

MESOTHELIOMA IN AUSTRALIA 2015

5th annual report



australian
mesothelioma
registry

Acknowledgements

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- Safe Work Australia
- Comcare
- Cancer Institute NSW
- Monash Centre for Occupational and Environmental Health, Monash University
- Asbestos Diseases Research Institute
- Dust Diseases Authority, Insurance and Care New South Wales
- School of Public Health, University of Sydney
- University of Western Australia and the Western Australian Cancer Registry
- Queensland Cancer Registry

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Abbreviations and acronyms

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ABS	Australian Bureau of Statistics
ACD	Australian Cancer Database
ACM	asbestos-containing material
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
AMR	Australian Mesothelioma Registry
ANZSCO	Australian and New Zealand Standard Classification of Occupations
HRF	Hunter Research Foundation
JSM	job-specific module
MonCOEH	Monash Centre for Occupational and Environmental Health
NDI	National Death Index
N.E.C.	not elsewhere classified
NMD	National Mortality Database
No.	Number
NOHSC	National Occupational Health and Safety Commission
NSW	New South Wales
NT	Northern Territory
OccIDEAS	Occupational Integrated Database Exposure Assessment System
Qld	Queensland
SA	South Australia
Tas	Tasmania
TWA	time-weighted average
Vic	Victoria
WA	Western Australia

Executive summary

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The Australian Mesothelioma Registry (AMR) became operational in 2011 and contains information about people diagnosed with mesothelioma in Australia from 1 July 2010.

The AMR also has a voluntary component that enables the collection of asbestos exposure information directly from people who have mesothelioma.

Number of new cases

As at 31 May 2016, the AMR had received 650 notifications of people newly diagnosed with mesothelioma between 1 January and 31 December 2015. Of these people, 505 were males and 145 were females, and the majority (82.6%) were aged 65 years or over at the time of diagnosis.

The annual age-specific incidence rates of mesothelioma peaked at 10.3 per 100,000 in females 80–84 years of age and 44.4 per 100,000 in males 80–84 years of age.

For diagnoses made during 2015, the most common subtype of mesothelioma was the epithelioid subtype (48.8%). The most common location was the pleura (93.7%).

An additional, 91 people with mesothelioma were notified to the AMR following publication of the AMR's 2014 report. This has increased the previously reported number of cases diagnosed in 2014, from 641 to 732.

Age-standardised incidence rates

The provisional age-standardised mesothelioma incidence rate in 2015 for males and females combined was 2.3 cases per 100,000 population.

The male age-standardised incidence rate declined between 2011 and 2015, from 5.3 per 100,000 to 3.9 per 100,000 respectively, while the female age-standardised incidence rate remained stable across the years at 0.8–1.0 per 100,000.

Number of deaths

At 31 May 2016, 626 mesothelioma patients on the AMR were recorded as having died in 2015. Where there was a known cause of death, 90.8% were recorded as being due to mesothelioma.

Asbestos exposure

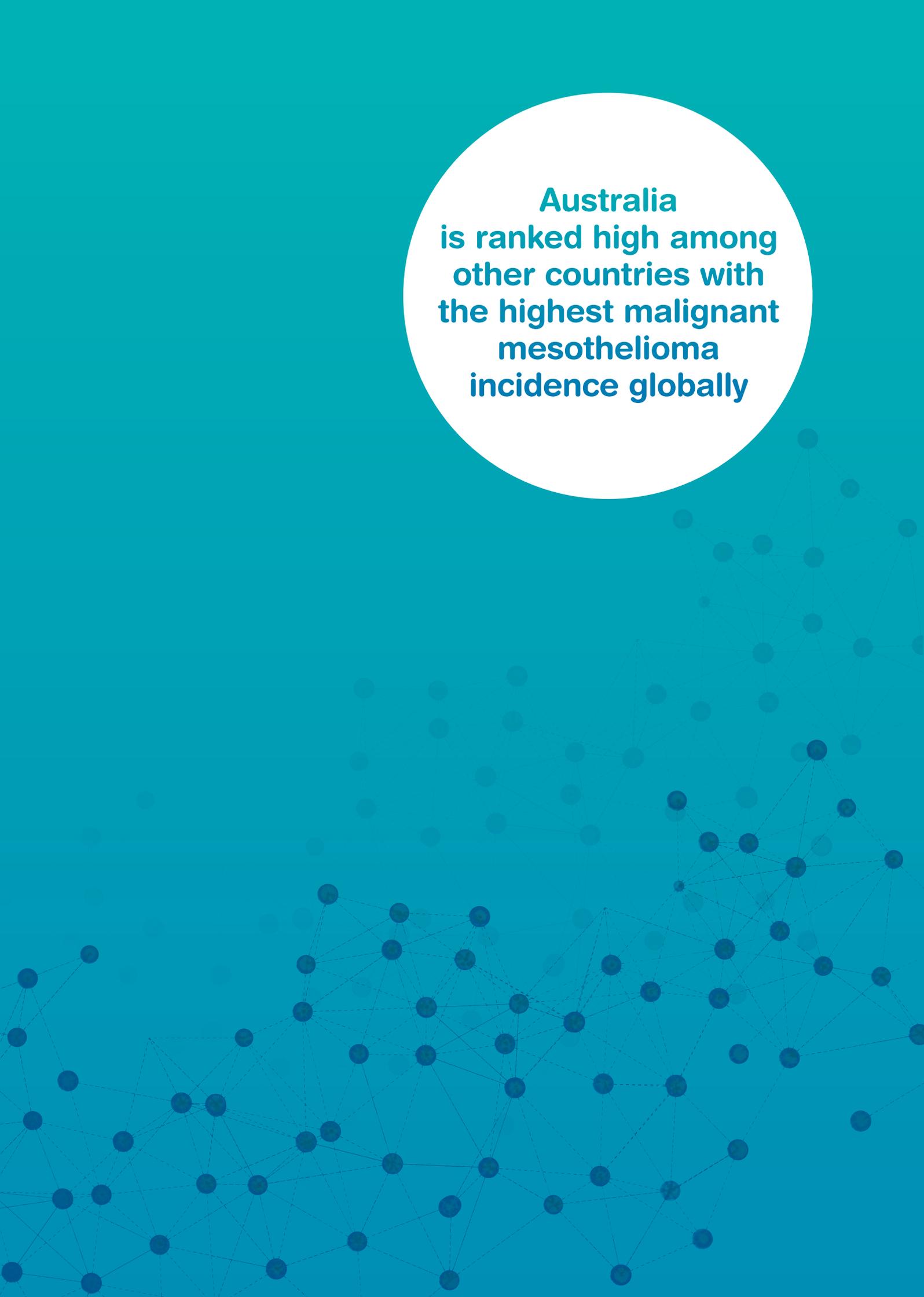
The AMR's data on asbestos exposure are based on the estimated exposure profiles of people diagnosed with mesothelioma since 1 July 2010.

Of the 651 people (520 males and 131 females) with mesothelioma who had completed the asbestos exposure questionnaire at 1 April 2016, 582 (89.4%, representing 464 males and 118 females) also completed the telephone interview.

Of the 582 who were interviewed:

- 351 (60.3%) respondents (343 males and 8 females) provided information indicating 'possible' or 'probable' occupational asbestos exposure
- 483 (82.9%) people (377 males and 106 females) provided information indicating 'possible' or 'probable' asbestos exposure in non-occupational contexts
- 548 (94.2%) respondents (441 males and 107 females) provided information indicating 'possible' or 'probable' asbestos exposure in either occupational or non-occupational settings, or both
- 34 (5.8%) people (23 males and 11 females) provided no information indicating asbestos exposure above background levels in either occupational or non-occupational spheres.

The assessments consider only the probability of asbestos exposure and the estimated level of exposure, but do not provide information about the duration, intensity or frequency of exposure, if exposure had occurred. Although a large proportion of interviewed participants reported information indicating non-occupational asbestos exposure, the majority of these exposures are less certain ('possible'), and of those classed as 'probable', the level of likely exposure was low in most cases.



**Australia
is ranked high among
other countries with
the highest malignant
mesothelioma
incidence globally**

1. Introduction

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Purpose

This is the fifth report of the Australian Mesothelioma Registry (AMR), a national registry that became operational in 2011. The AMR contains information about people diagnosed with mesothelioma in Australia from 1 July 2010. This report primarily presents data for the period from 1 January 2015 to 31 December 2015. Selected data for earlier calendar years are also shown to help understand patterns of change in mesothelioma incidence and mortality.

Background

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

Until the mid-1980s, Australia was a producer of asbestos 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, and 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).

Until the 1970s, ACMs were used extensively in construction (including residential homes), industrial plants and equipment, ship-building, train locomotives and motor vehicles. 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. Some exemptions 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 ACMs.

Asbestos exposure can cause asbestosis, lung cancer and is the predominant cause of mesothelioma, an aggressive form of cancer that arises in the mesothelium – the membranous tissue that surrounds the heart, lungs, gastrointestinal and urogenital organs, and lines the chest and abdominal cavities. The risk of lung cancer from inhaling asbestos fibres is also greater if you smoke (NSW Health 2007), and the symptoms of the diseases do not usually appear until about 20 to 30 years after the first exposure to asbestos. The mechanism by which asbestos causes cancer is only partly understood. Mesothelioma has been linked to both occupational and non-occupational exposure to asbestos; occupational exposure having been the most important source of exposure up to the present time.

Australia is ranked high among other countries, with the highest malignant mesothelioma incidence globally (Soeberg & van Zandwijk 2015). The incidence of mesothelioma increased in Australia from at least 1982 (when data on new cases first became available nationally) to 2003 (Safe Work Australia 2013). Some fluctuation has occurred in the number of new diagnoses since that time; however, a general increase is still apparent (AIHW 2016). There is currently no cure for mesothelioma and the progression of the disease is usually rapid. Average life expectancy from diagnosis to death is nine months, and even with aggressive treatment, few people survive longer than two years. However, there is increasing evidence that there is a substantial proportion of people with malignant mesothelioma who survive at least twice as long as the median survival time. In a study using NSW data, a quarter of the study population fell into this category (Linton et al. 2014).

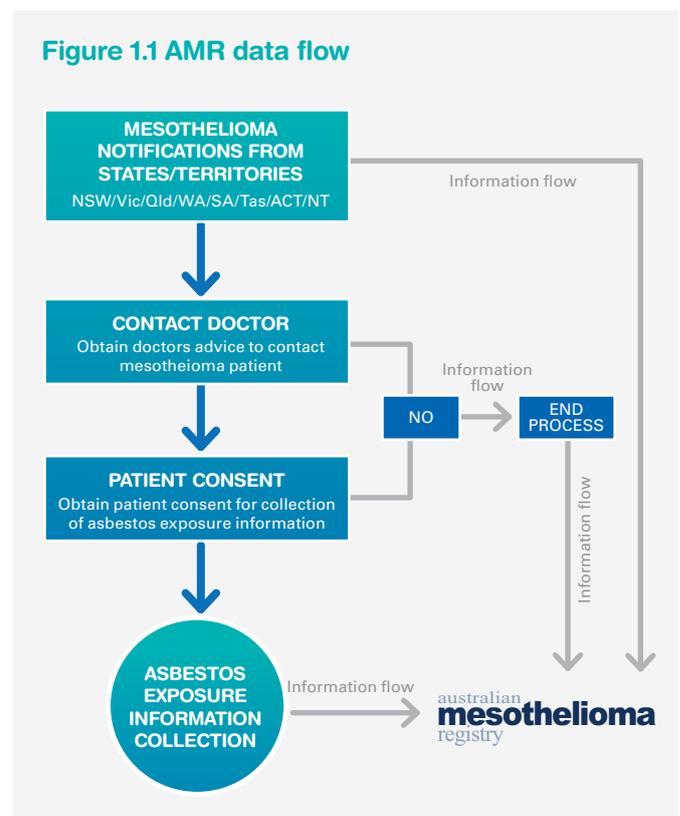
The AMR

Since 2011, the AMR has collected new cases of mesothelioma diagnosed (in Australia) from 1 July 2010. The Registry replaced the Australian Mesothelioma Register managed by the National Occupational Health and Safety Commission (NOHSC). In 1998, the voluntary notification of new cases to the Register by state and territory registries declined when new state and territory privacy legislation was 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:

- accurately measure the incidence of mesothelioma in Australia for the purposes of:
 - monitoring changes in the incidence of mesothelioma following the ban on all uses of asbestos
 - identifying increases in the incidence of mesothelioma that may result from ongoing, or possibly increasing, non-workplace exposure to asbestos already in the wider environment (the postulated third wave), or exposure to a new hazard entering the occupational or general environment
 - identifying the groups of workers most at risk of exposure to asbestos so that future exposures can be prevented.
- permit periodic assessment of mesothelioma survival to ascertain whether changes in care for mesothelioma are resulting in measurable improvements in survival
- document the asbestos or other exposure experience of people newly diagnosed with mesothelioma as a form of surveillance for new or increasing sources of exposure to asbestos, or other carcinogenic fibres
- provide a resource for research into the causes and control of mesothelioma, and to assist the development of policies to best deal with the asbestos still present in our environment.

The AMR collects asbestos exposure information via a postal questionnaire and telephone interview from eligible, consenting patients. The flow chart in Figure 1.1 shows the AMR's process of obtaining mesothelioma notifications and asbestos exposure data.



Notifications

Notifications refer to the cases of mesothelioma provided to the AMR by the state and territory cancer registries. Cancer registries are notified of all cases of cancer diagnosed in residents living in their jurisdiction. For the AMR, mesothelioma cases are 'fast-tracked' by each state and territory; meaning, 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 received, the state or territory cancer registry contacts the patient's clinician; either through a passive or active consent model, to confirm whether their patient meets the eligibility criteria for participation. Eligibility criteria include 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. Following this, the state and territory cancer registries contact the patient.

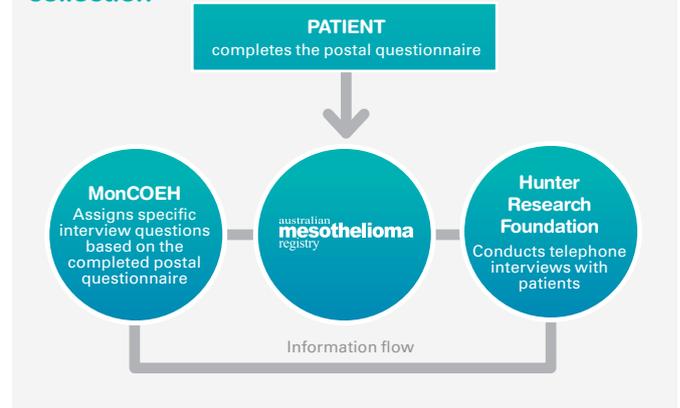
Patients are able to self-notify directly to the AMR. In this case, the AMR sends an information pack directly to the patient and the clinician is not contacted. Self-notifying patients are not included in the AMR report unless a notification is received from the respective state or territory cancer registry to confirm their mesothelioma diagnosis.

Asbestos exposure information is obtained from consenting mesothelioma patients through a postal questionnaire and telephone interview (Figure 1.2). In the postal questionnaire, patients list their residence, school and occupational histories. Patients are also asked about their family history of mesothelioma. Patients' residence and occupational information is systematically compiled through an online assessment tool called OccIDEAS (Occupational Integrated Database Exposure Assessment System). The Monash Centre for Occupational and Environmental Health (MonCOEH) uses information from the postal questionnaire to assign relevant telephone interview questions for each person.

Following the postal questionnaire, a telephone interview is conducted. Based on the individual's responses to the postal questionnaire, specific questions are asked in the interview to assess their potential for having been exposed to asbestos. This means the telephone interview is tailored to the participant. The Hunter Research Foundation (HRF) conducts the telephone interviews.

The information collected is used by MonCOEH to assess and assign values to each patient's lifetime asbestos exposure. Further information about the asbestos exposure assessments can be found in Appendix A.

Figure 1.2 AMR asbestos exposure information collection



This report

This is the fifth report presenting data collected through the AMR, including mesothelioma notifications and asbestos exposure information. This report primarily presents data for patients diagnosed during the calendar year 1 January 2015 to 31 December 2015.

Since the AMR's 2011 data were first published, an additional 88 people diagnosed with mesothelioma in 2011 have been notified to the AMR. Since the 2012 report, 112 new cases have been notified for that year, and since the publication of the 2013 and 2014 reports, 117 and 91 new cases have been notified for those two years respectively. Possible reasons for the extended time between diagnosis and notification include delays in:

- confirmation of diagnosis
- notification by pathology laboratories to cancer registries
- the cancer registry process (e.g. periodic shortage of experienced staff, time taken to code complex cases).

The reported incidence and mortality figures are based on the data recorded at the time of extraction from the AMR. Extraction dates and methods used may differ across AMR publications. Table A1 shows the differences in AMR reports published between 2012 and 2015.

The report includes additional sections on incidence, mortality and asbestos exposure. Appendix A details methods used for collating and reporting the data. Appendix B contains additional data tables underlying the figures. Appendix C lists the publications and key presentations on the AMR since 2010.

2. Incidence

Number of cases

In total, 650 people diagnosed with mesothelioma from 1 January 2015 to 31 December 2015 had been notified to the AMR at 31 May 2016 (Table 2.1). This compares with 641 cases reported for 2014 at 31 May 2015.

Table 2.1 People in Australia newly-diagnosed with mesothelioma, by year and sex, 2011–2015

Year of diagnosis	Males	Females	Persons
2011	595	105	700
2012	605	126	731
2013	561	131	692
2014	593	139	732
2015	505	145	650

Since the previous publication (AMR 2015), there have been additional notifications of people diagnosed with mesothelioma reported to the AMR for all previous years: 8 for 2011 (1.2% increase), 18 for 2012 (2.5% increase), 16 for 2013 (2.4% increase) and 91 for 2014 (14.2% increase). A similar increase is anticipated in the reported number of patients diagnosed in 2015.

Table 2.2 shows the number of males and females newly-diagnosed with mesothelioma by state and territory for the year 2015. The incidence rate for males and females combined was 2.3 per 100,000 population overall, and ranged from 0.5 in Tasmania to 4.2 in Western Australia. In 2015, no new cases of mesothelioma were diagnosed in Northern Territory. The rate for males was higher than for females in all jurisdictions, and overall (3.9 and 1.0, respectively).

The incidence rate age-standardised to the World Standard Population (Segi 1960) was 1.3 per 100,000 overall (Table A4). This is the figure that should be used when comparing incidence rates in Australia to those in other countries.

The overall 2015 age-standardised mesothelioma incidence rate is slightly lower than those in previous years of AMR data (Table A5).

Table 2.2 New cases of mesothelioma and age-standardised incidence rates, by sex and state/territory, 2015

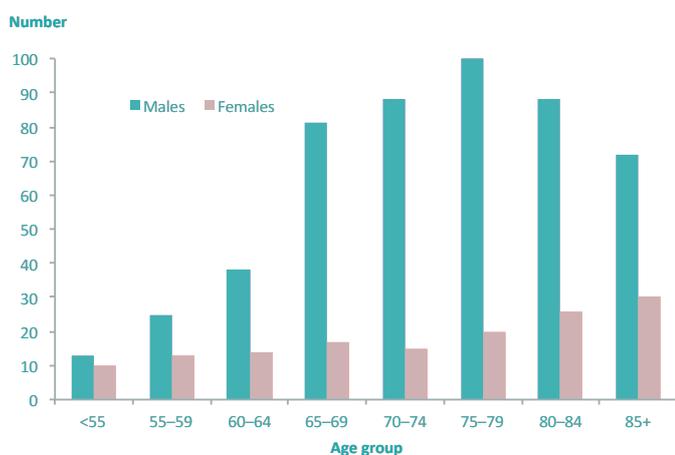
	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number									
Males	168	119	99	86	27	2	4	0	505
Females	44	28	35	25	11	2	0	0	145
Persons	212	147	134	111	38	4	4	0	650
Rate per 100,000 population^(a)									
Males	4.0	3.7	3.9	8.4	2.2	0.5	2.4	n.p.	3.9
Females	0.9	0.7	1.3	1.8	0.8	0.5	0.0	n.p.	1.0
Persons	2.3	2.1	2.5	4.2	1.6	0.5	1.1	np.	2.3

(a) Directly age-standardised using the 2001 Australian standard population.
n.p. Not published as requested by state/territory.

For patients diagnosed in 2015, the age ranged from 25 to 100 years, with the largest proportions of new diagnoses occurring in the 70–84 year age group (Table A6).

Figure 2.1 shows the distribution by age and sex of new cases of mesothelioma diagnosed in 2015. The largest numbers are in the 75–79 year age group (120 patients), with the majority (82.6%) aged 65 years or over at the time of diagnosis (Table A7). For the 505 males diagnosed with mesothelioma in 2015, the age distribution was concentrated in age groups above 65 years. The 145 females were more evenly spread across age groups, with a gradual increase in the number of cases recorded with age.

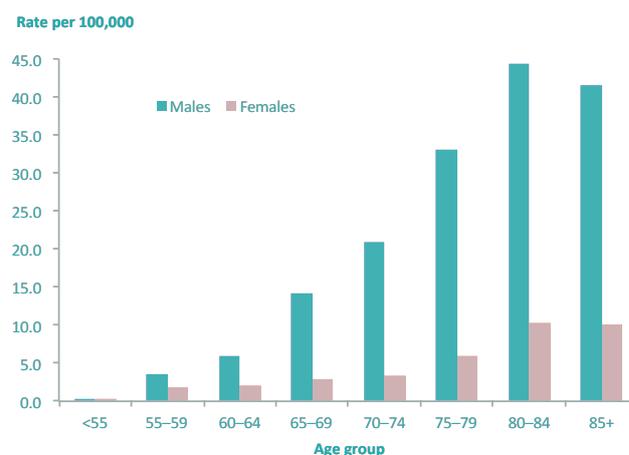
Figure 2.1 New cases of mesothelioma in Australia, by age group and sex, 2015



Source: Table A7.

Age-specific incidence rates of mesothelioma (Figure 2.2) generally increased with age. The rates were highest in the 80-84 year age group with rates of 44.4 per 100,000 and 10.3 per 100,000 for males and females respectively (Table A7).

Figure 2.2 Age-specific incidence rates of mesothelioma, by sex, Australia, 2015



Source: Table A7.

Diagnosis information

In 2015, epithelioid mesothelioma was the most common subtype (48.8%) of mesothelioma notified to the cancer registries. Sarcomatoid mesothelioma, which includes desmoplastic mesothelioma, accounted for 12.6%. Biphasic mesothelioma (where a combination of epithelioid and sarcomatoid cells are present represented 11.5%, while unspecified types of malignant mesothelioma accounted for 27.1% of cases (Table 2.3). The tumour location was the pleura for 93.7% of patients (Table 2.4).

Table 2.3 New cases of mesothelioma, by histological type, Australia, 2015

Type of mesothelioma	Number	Per cent
Epithelioid	317	48.8
Sarcomatoid ^(a)	82	12.6
Biphasic	75	11.5
Malignant (not otherwise specified)	176	27.1
Total	650	100.0

(a) Includes desmoplastic mesothelioma.

Table 2.4 New cases of mesothelioma, by location of tumour, Australia, 2015

Tumour location	Number	Per cent
Pleura ^(a)	609	93.7
Peritoneum ^(b)	41	6.3
Other	0	0.0
Total	650	100.0

(a) Includes pericardium, pleura and mediastinum.

(b) Includes peritoneum and specified parts of peritoneum.

Table 2.5 presents laterality information, excluding 22 cases for non-paired organs where this was not applicable and 203 cases where laterality was not stated. There was one case of bilateral mesothelioma reported in 2015: otherwise, the most common laterality was the right side (61.9%).

Table 2.5 New cases of mesothelioma, by laterality (where applicable), Australia, 2015

Laterality	Number	Per cent
Right	263	61.9
Left	161	37.9
Bilateral	1	0.2
Total	425	100.0

Note: Excludes cases where laterality was not known.

The most common 'best basis for diagnosis' category was histology (84.9%). There was only one case where diagnosis was based on the death certificate only for this period (Table 2.6). National death data for 2015 have not yet been received by all cancer registries; therefore, the total number of mesothelioma deaths reported here is likely to be underestimated. It is expected that at least 3–4% of all incident mesothelioma cases will ultimately be 'diagnosed' by death certificate only.

Table 2.6 New cases of mesothelioma, by best basis of diagnosis, Australia, 2015

Best basis	Number	Per cent
Death certificate only	1	0.2
Clinical, no investigation ^(a)	5	0.8
Clinical investigation ^(b)	31	4.8
Specific tumour markers	0	0.0
Cytology	60	9.2
Histology ^(c)	552	84.9
Not stated	1	0.2
Total	650	100.0

(a) Diagnosis made before death, but without any of the remaining types of information listed.

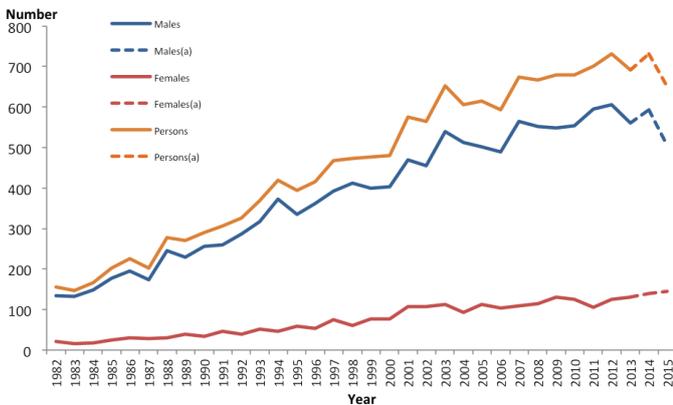
(b) All diagnostic techniques, including x-ray, endoscopy, imaging, ultrasound, exploratory surgery and autopsy, without a tissue diagnosis.

(c) Includes histology of metastasis, primary tumour or not otherwise specified.

Trends over time

There are limitations with reporting mesothelioma trends due to the lack of time series data in the AMR at this stage. However, Figures 2.3 and 2.4 present trends in mesothelioma incidence using available data from two sources: the Australian Cancer Database (ACD) (AIHW 2016) for 1982–2010, and the AMR for 2011–2015. To date, the highest overall number of new cases was reported in 2014 (732). It is important to note that the apparent decline seen in recent years may be due to delays in notifications of mesothelioma cases to the AMR, rather than a real decline in incidence.

Figure 2.3 New cases of mesothelioma, by year and sex, Australia, 1982–2015

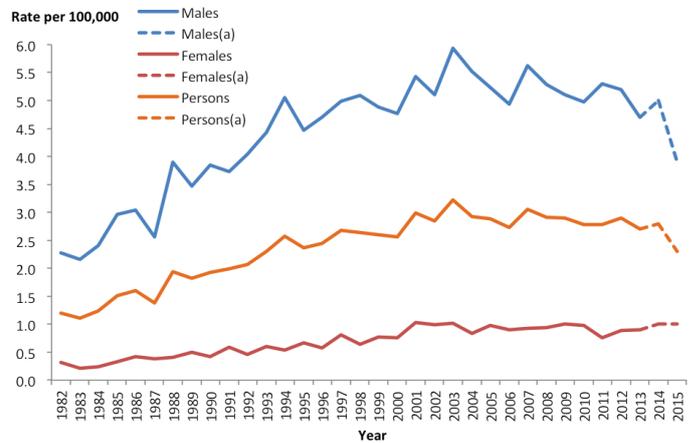


(a) Dotted lines indicate data that are expected to change by three or more percent as they are updated.

Source: Table A8.

Using the same sources, age-standardised incidence rates show some fluctuation. The overall incidence rate peaked at 2003 (3.2 per 100,000), and from that point, a gradual declining pattern is seen (Figure 2.4).

Figure 2.4 Age-standardised incidence rates of mesothelioma, by year and sex, Australia, 1982–2015



(a) Dotted lines indicate data that are expected to change by three or more percent as they are updated.

Source: Table A8.

3. Mortality

Mortality figures are obtained using data linkage of AMR cases to the National Death Index (NDI). Where NDI data are not available, date and cause of death information from state and territory cancer registry data are reported (see Appendix A).

Number of deaths

At 31 May 2016, 626 deaths of people with mesothelioma in 2015 had been notified to the AMR (Table 3.1). The total number of deaths in the AMR for 2011 and 2012 is lower than expected because the AMR only includes people diagnosed since 1 July 2010.

Table 3.1 Deaths of people with mesothelioma, by year and sex, Australia, 2011–2015

Year of death	Males	Females	Persons
2011	328	57	385
2012	489	93	582
2013	536	98	634
2014	557	115	672
2015	503	123	626

The age-standardised mortality rate for 2015 was 2.2 per 100,000 (Table 3.2). The number of deaths for previous years by state and territory are presented in Table A9. The 2015 death figures are expected to increase as death information becomes available for more cases.

Table 3.2 Deaths of people with mesothelioma, by state/territory, 2015

Deaths	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	199	134	128	99	52	4	10	0	626
Rate per 100,000 population ^(a)	2.1	1.9	2.5	3.8	2.2	0.5	2.6	n.p.	2.2

Note: Includes death information from the NDI where available, otherwise from state/territory cancer registries.

(a) Directly age-standardised using the 2001 Australian standard population. n.p. Not published as requested by state/territory.

Cause of death

Cause of death information from state and territory cancer registries was available for 250 of the 626 (39.9%) deaths recorded in 2015. Where cause of death was known, mesothelioma was reported as the primary cause in 90.8% of cases. In 23 cases, mesothelioma was not recorded as the underlying primary cause of death (Table 3.3).

Table 3.3 Cause of death for people with mesothelioma, Australia, 2015

Cause of death	Number	Per cent
Mesothelioma	227	90.8
Other ^(a)	23	9.2
Total	250	100.0

(a) May contain cases where Mesothelioma is a secondary cause of death.

Notes:

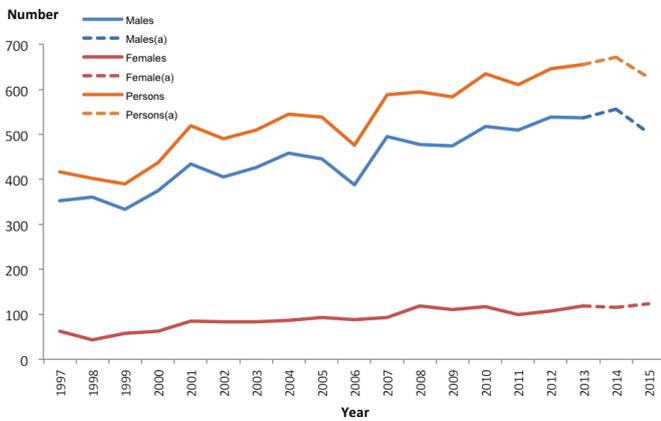
1. Excludes cases where cause of death was not known.
2. Death information from state/territory cancer registries only.

Cause of death from either the NDI or state and territory cancer registries was available for 379 of the 385 (98.4%) deaths recorded for 2011, for 576 of the 582 (98.9%) deaths recorded for 2012, for 437 of the 634 (68.9%) deaths recorded in 2013, and 441 of the 672 (65.6%) deaths recorded in 2014 (Table A10). Note that no cause of death information was available from the NDI for deaths in both 2014 and 2015, as cases are yet to be coded.

Trends over time

The AMR currently has insufficient data to report on trends and provide future projections in mortality and survival. However, this report can present trends in mesothelioma mortality (Figure 3.1) using available data from the National Mortality Database (NMD) (AIHW 2016) for 1997–2013, and the AMR for 2014–2015. To date, the highest overall number of deaths was reported in 2014 (672). It is important to note that the apparent decline seen in recent years may be due to delays in notifications of mesothelioma deaths to the AMR, or their lack of inclusion in the NDI linkage, rather than a real decline.

Figure 3.1 Deaths of people with mesothelioma, by year of death and sex, Australia, 1997–2015

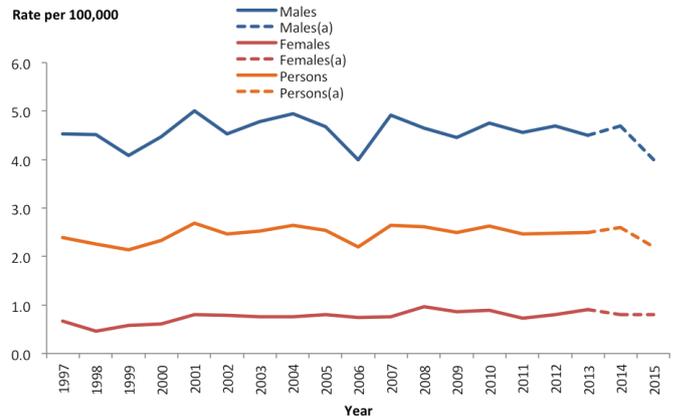


(a) Dotted line indicates data that are expected to change by 2.5 or more percent as they are updated.

Source: Table A11.

Using the same sources, age-standardised mortality rates show some fluctuation, although rates were generally stable over the period. From 2007–2014, the overall rate has remained between 2.5 and 2.6 per 100,000 (Figure 3.2).

Figure 3.2 Age-standardised mortality rates of mesothelioma, by year of death and sex, Australia, 1997–2015



(a) Dotted line indicates data that are expected to change by 2.5 or more percent as they are updated.

Source: Table A11.

4. Asbestos exposure

This section describes patient recruitment figures and the results of exposure assessment for participants diagnosed from 1 July 2010 onwards.

Patient Recruitment for the AMR

Table 4.1 presents the numbers of people who completed the recruitment process or were in the process of being recruited at 1 April 2016. This table should be interpreted in the context of Table A3 (Appendix A), which outlines the patient recruitment models used by the state and territory cancer registries.

The overall number of people diagnosed since 1 July 2010 who consented to participate in the asbestos exposure assessments was 651 at 1 April 2016. Of these, 582 people (89.4%) completed both the questionnaire and telephone interview components of the assessment (Table 4.1).

Table 4.1 Recruitment for asbestos exposure data collection, by year and state/territory, at 1 April 2016

Year of diagnosis	NSW/ACT ^(a)	Vic	Qld	WA	SA	Tas	NT	Total
Consenting patients/Postal questionnaires completed								
2010–2011	38	41	16	12	13	6	n.p.	127
2012	56	32	21	29	5	5	n.p.	148
2013	40	28	17	23	13	3	n.p.	125
2014	55	25	23	15	11	1	n.p.	131
2015	57	22	22	13	6	0	n.p.	120
Total	246	148	99	92	48	15	n.p.	651
Interviews conducted								
2010–2011	33	36	15	12	10	5	n.p.	112
2012	53	28	19	27	5	5	n.p.	137
2013	35	26	15	21	10	3	n.p.	111
2014	47	23	21	13	10	1	n.p.	116
2015	48	22	19	11	6	0	n.p.	106
Total	216	135	89	84	41	14	n.p.	582

(a) Includes six ACT participants.

n.p. Not published as requested by state/territory.

Of the 651 participants who completed the postal questionnaire, 33 (5.07%) reported having a family member who also had mesothelioma. 71 (10.9%) respondents did not answer this question.

All state and territory cancer registries undertake patient recruitment for the AMR except for ACT, which is carried out by NSW. The recruitment processes vary across the jurisdictions in line with the ethics approval and/or patient recruitment protocols in place. For AMR patient recruitment, states and territories use either a passive consent model or a non-passive model for doctor consent. A passive consent model is one where if doctors do not respond regarding their patient's eligibility within 3–4 weeks, consent is assumed and their patient is contacted. A non-passive model requires doctors' consent to be obtained before their patient could be contacted.

A passive doctor consent model is operating in majority of the states and territories, including New South Wales/ACT, Victoria, Western Australia, Tasmania and Queensland. Queensland commenced operating in a passive clinician consent model on 26 August 2015. South Australia and Northern Territory are the two remaining jurisdictions still using a non-passive doctor consent model.

Tables 4.2 and 4.3 below present actual doctor and patient recruitment numbers respectively for states and territories. These recruitment figures are provided by cancer registries in each jurisdiction as of 13 May 2016 for patients diagnosed with mesothelioma between 1 January 2015 and 31 December 2015. As there are no new cases of mesothelioma notification reported from the Northern Territory for 2015, no doctor or patient recruitment has been made.

Since Queensland Cancer Registry switched from a non-passive doctor consent recruitment model to a passive recruitment model in 2015, the Queensland doctor recruitment data is represented under both recruitment categories (Table 4.2).

Table 4.2 Doctor recruitment numbers for asbestos exposure component for patients diagnosed between 1 January 2015 and 31 December 2015, by state/territory, at 13 May 2016

	Passive consent						Non-passive consent			
	NSW/ACT	Vic	WA	Tas	Qld ^(c)	Total	Qld ^(b)	SA	NT	Total
Doctor approaches	173	100	98	4	87	462	34	37	–	71
Yes ¹	154	97	87	4	70	412	20	18	–	38
No ¹ responses	12	2	11	0	5	30	3	5	–	8
Pending passive consent period	7	1	0	0	6	14	–	–	–	0
Response rate (per cent)	–	–	–	–	–	–	68%	62%	–	65%
Consent assumed/consent 'yes' rate (per cent) ^(a)	89%	97%	89%	100%	80%	89%	59%	49%	–	54%

(a) Numbers and rates may be affected by deceased status of patients.

(b) Qld was operating as non-passive consent model between 1 January 2015 and 25 August 2015

(c) Qld has been operating with a passive consent model since 26 August 2015.

Note: Percentages may not be or add up to 100% within jurisdictions as some doctors had not yet responded and/or the passive consent period had not yet passed.

For states and territories operating the passive consent model, the overall percentage where clinician consent could be assumed or a 'yes' response received, was 89%. This is much higher than the consent/yes rate for those operating on non-passive consent models. The doctor 'yes' rate for Queensland and South Australia, operating in non-passive model, was 54% (Table 4.2). Since operating in a passive consent model, doctors' 'yes' or assumed consent rate for Queensland has improved by 36%, as compared with (59%) under the non-passive consent model.

Table 4.3 shows the number of patients approached, including questionnaires received and interviews conducted. The overall percentage of patients responding among those approached was 50.1%. This represented 31.8% of all notifications received. Of the 203 patients who responded, 127 (62.6%) consented to participate. The overall percentage of patients consenting ('yes' responses) among those approached, was 31.4%.

Table 4.3 Patient recruitment for asbestos exposure component for patients diagnosed between 1 January 2015 and 31 December 2015, by state and territory, at 13 May 2016

	Year of diagnosis							Total
	NSW/ACT ^(a)	Vic	Qld	WA	SA	Tas	NT	
Patient approaches	145	83	87	69	17	4	–	405
Responses ^(b)	86	39	43	25	10	0	–	203
Consenting patients (postal questionnaires completed)	61	22	24	13	7	0	–	127
Interviews conducted	50	22	20	11	6	0	–	109
Response rates (per cent) ^(b)								
of all approaches	59.3	47.0	49.4	36.2	58.8	0.0	–	50.1
of all notifications	41.7	26.9	32.1	22.5	26.3	0.0	–	31.8
Consent rates (per cent)								
of all responses	70.9	56.4	55.8	52.0	70.0	0.0	–	62.6
of all approaches	42.1	26.5	27.6	18.8	41.2	0.0	–	31.4
of all notifications	29.6	15.2	17.9	11.7	18.4	0.0	–	19.9

(a) Qld operating with a passive clinician consent model since 26 August 2015, which will lead to more patients being contacted.

(b) Includes both yes and no responses.

The remainder of this section includes information on the individuals who had consented to participate at 1 April 2016 and completed both a questionnaire and a telephone interview.

Asbestos exposure assessment: overview

The asbestos exposure assessment for each participant was, in the first instance, based on an assessment of each job held by the participant using job-specific modules (JSMs) (see Appendix A for detailed methodology). The occupational and non-occupational asbestos exposures of participants were assessed and classified according to the likelihood the person was exposed to asbestos above background levels.

It is important to note the assessment scheme used in this report is based on probability of exposure to asbestos and does not take into account intensity, duration or frequency of exposure. The classification used is a three-level scheme: asbestos exposure 'probable', 'possible' or 'unlikely' (Table 4.4). For jobs assessed as 'probable', exposure was further classified by level of exposure (eight-hour time-weighted average (TWA)) (Table 4.4).

For the purpose of this report, where a participant received the same JSM multiple times (i.e. for different jobs in the same field), with different jobs assessed as having different probabilities of exposure, then the highest probability of exposure derived from that JSM for that individual has been reported.

Table 4.4 Classification of assessments of exposure probability and estimated level of exposure (not taking into account frequency/duration of exposure)

Level	Description
Unlikely	No information from JSM interview to indicate exposure, or jobs not allocated JSMs because there was considered to be a low likelihood of exposure.
Possible	Information, usually from JSM interview, indicated that exposure may have occurred.
Probable	Convincing information from JSM interview data that exposure was more likely than not. Probable exposures are further classified by estimated maximum level of exposure, as follows:
	Probable low Maximum exposure less than 0.1 fibres/ml (8-hour TWA)
	Probable medium Maximum exposure 0.1–2.0 fibres/ml (8-hour TWA)
	Probable high Maximum exposure greater than 2 fibres/ml (8-hour TWA)

Note: The same categories of exposure probability have also been used in the assessment of non-occupational exposure.

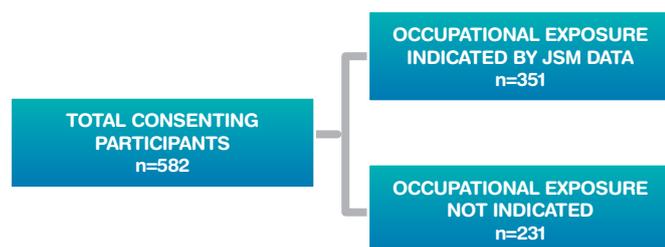
There were 582 participants who had participated fully in the exposure component at 1 April 2016. In summary, a total of 351 (60.3%) participants were assessed as having possible or probable occupational asbestos exposure, and of these, 286 also had indications of possible or probable non-occupational exposure. There were 197 (33.8%) participants with indications of non-occupational exposure but not occupational exposure. No information was found to indicate asbestos exposure in either occupational or non-occupational spheres for 34 participants (5.8%) (Table 4.5).

Table 4.5 Summary of occupational and non-occupational exposure assessment, by sex

	Exposure indicated				Total
	Occupational exposure only	Non-occupational exposure only	Both occupational and non-occupational exposure	Neither occupational or non-occupational exposure	
Males	64	98	279	23	464
Females	1	99	7	11	118
Persons	65	197	286	34	582

Figure 4.1 provides a summary of participants in relation to their occupational exposure assessment. Further details about occupational and non-occupational exposure findings are provided below. It is important to note that the data represents the exposure profiles of mesothelioma cases only. Because comparable exposure data from the general population are not available at this time, estimates of the risk of mesothelioma associated with particular exposure circumstances ascertained cannot be made.

Figure 4.1 Occupational exposure assessment summary



Note: JSM = job-specific module

Occupational asbestos exposure assessed by job-specific modules (JSMs)

JSMs were allocated to particular jobs the participant held during their working career for which more information was needed by the exposure assessment team. Job category assessments that were judged by expert assessors as having negligible asbestos exposure were not allocated JSMs, and where a participant had many similar jobs, JSMs were allocated to a representative selection.

Table 4.6 shows how many participants received each of the most commonly used JSMs at least once. A single participant could receive a particular JSM more than once for different jobs, and a single participant could receive JSMs of different types for different jobs. Each single job could only receive one JSM; therefore, the totals in Table 4.6 do not add up to the total number of participants.

The most frequently administered JSM was the Trades module, which had a total of 338 participants. The Trades module was intended to capture asbestos exposures in a wide range of trades and related jobs. In total, 141 participants were given this module to evaluate construction-related jobs, 42 participants received the Trades JSM for electrician-related jobs, 25 for plumbing-related jobs, 26 for boilermaker and/or welder-related jobs and 80 for other metal/mechanical-related jobs. JSMs for land and water transport-related jobs were given to 91 and 69 participants respectively. The Land Transport module was most frequently used for jobs involving driving or operating other mobile plant and jobs associated with maintenance of land vehicles (including heavy and light road vehicles as well as railway trains or other mobile plant). The Water Transport JSM was most frequently given for shipbuilding and/or maintenance jobs. The 'Asbestos Users N.E.C.' module was intended to capture asbestos exposure in a range of miscellaneous jobs and it was administered to 31 participants. The largest single group given this module were for laundry-related jobs.

Thirty-two participants were given other JSMs. The Asbestos Mine/Mill JSM was administered to only two participants, who reported jobs in the asbestos mining/milling industry (and exposure was assessed as probable and high for these jobs in both cases). Two participants completed the Asbestos Removal JSM, one for building demolition-related work (exposure assessed as probable/medium).

Table 4.6 Job-specific modules (JSMs) assigned to participants, by types of jobs

JSM name	Types of jobs covered by this JSM	No. of participants allocated this JSM at least once ^(a)
Trades	Construction (carpenter, joiner, builder, bricklayer etc.)	141
	Electrician	42
	Plumber	25
	Boilermaker, welder	26
	Other metal & mechanical trades (including fitters, turners, machinists)	80
	Engineer	11
	Telecommunications technician	12
	Other	77
	Total participants given Trades JSM	338
Land Transport	Driver	29
	Mechanic/fitter/panel beater	52
	Other	17
	Total participants given Land Transport JSM	91
Water Transport	Marine engineer/mechanic	22
	Other seagoing jobs (including military navy)	10
	Shipwright/boat builder	24
	Waterside worker/stevedore	7
	Other	4
	Total participants given Water Transport JSM	69
Asbestos Users N.E.C.	Laundry worker	7
	Other	25
	Total participants given Asbestos Users N.E.C. JSM	31
Other JSMs^(b)	Total participants given other JSMs	32

(a) Individuals can be allocated more than one JSM and therefore the totals in this table do not equal the total number of participants. An individual can receive the same JSM several times for different jobs, or can receive different JSMs for different jobs, as appropriate to the individual's job history.

(b) Other JSMs: furnace industry, insulator, asbestos mine/mill, asbestos removalist, automotive component manufacture, cement factory, tip worker and textile manufacture.

Table 4.7 shows how many participants received each of the most commonly reported JSMs. The highest probability/level of exposure estimated for these participants was based on the module in question. Given that participants can receive more than one type of JSM, the numbers in this table do not equal the number of participants.

Of those participants who received the Trades JSM, 273 (81.8%) were classified as probably exposed on the basis of the information they provided in response to that module. The majority of these were classified as having probable and high exposure. It is important to note that this exposure assessment method ('highest ever') tends to classify individuals as 'high' exposure level so the many 'high' exposure levels in this and subsequent tables should be interpreted with caution. It is also important to note that these findings are for mesothelioma cases, where higher levels of exposure are expected. For 45 (13.3%) of the recipients of the Trades JSM, asbestos exposure was considered unlikely based on this JSM. For the majority (62.6%) of those who received the Land Transport JSM, exposure was considered unlikely based on that JSM and for 52 (75.4%) of those who received the Water Transport JSM, evidence suggested exposure was probable.

Table 4.7 Job-specific module (JSM) exposure assessment results (probability and estimated level of exposure only), by JSM type (for JSMs used sufficiently often for meaningful interpretation)

JSM name	No. participants allocated this JSM at least once	Assessed probability of exposure (no. participants)					
		Unlikely	Possible	Probable ^(b)			
				Unknown	Low	Medium	High
Trades	338	45	20	0	3	4	266
Land Transport	91	57	1	0	0	0	33
Water Transport	69	9	8	0	8	10	34
Asbestos Users N.E.C.	31	16	4	2	0	0	9
All other JSMs ^(a)	32	11	5	1	0	7	8

(a) Other JSMs: furnace industry, insulator, asbestos mine/mill, asbestos removalist, automotive component manufacture, cement factory, tip worker and textile manufacture.

(b) These categories refer to the estimated level of asbestos exposure.

Table 4.8 shows the assessed exposure probability and level for the 338 participants who received the Trades JSM, by the most common job types reported by these participants. The majority of individuals given the Trades JSM for construction, electrical, plumbing, metal trades or other trade-related jobs were classified as having had probable asbestos exposure.

Table 4.8 Trades JSM exposure assessment results (probability and estimated level of exposure only) for largest categories of job titles

Job title	No. of participants allocated this JSM at least once	Assessed probability of exposure (no. of participants for whom asbestos exposure was assessed)				
		Unlikely	Possible	Probable ^(a)		
				Low	Medium	High
Construction (carpenter, joiner, builder, bricklayer etc.)	141	17	5	0	1	118
Electrician	42	8	6	0	0	28
Plumber	25	2	1	1	0	21
Boilermaker, welder	26	0	0	0	0	26
Other metal & mechanical trades (including fitters, turners, machinists)	80	15	6	0	2	57
Engineer	11	4	2	0	0	5
Telecommunications technician	12	7	2	0	0	3
Other	77	28	4	2	1	42
Total participants given Trades JSM	338					

(a) These categories refer to the estimated level of asbestos exposure.

Non-occupational exposure

All participants received a common questionnaire module to assess their non-occupational exposure, regardless of occupational history and irrespective of whether JSMs were also administered to that individual. Information from the non-occupational module was used to assess exposure probability and level of exposure for each participant in the same way as occupational exposure was assessed (probability: 'probable', 'possible' or 'unlikely', and level: 'high' 'medium' and 'low').

For 582 participants who completed the non-occupational questionnaire module, 483 were assessed as having had possible or probable exposure in non-occupational contexts based on data collected from this module. For 99 participants the non-occupational exposure assessment did not identify possible or probable asbestos exposure above background levels (Figure 4.2).

Figure 4.2 Non-occupational exposure assessment summary

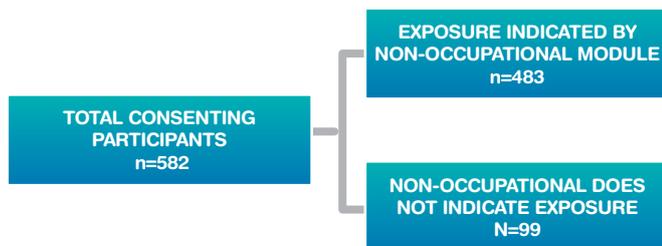


Table 4.9 shows the contexts of non-occupational asbestos exposure that were reported by the 582 participants who completed the non-occupational module.

Of the 582 participants represented in Table 4.9, 74 respondents (12.7%) reported having lived in a house made mainly of fibro and which was built between 1947 and 1987, and 15 participants (2.6%) reported having lived near an asbestos mine or factory. Three hundred and twelve respondents (53.6%) reported having ever done home renovations and 238 (40.9%) reported living in a house while renovations were occurring. Forty-five participants (7.7%) answered 'yes' to ever having visited Wittenoom.

One hundred and sixteen (19.9%) respondents reported a household member having a dusty job, however, most of these respondents either did not launder the worker's clothing and/or the worker's job details indicated that asbestos exposure was less than probable. Thirty four respondents were classified as having had probable exposure because they laundered the work clothes of a family member who had occupational asbestos exposure.

It is important to note there is an overlap between categories of exposure in Table 4.9. Among the 582 participants reported in the table, it was common to have indications of exposure in more than one non-occupational context. Therefore, a number of participants are counted in more than one category and the column totals do not add up to 582.

Although a large proportion of respondents reported information indicating the possibility of non-occupational exposure, the majority of these exposures are less certain ('possible'). Of those classed as 'probable', the level of likely exposure was 'low' in most cases.

Table 4.9: Sources of non-occupational asbestos exposure

Non-occupational module section	Assessed probability of exposure (no. of participants)						
	Total	Unlikely	Possible	Probable			
				Unknown	Low	Medium	High
Ever lived in a house made mainly of fibro (built 1947–1987)	582	508	0	0	74	0	0
Ever lived near asbestos mine or asbestos products factory	582	567	0	0	15	0	0
Ever did major home renovations which involved asbestos products (excluding paid work)	582	270	258	31	0	23	0
Ever lived in a house during major renovations (where house was built and the work undertaken during relevant periods)	582	344	238	0	0	0	0
Ever serviced car brakes/clutch (excluding paid work)	582	403	0	0	179	0	0
Ever lived in same home as someone with asbestos-exposed job who came home dusty	582	466	82	0	0	34	0
Ever visited Wittenoom in Western Australia (excluding paid work)	582	537	45	0	0	0	0
Ever visited another Australian asbestos mining town (excluding paid work)	582	571	11	0	0	0	0
Other self reported non occupational exposure	582	489	93	0	0	0	0

Exposure not indicated

For a total of 34 (5.8%) participants, no information was found to indicate asbestos exposure above background levels in either occupational or non-occupational contexts. Of these, 23 were males and 11 were females. These participants are classified as 'exposure unlikely'. It should be noted that although it has not been possible to identify asbestos exposure among these participants using the AMR exposure assessment, this does not mean that they have never been exposed to asbestos. It means that no evidence of above background exposure was obtained by the exposure assessment methods used.

Appendix A: Methods

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This report focuses on data for people diagnosed with mesothelioma during the period 1 January 2015 –31 December 2015 and notified to the AMR. The data presented in the report represents those who had been received by the Australian Mesothelioma Registry at 1 April 2016 for exposure data and 31 May 2016 for incidence data. Mortality data from the NDI was reported at 4 April 2016 and from state and territory cancer registries at 31 May 2016 (Table A1).

Table A1 Differences in AMR reports over time

AMR report	Year of publication	Date of recorded incidence	Population used for age-specific rates	Population used for age standardisation	Date of recorded mortality	Death data type and source
Mesothelioma in Australia 2011	2012	31 August 2012	Australian estimated resident population at 30 June 2011	Australian estimated resident population at 30 June 2011	12 April 2012	Number of deaths & cause of death – National Death Index
					31 August 2012	Number of deaths & cause of death – state/territory cancer registries
Mesothelioma in Australia 2012	2013	30 June 2013	Australian estimated resident population at 30 June 2012	Australian 2001 standard population	10 April 2013	Number of deaths – National Death Index
				World Standard Population (Segi 1960)	30 June 2013	Cause of death – state/territory cancer registries
Mesothelioma in Australia 2013	2014	31 May 2014	Australian estimated resident population at 30 June 2013	Australian 2001 standard population	10 March 2014	Number of deaths & cause of death – National Death Index
				World Standard Population (Segi 1960)	31 May 2014	Number of deaths & cause of death – state/territory cancer registries
Mesothelioma in Australia 2014	2015	31 May 2015	Australian estimated resident population at 30 June 2014	Australian 2001 standard population	30 March 2015	Number of deaths & cause of death – National Death Index
				World Standard Population (Segi 1960)	31 May 2015	Number of deaths & cause of death – state/territory cancer registries
Mesothelioma in Australia 2015	2016	31 May 2016	Australian estimated resident population at 30 June 2015	Australian 2001 standard population	4 April 2016	Number of deaths & cause of death – National Death Index
				World Standard Population (Segi 1960)	31 May 2016	Number of deaths & cause of death – state/territory cancer registries

Statistical methods

Age groups: The basis for most statistics is a summation of cases by five-year age groups. Age groups are expressed as whole years.

Age-specific rates are calculated by dividing the number of cases by the Australian estimated resident population of the same sex, age group and state/territory at 30 June of the year presented.

Age-standardised rates are calculated by the direct method and represent a summation of weighted age-specific rates. **The 2001 Australian standard population or the World Standard Population** (Segi 1960) is used for age-standardised rate calculations in tables, as indicated.

Rates in this report are calculated separately for males and females and are expressed as diagnoses per 100,000 population, with most data reported as the rate per 100,000.

Completeness

Notification data were complete for many data items for 2015 diagnoses. The percentage of missing mandatory fields ranged from 0.0% to 18.3%.

For 2015 deaths, there were 626 cases with a date of death recorded. Of these, the cause of death was not reported or unknown for 53.5% of the cases.

For South Australia (SA), the following data items were not provided unless the patient consented to participate: Indigenous status, country of birth, full date of birth (month and year are provided), full date of diagnosis (month and year are provided), address and all names. In Table A2, 31 of the missing cases for these fields are from SA. In addition, cause of death is provided by SA for all cases if it is sourced from linkage with the NDI; otherwise it is provided for consenting patients only, from other sources.

State and territory cancer registries may receive mesothelioma notifications without pathological confirmation. For these cases, there is some evidence to suggest mesothelioma, but not enough to satisfy the criteria of the different jurisdictions' internal coding policy, therefore, these unconfirmed mesothelioma cases have not been notified to the AMR.

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

Table A2 AMR notification fields and per cent of missing records, 2015

Field	Mandatory field	No. of records	No. of records missing/not stated	Per cent missing
Cancer registry ID/unique identifier	Yes	650	0	0.0
Record status	Yes	650	0	0.0
State/territory	Yes	650	0	0.0
Title	No	650	358	55.1
Last name	Yes	650	31	4.8
First name	Yes	650	31	4.8
Other names	No	650	258	39.7
Case address	Yes	650	31	4.8
Date of birth ^(a)	Yes	650	31	4.8
Sex	Yes	650	0	0.0
Indigenous status	Yes	650	119	18.3
Country of birth	No	650	114	17.5
Diagnosis date ^(b)	Yes	650	0	0.0
Best basis of diagnosis	Yes	650	1	0.2
Topography	Yes	650	0	0.0
Morphology	Yes	650	0	0.0
Laterality	No	650	203	31.2
Date of death ^(c)	No	626	0	0.0
Cause of death ^{(c)(d)}	No	626	335	53.5

(a) The 31 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 SA, although full dates are recorded by SA. These have not been included in missing figures as month and year of diagnosis is adequate.

(c) Based on 2015 year of death, not year of diagnosis.

(d) There are 9 cases where Cause of Death are known but this information has not been provided by SA due to patient consent status.

Data linkage with the National Death Index (NDI)

All records in the AMR at 4 April 2016 were sent to the Australian Institute of Health and Welfare (AIHW) for linkage with the NDI. The AMR data are linked with the NDI on an annual basis and the linkage provides updates to previously linked cases and those not successfully linked. The purpose of the linkage was to obtain death data, including date of death and cause of death, for all relevant records on the AMR.

Cases notified to the AMR after 4 April 2016 were not included in the data linkage; therefore, death figures may be an underestimate. However, data from state and territory cancer registries were used where NDI data were unavailable. From the recent NDI linkage, the cause of death information was not yet available for both 2014 and 2015 records. Subsequently, provisional data from states and territories were used for cause of death information for 2015, and for earlier years where NDI data were unavailable. Death data obtained from the NDI will be updated to allow reporting of death information for previous years in subsequent AMR reports.

The NDI data on deaths are based on collected data from state and territory Registrars of Births, Deaths and Marriages and coded cause of death from the Australian Bureau of Statistics (ABS). AIHW has obtained permission from National Coronial Information System to on-provide Coroner's cause of death codes to clients, and where available are included in the AMR linkage results. These data may differ to those reported by state and territory cancer registries, which may use a combination of sources including but not limited to pathology reports, other notifications and death certificates, to ascertain deaths for mesothelioma cases.

Small cells

Small cells of less than five cases have been presented in this report. This would allow the AMR to provide an accurate count of mesothelioma diagnoses and deaths in Australia, so as to inform public health and government policy relating to asbestos and mesothelioma. There is no personal information associated with these data that would allow any person to be identified; therefore it would not affect patient confidentiality or constitute a breach in privacy. Exceptions are, if state or territory cancer registry has requested for their age-standardised incidence rates for small cells to be suppressed for data presentation, or for patient recruitment counts to be suppressed for their jurisdiction.

The data in the asbestos exposure section are based on exposure judgements made by MonCOEH and not solely on demographic characteristics, so they do not directly represent information provided by interview participants. Therefore, cells of less than five cases have also been presented in this section.

Patient recruitment for asbestos exposure component

Patient recruitment for the AMR includes two main phases: contacting the patient's doctor to obtain advice on eligibility of the patient to participate in the postal questionnaire and telephone interview, and, if consent is 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 state or territory ethics approval or patient recruitment protocols. In South Australia and Northern Territory, an active or non-passive consent model is adopted, where doctors need to return a completed consent form to the relevant cancer registry to indicate consent. All other jurisdictions (NSW/ACT, Victoria, Western Australia and Tasmania) are operating on a 'passive consent' (opt out) model. A passive consent model is one where consent is assumed and the patient is contacted if doctors do not respond within three to four weeks. During August 2015, Queensland moved from operating on a non-passive clinician consent model, to recruiting on a passive clinician consent model. Table A3 presents some characteristics of the different patient recruitment processes.

For Victoria, Queensland and South Australia, consent forms are returned to the relevant cancer registry. Only those where the patient gives consent to participate are forwarded on to the AMR, along with the completed postal questionnaire.

Table A3 Characteristics of patient recruitment process, by state and territory

	NSW/ ACT	Vic	Qld	WA	SA	Tas	NT
Doctor stage							
'Opt out' for clinicians	Yes	Yes	Yes (since Aug15)	Yes	No	Yes	No
Timeframe for 'opt out'	4 wks	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 2013). These data are not presented in this report. However, all data have been coded down to the Unit Group level (six-digit classification) where possible.

Assessment of asbestos exposure

Occupation and residence 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 that 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 that can then be used to estimate the individual's occupational asbestos exposure. Participants may receive several JSMs for different jobs, or none depending on how many jobs they had for which the exposure assessor judges as requiring further investigation. Where the participant has a large number of jobs of interest, it is not feasible to administer JSMs for all jobs. A judgement is made taking into consideration the number of relevant jobs and the module lengths, with the aim to keep the telephone interview to 30 minutes or less.

Exposure in some jobs may be assessed by extrapolation of exposure probability in similar jobs held by the same participant. JSMs are not allocated to jobs with very low probability of exposure (MacFarlane et al. 2012).

Since non-occupational asbestos exposure is also relevant, a non-occupational 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 this report, exposure to asbestos has been assessed as the probability of any exposure and the estimated level of exposure. The classification of exposure probability uses a three-level scheme: 'probable', 'possible' and 'unlikely'. Jobs where there is information to indicate that exposure above background levels was likely, were assessed as 'probably exposed'. 'Possibly exposed' indicates that exposure may have occurred but was judged not to be probable. Jobs where no information was found to indicate asbestos exposure above background levels were classified as 'exposure unlikely'. The non-occupational module was assessed and classified in the same way.

For jobs assessed as 'probable' (Table 4.4), exposure was further classified by the estimated level of exposure; as 'probable high', 'probable medium' and 'probable low' (eight-hour time-weighted average). The classification of likely level of exposure in participants' jobs was informed by published exposure data supplemented by expert judgement (Fritschi et al. 2003). Estimated levels of non-occupational exposure have also been calculated. Note that some of the asbestos exposure categories presented in tables are not mutually exclusive and would not add up to 100%.

Appendix B: Additional tables

Table A4: Age-standardised incidence rates (World Standard Population), by sex and state/territory, 2015

Sex	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Rate per 100,000 population^(a)									
Males	2.0	2.0	2.2	4.7	1.1	0.3	1.2	n.p.	2.1
Females	0.6	0.4	0.7	0.9	0.4	0.5	0.0	n.p.	0.5
Persons	1.2	1.2	1.4	2.3	0.8	0.4	0.6	n.p.	1.3

(a) Directly age-standardised using the World Standard Population (Segi 1960).

n.p. Not published as requested by state/territory.

Table A5: New cases of mesothelioma and age-standardised incidence rates by sex and state/territory, 2011 to 2014

Year/Sex	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
2011									
Number									
Males	195	107	121	91	52	13	11	5	595
Females	29	30	21	12	11	1	0	1	105
Persons	224	137	142	103	63	14	11	6	700
Rate per 100,000 population^(a)									
Males	5.2	3.8	5.6	9.6	4.9	4.3	7.4	n.p.	5.3
Females	0.6	0.9	0.8	1.0	0.8	0.3	0.0	n.p.	0.8
Persons	2.7	2.2	3.0	4.4	3.0	2.1	3.4	n.p.	2.8
2012									
Number									
Males	189	128	139	87	40	14	8	0	605
Females	41	22	33	21	6	1	2	0	126
Persons	230	150	172	108	46	15	10	0	731
Rate per 100,000 population^(a)									
Males	4.9	4.4	6.2	8.9	3.6	4.2	5.5	n.p.	5.2
Females	0.8	0.6	1.3	2.1	0.5	0.2	0.4	n.p.	0.9
Persons	2.7	2.3	3.6	4.5	2.2	2.1	2.9	n.p.	2.9
2013									
Number									
Males	179	101	110	81	68	15	3	4	561
Females	40	35	25	14	12	2	3	0	131
Persons	219	136	135	95	80	17	6	4	692
Rate per 100,000 population^(a)									
Males	4.5	3.4	4.9	8.4	6.0	4.3	2.2	n.p.	4.7
Females	0.9	0.9	1.0	1.3	0.9	0.3	1.7	n.p.	0.9
Persons	2.5	2.0	2.8	3.9	3.6	2.5	1.8	n.p.	2.7
2014									
Number									
Males	176	130	140	84	47	5	8	3	593
Females	42	36	21	18	14	7	1	0	139
Persons	218	166	161	102	61	12	9	3	732
Rate per 100,000 population^(a)									
Males	4.3	4.2	6.0	8.3	4.1	1.4	3.7	n.p.	5.0
Females	0.9	1.0	0.8	1.4	1.1	1.8	0.5	n.p.	1.0
Persons	2.4	2.5	3.2	3.9	2.7	1.7	2.4	n.p.	2.8

(a) Directly age-standardised using the 2001 Australian standard population.

n.p. Not published as requested by state/territory.

Table A6 New cases of mesothelioma by age group, 2015

Age group	Number	Per cent
Less than 40	6	0.9
40–44	1	0.2
45–49	1	0.2
50–54	15	2.3
55–59	38	5.8
60–64	52	8.0
65–69	98	15.1
70–74	103	15.8
75–79	120	18.5
80–84	114	17.5
85–89	78	12.0
90 and over	24	3.7
Total	650	100.0

Table A7 New cases of mesothelioma and age-specific incidence rates, by sex and age group, 2015

Sex	<55	55–59	60–64	65–69	70–74	75–79	80–84	85+	Total
Number									
Males	13	25	38	81	88	100	88	72	505
Females	10	13	14	17	15	20	26	30	145
Persons	23	38	52	98	103	120	114	102	650
Rate per 100,000 population^(a)									
Males	0.1	3.5	6.0	14.2	21.0	33.1	44.4	41.6	4.3
Females	0.1	1.8	2.1	2.9	3.4	6.0	10.3	10.0	1.2
Persons	0.1	2.6	4.0	8.5	12.0	18.9		21.6	2.7

(a) Age-specific rates using the Australian estimated resident population at 30 June 2015.

Table A8 New cases of mesothelioma and age-standardised incidence rates by year and sex, 1982–2015

Year	Number			Rate per 100,000 population ^(a)		
	Males	Females	Persons	Males	Females	Persons
1982	134	22	156	2.3	0.3	1.2
1983	132	15	147	2.2	0.2	1.1
1984	149	17	166	2.4	0.2	1.2
1985	178	24	202	3.0	0.3	1.5
1986	195	30	225	3.0	0.4	1.6
1987	174	29	203	2.6	0.4	1.4
1988	246	31	277	3.9	0.4	1.9
1989	230	40	270	3.5	0.5	1.8
1990	256	34	290	3.9	0.4	1.9
1991	260	47	307	3.7	0.6	2.0
1992	287	39	326	4.0	0.5	2.1
1993	318	51	369	4.4	0.6	2.3
1994	373	47	420	5.0	0.5	2.6
1995	335	59	394	4.5	0.7	2.4
1996	362	53	415	4.7	0.6	2.4
1997	393	75	468	5.0	0.8	2.7
1998	412	61	473	5.1	0.6	2.6
1999	400	76	476	4.9	0.8	2.6
2000	403	77	480	4.8	0.8	2.6
2001	469	107	576	5.4	1.0	3.0
2002	456	108	564	5.1	1.0	2.8
2003	540	113	653	5.9	1.0	3.2
2004	512	93	605	5.5	0.8	2.9
2005	501	113	614	5.2	1.0	2.9
2006	490	103	593	5.0	0.9	2.7
2007	565	108	673	5.6	0.9	3.0
2008	552	115	667	5.4	0.9	2.9
2009	549	135	684	5.2	1.0	2.9
2010 ^(b)	554	132	686	5.0	1.0	2.8
2011	595	105	700	5.3	0.8	2.8
2012	605	126	731	5.2	0.9	2.9
2013 ^(c)	561	131	692	4.7	0.9	2.7
2014 ^(c)	593	139	732	5.0	1.0	2.8
2015 ^(c)	505	145	650	3.9	1.0	2.3

(a) Directly age-standardised using the 2001 Australian standard population.

(b) AMR data are available from 1 July 2010 only. For the 6-month period 1 July–31 December 2010, 350 cases have been reported to the AMR: 285 males and 65 females.

(c) Note: 2013–2015 data are expected to change by 3 or more percent as they are updated.

Source: 1982 to 2010: (AIHW 2016). 2011 to 2015: AMR.

Table A9 Deaths of people with mesothelioma by year and state/territory, 2011–2014

Year of death	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
2011	136	71	85	54	23	8	7	1	385
2012	196	116	134	60	48	13	14	1	582
2013	189	136	119	111	53	13	6	7	634
2014	194	138	157	93	73	12	4	1	672

Note: Death information from the NDI where available, otherwise from state/territory cancer registries.

Table A10 Cause of death for people with mesothelioma by year, 2011–2014

Cause of death	2011		2012		2013		2014	
	No.	Per cent						
Mesothelioma	357	94.2	544	94.4	408	93.4	381	86.4
Other ^(a)	22	5.8	32	5.6	29	6.6	60	13.6
Total	379	100	576	100	437	100	441	100

(a) May contain cases where Mesothelioma is a secondary cause of death.

Notes:

1. Excludes cases where cause of death was not known.
2. Includes cause of death information from the NDI where available, otherwise from state/territory cancer registries.

Table A11 Deaths of people with mesothelioma and age-standardised mortality rates by year of death and sex, 1997–2015

Year	Number			Rate per 100,000 population ^(a)		
	Males	Females	Persons	Males	Females	Persons
1997	353	63	416	4.5	0.7	2.4
1998	360	43	403	4.5	0.5	2.3
1999	333	57	390	4.1	0.6	2.1
2000	375	62	437	4.5	0.6	2.3
2001	434	85	519	5.0	0.8	2.7
2002	406	84	490	4.5	0.8	2.5
2003	426	84	510	4.8	0.8	2.5
2004	458	87	545	5.0	0.8	2.6
2005	445	93	538	4.7	0.8	2.5
2006	388	88	476	4.0	0.7	2.2
2007	496	93	589	4.9	0.8	2.6
2008	477	118	595	4.7	1.0	2.6
2009	474	110	584	4.5	0.9	2.5
2010	517	117	634	4.8	0.9	2.6
2011	510	100	610	4.6	0.7	2.5
2012	538	108	646	4.7	0.8	2.5
2013	537	119	656	4.5	0.9	2.5
2014 ^(b)	557	115	672	4.7	0.8	2.6
2015 ^(b)	503	123	626	4.0	0.8	2.2

(a) Directly age-standardised using the 2001 Australian standard population

(b) Note: 2014–2015 data are expected to change by 3 or more percent as they are updated.

Source: 1997 to 2013: (AIHW 2016). 2014 to 2015: AMR.

Appendix C: AMR publications

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2015

Publications

AMR (Australian Mesothelioma Registry) 2015. *Australian Mesothelioma Registry 4th annual report: Mesothelioma in Australia 2014*. NSW Health: Cancer Institute NSW. Available at: <http://www.mesothelioma-australia.com/publications-and-data/publications>.

Presentations

Benke G 2015. Australian Mesothelioma Registry. *Oral presentation at 2nd International Conference on Asbestos Awareness and Management*, Brisbane, November 2015.

2014

Publications

AMR (Australian Mesothelioma Registry) 2014. *Australian Mesothelioma Registry 3rd annual report: Mesothelioma in Australia 2013*. NSW Health: Cancer Institute NSW. Available at: <http://www.mesothelioma-australia.com/publications-and-data/publications>.

Champion de Crespigny FE, MacFarlane E, Laws P, Sim MR 2014. *Mesothelioma in Australia: monitoring disease incidence and past asbestos exposure with the Australian Mesothelioma Registry*. *Asian-Pacific Newsletter on Occupational Health and Safety* 21(2): 28–32.

Conference papers

Brims F, Laws P, MacFarlane E, van Zandwijk N, Driscoll T, Benke G, Sim MR 2014. *Mesothelioma in Australia 2013: Recent data from the Australian Mesothelioma Registry*. Oral presentation at Australian Lung Cancer Conference, Brisbane, October 2014.

Sim M, MacFarlane E, Laws P, Benke GP, Huang L, de Crespigny F, Anderson A, van Zandwijk N, Musk W, Dalton V, Scott C, Ratchford A, Armstrong B 2014. *Patterns of workplace and non-occupational asbestos exposure among mesothelioma cases in Australia: Data from the Australian Mesothelioma Registry*. Oral presentation at International Conference on Monitoring and Surveillance of Asbestos-Related Diseases, Helsinki, February 2014.

van Zandwijk N, Laws P, MacFarlane E, Brims F, Driscoll T, Benke G, Sim MR 2014. *Mesothelioma in Australia: Data from the Australian Mesothelioma Registry*. Oral presentation at International Mesothelioma Interest Group meeting, Cape Town, October 2014.

van Zandwijk N, Laws P, MacFarlane E, Benke G, Brims F, Driscoll T, Soeberg M, Sim MR 2014. *Mesothelioma in Australia*. Oral presentation at *Asian Conference on Occupational Health*, Fukuoka, September 2014.

Presentations

van Zandwijk N 2014. *Asbestos-related cancer research and prevention*. Oral presentation at 1st International Conference on Asbestos Awareness and Management, Melbourne, November 2014.

2013

Publications

AMR (Australian Mesothelioma Registry) 2013. *Australian Mesothelioma Registry 2nd annual report: Mesothelioma in Australia 2012*. NSW Health: Cancer Institute NSW. Available at: <http://www.mesothelioma-australia.com/publications.aspx>.

Conference papers

Huang L, Armstrong B, MacFarlane E, Sim MR, De Crespigny F, Anderson A, Van Zandwijk N, Musk AW, Dalton V, Scott C, Ratchford A & Laws P 2013. *Mesothelioma in Australia 2012: Data from the new Australian Mesothelioma Registry*. Poster presentation at World Conference on Lung Cancer, Sydney, October 2013.

Laws P, MacFarlane E, Sim MR, De Crespigny F, Van Zandwijk N, Musk AW, Armstrong B, Anderson A, Dalton V, Kwaan G & Forrest A 2013. *Mesothelioma in Australia 2011: Data from the new Australian Mesothelioma Registry*. Oral presentation at Thoracic Society of Australia and New Zealand Annual Scientific Meeting, Darwin, March 2013.

Presentations

Van Zandwijk N 2013. *Australian Mesothelioma Registry. Better Living with Mesothelioma workshop*, Sydney, May 2013.

2012

Publications

AMR (Australian Mesothelioma Registry) 2012. *Australian Mesothelioma Registry 1st annual report: Mesothelioma in Australia 2011*. NSW Health: Cancer Institute NSW. Available at: <http://www.mesothelioma-australia.com/publications.aspx>.

MacFarlane E, Benke G, Sim M & Fritschi L 2012. OccIDEAS: An innovative tool to assess past asbestos exposure in the Australian Mesothelioma Registry. *Safety and Health at Work* 3(1): 71–6.

Conference papers

Laws P, Huang L, Raftery A, Sim MR, Musk AW, Anderson A, Hill J, Armstrong B, van Zandwijk N 2012. *Australian Mesothelioma Registry*. Poster with oral presentation at Thoracic Society of Australia and New Zealand Annual Scientific Meeting, Canberra, April 2012.

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2010

Conference papers

Birch M-R, Huang L, Burnham A, Grayson N, Sim MR, Musk AW, Anderson A, Hill J, Armstrong B, van Zandwijk N 2010. *Australian Mesothelioma Registry*. Poster presentation at Australian Lung Cancer Conference, Melbourne, October 2010.

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Other Studies where AMR data have been published

2016

Soeberg MJ, Leigh J, Driscoll T, Armstrong B, Young JM, van Zandwijk N 2016. *Incidence and survival trends for malignant pleural and peritoneal mesothelioma, Australia, 1982–2009*. *Occupational and Environmental Medicine*. 73(3): 187-94.

Glossary

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Terms	Definition
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 that 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 a 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 some body organs and cavities.
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 and 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 and 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 programmed 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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