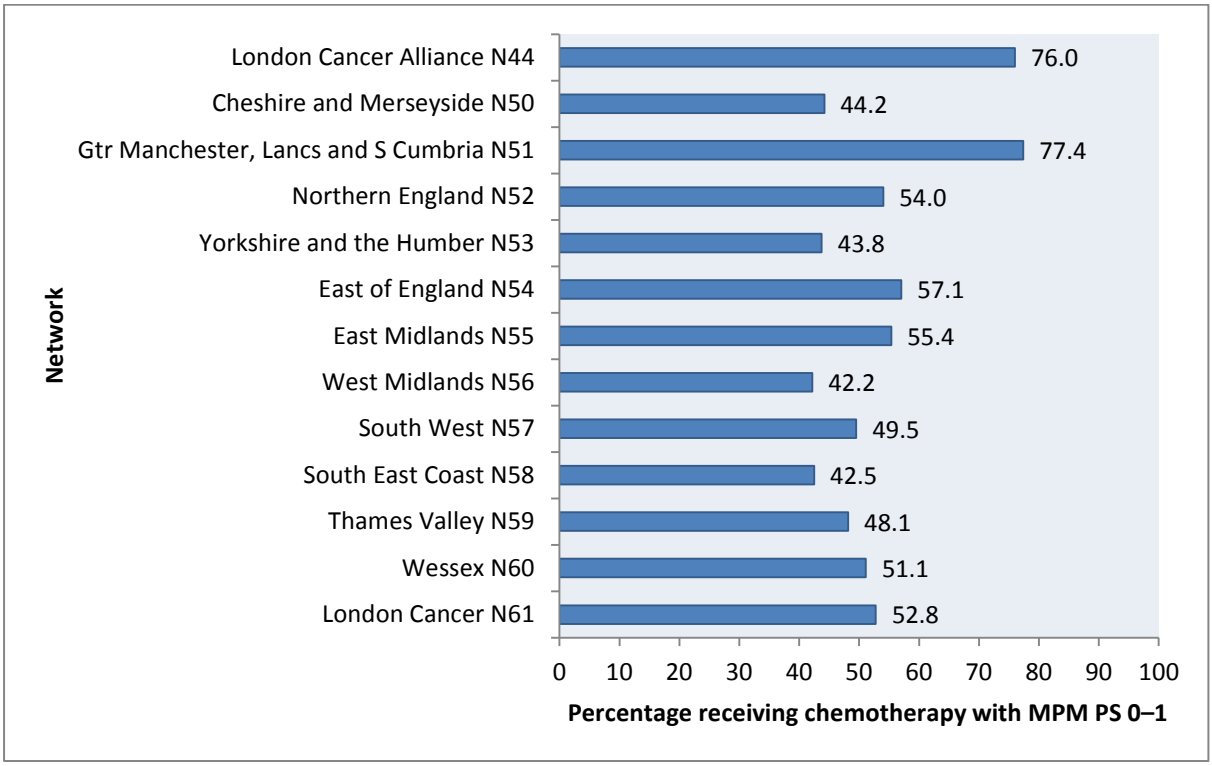
In general, the use of palliative chemotherapy has increased since the first audit (previously 30.3% of all patients or 41% of patients with PS 0–1). However, the extent of variation between networks offering palliative chemotherapy to PS 0–1 patients is unchanged (46% to 71% range in previous report).

After first-line chemotherapy, there is still no established second-line treatment for MPM. The role of immunotherapy and biological treatments are still a matter for debate. In the meantime, it is recommended that fit patients be offered referral to specialist centres if they wish, for consideration of systemic treatment within clinical trials, even if this involves travelling.

Table 9 shows the number of cases by network.

Table 9: Patients receiving chemotherapy for MPM by network in 2014				
Network	Number of cases	Percentage received chemotherapy	Unadjusted odds ratio	95% confidence interval
N44 London Cancer Alliance	150	40.7	1.77	(1.27–2.48)
N50 Cheshire and Merseyside	89	29.2	0.58	(0.36–0.96)
N51 Greater Manchester, Lancashire and South Cumbria	195	55.4	2.25	(1.65–3.06)
N52 Northern England	171	37.4	1.41	(1.00–1.99)
N53 Yorkshire and the Humber	233	28.8	0.62	(0.46–0.83)
N54 East of England	285	38.9	0.94	(0.74–1.19)
N55 East Midlands	160	33.1	0.93	(0.65–1.34)
N56 West Midlands	153	26.8	0.65	(0.43–0.98)
N57 South West	202	35.1	0.9	(0.66–1.23)
N58 South East Coast	203	36.5	0.96	(0.70–1.32)
N59 Thames Valley	92	34.8	0.71	(0.45–1.12)
N60 Wessex	147	37.4	0.97	(0.68–1.40)
N61 London Cancer	99	32.3	1.18	(0.76–1.83)

Fig 11: Patients receiving chemotherapy with MPM PS 0–1 by network in 2014



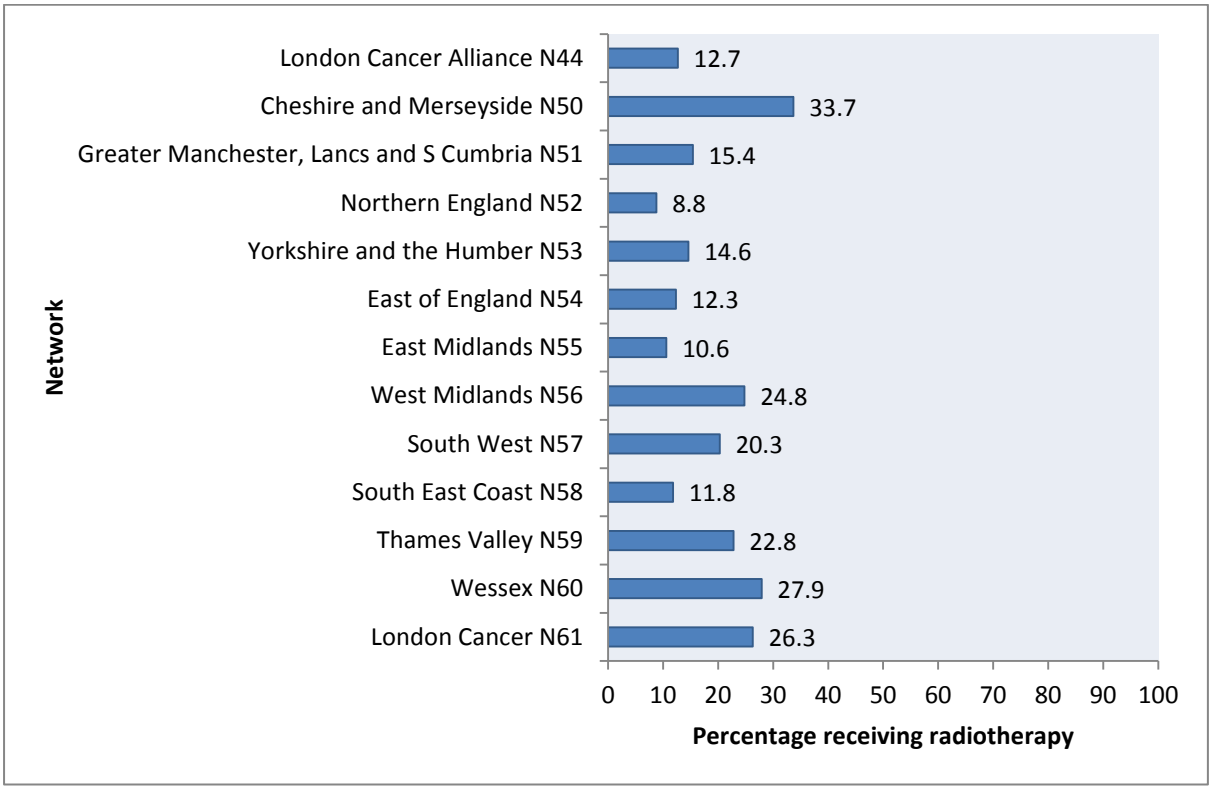
Radiotherapy in mesothelioma

In 2014, 17% of patients received radiotherapy. This ranged from 8.8% to 33.7% by network (Fig 12). In the first audit, 27% patients received radiotherapy. The use of radiotherapy has been reducing, perhaps in part due to the fact that routine prophylactic intervention site irradiation is on the decline after one randomised control trial showed no benefit.[11]

Two further randomised trials evaluating the role of prophylactic radiotherapy were still open in 2014.[12,13] Radiotherapy treatment variation is therefore difficult to interpret but is shown in Fig 12.

With the decline in extra-pleural pneumonectomy (EPP), the role of post-operative hemi-thoracic radiotherapy has also become obsolete. In contrast to these radiotherapy indications, the use of palliative radiotherapy for active symptom control may well be on the increase with a recent focus on the role of high-dose palliative radiotherapy in MPM.[14]

Fig 12: Percentage of patients who received radiotherapy by network in 2014



Surgery in mesothelioma

The lack of large randomised controlled trial evidence means that no surgical treatment option can be considered 'standard'. Within the UK, since the MARS trial[15] was reported, extrapleural pneumonectomy (EPP) is rarely offered. The Society for Cardiothoracic Surgery (SCTS) Thoracic Surgery Registry recorded eight extrapleural pneumonectomy operations in MPM in the 3 years April 2011–March 2012 to April 2013–March 2014 across the UK and Ireland.[16] The MesoVATS trial[17] found that partial pleurectomy did not improve overall survival compared with medical pleurodesis.

Currently, according to the SCTS database, open or VATS (video-assisted thoracic surgery) lung-sparing pleurectomy decortication (P/D) is the commonest surgical treatment offered for MPM, although the exact extent of this surgery and its benefits are still a matter of debate and are also being investigated within a clinical trial (MARS2). This audit uses surgical procedure OPCS-4 codes (see Appendix 3) that correlate with the SCTS data for reporting radical debulking surgical treatments, with other palliative or diagnostic OPCS-4 procedure codes grouped separately.

Of the patients diagnosed in 2014, 5.2% received debulking surgery while 73.3% cases received other palliative surgical procedures – primarily pleurodesis. Debulking pleurectomy (open or VATS) is the most common active surgical treatment for MPM within the UK, based on SCTS data.[18] There appears to be an increase in the use of surgical debulking in 2014, compared with the first audit report which showed that 2.3% patients received debulking pleurectomy. In view of the debate as to the clinical benefit of debulking surgery, variation across networks is difficult to interpret but can be viewed in Table 10.

Table 10: Patients receiving radical debulking surgery by network

Network first seen	Number of cases	Percentage had radical surgery	Odd ratios	95% confidence interval
N44 London Cancer Alliance	150	4.0	0.78	(0.34–1.82)
N50 Cheshire and Merseyside	89	3.4	0.43	(0.16–1.12)
N51 Greater Manchester, Lancashire and South Cumbria	195	2.1	0.47	(0.16–1.36)
N52 Northern England	171	0.0		
N53 Yorkshire and the Humber	233	3.0	0.63	(0.31–1.29)
N54 East of England	285	9.1	1.74	(1.20–2.51)
N55 East Midlands	160	18.8	3.87	(2.67–5.61)
N56 West Midlands	153	5.9	1.42	(0.71–2.81)
N57 South West	202	0.5	0.10	(0.014–0.71)
N58 South East Coast	203	5.4	0.96	(0.54–1.72)
N59 Thames Valley	92	12.0	2.38	(1.37–4.13)
N60 Wessex	147	2.7	0.49	(0.18–1.30)
N61 London Cancer	99	1.0	0.22	(0.03–1.66)

Patient story: Graham Sherlock-Brown, aged 69

I was diagnosed with mesothelioma in 2002 before Mesothelioma UK existed and underwent surgery (EPP) as the only realistic option available. Having survived 14 years, and with possibly a unique patient perspective, I have watched Meso UK grow from almost a sub-division of Macmillan to the flourishing, independent charity it is today. It is wonderful the charity is now looking to support a national audit programme specifically for mesothelioma, as clearly without their support it would not exist.

The recommendations from the 2014 Mesothelioma Audit report, if implemented, provide the right basis for measuring and managing progress and are extremely useful. From a patient perspective, I would like to see it expanded. Firstly, an indication of how corresponding improvements in outcomes can be measured and reported on. Secondly, include fields in the data collection to try and capture if mesothelioma treatment and care in the UK is responding to the rapidly emerging shift from standard chemotherapy to personalised treatment with immunotherapy.

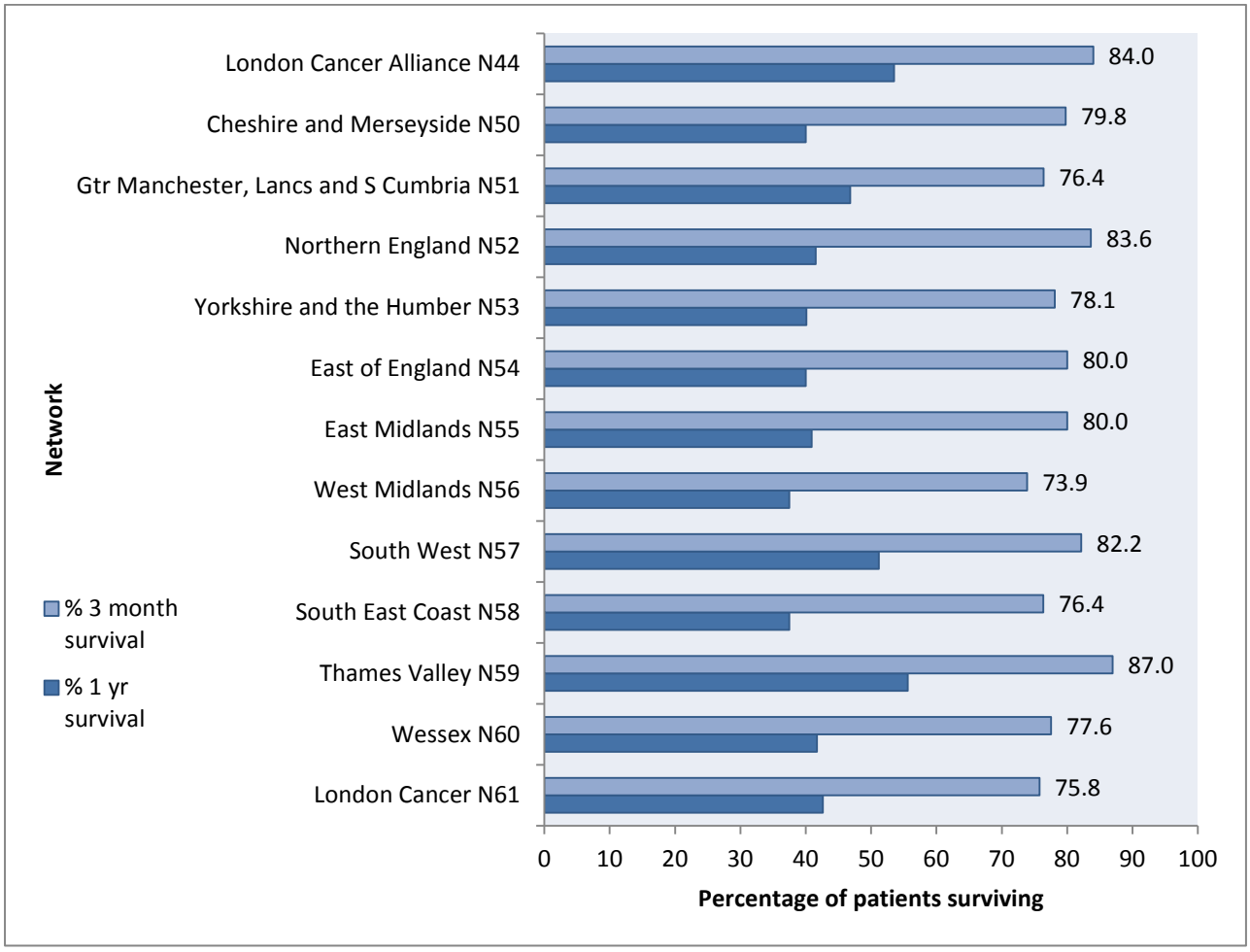
Supportive and end-of-life care

Although it is not easy to directly collect data on this from the cancer registry, it is recognised that optimising quality of life and support for MPM patients and their carers is of huge importance. Ongoing support from a key worker and regular holistic needs assessment should be maintained. Given the symptom burden associated with a mesothelioma diagnosis, timely referral to specialist palliative care or a pain management team should be available to all patients but access may vary across the country. In addition, despite limited access, referral to centres offering access to cordotomy for pain management should be considered. Patient-reported outcome measures and patient-reported experience measures (PROMs/PREMs) are also possible. Novel interrogations of registry data (GP prescription of analgesia, hospice referral etc) may help to enrich this picture in future reports.

Survival

Survival of patients has been calculated from the date of diagnosis to the date of death. This definition differs from the previous audit where survival was measured from the date first seen in a secondary care hospital trust. In 2014, the percentage of patients surviving to 3 months after diagnosis was 79.4%; and patients surviving to 1 year after diagnosis was 43.1%. The survival of patients can be seen to vary by network as shown in Fig 13 and Table 11.

Fig 13: Percentage of patients surviving to 3 months and 1 year after diagnosis by network in 2014



Numbers are too small for this interim 1-year audit to analyse survival by PS, stage, chemotherapy or pathological subtype.

Table 11: Percentage of patients surviving to 1 year after diagnosis by network in 2014				
Network	**Number of cases**	**% surviving to 1 year***	**OR****	**95% confidence interval**
N44 London Cancer Alliance	99	53.5	1.56	(1.05–2.31)
N50 Cheshire and Merseyside	55	40.0	0.82	(0.50–1.34)
N51 Greater Manchester, Lancashire and South Cumbria	124	46.8	1.31	(0.90–1.91)
N52 Northern England	118	41.5	1.07	(0.74–1.54)
N53 Yorkshire and the Humber	157	40.1	0.94	(0.68–1.30)
N54 East of England	190	40.0	0.92	(0.69–1.23)
N55 East Midlands	115	40.9	0.88	(0.61–1.27)
N56 West Midlands	104	37.5	0.84	(0.58–1.24)
N57 South West	127	51.2	1.46	(1.02–2.07)
N58 South East Coast	144	37.5	0.80	(0.58–1.11)
N59 Thames Valley	63	55.6	1.40	(0.86–2.27)
N60 Wessex	103	41.7	0.80	(0.54–1.20)
N61 London Cancer	68	42.6	1.08	(0.68–1.73)

**Odds ratio of surviving 1 year in specified network relative to the whole population, adjusted for composition of population in terms of age, sex, socio-economic status, performance status, stage. Variables are explained on 'casemix explanatory notes' in the MPM information sheet available at www.rcplondon.ac.uk/NLCA.

Appendices

Appendix 1: Trusts in England by network

*Participated via COSD, but did not submit LUCADA data file
** Tertiary centre NHS trust

Network	Trust name
N44	**London Cancer Alliance**
RAS	The Hillingdon Hospitals NHS FT
RAX	Kingston Hospital NHS Trust
R1K04*	Ealing Hospital NHS Trust (was RC3)
RFW	West Middlesex University Hospital NHS Trust
RJ1	Guy's and St Thomas' NHS FT
RJ2	Lewisham and Greenwich NHS Trust
RJ6*	Croydon Health Services NHS Trust
RJ7	St George's Healthcare NHS Trust
RJZ	King's College Hospital NHS FT
RPY**	The Royal Marsden NHS FT
RQM	Chelsea and Westminster Hospital NHS FT
RT3*	Royal Brompton and Harefield NHS FT
R1K99	North West London Hospitals NHS Trust (was RV8)
RVR*	Epsom and St Helier University Hospitals NHS Trust
RYJ	Imperial College Healthcare NHS Trust
N50	**Cheshire and Merseyside**
LLCU	Liverpool Lung Cancer Unit
RBL	Wirral University Teaching Hospital NHS FT
RBN	St Helens and Knowsley Hospitals NHS Trust*
REM	Aintree University Hospital NHS FT
REN	The Clatterbridge Cancer Centre NHS FT**
RJR	Countess of Chester Hospital NHS FT*
RVY	Southport and Ormskirk Hospital NHS Trust
RWW	Warrington and Halton Hospitals NHS FT
N51	**Greater Manchester, Lancashire and South Cumbria**
RBT	Mid Cheshire Hospitals NHS FT
RBV	The Christie NHS FT**
RJN	East Cheshire NHS Trust
RM2	University Hospital of South Manchester NHS FT**
RM3	Salford Royal NHS FT
RMC	Bolton NHS FT
RMP	Tameside Hospital NHS FT
RRF	Wrightington, Wigan and Leigh NHS FT
RTX	University Hospitals of Morecambe Bay NHS FT
RW3	Central Manchester University Hospitals NHS FT
RW6	Pennine Acute Hospitals NHS Trust
RWJ	Stockport NHS FT
RXL	Blackpool Teaching Hospitals NHS FT

RXN	Lancashire Teaching Hospitals NHS FT
RXR	East Lancashire Hospitals NHS Trust
N52	**Northern England**
RE9	South Tyneside NHS FT*
RLN	City Hospitals Sunderland NHS FT
RNL	North Cumbria University Hospitals NHS Trust
RR7	Gateshead Health NHS FT
RTD	The Newcastle Upon Tyne Hospitals NHS FT
RTF	Northumbria Healthcare NHS FT
RTR	South Tees Hospitals NHS FT*
RVW	North Tees and Hartlepool NHS FT
RXP	County Durham and Darlington NHS FT
N53	**Yorkshire and the Humber**
RAE	Bradford Teaching Hospitals NHS FT
RCB55	York Hospital (Historic RCB)
RCBCA	Scarborough General Hospital (Historic RCC)
RCD	Harrogate and District NHS FT
RCF	Airedale NHS FT
RFF	Barnsley Hospital NHS FT
RFR	The Rotherham NHS FT
RFS	Chesterfield Royal Hospital NHS FT
RHQ	Sheffield Teaching Hospitals NHS FT
RJL	Northern Lincolnshire and Goole Hospitals NHS FT
RP5	Doncaster and Bassetlaw Hospitals NHS FT
RR8	Leeds Teaching Hospitals NHS Trust
RWA	Hull and East Yorkshire Hospitals NHS Trust
RWY	Calderdale and Huddersfield NHS FT
RXF	Mid Yorkshire Hospitals NHS Trust
N54	**East of England**
RAJ	Southend University Hospital NHS FT
RC1	Bedford Hospital NHS Trust
RC9	Luton and Dunstable Hospital NHS FT
RCX	The Queen Elizabeth Hospital, King's Lynn, NHS FT
RDD	Basildon and Thurrock University Hospitals NHS FT
RDE	Colchester Hospital University NHS FT
RGM	Papworth Hospital NHS FT
RGN	Peterborough and Stamford Hospitals NHS FT
RGP	James Paget University Hospitals NHS FT
RGQ	Ipswich Hospital NHS Trust
RGR	West Suffolk NHS FT
RGT	Cambridge University Hospitals NHS FT
RM1	Norfolk and Norwich University Hospitals NHS FT
RQ8	Mid Essex Hospital Services NHS Trust
RQQ	Hinchingbrooke Health Care NHS Trust
RWG	West Hertfordshire Hospitals NHS Trust

RWH	East and North Hertfordshire NHS Trust
N55	**East Midlands**
RJF	Burton Hospitals NHS FT
RK5	Sherwood Forest Hospitals NHS FT
RNQ	Kettering General Hospital NHS FT
RNS	Northampton General Hospital NHS Trust
RTG	Derby Hospitals NHS FT
RWD	United Lincolnshire Hospitals NHS Trust*
RWE	University Hospitals of Leicester NHS Trust
RX1	Nottingham University Hospitals NHS Trust
N56	**West Midlands**
RBK	Walsall Healthcare NHS Trust
RJC	South Warwickshire NHS FT
RJE	University Hospital of North Midlands NHS Trust
RKB	University Hospitals Coventry and Warwickshire NHS Trust
RL4	The Royal Wolverhampton NHS Trust
RLQ	Wye Valley NHS Trust
RLT	George Eliot Hospital NHS Trust*
RNA	The Dudley Group NHS FT
RR1	Heart of England NHS FT
RRK	University Hospitals Birmingham NHS FT
RWP	Worcestershire Acute Hospitals NHS Trust (RWP31/50)*
RWP01	Worcestershire Acute Hospitals NHS Trust (RWP01)*
RXK	Sandwell and West Birmingham Hospitals NHS Trust
RXW	Shrewsbury and Telford Hospital NHS Trust*
N57	**South West**
RA3	Weston Area Health NHS Trust
RA4	Yeovil District Hospital NHS FT
RA7	University Hospitals Bristol NHS FT
RA9	South Devon Healthcare NHS FT
RBA	Taunton and Somerset NHS FT
RBZ	Northern Devon Healthcare NHS Trust
RD1	Royal United Hospital Bath NHS Trust
REF	Royal Cornwall Hospitals NHS Trust
RH8	Royal Devon and Exeter NHS FT
RK9	Plymouth Hospitals NHS Trust
RTE	Gloucestershire Hospitals NHS FT
RVJ	North Bristol NHS Trust
N58	**South East Coast**
RA2	Royal Surrey County Hospital NHS FT
RDU	Frimley Park Hospital NHS FT
RN7	Dartford and Gravesham NHS Trust
RPA	Medway NHS FT
RTK	Ashford and St Peter's Hospitals NHS FT
RTP*	Surrey and Sussex Healthcare NHS Trust

RVV	East Kent Hospitals University NHS FT
RWF	Maidstone and Tunbridge Wells NHS Trust
RXC	East Sussex Healthcare NHS Trust
RXH	Brighton and Sussex University Hospitals NHS Trust
RYR16	Western Sussex Hospitals NHS Trust (RYR16)
RYR18	Western Sussex Hospitals NHS Trust (RYR18)
N59	**Thames Valley**
RD7	Heatherwood and Wexham Park Hospitals NHS FT*
RD8	Milton Keynes Hospital NHS FT
RHW	Royal Berkshire NHS FT
RN3	Great Western Hospitals NHS FT
RTH	Oxford University Hospitals NHS Trust
RXQ	Buckinghamshire Healthcare NHS Trust
N60	**Wessex**
R1F	Isle of Wight NHS Trust
RBD	Dorset County Hospital NHS FT
RD3	Poole Hospital NHS FT
RDZ	The Royal Bournemouth and Christchurch Hospitals NHS FT
RHM	University Hospital Southampton NHS FT
RHU	Portsmouth Hospitals NHS Trust
RN506	Hampshire Hospitals NHS FT (RN5)
RN541	Hampshire Hospitals NHS FT (RN1)
RNZ	Salisbury NHS FT
N61	**London Cancer**
R1HKH	Barts Health NHS Trust (Whipps Cross)
R1HM0	Barts Health NHS Trust (St Barts)
R1HNH	Barts Health NHS Trust (Newham)
RAL	Royal Free London NHS FT
RAP*	North Middlesex University Hospital NHS Trust
RF4	Barking, Havering and Redbridge University NHS Trust
RKE*	The Whittington Hospital NHS Trust
RQW	The Princess Alexandra Hospital NHS Trust
RQX	Homerton University Hospital NHS FT
RRV*	University College London Hospitals NHS FT
RVL*	Barnet and Chase Farm Hospitals NHS Trust

FT = Foundation Trust

Appendix 2: International Mesothelioma Interest Group Staging System for diffuse malignant pleural mesothelioma

Primary tumour (T)	
TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
T1	Tumour limited to the ipsilateral parietal pleura with or without mediastinal pleura and with or without diaphragmatic pleural involvement
T1a	No involvement of the visceral pleura
T1b	Tumour also involving the visceral pleura
T2	Tumour involving each of the ipsilateral pleural surfaces (parietal, mediastinal, diaphragmatic, and visceral pleura) with at least one of the following: involvement of diaphragmatic muscle; extension of tumour from visceral pleura into the underlying pulmonary parenchyma.
T3	Locally advanced but potentially resectable tumour. Tumour involving all of the ipsilateral pleural surfaces (parietal, mediastinal, diaphragmatic, and visceral pleura) with at least one of the following: involvement of the endothoracic fascia; extension into the mediastinal fat; solitary, completely resectable focus of tumour extending into the soft tissues of the chest wall; nontransmural involvement of the pericardium.
T4	Locally advanced technically unresectable tumour. Tumour involving all of the ipsilateral pleural surfaces (parietal, mediastinal, diaphragmatic, and visceral pleura) with at least one of the following: diffuse extension or multifocal masses of tumour in the chest wall, with or without associated rib destruction; direct transdiaphragmatic extension of tumour to the peritoneum; direct extension of tumour to the contralateral pleura; direct extension of tumour to mediastinal organs; direct extension of tumour into the spine; tumour extending through to the internal surface of the pericardium with or without a pericardial effusion or tumour involving the myocardium.

Regional lymph nodes (N)	
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastases
N1	Metastases in the ipsilateral bronchopulmonary or hilar lymph nodes
N2	Metastases in the subcarinal or the ipsilateral mediastinal lymph nodes including the ipsilateral internal mammary and peridiaphragmatic nodes
N3	Metastases in the contralateral mediastinal, contralateral internal mammary, ipsilateral or contralateral supraclavicular lymph nodes

Distant metastasis (M)	
M0	No distant metastasis
M1	Distant metastases present

Anatomic stage/prognostic groups			
Stage	T	N	M
I	T1	N0	M0
IA	T1a	N0	M0
IB	T1b	N0	M0
II	T2	N0	M0
III	T1, T2	N1	M0
	T1, T2	N2	M0
	T3	N0, N1, N2	M0
IV	T4	Any N	M0
	Any T	N3	M0
	Any T	Any N	M1

Appendix 3: OPCS descriptors

OPCS-4, or more formally OPCS Classification of Interventions and Procedures version 4, is the procedural classification used by clinical coders within NHS hospitals of NHS England. We have used recording of a code within the 'Soft Tissue' chapter of OPCS, specifically from sections T01–T17 which cover operations/procedures on the chest wall, diaphragm and pleura.

T. SOFT TISSUE Chest wall pleura and diaphragm (T01–T03, T05, T07–T17)	
T01	Partial excision of chest wall
T02	Reconstruction of chest wall
T03	Opening of chest
T05	Other operations on chest wall
T07	Open excision of pleura
T08	Open drainage of pleural cavity
T09	Open other operations on pleura
T10	Therapeutic endoscopic operations on pleura
T11	Diagnostic endoscopic examination of pleura
T12	Puncture of pleura
T13	Introduction of substance into pleural cavity
T14	Other operations on pleura
T15	Repair of rupture of diaphragm
T16	Other repair of diaphragm
T17	Other operations on diaphragm

Using the full 4 digit OPCS code, we have defined radical surgery as any of the following:

- T07.1 Decortication of pleura
- T07.2 Open excision of lesion of pleura
- T07.8 Open excision of pleura – other specified
- T07.9 Open excision of pleura – unspecified

Appendix 4: Glossary of terms and abbreviations

Active treatment: a term used to define treatments for MPM 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, anthrophyllite, and crocidolite) and serpentines (chrysotile). It is virtually insoluble and is used to provide tensile strength and moldability, thermal insulation, and resistance to fire, heat, and corrosion. Inhalation of asbestos particles can cause asbestosis, pleural plaques, pleural fibrosis, pleural effusion, MPM, and lung cancer.

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

Casemix: refers to the different characteristics of patients seen in different hospitals (for example age, sex, disease stage, social deprivation and general health). Knowledge of differing casemix enables a more accurate method of comparing quality of care (casemix adjustment).

Casemix adjustment: a statistical method of comparing quality of care between organisations that takes into account important and measurable patient characteristics

Chemotherapy: 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

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.

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, as of the pleura or lung

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

EPP: extrapleural pneumonectomy – removal of the whole lung and its lining, together with the chest wall lining, diaphragm muscle and part of the pericardium (the fibrous sac around the heart)

ESMO: European Society for Medical Oncology

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 radiolabeled monoclonal antibody that travels in the blood to tissues throughout the body. Also called radiation therapy and radiotherapy.

LUCADA: the acronym given to the bespoke lung cancer dataset that was previously used by NHS trusts to upload their lung cancer and MPM patient data. It has been replaced with COSD.

Lung cancer nurse specialist (LCNS): a nurse specialising in care of people diagnosed with lung cancer or MPM

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

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: pertaining to the study of the microscopic anatomical and physiological characteristics of tissues and the cells found therein

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: the serous membrane that lines the walls of the abdominal cavity and folds inward to enclose the viscera

Pleural: refers to the pleura or membrane that enfolds the lungs

Pleurectomy: excision of part of the pleura

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

PREM: patient-reported experience measures

PROM: patient-reported outcome measures

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

RCP: Royal College of Physicians

Registry dataset: processed data that the NCRAS produce. 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.

Townsend Index: a measure of deprivation calculated using four variables derived from census data

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

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