MESOTHELIOMA IN AUSTRALIA 2016

6th Annual Report

australian **mesothelioma** registry

Acknowledgements

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safe work australia

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Abbreviations and acronyms

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
JSM	job-specific module
MonCOEH	Monash Centre for Occupational and Environmental Health
N.E.C.	not elsewhere classified
NCIS	National Coronial Information System
NDI	National Death Index
NMD	National Mortality Database
NOHSC	National Occupational Health and Safety Commission
n.p.	not published
NSW	New South Wales
NT	Northern Territory
OccIDEAS	Occupational Integrated Database Exposure Assessment System
Qld	Queensland
SA	South Australia
SRC	Social Research Centre
Tas	Tasmania
TWA	time-weighted average
Vic	Victoria
WA	Western Australia

Executive summary

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 2017, the AMR had received 700 notifications of people newly diagnosed with mesothelioma between 1 January and 31 December 2016. Of these people, 559 were males and 141 were females, and the majority (83.9%) were aged 65 years or over at the time of diagnosis.

The annual age-specific incidence rates of mesothelioma peaked at 7.4 per 100,000 in females 80–84 years of age and 52.9 per 100,000 in males 85 plus years of age.

For diagnoses made during 2016, the most common subtype of mesothelioma was the "epithelioid" subtype (48.6%), followed by "malignant – not otherwise specified" (26.9%). The most common location was the pleura (93.1%).

An additional 60 people with mesothelioma were notified to the AMR following publication of the AMR's 2015 report. This has increased the previously reported number of cases diagnosed in 2015 from 650 to 710.

Age-standardised incidence rates

The provisional age-standardised mesothelioma incidence rate in 2016 for males and females combined was 2.5 cases per 100,000 population. For 2016, the male and female age-standardised incidence rate is 4.2 and 0.9 per 100,000 population respectively.

For the period between 2011 and 2016, the male age-standardised incidence rate had fluctuations across the years from 4.2 – 5.3 per 100,000 population, while the female age-standardised incidence rate remained stable across the years at 0.8 – 0.9 per 100,000 population.

Number of deaths

At 31 May 2017, 575 mesothelioma patients on the AMR were recorded as having died in 2016. Where there was a known cause of death, 90.4% were recorded as being due to mesothelioma.

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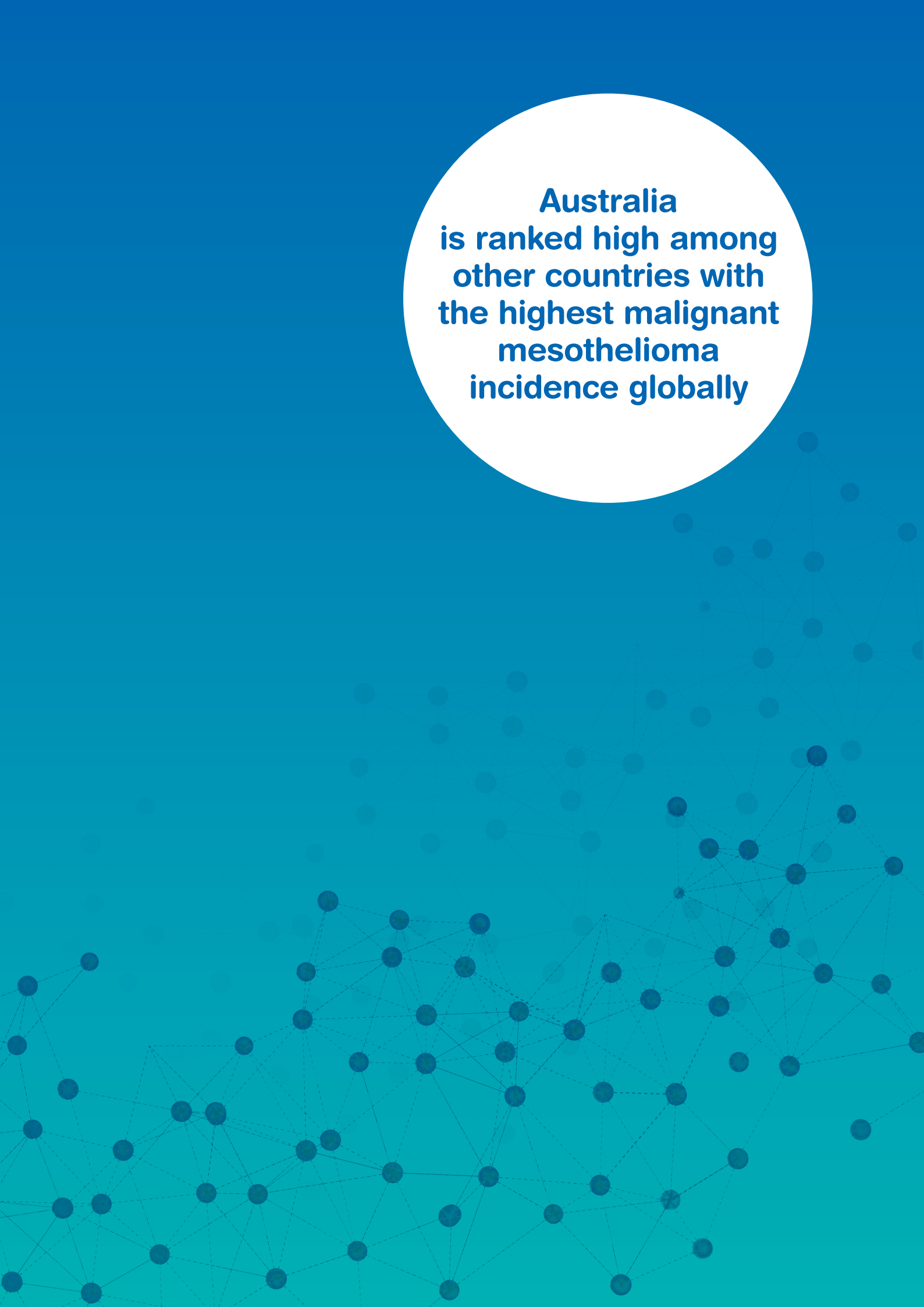
The AMR's data on asbestos exposure are based on the estimated exposure profiles of people diagnosed with mesothelioma since 1 July 2010.

Of the 793 people (628 males and 165 females) with mesothelioma who had completed the asbestos exposure questionnaire at 3 April 2017, 701 (88.4%, representing 554 males and 147 females) also completed the telephone interview.

Of the 701 who were interviewed:

- 419 (59.8%) respondents (411 males and 8 females) provided information indicating 'possible' or 'probable' occupational asbestos exposure.

- 570 (81.3%) respondents (444 males and 126 females) provided information indicating 'possible' or 'probable' asbestos exposure in non-occupational contexts.

- 651 (92.9%) respondents (524 males and 127 females) provided information indicating 'possible' or 'probable' asbestos exposure in either occupational or non-occupational settings, or both.

- 50 (7.1%) respondents (30 males and 20 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 classified 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

Purpose

This is the sixth 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 2016 to 31 December 2016. 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 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 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 in 2003
  - 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.

Figure 1.1 AMR data flow
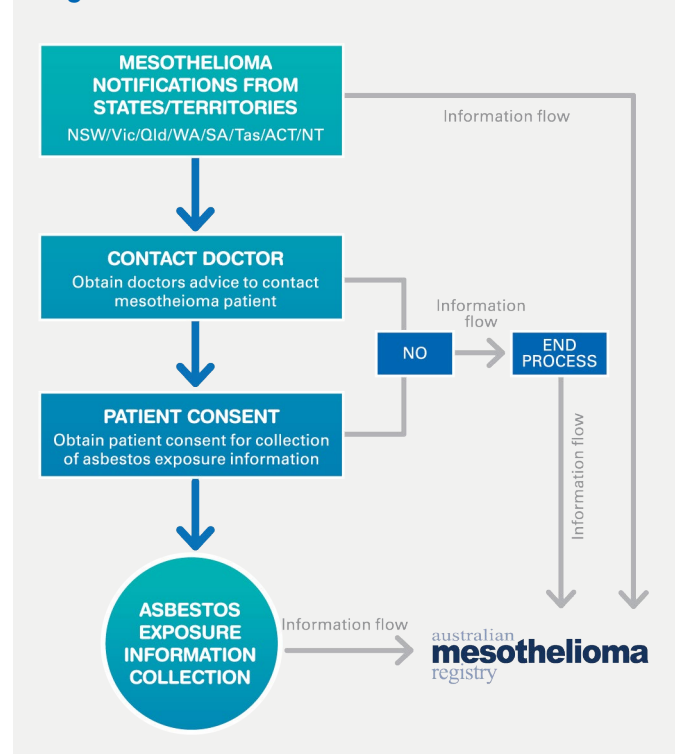
Notifications

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 and occupation histories. Until mid 2016 school histories was also collected on the postal questionnaire. Patients are also asked about their family history of mesothelioma. Patients' residence and occupation 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 the 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 telephone interview company, Social Research Centre (SRC) 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

PATIENT
completes the postal questionnaire

MonCOEH
Assigns specific interview questions based on the completed postal questionnaire

australian mesothelioma registry

Telephone Interview Company
Conducts telephone interviews with patients

Information flow

This report

This is the sixth 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 2016 to 31 December 2016.

Since the AMR's 2011 data were first published, an additional 89 people diagnosed with mesothelioma in 2011 have been notified to the AMR. Since the 2012 report, 116 new cases have been notified for that year, and since the publication of the 2013, 2014 and 2015 reports, 130, 115 and 60 new cases have been notified for those three 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 2017.

The report includes the following 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, 700 people diagnosed with mesothelioma from 1 January 2016 to 31 December 2016 had been notified to the AMR at 31 May 2017 (Table 2.1). This compares with 650 cases reported for 2015 at 31 May 2016.

Table 2.1 People in Australia newly diagnosed with mesothelioma, by year and sex, 2011 to 2016

Year of diagnosis	Males	Females	Persons
2011	595	106	701
2012	609	126	735
2013	574	131	705
2014	614	142	756
2015	554	156	710
2016	559	141	700

Since the previous publication (AMR 2016), there have been additional notifications of people diagnosed with mesothelioma reported to the AMR for all previous years: 1 for 2011 (0.1% increase), 4 for 2012 (0.5% increase), 13 for 2013 (1.9% increase), 24 for 2014 (3.3% increase) and 60 for 2015 (9.2% increase). A similar increase is anticipated in the reported number of patients diagnosed in 2016.

Table 2.2 shows the number of males and females newly diagnosed with mesothelioma by state and territory for the year 2016. The incidence rate for males and females combined was 2.5 per 100,000 population overall, and ranged from 0.5 in Tasmania to 4.5 in Western Australia. The rate for males was higher than for females in all jurisdictions and overall (4.2 and 0.9, respectively).

Table 2.2 New cases of mesothelioma and age-standardised incidence rates, by sex and state or territory, 2016

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number									
Males	210	112	91	99	34	3	9	1	559
Females	49	33	20	25	12	1	1	0	141
Persons	**259**	**145**	**111**	**124**	**46**	**4**	**10**	**1**	**700**
Rate per 100,000 population[a]									
Males	4.8	3.4	3.5	9.3	2.7	0.8	5.2	n.p.	4.2
Females	1.0	0.9	0.7	1.7	0.9	0.3	0.5	n.p.	0.9
Persons	**2.7**	**2.0**	**2.0**	**4.5**	**1.9**	**0.5**	**2.7**	**n.p.**	**2.5**

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

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 2016 age-standardised mesothelioma incidence rate is slightly lower than those in previous years of AMR data (Table A5).

For patients diagnosed in 2016, the age ranged from 21 to 95 years, with the largest proportions of new diagnoses occurring in the 65 to 84 years age groups (Table A6).

Figure 2.1 New cases of mesothelioma in Australia, by age group and sex, 2016

Source: Table A7.

Figure 2.2 Age-specific incidence rates of mesothelioma in Australia, by sex, 2016
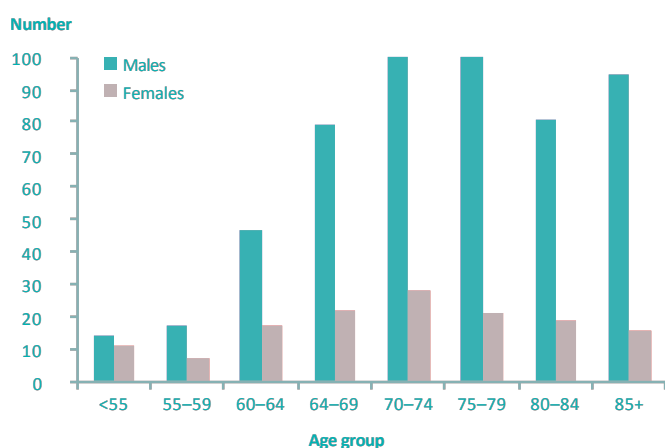
Source: Table A7.

Figure 2.1 shows the distribution by age and sex of new cases of mesothelioma diagnosed in 2016. The largest numbers are in the 75–79 year age group (145 patients), with the majority (83.9%) aged 65 years or over at the time of diagnosis (Table A7). For the 559 males diagnosed with mesothelioma in 2016, the age distribution was concentrated in age groups above 65 years. The 141 females were more evenly spread across age groups.

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 7.4 per 100,000 for females and 85 plus years of age with rates of 52.9 per 100,000 for males (Table A7).

Diagnosis information

In 2016, epithelioid mesothelioma was the most common subtype (48.6%) of mesothelioma notified to the cancer registries. Sarcomatoid mesothelioma, which includes desmoplastic mesothelioma, accounted for 13.4%. Biphasic mesothelioma (where a combination of epithelioid and sarcomatoid cells are present) represented 11.1%, while unspecified types of malignant mesothelioma accounted for 26.9% of cases (Table 2.3).

Table 2.3 New cases of mesothelioma in Australia, by histological type, 2016

Type of mesothelioma	Number	%
Epithelioid	340	48.6
Sarcomatoid[a]	94	13.4
Biphasic	78	11.1
Malignant – not otherwise specified	188	26.9
Total	**700**	**100.0**

(a) Includes desmoplastic mesothelioma.

Table 2.4 presents location of tumour information, excluding 1 case where tumour location was not stated. The most common tumour location reported in 2016 was the pleura for 93.1% of patients. Peritoneum tumour location accounted for 6.6%. Other tumour location, which includes tunica vaginalis, represented 0.3%.

Table 2.4 New cases of mesothelioma in Australia, by location of tumour, 2016

Tumour location	Number	%
Pleura[a]	651	93.1
Peritoneum[b]	46	6.6
Other[c]	2	0.3
Total	**699**	**100.0**

(a) Includes pericardium, pleura and mediastinum.

(b) Includes peritoneum and specified parts of peritoneum.

(c) Includes tunica vaginalis.

Table 2.5 shows the number of new mesothelioma cases by location of tumour diagnosed over the period 2011 – 2016. Over this period, the numbers for each category remain relatively stable with only slight variation year-on-year. In line with Table 2.4, the vast majority of mesothelioma cases diagnosed each year over the period have the tumour location as pleura. Only 7 cases have been diagnosed over the six years with a tumour location of 'other' – this includes malignant neoplasm of ovary and tunica vaginalis. Tumour location is still not known for 5 cases.

Table 2.5 New cases of mesothelioma in Australia, by location of tumour, 2011 to 2016

Year of diagnosis	Pleura[a]	Peritoneum[b]	Other[c]	Unknown	Total
2011	655	43	3	0	701
2012	694	38	0	3	735
2013	663	40	1	1	705
2014	713	42	1	0	756
2015	667	43	0	0	710
2016	651	46	2	1	700

(a) Includes pericardium, pleura and mediastinum.

(b) Includes peritoneum and specified parts of peritoneum.

(c) Includes malignant neoplasm of ovary and tunica vaginalis.

Table 2.6 presents laterality information, excluding 27 cases for non-paired organs where this was not applicable and 224 cases where laterality was not stated. There was one case of bilateral mesothelioma reported in 2016; otherwise, the most common laterality was the right side (59.2%).

Table 2.6 New cases of mesothelioma in Australia, by laterality (where applicable), 2016

Laterality	Number	%
Right	266	59.2
Left	182	40.5
Bilateral	1	0.2
Total	**449**	**100.0**

Note: Excludes cases where laterality was not known.

Table 2.7 New cases of mesothelioma in Australia, by best basis of diagnosis, 2016

Best basis	Number	%
Death certificate only	3	0.4
Clinical, no investigation[a]	4	0.6
Clinical investigation[b]	41	5.9
Specific tumour markers	0	0.0
Cytology	52	7.4
Histology[c]	600	85.7
Not stated	0	0.0
Total	**700**	**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.

The most common best basis for diagnosis category was histology (85.7%). There were three cases where diagnosis was based on the death certificate only for this period (Table 2.7). National death data for 2016 have not yet been received by all cancer registries; therefore, the total number of mesothelioma deaths reported by the AMR is likely to be an underestimate. It is expected that at least 3–4% of all incident mesothelioma cases will ultimately be 'diagnosed' by death certificate only.

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 2017) for the period 1982–2010, and the AMR for the period 2011–2016 (Table A8). To date, the highest overall number of new cases was reported in 2014 (756). 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 in Australia, by year and sex, 1982 to 2016
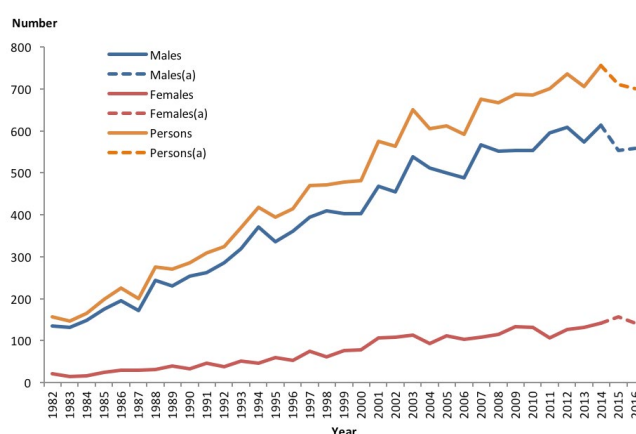
(a) Dotted lines indicate data that are expected to change by three or more percent as they are updated.

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 in Australia, by year and sex, 1982 to 2016

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

Source: Table A8.

3. Mortality

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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 2017, 575 deaths of people with mesothelioma in 2016 had been notified to the AMR (Table 3.1). The total number of deaths in the AMR for 2011 is lower than expected because the AMR only includes people diagnosed since 1 July 2010.

Table 3.1 Deaths of people with mesothelioma in Australia, by year and sex, 2011 to 2016

Year of death	Males	Females	Persons
2011	328	57	385
2012	490	93	583
2013	543	98	641
2014	568	114	682
2015	533	135	668
2016	481	94	575

The age-standardised mortality rate for 2016 was 2.0 per 100,000 (Table 3.2). The number of deaths for previous years by state and territory are presented in Table A9. The 2016 death figures are expected to increase as death information becomes available for more cases.

Table 3.2 Deaths of people with mesothelioma in Australia, by state/territory, 2016

Deaths	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	222	95	115	108	21	5	7	2	**575**
Rate per 100,000 population[a]	2.3	1.3	2.1	3.9	0.8	0.6	1.9	n.p.	**2.0**

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

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

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

Cause of death

Cause of death information from state and territory cancer registries was available for 260 of the 575 (45.2%) deaths recorded in 2016. Where cause of death was known, mesothelioma was reported as the primary cause in 90.4% of cases (in 25 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 in Australia, 2016

Cause of death	Number	%
Mesothelioma	235	90.4
Other[a]	25	9.6
Total	**260**	**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:

- 383 of the 385 (99.5%) deaths recorded for 2011
- 579 of the 583 (99.3%) deaths recorded for 2012
- 637 of the 641 (99.4%) deaths recorded in 2013
- 659 of the 682 (96.6%) deaths recorded in 2014
- 637 of the 668 (95.4%) deaths recorded in 2015 (Table A10).

Note that no cause of death information was available from the NDI for deaths in 2016, 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 2017) for 1997 – 2014, and the AMR for 2015 – 2016. To date, the highest overall number of deaths was reported in 2014 (692). 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 in incidence.

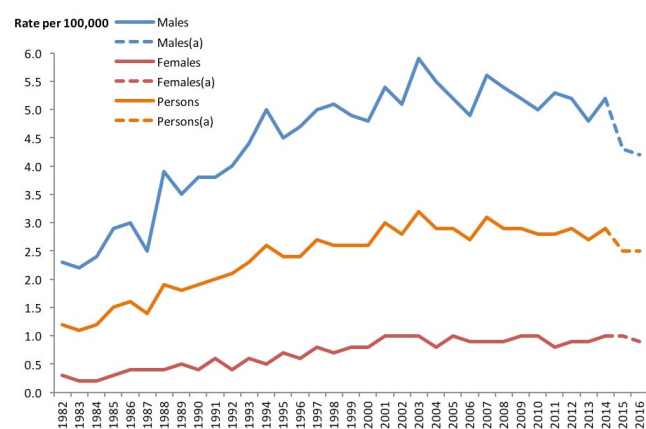### Figure 3.1 Deaths of people with mesothelioma in Australia, by year of death and sex, 1997 to 2016
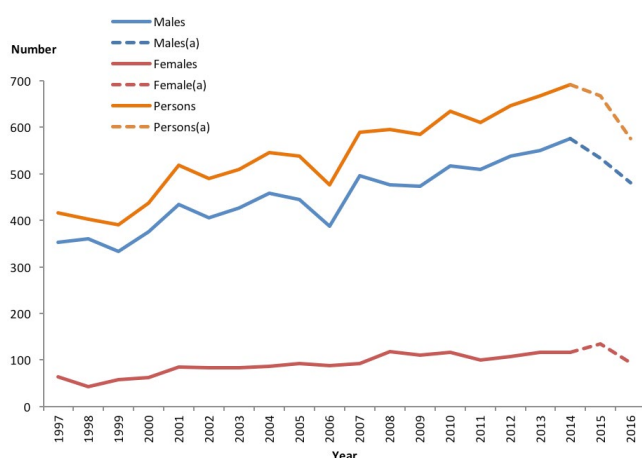
(a) Dotted line indicates data that are expected to change by 2.5 or more percent as they are updated.

Source: Table A11.

Using the same sources, age-standardised mortality rates show some fluctuation, although rates were generally stable over the period from 2007 – 2015 and the overall rate has remained stable between 2.4 and 2.6 per 100,000 (Figure 3.2).

Figure 3.2 Age-standardised mortality rates of mesothelioma in Australia, by year of death and sex, 1997 to 2016
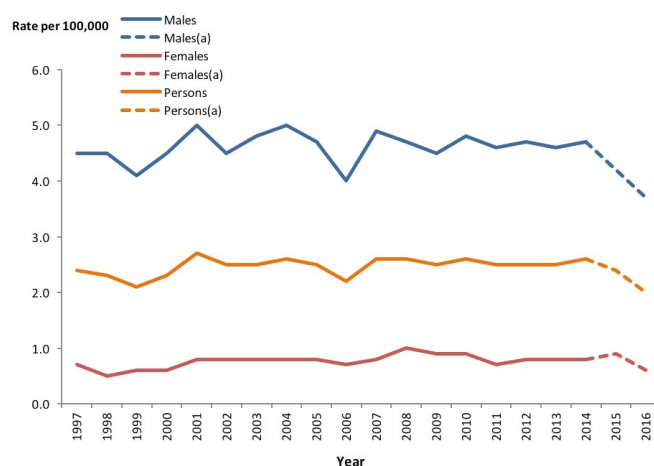
(a) Dotted line indicates data that are expected to change by 2.5 or more percent as they are updated.

Source: Table A11.

4. Asbestos exposure

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

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 3 April 2017. 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 793 (628 males and 165 females) at 3 April 2017. Of these, 701 people (88.4%, representing 554 males and 147 females) 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 3 April 2017

Year of diagnosis	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Consenting patients/Postal questionnaires completed									
2010–11	36	41	16	12	13	6	2	n.p.	127
2012	55	32	21	29	5	5	1	n.p.	148
2013	38	28	17	23	13	3	2	n.p.	125
2014	56	25	23	15	12	1	1	n.p.	134
2015	67	26	26	16	7	0	0	n.p.	142
2016	57	18	15	21	3	1	2	n.p.	117
Total	**309**	**170**	**118**	**116**	**53**	**16**	**8**	**n.p.**	**793**
Interviews conducted									
2010–11	31	36	15	12	10	5	2	n.p.	112
2012	52	28	19	27	5	5	1	n.p.	137
2013	33	26	15	21	10	3	2	n.p.	111
2014	48	23	21	13	11	1	1	n.p.	119
2015	56	26	24	14	6	0	0	n.p.	126
2016	50	13	12	16	2	1	2	n.p.	96
Total	**270**	**152**	**106**	**103**	**44**	**15**	**8**	**n.p.**	**701**

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

Of the 793 participants who completed the postal questionnaire, 47 (5.9%) reported a family member who also had mesothelioma. 82 (10.3%) respondents did not answer this question. The most common family member who had mesothelioma was brother (32.1%), followed by other family member (18.9%).

Table 4.2 Family member with mesothelioma, at 3 April 2017

Relationship	Number	%
Spouse	3	5.7
Mother	3	5.7
Father	9	17.0
Sister	3	5.7
Brother	17	32.1
Uncle	6	11.3
Grandfather	1	1.8
Grandmother	1	1.8
Other[a]	10	18.9
Total	**53**	**100.0**

(a) Other family member includes brother-in law and cousins

Note: The total does not add up to 47 as some participants reported that more than one family member had mesothelioma

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, Australian Capital Territory, Victoria, Western Australia, Tasmania, South Australia and Queensland. South Australia has moved to passive consent model from April 2017. Northern Territory is the only one jurisdiction still using a non-passive doctor consent model.

Tables 4.3 and 4.4 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 20 April 2017, for patients diagnosed with mesothelioma between 1 January 2016 and 31 December 2016.

Table 4.3 Doctor recruitment numbers for asbestos exposure component for patients diagnosed between 1 January 2016 and 31 December 2016, at 20 April 2017

	Passive consent							Non-passive consent	
	NSW	Vic	Qld	WA	Tas	ACT	Total	SA	NT
Doctor approaches	183	102	95	104	4	7	**495**	37	—
'Yes' responses/ consent assumed	162	100	86	88	3	7	**446**	19	—
'No' responses	12	0	9	10	1	0	**32**	6	—
Pending passive consent period	9	2	0	6	0	0	**17**	—	—
Response rate (per cent)	—	—	—	—	—	—	**—**	67.6	—
Consent assumed/ consent 'yes' rate (per cent)[a]	88.5	98.0	90.5	84.6	75.0	100.0	**90.1**	51.4	—

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

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 in passive consent model, the overall percentage where clinician consent could be assumed or a 'yes' response received, was 90.1%. This is much higher than the consent/yes rate for those operating on non-passive consent models. The doctor 'yes' rate for South Australia, operating in non-passive model was 51.4% (Table 4.3).

Table 4.4 shows the number of patients approached, including questionnaires received and interviews conducted. The overall percentage of patients responding among those approached, was 45.8%. This represented 29.3% of all notifications received. Of the 200 patients who responded, 123 (61.5%) consented to participate. The overall percentage of patients consenting ('yes' responses) among those approached, was 28.1%.

Table 4.4 Patient recruitment numbers for asbestos exposure component for patients diagnosed between 1 January 2016 and 31 December 2016, at 20 April 2017

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Patient approaches	149	92	79	90	18	2	7	—	**437**
Responses [a]	83	39	31	33	8	1	5	—	**200**
Consenting patients (postal questionnaires completed)	59	20	15	21	5	1	2	—	**123**
Interviews conducted	50	15	13	16	2	1	2	—	**99**
Response rates (per cent) [a]									
of all approaches	55.7	42.4	39.2	36.7	44.4	50.0	71.4	—	**45.8**
of all notifications	32.8	27.5	28.7	28.0	17.4	25.0	50.0	—	**29.3**
Consent rates (per cent)									
of all responses	71.1	51.3	48.4	63.6	0.0	0.0	40.0	—	**61.5**
of all approaches	39.6	21.7	19.0	23.3	27.8	50.0	28.6	—	**28.1**
of all notifications	23.3	14.1	13.9	17.8	10.9	25.0	20.0	—	**18.0**

(a) Includes both yes and no responses

The remainder of this section includes information on the individuals who had consented to participate at 3 April 2017 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 that 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 4.5). For jobs assessed as 'probable', exposure was further classified by level of exposure (eight-hour time-weighted average (TWA)) (Table 4.5).

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 4.5 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 high Maximum exposure greater than 2 fibres/ml (8-hour TWA)
	Probable medium Maximum exposure 0.1–2.0 fibres/ml (8-hour TWA)
	Probable low Maximum exposure less than 0.1 fibres/ml (8-hour TWA)

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

Table 4.6 Summary of occupational and non-occupational exposure assessment, by sex

	Exposure indicated				
	Occupational exposure only	Non-occupational exposure only	Both occupational and non-occupational exposure	Neither occupational or non-occupational exposure	Total
Males	80	113	331	30	554
Females	1	119	7	20	147
Persons	**81**	**232**	**338**	**50**	**701**

As at 3 April 2017, there were 701 participants who had participated fully in the exposure assessment. In summary, a total of 419 (59.8%) participants were assessed as having possible or probable occupational asbestos exposure, and of these, 338 also had indications of possible or probable non-occupational exposure. There were 232 (33.1%) participants with indications of non-occupational exposure but not occupational exposure. For 50 participants (7.1%) the exposure assessment process did not yield information indicating asbestos exposure in either occupational or non-occupational contexts (Table 4.6).

Figure 4.1 shows numbers of men and women participants for whom occupational and/or non-occupational exposure were assessed as possible or probable. Further details about occupational and non-occupational exposure findings are provided below. It is important to note that the data presented represent the exposure profiles of participating 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 cannot be made.

Figure 4.1 Occupational exposure assessment summary

TOTAL CONSENTING PARTICIPANTS
n=701

OCCUPATIONAL EXPOSURE INDICATED BY JSM DATA
n=419

OCCUPATIONAL EXPOSURE NOT INDICATED
n=282
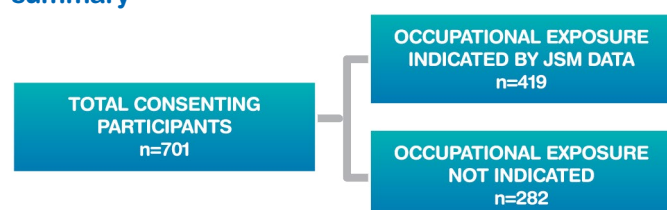
Note: JSM = job-specific module

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

Job Specific Modules (JSMs) were allocated to particular jobs that the participant held during their working career for which more information was needed by the exposure assessment team. Jobs reported by participants judged by the exposure assessors as having negligible likelihood of asbestos exposure were not allocated JSMs, and where a participant had many similar jobs, JSMs were allocated to a representative selection.

Table 4.7 shows how many participants received each of the most commonly used JSMs at least once. Although each job can receive only one JSM, a single participant can receive a particular JSM more than once for different jobs, and a single participant can receive JSMs of different types for different jobs. Therefore, the totals in Table 4.7 do not equal the number of participants.

The most frequently administered JSM was the Trades module, which had a total of 401 participants given this module. The Trades JSM is intended to capture asbestos exposures in a wide range of trades and related jobs. In total, 168 participants were given this module to evaluate construction-related jobs, 52 participants received the Trades JSM for electrician-related jobs, 29 for plumbing-related jobs, 29 for boilermaker and/or welder-related jobs and 94 for other metal/mechanical-related jobs. JSMs for land and water transport-related jobs were given to 106 and 79 participants respectively. The Land Transport module was most frequently used for jobs involving driving vehicles or 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 marine maintenance jobs. The 'Asbestos Users N.E.C.' JSM is intended to capture asbestos exposure in a range of miscellaneous jobs and it was administered to 45 participants. Used for a wide range of diverse miscellaneous jobs, the largest single group given this module were given it for laundry-related jobs.

Forty six participants were given other JSMs. The Asbestos Mining/Milling JSM was administered to only three participants who reported jobs in asbestos mining/milling operations and exposure was assessed as probable for all these jobs. Three participants completed the Asbestos Removal JSM, two for building demolition-related work and exposure was assessed as probable for all these jobs.

Table 4.7 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.)	168
	Electrician	52
	Plumber	29
	Boilermaker, welder	29
	Other metal & mechanical trades (including fitters, turners, machinists)	94
	Engineer	11
	Telecommunications technician	12
	Other	103
	Total participants given Trades JSM	**401**
Land Transport	Driver	33
	Mechanic/fitter/panel beater	59
	Other	24
	Total participants given Land Transport JSM	**106**
Water Transport	Marine engineer/mechanic	25
	Other seagoing jobs (including military navy)	17
	Shipwright/boat builder	31
	Waterside worker/stevedore	7
	Other	4
	Total participants given Water Transport JSM	**79**
Asbestos Users N.E.C.	Laundry worker	8
	Other	38
	Total participants given Asbestos Users N.E.C. JSM	**45**
Other JSMs[b]	**Total participants given other JSMs**	**46**

(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 4.8 shows how many participants received each of the most commonly allocated JSMs and 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, 329 (82%) 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 had a high level of exposure. It is important to note that this exposure assessment metric ('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 this in mind. It is also important to note that these findings are for mesothelioma cases, where higher levels of exposure are to be expected. For 51 (12.7%) of the recipients of the Trades JSM, asbestos exposure was considered unlikely based on this JSM. For the majority (61.3%) of those who received the Land Transport JSM, exposure was considered unlikely based on that JSM and the majority (74.6%) of those who received the Water Transport JSM, exposure was considered probable.

Table 4.8 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	401	51	21	0	3	4	322
Land Transport	106	65	1	0	0	0	40
Water Transport	79	10	10	0	9	13	37
Asbestos Users N.E.C.	45	25	4	3	0	0	13
All other JSMs[a]	46	16	8	4	0	8	10

(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 4.9 shows the assessed exposure probability and level for the 401 participants who received the Trades JSM, the most frequently administered JSM module, by the most common job types for which this JSM was given. 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 4.9 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.)	168	22	5	0	1	140
Electrician	52	9	7	0	0	36
Plumber	29	2	1	1	0	25
Boilermaker, welder	29	0	0	0	0	29
Other metal & mechanical trades (including fitters, turners, machinists)	94	15	6	1	2	70
Engineer	11	4	2	0	0	5
Telecommunications technician	12	7	2	0	0	3
Other	103	34	5	2	2	60
Total participants given Trades JSM	**401**					

(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 any Job Specific Modules 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 701 participants who completed the non-occupational questionnaire module, 570 were assessed as having had possible or probable exposure in non-occupational context/s based on data collected from this module. For 131 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
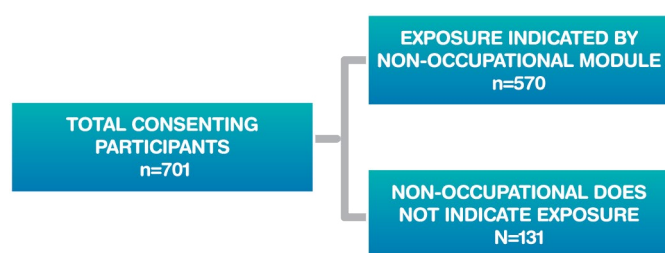
Table 4.10 shows the contexts of non-occupational asbestos exposure that were reported by the 701 participants who completed the non-occupational module.

Of the 701 participants represented in Table 4.10, 79 respondents (11.3%) reported ever living in a house made mainly of fibro and which was built between 1947 and 1987 and 16 participants (2.3%) reported having lived near an asbestos mine or factory. Three hundred and sixty three respondents (51.8%) reported having ever done home renovations, however only a minority of these were assessed as having had probable exposure in this context (16.5% of those who had reported having done any home renovations). Two hundred and eighty six (40.8%) reported living in a house while renovations were occurring. Fifty-six participants (7.9%) answered 'yes' to ever having visited Wittenoom.

One hundred and thirty six (19.4%) respondents reported ever living in a household with someone who had a dusty job, however, most of these respondents either did not launder the worker's clothing and/or the worker's job details provided indicated that asbestos exposure was less than probable. Forty three respondents were classified as having had probable exposure because they laundered the work clothes of a household member for whom the details of their job provided by the respondent was consistent with plausible asbestos exposure.

It is important to note there is overlap between categories of exposure in Table 4.10. Among the 701 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 exceed 701.

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 likely to have been 'low' in most cases.

Table 4.10 Sources of non-occupational asbestos exposure

Non-occupational module section	Total	Unlikely	Possible	Probable			
				Unknown	Low	Medium	High
Ever lived in a house made mainly of fibro (built 1947–1987)	701	622	0	0	79	0	0
Ever lived near asbestos mine or asbestos products factory	701	685	0	0	16	0	0
Ever did major home renovations which involved asbestos products (excluding paid work)	701	338	303	34	0	26	0
Ever lived in a house during major renovations (where house was built and the work undertaken during relevant periods)	701	415	286	0	0	0	0
Ever serviced car brakes/clutch (excluding paid work)	701	484	0	0	217	0	0
Ever lived in same home as someone with asbestos-exposed job who came home dusty	701	565	93	0	0	43	0
Ever visited Wittenoom in Western Australia (excluding paid work)	701	645	56	0	0	0	0
Ever visited another Australian asbestos mining town (excluding paid work)	701	687	14	0	0	0	0
Other self reported non occupational exposure	701	587	114	0	0	0	0

The header "Assessed probability of exposure (no. of participants)" spans across the Total, Unlikely, Possible, and Probable columns.

Exposure not indicated

For a total of 50 participants (7.1% of all participants, 30 men and 20 women), the exposure assessment process found no information to indicate asbestos exposure above background levels in either occupational or non-occupational contexts. However, it should be noted that although it has not been possible to identify asbestos exposure among these participants, this should not be taken to mean that these participants have never been exposed to asbestos, rather 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 2016 to 31 December 2016 and notified to the AMR. The data presented in the report represent those that had been received by the Australian Mesothelioma Registry at 3 April 2017 for exposure data and 31 May 2017 for incidence data. Mortality data from the NDI are reported at 4 April 2017 and from state and territory cancer registries at 31 May 2017 (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
Mesothelioma in Australia 2016	2017	31 May 2017	Australian estimated resident population at 30 June 2016	Australian 2001 standard population	4 April 2017	Number of deaths & cause of death – National Death Index
				World Standard Population (Segi 1960)	31 May 2017	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 2016 diagnoses. However, the percentage of missing mandatory fields ranged from 0.0% to 25.7%.

For 2016 deaths, there were 575 cases with a date of death recorded. Of these, the cause of death was not reported or unknown for 57.9% 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, 41 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.

States and territories 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, 2016

Field	Mandatory field	No. of records	No. of records missing/ not stated	Per cent missing
Cancer registry ID/unique identifier	Yes	700	0	0.0
Record status	Yes	700	0	0.0
State/territory	Yes	700	0	0.0
Title	No	700	386	55.1
Last name	Yes	700	41	5.9
First name	Yes	700	41	5.9
Other names	No	700	332	47.4
Case address	Yes	700	41	5.9
Date of birth[a]	Yes	700	41	5.9
Sex	Yes	700	0	0.0
Indigenous status	Yes	700	180	25.7
Country of birth	No	700	181	25.9
Diagnosis date[b]	Yes	700	0	0.0
Best basis of diagnosis	Yes	700	0	0.0
Topography	Yes	700	0	0.0
Morphology	Yes	700	0	0.0
Laterality	No	700	224	32.0
Date of death[c]	No	575	0	0.0
Cause of death[c][d]	No	575	333	57.9

(a) The 41 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 2016 year of death, not year of diagnosis.

(d) There are 18 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 2017 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 2017 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 2016 records. Subsequently, provisional data from states and territories were used for cause of death information for 2016, 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 (NCIS) 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 the state or territory cancer registry have 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 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 a state's or territory's ethics approval or patient recruitment protocols. In 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 (New South Wales, Australian Capital Territory, Victoria, Queensland, Western Australia, South 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. 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	Yes	Yes	Yes	Yes
Timeframe for 'opt out'	4 wks	4 wks	4 wks	3–4 wks	3 wks	3 wks	—
Patient stage							
Return of consents/ questionnaire directly to AMR	Yes	No	No	Yes	No	Yes	Yes

Note: South Australia moved to passive consent model from April 2017.

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, 2016

Sex	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
	Rate per 100,000 population[a]								
Males	2.4	1.8	1.9	5.1	1.3	0.5	2.8	n.p.	2.2
Females	0.6	0.6	0.4	1.1	0.5	0.2	0.3	n.p.	0.6
Persons	**1.4**	**1.2**	**1.1**	**2.5**	**0.9**	**0.3**	**1.4**	**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 2015

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	31	21	12	11	1	0	1	106
Persons	**224**	**138**	**142**	**103**	**63**	**14**	**11**	**6**	**701**
				Rate per 100,000 population[a]					
Males	5.2	3.8	5.6	9.8	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	193	128	139	87	40	14	8	0	609
Females	41	22	33	21	6	1	2	0	126
Persons	**234**	**150**	**172**	**108**	**46**	**15**	**10**	**0**	**735**
				Rate per 100,000 population[a]					
Males	5.0	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	0.9	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	184	104	112	81	71	15	3	4	574
Females	40	35	25	14	12	2	3	0	131
Persons	**224**	**139**	**137**	**95**	**83**	**17**	**6**	**4**	**705**
				Rate per 100,000 population[a]					
Males	4.6	3.5	5.0	8.4	6.3	4.7	2.2	n.p.	4.8
Females	0.9	0.9	1.0	1.3	0.9	0.6	1.7	n.p.	0.9
Persons	**2.5**	**2.1**	**2.8**	**3.9**	**3.7**	**2.5**	**1.8**	**n.p.**	**2.7**
2014				Number					
Males	183	129	147	83	55	7	8	2	614
Females	45	37	20	18	15	6	1	0	142
Persons	**228**	**166**	**167**	**101**	**70**	**13**	**9**	**2**	**756**
				Rate per 100,000 population[a]					
Males	4.5	4.2	6.2	8.2	4.7	2.0	5.1	n.p.	5.2
Females	1.0	1.0	0.7	1.4	1.2	1.6	0.5	n.p.	1.0
Persons	**2.5**	**2.5**	**3.3**	**3.9**	**3.1**	**1.8**	**2.4**	**n.p.**	**2.9**
2015				Number					
Males	182	128	106	91	39	3	4	1	554
Females	48	28	36	25	16	3	0	0	156
Persons	**230**	**156**	**142**	**116**	**55**	**6**	**4**	**1**	**710**
				Rate per 100,000 population[a]					
Males	4.3	4.0	4.2	8.9	3.2	0.9	2.4	n.p.	4.3
Females	1.0	0.6	1.4	1.8	1.3	0.8	0.0	n.p.	1.0
Persons	**2.5**	**2.2**	**2.7**	**4.4**	**2.4**	**0.8**	**1.1**	**n.p.**	**2.5**

(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, 2016

Age group	Number	%
Less than 40	5	0.7
40–44	5	0.7
45–49	3	0.4
50–54	12	1.7
55–59	24	3.4
60–64	64	9.1
65–69	101	14.4
70–74	130	18.6
75–79	145	20.7
80–84	100	14.3
85–89	79	11.3
90 and over	32	4.6
Total	**700**	**100.0**

Table A7 New cases of mesothelioma and age-specific incidence rates, by sex and age group, 2016

Sex	<55	55–59	60–64	65–69	70–74	75–79	80–84	85+	Total
Number									
Males	14	17	47	79	102	124	81	95	559
Females	11	7	17	22	28	21	19	16	141
Persons	**25**	**24**	**64**	**101**	**130**	**145**	**100**	**111**	**700**
Rate per 100,000 population[a]									
Males	0.2	2.3	7.3	13.5	23.2	39.5	39.8	52.9	4.7
Females	0.1	0.9	2.5	3.7	6.1	6.2	7.4	5.2	1.2
Persons	**0.1**	**1.6**	**4.9**	**8.5**	**14.5**	**22.1**	**21.7**	**22.9**	**2.9**

(a) Age-specific rates using the Australian estimated resident population at 30 June 2016.

Table A8 New cases of mesothelioma and age-standardised incidence rates, by year and sex, 1982 to 2016

Year	Males	Females	Persons	Males	Females	Persons
	Number			**Rate per 100,000 population[a]**		
1982	135	22	157	2.3	0.3	1.2
1983	132	15	147	2.2	0.2	1.1
1984	148	17	165	2.4	0.2	1.2
1985	175	24	199	2.9	0.3	1.5
1986	195	30	225	3.0	0.4	1.6
1987	172	29	201	2.5	0.4	1.4
1988	244	31	275	3.9	0.4	1.9
1989	230	40	270	3.5	0.5	1.8
1990	253	33	286	3.8	0.4	1.9
1991	262	47	309	3.8	0.6	2.0
1992	286	38	324	4.0	0.4	2.1
1993	319	51	370	4.4	0.6	2.3
1994	371	46	417	5.0	0.5	2.6
1995	335	59	394	4.5	0.7	2.4
1996	361	53	414	4.7	0.6	2.4
1997	394	75	469	5.0	0.8	2.7
1998	410	62	472	5.1	0.7	2.6
1999	402	76	478	4.9	0.8	2.6
2000	403	78	481	4.8	0.8	2.6
2001	468	107	575	5.4	1.0	3.0
2002	455	108	563	5.1	1.0	2.8
2003	538	113	651	5.9	1.0	3.2
2004	512	93	605	5.5	0.8	2.9
2005	500	112	612	5.2	1.0	2.9
2006	488	104	592	4.9	0.9	2.7
2007	567	108	675	5.6	0.9	3.1
2008	552	115	667	5.4	0.9	2.9
2009	553	134	687	5.2	1.0	2.9
2010[b]	554	132	686	5.0	1.0	2.8
2011	595	106	701	5.3	0.8	2.8
2012	609	126	735	5.2	0.9	2.9
2013	574	131	705	4.8	0.9	2.7
2014[c]	614	142	756	5.2	1.0	2.9
2015[c]	554	156	710	4.3	1.0	2.5
2016[c]	559	141	700	4.2	0.9	2.5

(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, 352 cases have been reported to the AMR: 285 males and 67 females.

(c) Note: 2014-2016 data are expected to change by 3 or more percent as they are updated.

Source: 1982 to 2010: (AIHW 2017). 2011 to 2016: AMR.

Table A9 Deaths of people with mesothelioma, by year and state/territory, 2011 to 2015

Year of death	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
2011	136	71	85	54	23	8	7	1	385
2012	197	116	134	60	48	13	14	1	583
2013	196	136	119	111	53	13	6	7	641
2014	194	138	161	93	78	13	4	1	682
2015	203	164	129	100	57	5	10	0	668

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 to 2015

Cause of death	Mesothelioma	Other[a]	Total
2011			
Number	351	32	**383**
%	91.6	8.4	**100**
2012			
Number	523	56	**579**
%	90.3	9.7	**100**
2013			
Number	589	48	**637**
%	92.5	7.5	**100**
2014			
Number	602	57	**659**
%	91.4	8.6	**100**
2015			
Number	575	62	**637**
%	90.3	9.7	**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 to 2016

Year	Males	Females	Persons	Males	Females	Persons
	Number			**Rate per 100,000 population[a]**		
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	550	117	667	4.6	0.8	2.5
2014	575	117	692	4.7	0.8	2.6
2015[b]	533	135	668	4.2	0.9	2.4
2016[b]	481	94	575	3.7	0.6	2.0

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

(b) *2015-2016 data are expected to change by 3 or more percent as they are updated.*

Source: 1997 to 2014: (AIHW 2017). 2015 to 2016: AMR

Appendix C: AMR publications

2016

Publications

AMR (Australian Mesothelioma Registry) 2016. *Australian Mesothelioma Registry 5th annual report: Mesothelioma in Australia 2015*. NSW Health: Cancer Institute NSW. Available at: http://www.mesothelioma-australia.com/publications-and-data/publications.

Conference papers

Brims F, Kwaan G, Laws P, Sim MR, Benke G, MacFarlane E, Driscoll T, van Zandwijk N 2016. *Australian Mesothelioma Registry*. Oral presentation at Australian Lung Cancer Conference, Melbourne, August 2016.

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-and-data/publications.

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-and-data/publications.

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.

Burnham A, Grayson N, Huang L, Sim MR, Musk AW, Anderson A, Hill J, Armstrong B, van Zandwijk N 2010. *Australian Mesothelioma Registry*. Poster presentation at Clinical Oncology Society of Australia Annual Scientific Meeting, Melbourne, November 2010.

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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If you would like to know more about the AMR or have any questions please contact:

Helpline
1800 378 861

Email
amr@aihw.gov.au

Website
mesothelioma-australia.com

Write to:
Australian Mesothelioma Registry
Australian Institute of Health and Welfare

GPO Box 570
Canberra ACT 2601

australian mesothelioma registry