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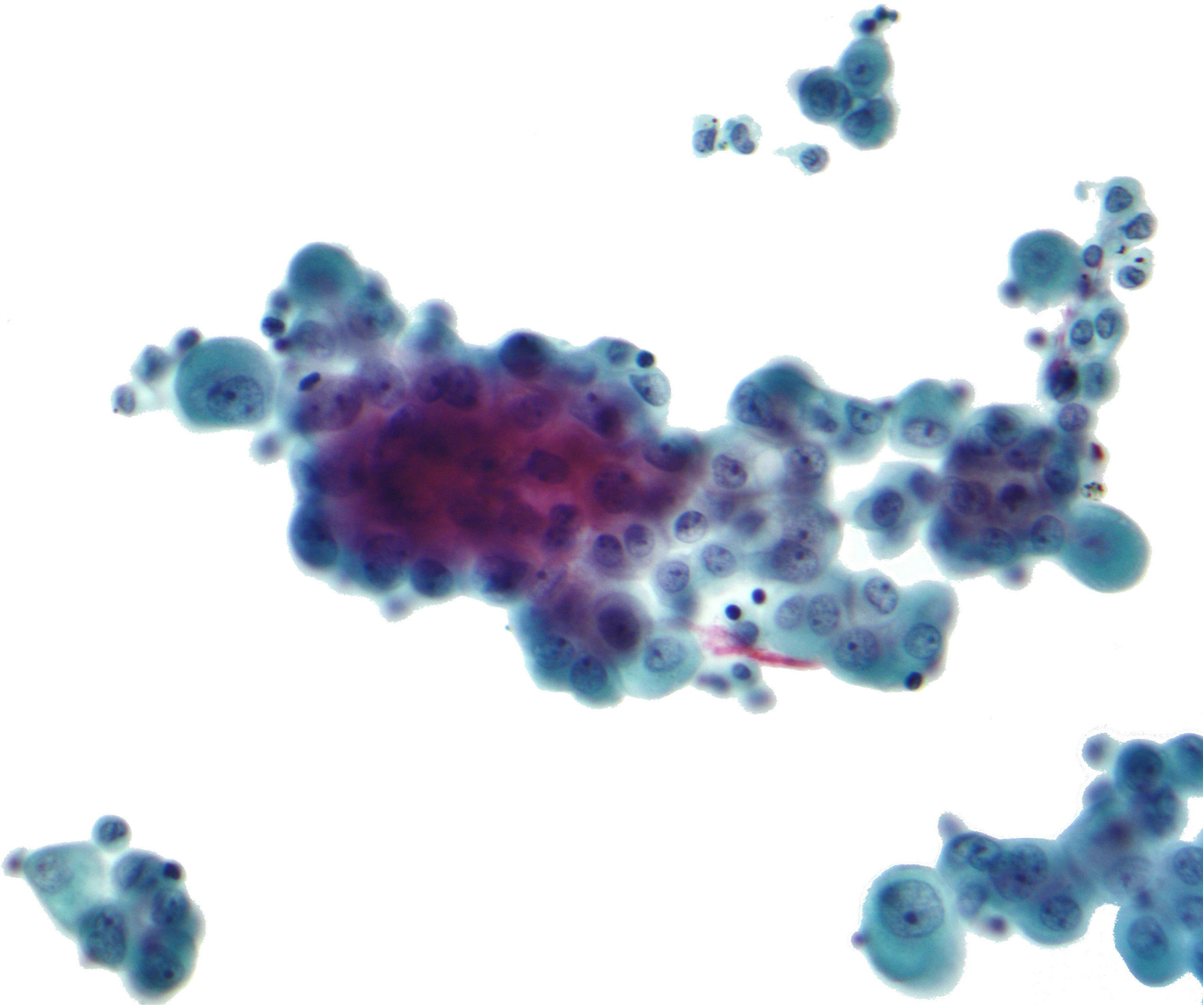

1st Annual Report
Mesothelioma in Australia 2011

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Abbreviations

ACD	Australian Cancer Database
ACM	Asbestos containing materials
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
AMR	Australian Mesothelioma Registry
ANZSCO	Australian and New Zealand Standard Classification of Occupations
CINSW	Cancer Institute NSW
HVRF	Hunter Valley Research Foundation
JSM	Job-specific module
MonCOEH	Monash Centre for Occupational and Environmental Health
NDI	National Death Index
NSW	New South Wales
NT	Northern Territory
OccIDEAS	Occupational Integrated Database Exposure Assessment System
Qld	Queensland
SA	South Australia
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Executive summary

The Australian Mesothelioma Registry (AMR) became operational in 2011 and contains information about all people diagnosed with mesothelioma in Australia from 1 July 2010. The AMR also has a voluntary component to collect details of asbestos exposure directly from people who have mesothelioma.

As at 31 August 2012, 612 diagnoses of mesothelioma had been reported to the AMR, representing a rate of 2.7 per 100,000 population. This is considered an underestimate of the total number of people diagnosed in 2011 at this stage, due to possible delays in confirming or coding of some diagnoses.

Men accounted for 84.5 per cent of notified cases and 78.8 per cent of people were aged 65 years or over at diagnosis. The most common subtype of mesothelioma was epithelioid subtype (44.1%) and the most common location was the pleura (92.3%).

At 31 August 2012, there had been 310 deaths of people diagnosed in 2011, or 50.7 per cent. Mesothelioma was the cause of death in 91.0 per cent of cases where cause of death was known.

Data on asbestos exposure has been collected from only a small proportion of people diagnosed with mesothelioma in 2011 and generalisations should not be made at this stage. Of the 100 people with mesothelioma who have completed the asbestos exposure questionnaire, 87 also completed the telephone interview. Of the 87 patients for whom asbestos exposure was assessed:

- six were assessed as having neither occupational nor non-occupational exposure
- 14 were assessed as having occupational exposure/s only
- 35 were assessed as having both occupational and non-occupational exposures
- 32 were assessed as having non-occupational exposure/s only.

The job type with the highest exposure likelihood was construction and building trades, followed by electrical and related trades. The most common circumstance of non-occupational exposure was home renovation-related activities followed by car maintenance. These assessments consider the probability of any exposure and do not take into account the intensity or frequency of exposure.

1. Introduction

Purpose

This is the first report of the Australian Mesothelioma Registry (AMR), a new national registry, which became operational in 2011. The AMR includes information about all people diagnosed with mesothelioma in Australia from 1 July 2010 onwards.

Background

Asbestos is a well-established occupational carcinogen. The term 'asbestos' refers to a group of naturally occurring fibrous silicate mineral composed of fibres that do not readily break down and are resistant to fire and chemical corrosion. The lengths of asbestos fibres are so small they are invisible to the naked eye and can be inhaled and breathed into the lungs.

Prior to the mid-1980s, Australia has historically been a producer of and one of the world's highest users per capita of asbestos (Leigh et al, 2002). Asbestos containing materials (ACMs) were used extensively in Australia due to their qualities of durability, fire and chemical resistance. Examples of ACMs include insulation and flooring materials, wall and roof sheeting, brake linings, paints, rope, gas mask filters, oven insulation, fire proofing, pipes and lagging (Foster, 1997). ACMs were used extensively in construction (including residential homes), industrial plant and equipment, ship building, train locomotives, and motor vehicles until the 1970s. General use of asbestos in gaskets and brakes was only discontinued on 31 December 2003, when the use and importation of all forms of asbestos was prohibited in Australia, although some exceptions were granted for specialised use in the Australian Armed Forces. The legacy is a large amount of asbestos in buildings and other infrastructure, and thousands of different products containing asbestos are still in use today. Many homes built in Australia before the late 1980s contain some ACM.

Australia has one of the highest incidence rates of malignant mesothelioma in the world. Mesothelioma is an aggressive form of cancer that arises in the mesothelium, membranous tissue that surrounds the organs and body cavities. The exact mechanism of mesothelioma development is only partly understood, however, it has been linked to occupational and increasingly non-occupational exposure to asbestos.

There is currently no cure for mesothelioma and the progression of the disease is rapid. Average life expectancy from diagnosis to death is nine months, and even with aggressive treatment, few people survive two years. Overall, the incidence of mesothelioma has been increasing in Australia since 1982, when data on new cases first became available nationally (Safe Work Australia 2011). Due to the long latency between exposure to asbestos and the onset of the disease (up to 50 years), the incidence of mesothelioma in Australia is likely yet to peak.

The AMR

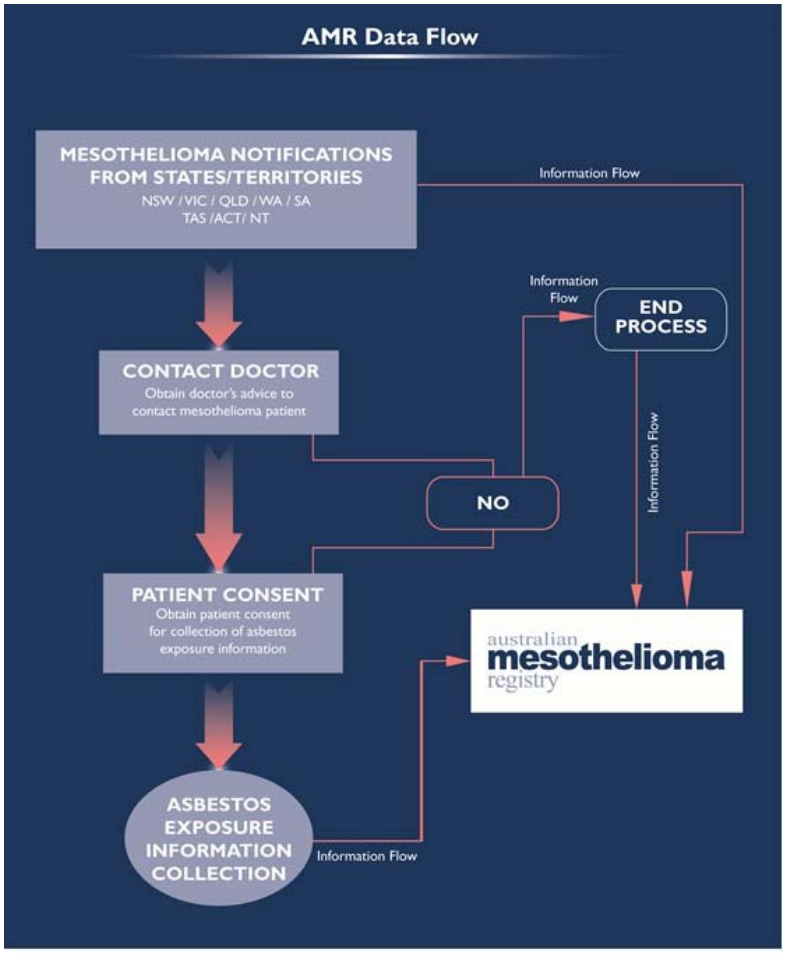
The AMR became operational in 2011 and includes all new cases of mesothelioma diagnosed from 1 July 2010 in Australia. The Registry replaces the previous Australian Mesothelioma Register managed by the National Occupational Health and Safety Commission. In 1998, the voluntary notification of new cases to the Register by state and territory registries declined when new state and territory privacy legislation were enacted. As a result, the incidence of mesothelioma was dramatically under reported and the reporting of asbestos exposure information dropped to less than 50 per cent of new cases reported. Due to incompleteness of data, published reports ceased in 2004 and the Register was suspended in December 2007.

The new AMR collects information about cases of mesothelioma to:

- better understand the exact relationship between asbestos exposure and mesothelioma
- better understand the nature and levels of asbestos exposure that can result in mesothelioma
- identify the groups of workers exposed to potentially dangerous levels of asbestos and to prevent that exposure
- assist the development of policies to best deal with the asbestos still present in our environment (mainly our built environment)
- provide information to assist researchers in undertaking investigations with the aim of preventing mesothelioma in the future
- possibly identify other potential exposures that may cause mesothelioma.

The AMR includes collection of asbestos exposure information via a postal questionnaire and telephone interview. This information has been collected from eligible consenting patients diagnosed from 1 January 2011. The flow chart in Figure 1.1 shows the process of mesothelioma notifications and asbestos exposure data to the AMR.

Figure 1.1: AMR data flow



Notifications

Notifications refer to the cases of mesothelioma provided by the state and territory cancer registries. Each cancer registry is notified of all cases of cancer diagnosed in residents living in their jurisdiction. For the AMR, mesothelioma cases are being 'fast-tracked' by each state and territory; that is, these records are given priority and are processed and coded as quickly as possible. The state and territory cancer registries submit notifications to the AMR on a regular basis. Notified records include demographic information, and details of the diagnosis and death.

Asbestos exposure information

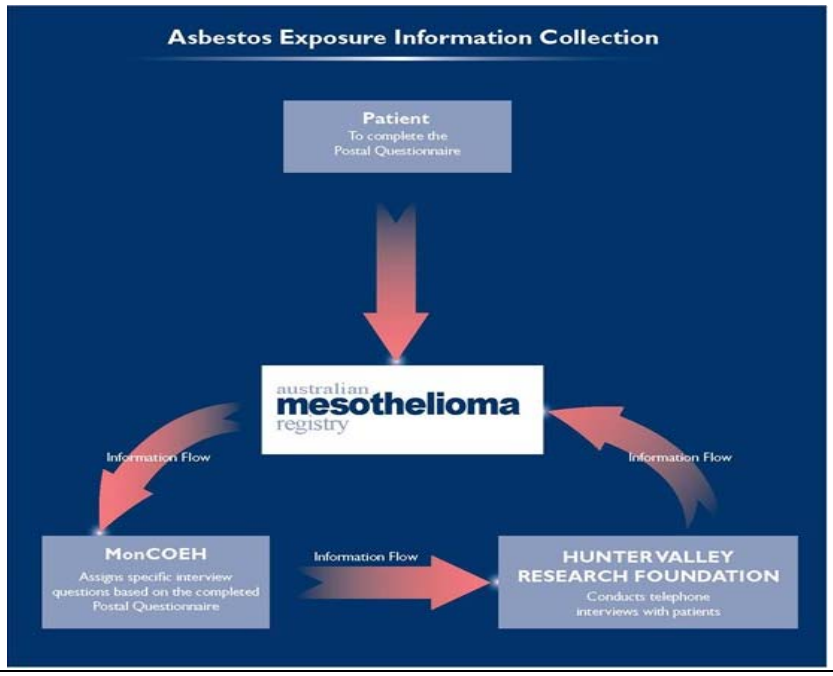
Once a notification of mesothelioma is made, the state or territory cancer registry contacts the patient's clinician to confirm whether their patient meets various eligibility criteria, including confirmation of mesothelioma diagnosis on or after 1 July 2010, and that the patient is well enough to be contacted about their exposure to asbestos. The state and territory cancer registries then contact the patient.

Patients can also self-notify directly to the AMR. In this case, the AMR send an information pack directly to the patient and the clinician is not contacted.

Asbestos exposure information is then obtained from consenting mesothelioma patients through a postal questionnaire and telephone interview (Figure 1.2).

1. Postal questionnaire – requests that patients list their residential, school and occupational histories. Patients are also asked about their family history of mesothelioma. Patients' asbestos information is systematically compiled through an online assessment tool called OccIDEAs. The Monash Centre for Occupational and Environmental Health (MonCOEH) use information from the postal questionnaire to assign relevant interview questions for each person.
2. Telephone interview – Based on patients' responses to the postal questionnaire, specific questions are asked to assess their potential asbestos exposure in a telephone interview. This means the telephone interview is tailored to the participant. The Hunter Valley Research Foundation (HVRF) conducts the telephone interviews.

Figure 1.2: AMR asbestos exposure information collection



The information collected is used by MonCOEH staff to assess and assign values to each patients' life-time asbestos exposure. Further information about the exposure assessments can be found in Appendix A.

This report

This report is the first presenting data collected from the new Australian Mesothelioma Registry (AMR). It includes data from both mesothelioma notifications, and from the asbestos exposure information collection. In this report, data for patients diagnosed during the calendar year 1 January–31 December 2011 are presented. Incidence and mortality figures are as recorded on the AMR at 31 August 2012 and exposure data are as at 30 June 2012.

It is important to note that due to the Registry being new and also due to the rapid notification process, the incidence figures presented in this report may be an underestimate of mesothelioma

cases for 2011. It is likely that further cases for 2011 will be notified to the AMR in the future. Possible reasons for a longer timeframe between diagnosis and notification include delays in confirmation of diagnosis, notification from pathology laboratories, or coding of difficult cases.

The report includes the following remaining sections:

2. Incidence
3. Mortality
4. Asbestos exposure

Methods are detailed in Appendix A. Appendix B contains the tables underlying figures.

2. Incidence

Number of cases

The number of mesothelioma cases notified to the AMR for 2011 was 612 nationally at 31 August 2012. For the first six months of AMR data collection, 1 July–31 December 2010, the total cases were 330. Table 2.1 shows the notification numbers for men and women for each period.

There were an additional 14 cases for 2011 from NSW without pathological confirmation, which were yet to be confirmed. These cases have not been included in the tables in this report.

Table 2.1: New cases of mesothelioma by sex and six-month period, 1 July 2010–31 December 2011

	1 Jul–31 Dec 2010	1 Jan–30 June 2011	1 Jul–31 Dec 2011	*1 Jan–31 Dec 2011*	Total
Men	266	255	262	*517*	783
Women	64	55	40	*95*	159
Persons	**330**	**310**	**302**	***612***	**942**

Table 2.2 shows the 2011 notification numbers for men and women by state and territory. Age-standardised rates of mesothelioma in the population were calculated for each jurisdiction for the year 2011. The incidence rate was 2.7 per 100,000 population overall and ranged from 2.3 in both New South Wales and Victoria to 4.8 in Western Australia. The rate for men was higher than for women in all jurisdictions and overall (5.0 per 100,000 compared with 0.8 per 100,000).

Table 2.2: New cases of mesothelioma and age-standardised rates by sex and state/territory, 2011

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Men	149	101	106	91	44	n.p.	9	<5	517
Women	22	29	20	12	10	<5	0	<5	95
Persons	**171**	**130**	**126**	**103**	**54**	**14**	**9**	**5**	**612**
				Rate per 100,000 population[(a)]					
Men	4.3	4.0	5.3	10.5	4.5	n.p.	n.p.	n.p.	5.0
Women	0.5	0.9	0.9	1.2	0.9	n.p.	n.p.	n.p.	0.8
Persons	**2.3**	**2.3**	**2.9**	**4.8**	**2.8**	**2.4**	**n.p.**	**n.p.**	**2.7**

(a) Directly age-standardised using the Australian estimated resident population at 30 June 2011.

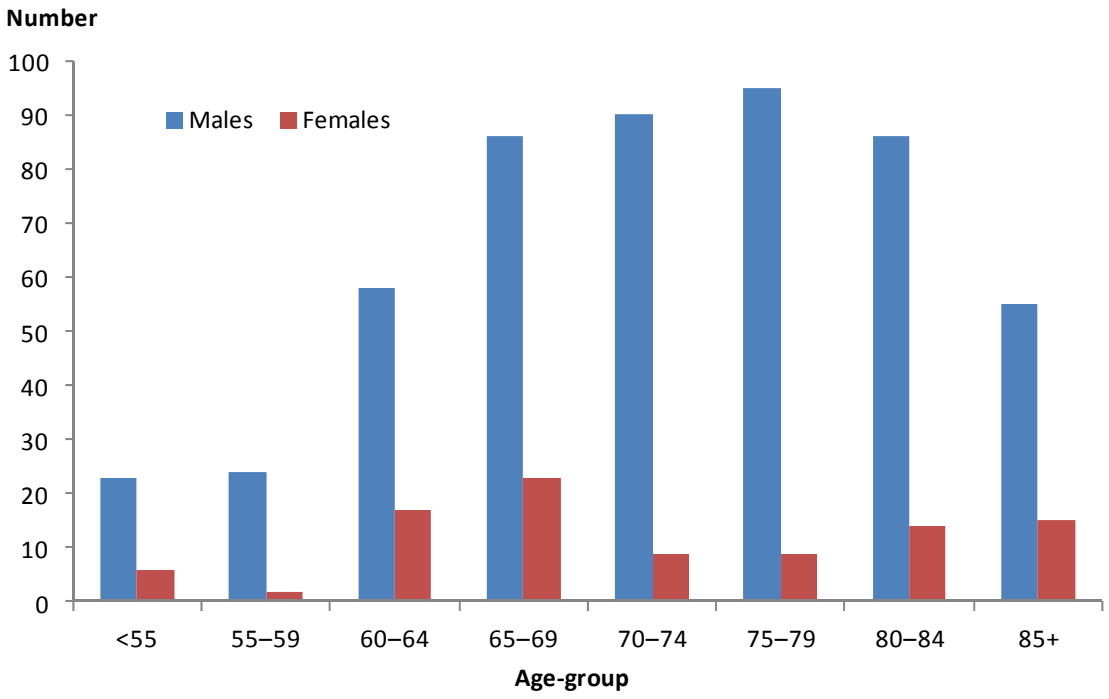
n.p. Numbers and rates not published to protect confidentiality of small numbers.

Age at diagnosis for patients diagnosed in 2011 ranged from 32–100 years. The largest proportions were in the age groups ranging from 65 years to 84 years (Table 2.3). The largest number of men was in the 75–79 year group (95 patients). Women were more evenly spread across age groups (Figure 2.1).

Table 2.3: New cases of mesothelioma by age-group, 2011

Age group	Number	Per cent
Less than 40	4	0.7
40–44	7	1.1
45–49	5	0.8
50–54	13	2.1
55–59	26	4.2
60–64	75	12.3
65–69	109	17.8
70–74	99	16.2
75–79	105	17.2
80–84	100	16.3
85–89	53	8.7
90 and over	16	2.6
Total	**612**	**100.0**

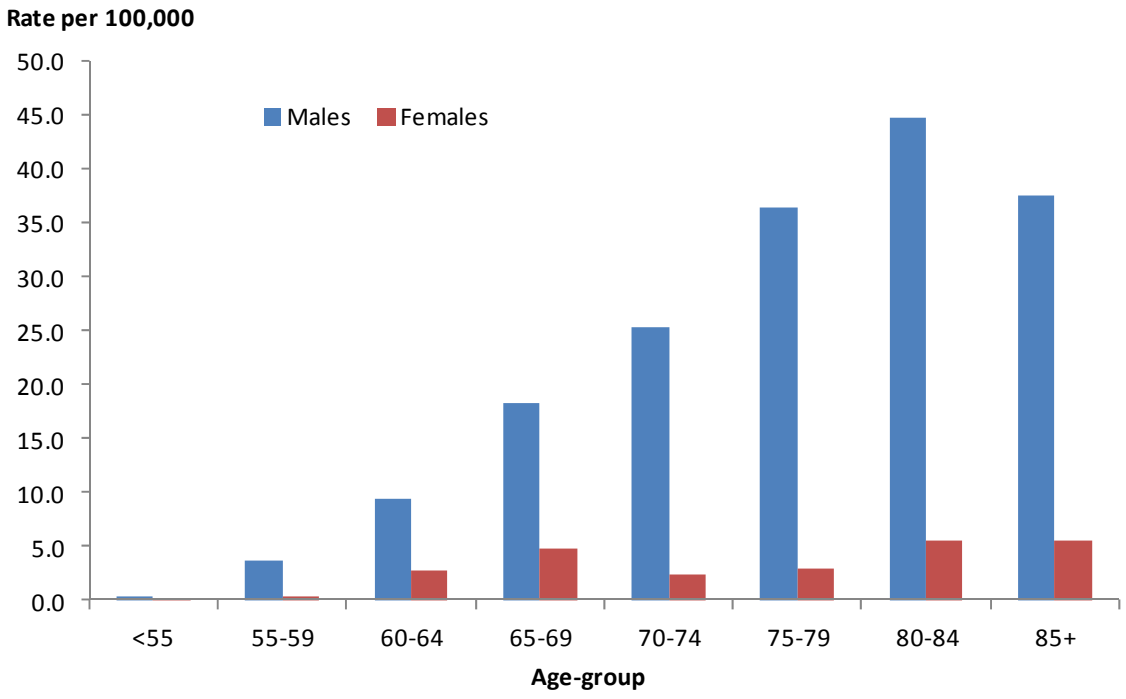
Figure 2.1: New cases of mesothelioma by age-group and sex, 2011



Source: Table A3.

Age-specific incidence rates show the cases of mesothelioma per 100,000 population (Figure 2.2). Incidence rates generally increased with age and were highest among people aged 80–84 years: 44.7 per 100,000 males and 5.6 per 100,000 females.

Figure 2.2 Age-specific rates of mesothelioma by sex, 2011



Source: Table A4.

Diagnosis information

Diagnosis data showed that epithelioid mesothelioma was the most common type (44.1%). Sarcomatoid mesothelioma, which includes desmoplastic mesothelioma, accounted for 14.7 per cent. Biphasic mesothelioma, where a combination of epithelioid and sarcomatoid cells are present, represented 10.5 per cent, while unspecified types of malignant mesothelioma accounted for one-third (30.7%) (Table 2.4). The tumour location was the pleura for almost all patients (92.3%) (Table 2.5).

Table 2.4: New cases of mesothelioma by histological type, 2011

Type of mesothelioma	Number	Per cent
Epithelioid	270	44.1
Sarcomatoid[(a)]	90	14.7
Biphasic	64	10.5
Malignant–Not otherwise specified	188	30.7
Total	**612**	**100.0**

(a) Includes Desmoplastic mesothelioma.

Table 2.5: New cases of mesothelioma by location of tumour, 2011

Tumour location	Number	Per cent
Pleura[(a)]	565	92.3
Peritoneum[(b)]	38	6.2
Other[(c)]	3	0.5
Not stated	6	1.0
Total	**612**	**100.0**

(a) Includes Pericardium, Pleura and Overlapping lesion of heart, mediastinum and pleura.
(b) Includes Peritoneum, Specified parts of peritoneum, Malignant neoplasm of retroperitoneum and peritoneum and Overlapping lesion of retroperitoneum.
(c) Includes Malignant neoplasm of ovary and Tunica vaginalis.

Table 2.6 presents laterality information, excluding cases where this is not applicable. None of the reported tumours were bilateral.

Table 2.6: New cases of mesothelioma by laterality (where applicable), 2011

Laterality	Number	Per cent
Right	209	34.9
Left	155	25.9
Bilateral	0	0.0
Not stated	235	39.2
Total	**599**	**100.0**

The most common basis for diagnosis was histology (84.5%). There was only one case for this period where diagnosis was based on death certificate only (Table 2.7). National death data for 2011 has not yet been received by all cancer registries and therefore the number of mesothelioma deaths reported here are likely to be an underestimate. It is expected that at least 3–4 per cent of all incident mesothelioma cases would be diagnosed via death certificates only.

Table 2.7: New cases of mesothelioma by best basis of diagnosis, 2011

Best basis	Number	Per cent
Death certificate only	1	0.2
Clinical, no investigation[(a)]	10	1.6
Clinical investigation[(b)]	19	3.1
Specific tumour markers	0	0.0
Cytology	56	9.2
Histology[(c)]	517	84.5
Not stated	9	1.5
Total	**612**	**100.0**

(a) Diagnosis made before death, but without any of the remaining types of information listed.
(b) All diagnostic techniques, including x-ray, endoscopy, imaging, ultrasound, exploratory surgery, and autopsy, without a tissue diagnosis.
(c) Includes histology of metastasis, primary tumour or not otherwise specified.

There are limitations with reporting of trends and projections due to the lack of time series data in the AMR at this stage. These will be reported in the future once further data have been collected. The annual Safe Work Australia report presents trends in mesothelioma incidence and mortality using available data from the Australian Cancer Database (ACD) (e.g. Safe Work Australia 2011).

3. Mortality

Number of deaths

The number of deaths of mesothelioma patients notified to the AMR as being diagnosed in the period 1 January–31 December 2011 was 310 nationally (Table 3.1). These figures have been obtained using data from state and territory cancer registries and data linkage of AMR cases to the National Death Index (NDI) (See Appendix A: Methods). The figures are likely to be an underestimate as death information would not yet be available for all relevant cases.

Table 3.1: Deaths of patients diagnosed in 2011

Deaths	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	88	69	62	55	22	10	4	0	310
Per cent of patients diagnosed	51.8	53.1	49.2	52.9	40.7	71.4	44.4	0.0	50.7

Cause of death

Cause of death information was available for only 68.1 per cent of deaths for this period. Mesothelioma was the cause of death for 61.9 per cent of all cases (Table 3.2) and 91.0 per cent of cases where cause of death was known. Cause of death is not yet available for all relevant records as cases are yet to be coded.

Table 3.2: Cause of death for patients diagnosed in 2011

Cause of death	Number	Per cent
Mesothelioma	192	61.9
Non-mesothelioma	19	6.1
Not stated/Not available	99	31.9
Total	**310**	**100.0**

There are limitations with reporting of survival, trends and projections. This is due to the lack of time series data in the AMR at this stage. These figures will be presented in future AMR reports.

4. Asbestos exposure

Table 4.1 presents the numbers of patients diagnosed between 1 January and 31 December 2011 who had successfully completed the recruitment process, or were in the process of being recruited at 30 June 2012. This table should be interpreted in the context of Table A2, which outlines the patient recruitment models being used by the state and territory cancer registries.

The overall number of people diagnosed in 2011 who had consented to participate was 100 at 30 June 2012. Of these, 87 people had completed both the questionnaire and telephone interview (Table 4.1).

Table 4.1: Recruitment for asbestos exposure data collection for patients diagnosed in 2011 by state/territory

	NSW/ACT	Vic	Qld	WA	SA	Tas	NT	Total
Consenting patients/Postal questionnaires completed	29	27	15	12	10	6	1	100
Interviews conducted	25	21	14	12	7	5	1	87

Of the 100 participants completing the postal questionnaire, four participants reported a family member who also had mesothelioma. This was either the person's brother or brother-in law, husband or grandfather. It is important to note that 24.0 per cent of respondents did not answer this question, so these figures may be an underestimate.

The remainder of the section includes information on only the 87 people for whom both a questionnaire was received and an interview conducted. Each job held by every participant was assessed for likelihood of asbestos exposure. This assessment, or metric, does not take into account intensity or frequency of exposure at this time; it is purely an indication of the probability of any exposure.

The classification used is a three-level scheme: unlikely, possible, and probable (Table 4.2). Jobs assessed as probably exposed, are those for which there is convincing evidence from Job Specific Module (JSM) interview data that exposure was more likely than not. Possibly exposed jobs are those for which the evidence (usually from JSM interview data or extrapolation from similar jobs held by the same case) indicated that exposure may have occurred. Jobs assessed as unlikely were those for which JSM interview data indicated no evidence of exposure and also those jobs which were not allocated JSMs because there was a very low *a priori* likelihood of exposure – for example most office jobs would not be allocated a JSM on this basis. Jobs which were allocated JSMs but where the resultant data indicated no evidence of exposure were also classified as exposure unlikely.

Table 4.2: Classification of assessments of exposure probability

Level	Description
Unlikely	No evidence of exposure or jobs not allocated JSMs because there was a very low likelihood of exposure.
Possible	Evidence, usually from JSM interview data or extrapolation from similar jobs held by the same case, indicated that exposure may have occurred.
Probable	Convincing evidence from JSM interview data that exposure was more likely than not.

Non-occupational exposure was assessed using information collected from a non-occupational module. The non-occupational module was administered to all telephone interview participants, regardless of occupational history. Information from the non-occupational module was used to assess exposure probability for each participant, in the same way as occupational exposure probability was assessed, using a three-level exposure scheme: unlikely, possible and probable. It is important to note that this classification is based entirely on the probability of any exposure and does not take into account intensity or frequency of exposure at this time.

The data include 71 men and 16 women who completed the exposure assessment interviews. Exposure assessment classified 23 men (32.4% of men) and 14 women (87.5% of women) as unlikely to have had occupational exposure to asbestos. The remaining 47 men and two women were assessed as having possible or probable occupational asbestos exposure.

Table 4.3: Summary of exposure assessment by sex, 2011 (persons)

	Men	Women	Persons	Per cent of all persons
Neither occupational nor non occupational exposure likely	5	1	6	6.9
Occupational exposure possible/probable, non-occupational exposure unlikely	13	0	13	16.1
Both occupational and non-occupational-exposure possible/probable	33	2	35	40.2
Non-occupational exposure possible/probable, occupational exposure unlikely	19	13	32	36.8
Total	**70**	**16**	**[(a)]86**	**100.0**

(a) The total number of individuals represented in this table is 86, because one interview participant could not be assessed for non-occupational exposure. This participant was assessed as having probable occupational exposure.

There were five men and one woman assessed as having no evidence of likely exposure in either occupational or non-occupational spheres. One man was unable to be assessed for non-occupational exposure.

Five men had unlikely exposure in either occupational or non-occupational spheres. There were 19 men with unlikely occupational exposure and possible/probable non-occupational exposure. There were 33 men assessed as having both possible/probable exposure both in occupational and non-occupational spheres.

Two women were assessed as having possible occupational exposure; they also had possible/probable non-occupational exposure. Fourteen women were assessed as having unlikely occupational exposure, and of these, 13 had possible/probable non-occupational exposure.

Of those participants assessed as having had possible/probable occupational exposure, the job types presented in Table 4.4 represent the particular jobs which had the highest exposure likelihood (possible or probable) for each person. These are the particular job/s within a person's job history which were most influential in determining the likelihood of exposure.

Table 4.4: Occupation types of highest likelihood of possible/probable exposure, 2011

Job type	Possible exposure	Probable exposure	Total
Asbestos/asbestos products production	0	1	1
Boilermaker/boiler attendant	2	4	6
Construction & building-related trades	2	14	16
Electrical and related trades	1	6	7
Engineering jobs	2	1	3
Marine maintenance jobs	0	4	4
Mechanic/mechanical maintenance jobs	1	4	5
Plumbing jobs	0	3	3
Other[(a)]	4	3	7
Total jobs	**12**	**40**	**[(b)]52**

(a) The 'Other' category includes jobs which do not fall within any of the groupings above. Except for asbestos industry jobs which have been reported as a distinct category because it is of *a priori* interest, other jobs which have triggered exposure probability in only one instance have been reported as 'Other'.

(b) Among 49 individuals with possible/probable occupational exposure (3 individuals had two distinct job types both with equal likelihood of exposure).

In Table 4.4, both the women assessed as having likely occupational exposure were judged to have had probable exposure at work. Their particular jobs which triggered the assessment of 'probable exposure' were classified in the 'Other' category.

It is important to note that the numbers of people exposed in different types of jobs needs to be considered in relation to the job histories of the general population. Since the AMR does not collect job history and occupational exposure data from non-cases, it is not possible to make such comparisons.

Non-occupational exposure was judged unlikely for 18 men (25.4% of men) and one woman (6.3% of women). There were 21 men and three women assessed as having possible non-occupational exposure and 31 males and 12 females were assessed as having probable non-occupational exposure. Non-occupational exposure could not be assessed for one male who did not complete the non-occupational questionnaire module. Table 4.5 summarises the circumstances of exposure in the 52 men and 15 women who had possible/probable non-occupational exposure.

Table 4.5: Possible/probable non-occupational exposure by sex, 2011 (persons)

Circumstance of non-occupational exposure	Men	Women	Persons
Living near an asbestos mine or asbestos-related factory	4	2	6
Home renovation-related	48	19	67
Car maintenance	29	0	29
Living with an asbestos worker, handling laundry	2	7	9
Visited Wittenoom, ever	8	1	9
Visited other asbestos-mining town	1	0	1
Other non-occupational exposure	6	2	8

It is important to note that the numbers in Table 4.5 do not add up to the total number of participants since individuals typically reported more than one circumstance of possible/probable non-occupational exposure. Also, when interpreting these data note that the proportions of those in the general population who have had non-occupational exposure is ill-defined and the AMR does not collect this information from non-cases. Therefore it is not possible to comment on whether the participants' experience of non-occupational exposure is similar to or different to the general population.

Appendix A: Methods

Apart from Table 2.1, which presents 2010 data, this report includes AMR patients diagnosed during the period 1 January–31 December 2011. All data presented in the report represent that which had been received by the Australian Mesothelioma Registry at 30 June 2012 for exposure data and 31 August 2012 for incidence and mortality data.

Completeness

Notification data were complete for the majority of data items. The 2011 data show the percentage missing for mandatory fields ranged from 0.0 per cent to 38.7 per cent. In Table A1, the missing totals in the column 'No. missing' include both cases where the field was blank and those where a 'Not stated' code has been provided.

There were 310 cases with either a date of death, cause of death, or both. Of these, the cause of death was unknown for 31.9 per cent of the cases.

For South Australia, the following data items are not being provided unless the patient consents to participate: Indigenous status, full date of birth (month and year are provided), full date of diagnosis (month and year are provided), address, and all names. In Table A1, 43 of the missing cases for these fields are from South Australia.

Table A1: AMR notification fields and percent of missing records, 2011

Field	Mandatory field	No. of records	No. missing/ not stated	Per cent missing
Cancer registry ID/unique identifier	Yes	612	0	0.0
Record status	Yes	612	0	0.0
State/territory	Yes	612	0	0.0
Title	No	612	493	80.6
Last name	Yes	612	0	0.0
First name	Yes	612	0	0.0
Other names	No	612	223	36.4
Case address	Yes	612	43	7.0
Date of birth[(a)]	Yes	612	43	7.0
Sex	Yes	612	0	0.0
Indigenous status	Yes	612	237	38.7
Country of birth	No	612	184	30.1
Diagnosis date[(b)]	Yes	612	0	0.0
Best basis of diagnosis	Yes	612	9	1.5
Topography	Yes	612	6	1.0
Morphology	Yes	612	0	0.0
Laterality	No	599	235	39.2
Date of death	No	310	1	0.0
Cause of death code	No	310	99	31.9

(a) The 43 missing cases are for SA where only MM/YYYY has been provided, although full dates are recorded by SA.

(b) Diagnosis date is only available as MM/YYYY for NSW/ACT. SA also only provide MM/YYYY, although full dates are recorded by SA. These have not been included in missing figures as month and year of diagnosis is adequate.

New South Wales reported receiving mesothelioma notifications without pathological confirmation. At 31 August 2012, there were 14 reported cases of mesothelioma yet to be confirmed for NSW for 2011. For these cases, there is some evidence to suggest mesothelioma, but not enough to satisfy the criteria of the state's internal coding policy. These additional diagnoses have not been included in figures for this report.

Cases may be notified to the AMR and then removed due to identification as a duplicate, a change in diagnosis, date of diagnosis or other details. The records which have been removed are retained in the AMR system and recorded as 'inactive' records. Inactive records are not included in this report.

Data linkage with the National Death Index

All records in the AMR at 12 April 2012 were sent to the Australian Institute of Health and Welfare (AIHW) for linkage with the National Death Index (NDI). The purpose of the linkage was to obtain death data, including date and cause of death, for records for which this information was not available or was incomplete on the AMR.

For patients diagnosed in 2011, there were 225 successful linkages and 133 records were updated to include the date of death. Cases notified to the AMR after 12 April 2012 were not included in the data linkage, therefore, death figures are an underestimate. Due to the AMR data being relatively recent, cause of death information was not yet available for most linked records. A further data linkage will be carried out by AIHW later in 2012 to obtain cause of death information for more records. The AMR data will be linked with the NDI on an annual basis and the linkage will include all cases not previously successfully linked.

Small cells

Small cells of less than five cases have been presented in some tables in this report. Exceptions are state/territory tables disaggregated by more than one demographic factor, such as sex and age group, and where rates are based on cells of less than 10 cases. The data in the asbestos exposure section are based on exposure judgements made by MonCOEH, and not solely on demographic characteristics, nor do they directly represent information provided by interview participants. Therefore cells of less than five cases have been presented in this section.

Patient recruitment for asbestos exposure component

Patient recruitment for the AMR includes two main phases: contacting the patients' doctor to obtain advice on eligibility of the patient to participate in the postal questionnaire and telephone interview, and, if consent received, contacting the patient to see if they are interested in participating.

The patient recruitment processes vary across the states and territories in line with the state or territory ethics approval or patient recruitment protocols. Currently, in all jurisdictions except for Victoria and Tasmania, doctors need to return a completed consent form to the relevant cancer registry to indicate consent. In Tasmania and Victoria, if doctors do not respond within 3 or 4 weeks respectively, consent is assumed and the patient is contacted.

NSW/ACT moved to this model from 1 May 2012, however, the majority of patients diagnosed in 2011 and recruited to the AMR would have been recruited via the previous patient recruitment model. WA plan to move to this 'passive consent' ('opt-out') model, however, this has not yet been approved or implemented. Table A2 presents some characteristics of the different processes.

Table A2: Characteristics of patient recruitment process by state/territory

	NSW/ACT	Vic	Qld	WA	SA	Tas	NT
				Doctor stage			
'Opt out' for clinicians	No	Yes	No	No	No	Yes	No
Change to 'opt out'	Yes	—	No	Yes	No	—	No
	1 May 2012			Late 2012			
Timeframe for 'opt out'	4 wks	4 wks	—	3–4 wks	—	3 wks	—
				Patient stage			
Return of consents/questionnaire directly to AMR	Yes	No	No	Yes	No	Yes	Yes

Coding of occupations

All occupations reported by patients via the AMR postal questionnaire are coded according to the Australian and New Zealand Standard Classification of Occupations (ANZSCO) (ABS 2006). In this report, these data are not presented, however, all data have been coded down to the Unit Group level (six-digit classification) where possible.

Assessment of asbestos exposure

Job and residential histories provided via the postal questionnaire are entered into OccIDEAS and MonCOEH staff review the job history to assign JSMs for the telephone interviewers to administer. JSMs are allocated to particular jobs which the participant has reported, based on judgement by MonCOEH of possible asbestos exposure. The purpose of a JSM is to ask a systematic series of questions about a possible asbestos-exposed job, in a standardised way, to elicit task and exposure information which can then be used to estimate that individual's occupational asbestos exposure over his or her working life. Participants may receive several JSMs for different jobs or none depending on how many jobs they had for which the exposure assessor judges required further investigation. In particular cases where the participant has more jobs of interest than it is feasible to administer JSMs for, exposure in some jobs may be assessed by extrapolation of exposure probability in similar jobs held by the same participant (MacFarlane et al 2012).

Since non-occupational asbestos exposure is relevant for a proportion of participants, a non-occupational (environmental) module has been constructed in OccIDEAS. This module is similar to a conventional OccIDEAS JSM except that it asks about non-occupational exposures across the patient's lifespan, such as home renovations and whether the patient had ever visited an asbestos mining town. All interview participants receive the non-occupational module, irrespective of their occupational history and whether or not that participant also received any JSMs.

For the purposes of the present report, exposure has been assessed as probability of any exposure. The classification of exposure probability uses a three-level scheme: *unlikely, possible* and *probable*. Jobs assessed as probably exposed are those for which there is convincing evidence from JSM interview data that exposure was more likely than not. Possibly exposed jobs are those for which the evidence, usually from JSM interview data or extrapolation from similar jobs held by the same participant, indicated that exposure may have occurred. Jobs assessed as unlikely were those for which JSM interview data indicated no evidence of exposure and also those jobs which were not allocated JSMs because there was a very low *a priori* likelihood of exposure. At this stage, this metric does not take into account intensity or frequency of exposure; it is purely an indication of the probability of any exposure.

Appendix B: Tables underlying figures

Table A3: New cases of mesothelioma by sex and age-group, 2011

	<55	55–59	60–64	65–69	70–74	75–79	80–84	85+
Men	23	24	58	86	90	96	86	54
Women	6	2	17	23	9	9	14	15
Persons	**29**	**26**	**75**	**109**	**99**	**105**	**100**	**69**

Table A4: Age-specific rates of mesothelioma, 2011

	<55	55–59	60–64	65–69	70–74	75–79	80–84	85+
Men	0.3	3.6	9.4	18.2	25.4	36.8	44.7	36.9
Women	0.1	0.3	2.7	4.8	2.4	3.0	5.6	5.6
Persons	**0.3**	**1.9**	**6.0**	**11.4**	**13.5**	**18.8**	**22.5**	**16.6**

Glossary

Best basis of diagnosis: The most valid basis of diagnosis in a person with cancer.

Cytology: Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates.

Histology: Microscopic examination of cells and tissues.

Job-specific module (JSM): telephone questionnaire modules which are specific to certain kinds of jobs and industries. The MonCOEH team allocate JSMs to be administered to each patient in their telephone interview, based on the job history provided by the patient in the postal questionnaire. The purpose of a JSM is to ask a systematic sequence of questions about the job in question in order to elicit specific information needed to estimate that individual's asbestos exposure in that job. A non-occupational module is administered to all patients who consent to telephone interview.

Laterality: The side of a paired organ that is the origin of the primary cancer in a person with cancer.

Mesothelioma: An aggressive form of cancer that arises in the mesothelium, membranous tissue that surrounds the organs and body cavities.

METeOR: The Australian Institute of Health and Welfare's metadata online registry, available at: http://meteor.aihw.gov.au

Morphology: The histological classification of the cancer tissue (histopathological type) in a person with cancer, and a description of the course of development that a tumour is likely to take: benign or malignant (behaviour).

National Death Index (NDI): A database which contains records of all deaths occurring in Australia since 1980.

Notification: A case of mesothelioma provided to the AMR from the state/territory cancer registries. Each notification contains demographic information, diagnosis information and, if relevant, death information. All notifications of cancer are first notified to the state/territory cancer registries from pathology laboratories, radiotherapy and medical oncology departments, and hospitals.

OccIDEAS (Occupational Integrated Database Exposure Assessment System): a secure web-based survey tool used in research projects where accurate, subject-specific exposure assessment is needed. It is a computerised interview tool for collecting exposure data from individual subjects. OccIDEAS also manages and organises the exposure information and is programmable to calculate exposure assessments automatically by algorithm and/or utilising case by case expert judgement. OccIDEAS is based on a modular structure which enables each interview to be customised to the particular subject based on their work history and other information collected in the postal questionnaire (MacFarlane et al 2012).

Self-notifier: A person diagnosed with mesothelioma who notifies the AMR of their diagnosis.

Topography: The site in which the tumour originated in a person with cancer.

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