



Mesothelioma in Australia 2019

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Australia has one of the highest measured incidence rates of mesothelioma in the world (Bray et al. 2017). Each year in Australia, between 700 and 800 people are diagnosed with the rare and aggressive cancer. Males are more likely to be diagnosed with mesothelioma than females across all age groups, and the number of cases diagnosed each year for both males and females has steadily increased over the past 40 years. There is no cure for mesothelioma. The main cause is exposure to asbestos—a material that has been banned in Australia since 2003.

This report presents the latest available statistics from the Australian Mesothelioma Registry (AMR), supplemented by data from the National Mortality Database (NMD), the Australian Cancer Database (ACD) and the National Death Index (NDI).

Main findings



659 cases of mesothelioma diagnosed in 2019 had been reported to the AMR as at 1 April 2020—the **median age at diagnosis was 75**.



Between 1987–1991 and 2012–2016, the age-adjusted **relative survival of people with mesothelioma has increased**, most notably 1-year relative survival.



In 2019, 724 deaths of people with mesothelioma (from any cause of death including mesothelioma) were recorded on the AMR—a **mortality rate of 2.9 deaths per 100,000 population**.



More than **9 in 10** of the exposure assessment participants were assessed as having **possible or probable exposure** to asbestos.

The AMR collects information on new cases of mesothelioma diagnosed in Australia since 1 July 2010. The Registry's main goals are to better understand the relationship between asbestos exposure and mesothelioma, to assist in the development of policies to best deal with asbestos still in the environment, and to provide reliable information to policy makers and researchers. For more information on the AMR, see *Mesothelioma in Australia 2019—methodology paper*.



What is mesothelioma?

Mesothelioma is a form of cancer in the mesothelium—the protective lining on the inside of body cavities and the outside of internal organs. In 2019, around 93% of cases reported to the AMR (for which tumour location information was available) were pleural mesothelioma—that is, the cancer occurs around the lungs. The other 7% of cases were mesothelioma in other areas of the body. More information on the diagnostic characteristics of cases of mesothelioma diagnosed in 2019 is available in Table A10 of *Mesothelioma in Australia 2019—data tables*. Although mesothelioma most commonly occurs in the chest, it is not a lung cancer and requires different forms of treatment (Cancer Council 2019a).

Although mesothelioma is not curable, patients can undergo one or more different treatments to increase their survival period—including chemotherapy, radiotherapy, and surgery (or all three, which is referred to as ‘trimodality therapy’) (Cancer Council 2019b). However, in the more advanced stages of the disease, the focus is on improving quality of life and easing symptoms (Cancer Council 2019c).

The main cause of mesothelioma is exposure to asbestos—a group of naturally occurring fibrous silicate materials that are invisible to the naked eye and can be inhaled into the lungs (AMR 2017) where they do not readily break down.

Australia’s use of asbestos

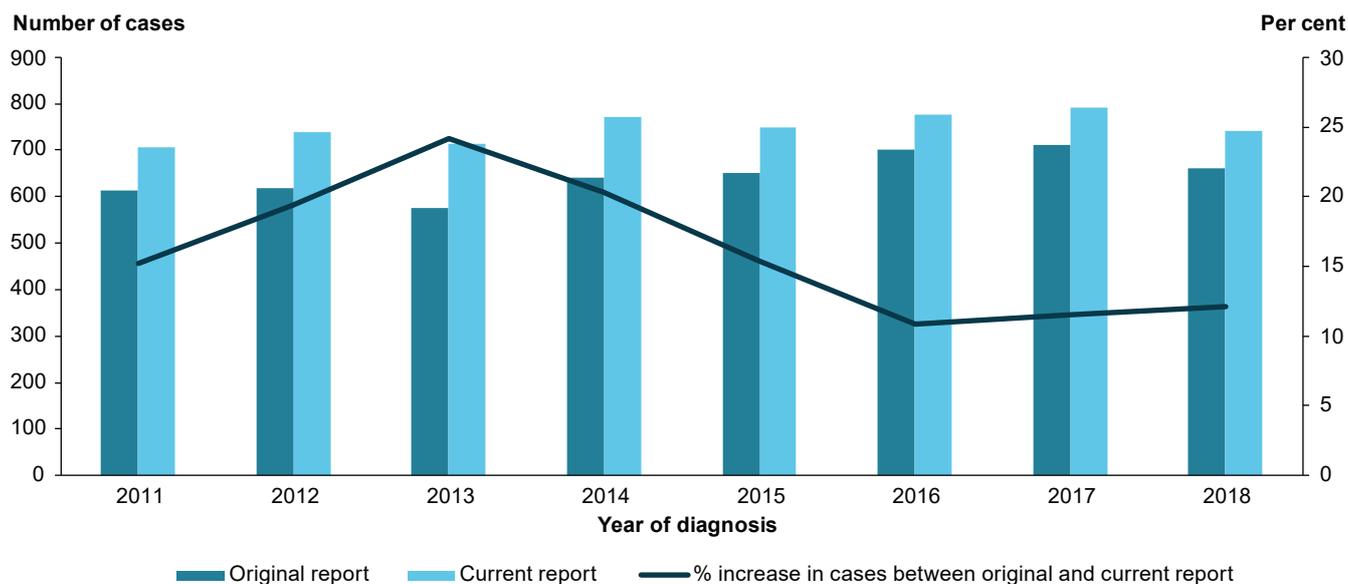
Australia’s consumption of asbestos peaked at a total of around 700,000 metric tonnes during the period 1970–1979 (Soeberg 2016; Leigh et al. 2002). Australia mined and imported asbestos, which was primarily used in the construction and transport industries because it was durable and resistant to fire and chemicals (ASEA 2016). Asbestos-related regulatory controls have been significantly tightened over time—asbestos-containing materials (ACMs) have been banned in Australia since December 2003, and it is now illegal to make, use or import it from another country. However, a large amount of asbestos still remains in older structures and products, potentially exposing workers and/or the public to asbestos if relevant safety procedures that have been identified are not followed. The Commonwealth and state and territory work health and safety authorities have put in place strict asbestos-related regulatory measures to control asbestos exposure in workplaces (including safe management and removal of asbestos), to minimise asbestos-related diseases such as mesothelioma, asbestosis and lung cancer.

How have the number of cases changed over time?

The AMR is the most up-to-date source of data on mesothelioma incidence (number of new cases) in Australia, because case notifications are fast-tracked from state and territory cancer registries to the AMR. However, most notifications are still received in the year after diagnosis because of the time it takes to make a definitive diagnosis, and the time between diagnosis and notification to cancer registries and to the AMR. For more information on AMR processes, see *Mesothelioma in Australia 2019—methodology paper*.

Because not all cases of mesothelioma are reported to the AMR in the year that they are diagnosed, the number of cases recorded for each year continues to rise for all years dating back to 2011 (Figure 1). For example, of the 714 cases of mesothelioma diagnosed in 2013 and notified to the AMR, 48% of notifications were received in the year they were diagnosed, 45% in 2014, and 7% were received between 2015 and 2018.

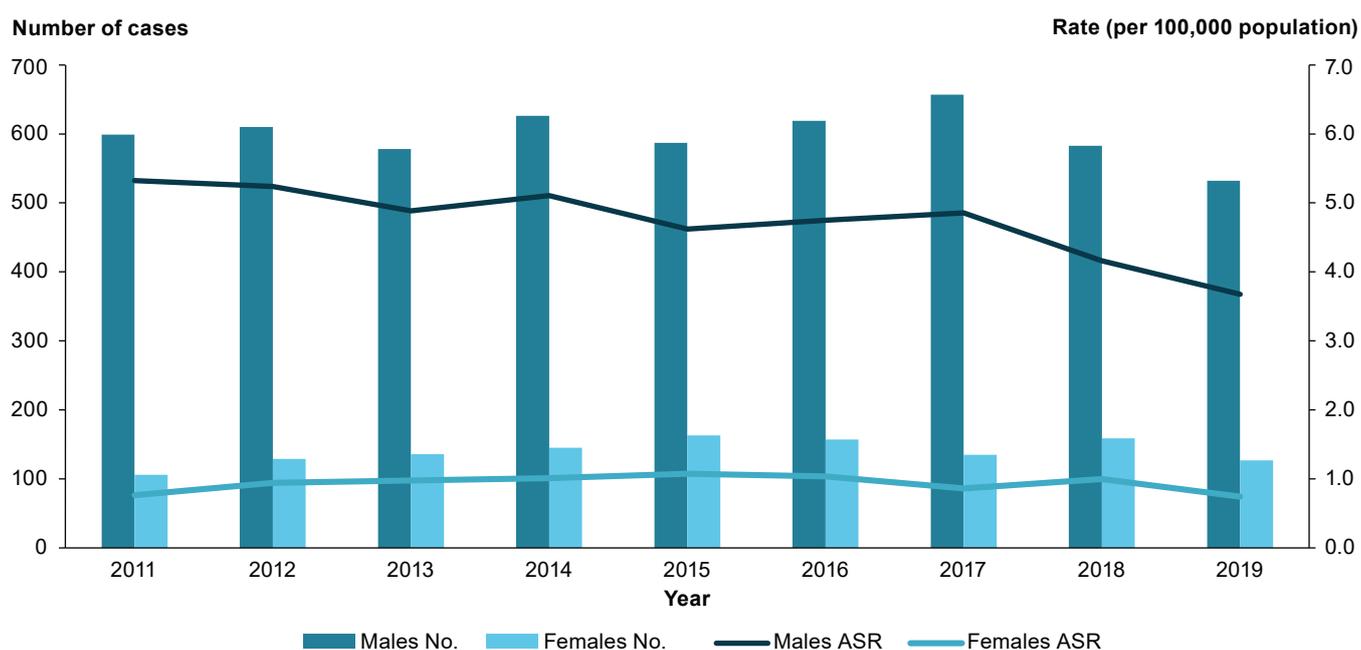
Figure 1: Difference in number of mesothelioma cases between original and current report during 2011 to 2018



Sources: AMR 2012, 2013, 2014, 2015, 2016, 2017; AIHW 2018b; AIHW 2019; AIHW analysis of AMR data at 1 April 2020; Table A1 in *Mesothelioma in Australia 2019—data tables*.

At 1 April 2020, 659 cases of mesothelioma diagnosed in 2019 had been reported to the AMR (Figure 2). Males have been consistently more likely to be diagnosed with mesothelioma than females—this is expected because the majority of cases are from exposure to asbestos in the type of environments in which males more commonly work, such as the mining and construction industries. After adjusting for differences in the age structure of the populations, current available data show that the rate for persons was around 2.7 cases per 100,000 people between 2011 and 2019; for males, it averaged 4.7 per 100,000, and for females, it averaged 0.9 per 100,000.

Figure 2: Number and age-standardised rate (per 100,000 population) of people diagnosed with mesothelioma, by year and sex, 2011 to 2019



Note: Rates have been age-standardised to the 2001 Australian Standard Population.

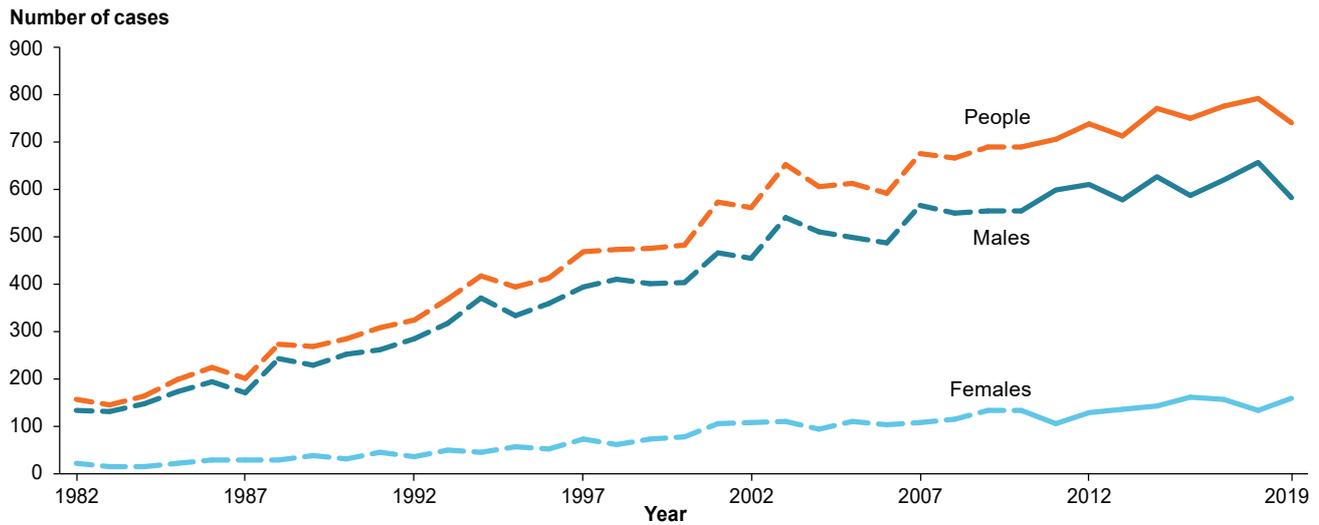
Source: AIHW analysis of AMR data at 1 April 2020; Table A2 in *Mesothelioma in Australia 2019—data tables*.

Long-term trend shows a steady increase

Reporting using AMR data is only possible for the period since July 2010 as that is when the data collection began. However, longer time trends in the number and incidence rates of mesothelioma cases can be described by combining data from the ACD for 1982–2010 and the AMR for 2011–2019.

Between 1982 and 2019, the number of new cases of mesothelioma reported annually steadily increased—from 135 to 532 for males and from 22 to 127 for females (Figure 3). To date, the highest overall number of cases (792) were those with a date of diagnosis in 2017. However, it is important to note that the apparent fall in cases in 2019 is likely due to delays in the AMR receiving notifications—the number of cases for 2019 is expected to rise in 2020 and subsequent years.

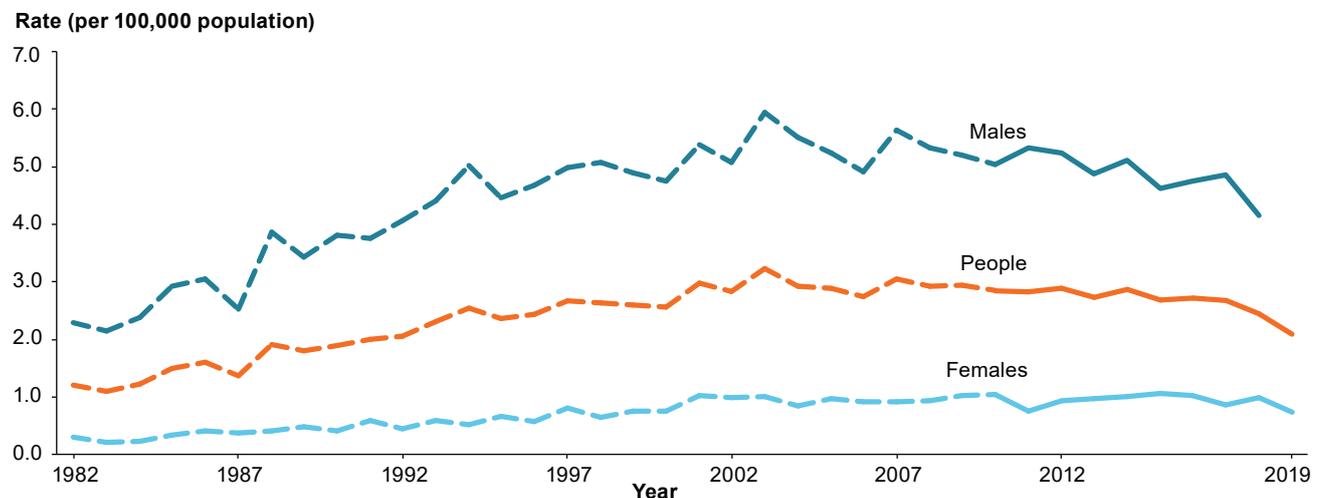
Figure 3: Number of people diagnosed with mesothelioma, by year and sex, 1982 to 2019



Sources: 1982–2010 (dotted line): AIHW 2018a; 2011–2019 (solid line): AIHW analysis of AMR data at 1 April 2020; Table A3 in *Mesothelioma in Australia 2019—data tables*.

Between 1982 and 2003, the age-adjusted incidence rate rose for both males (2.3 to 5.9 cases per 100,000 population) and females (0.3 to 1.0 cases per 100,000 population) (Figure 4). The overall incidence rate rose from 1.2 to a peak of 3.2 cases per 100,000 population in 2003, and has since remained at around 2.8 cases per 100,000 population.

Figure 4: Age-standardised rate (per 100,000 population) of people diagnosed with mesothelioma, by year and sex, 1982 to 2019



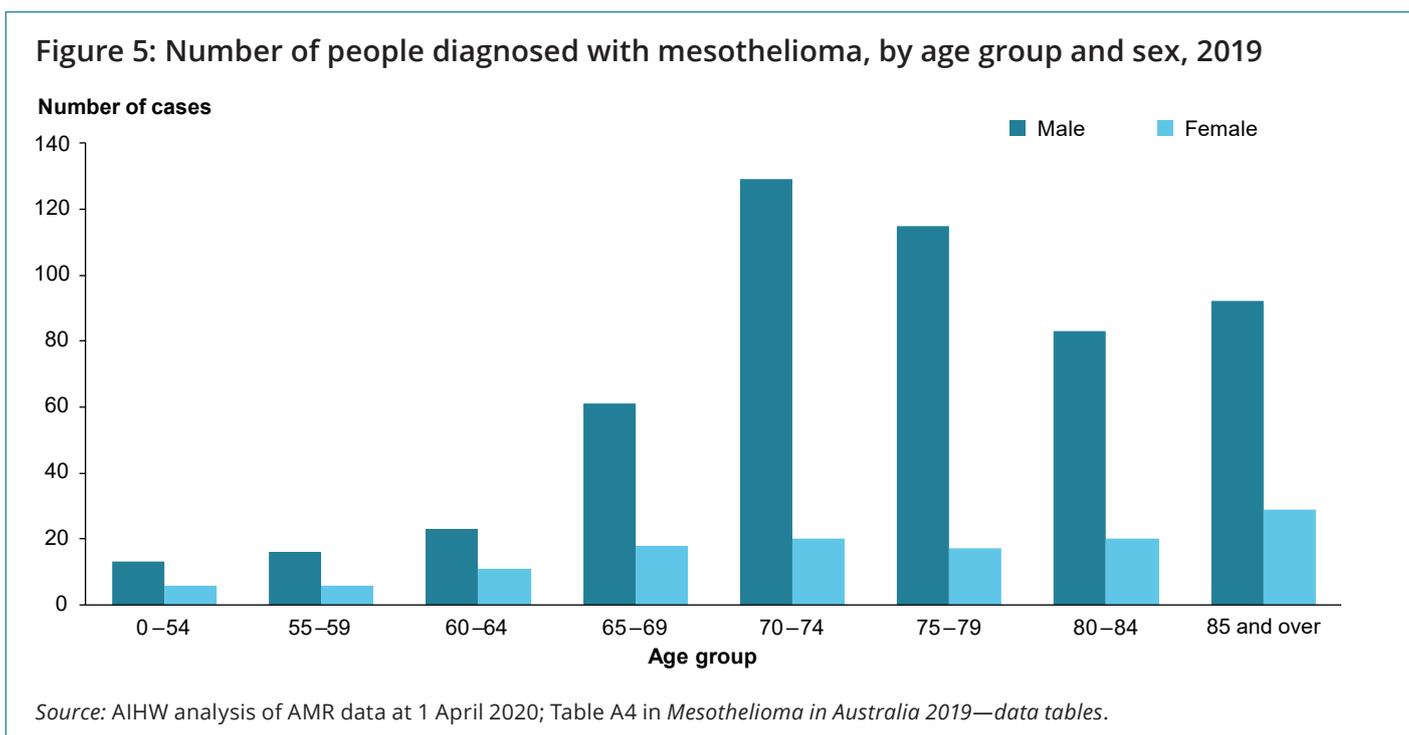
Note: Rates have been age-standardised to the 2001 Australian Standard Population.

Sources: 1982–2010 (dotted line): AIHW 2018a; 2011–2019 (solid line): AIHW analysis of AMR data at 1 April 2020; Table A3 in *Mesothelioma in Australia 2019—data tables*.

How does mesothelioma diagnosis vary by age and sex?

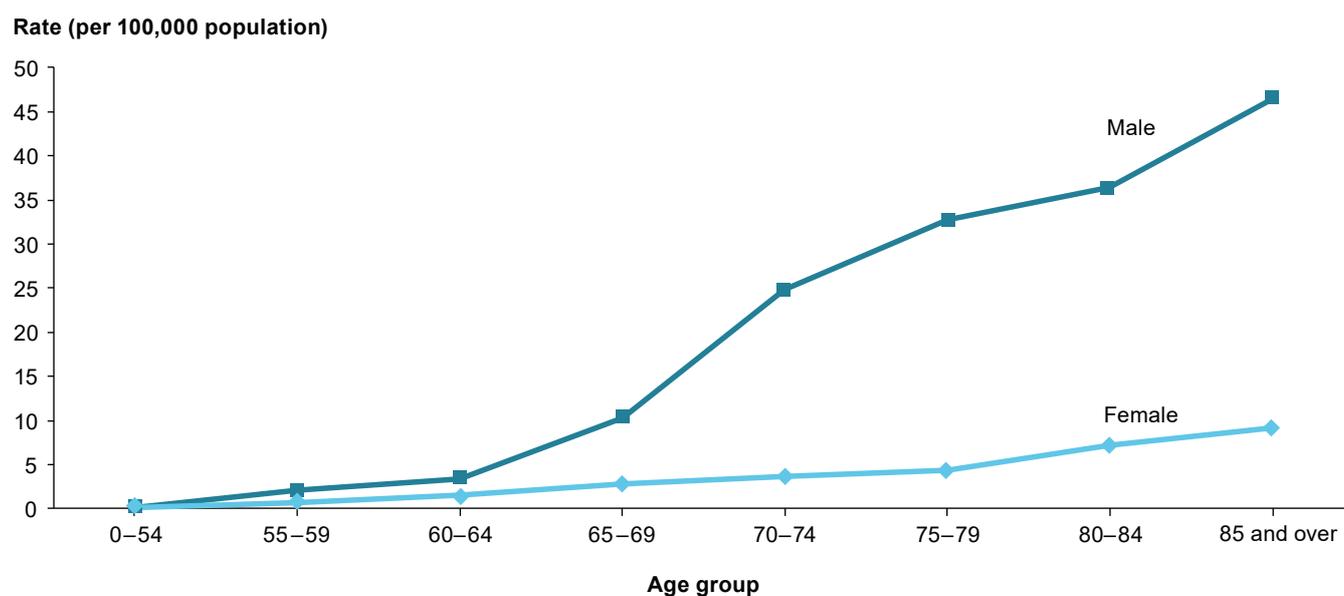
The age of people in the AMR who were diagnosed in 2019 ranged from 19 to 100 (Figure 5). The median age at diagnosis was 75, and a greater number of males than females were diagnosed across most age groups.

Mesothelioma has a long and highly varied latency period (Marinaccio et al. 2007; Shavelle et al. 2017), with symptoms typically appearing decades after a person has been exposed to asbestos. A study by Reid et al. (2014) that analysed the data of more than 22,000 people who had been exposed to asbestos found that for those with mesothelioma, the median time since first exposure to diagnosis was 38 years. A similar study by Olsen et al. (2011) based on data from people diagnosed in Western Australia between 1960 and 2008 reported a latency period of between 33 and 44 years. Most mesothelioma diagnoses are made later in life.



In 2019, age-specific mesothelioma incidence rates (the number of new mesothelioma cases per 100,000 population in specific age groups) increased with increasing age up to 85 and over for males (46.4 cases per 100,000 population) and females (9.1 cases per 100,000 population). Males consistently had higher rates than females across all age groups, with males aged 75–79 being 7 times as likely to be diagnosed as their female counterparts (Figure 6).

Figure 6: Rate (per 100,000 population) diagnosed with mesothelioma, by age and sex, 2019



Source: AIHW analysis of AMR data at 1 April 2020; Table A4 in *Mesothelioma in Australia 2019—data tables*.

How do rates vary by state and territory?

Because of the small number of people diagnosed in many age groups in some states and territories, data have been grouped for the years 2016–2019. This enables the data to be directly age standardised to remove the effect of differing age structures between the populations, which can affect incidence rates. During the period 2016–2019, age-standardised rates of mesothelioma ranged from 1.3 cases per 100,000 people in Tasmania to 4.2 cases per 100,000 people in Western Australia (Table 1)—likely due to extensive asbestos mining in the past (Cancer Council 2019a). Additional data are available for 2012–2015 in *Mesothelioma in Australia 2019—data tables*.

Table 1: Number and age-standardised rate (per 100,000 population) of people diagnosed with mesothelioma, by sex and state/territory, 2016–2019

State of diagnosis	Males		Females		People	
	No.	Rate	No.	Rate	No.	Rate
NSW	742	4.1	165	0.8	907	2.3
Vic	515	3.7	128	0.8	643	2.1
Qld	476	4.4	120	1.0	596	2.6
WA	385	7.3	98	1.6	483	4.2
SA	191	4.3	58	1.1	249	2.6
Tas	37	2.5	5	0.3	42	1.3
ACT	35	4.8	3	0.3	38	2.3
NT	10	3.8	1	0.2	11	2.0
Australia	2,391	4.3	578	0.9	2,969	2.5

Note: Due to small counts in some states and territories, data have been grouped into the years 2016–2019, to enable rates to be directly age-standardised to the 2001 Australian Standard Population.

Source: AIHW analysis of AMR data at 1 April 2020.

How long do people live after diagnosis?

What is relative survival?

Relative survival is a measure of the survival of people with cancer compared with that of the general population, and is calculated by dividing the observed survival (of people with cancer) by expected survival (of the general population), where the numerator and denominator have been matched for age, sex and calendar year.

The population diagnosed with mesothelioma continues to change over time and is more commonly older in more recent years, averaging around 75 years of age at diagnosis between 2011 and 2019 (AMR data). Even though relative survival for people with mesothelioma is improving over time, the extent of improvement reflected in relative survival rates is diminished because an increasing proportion of people with mesothelioma are older in more recent years than in the past, and survival rates for older people tend to be lower.

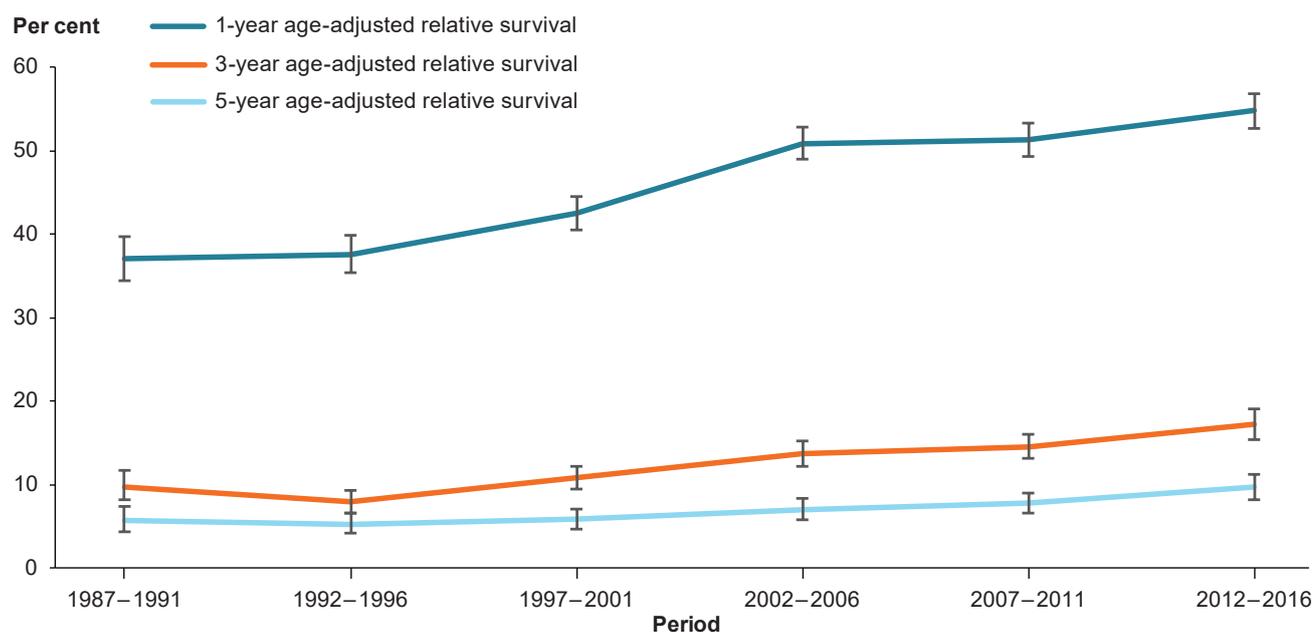
By age-adjusting to a group with a consistent age structure, such as those people with mesothelioma in 1987-1991, age-adjusted relative survival rates accounts for the impact different age structures can have on comparisons over time in relative survival rates.

Note that results presented here are not comparable with the survival rates presented in previous AMR reports. For further information see *Mesothelioma in Australia 2019—methodology paper*.

Due to its aggressive nature, mesothelioma has a very low survival rate, and this has shown little improvement over time (Faig et al. 2015). The condition is often diagnosed at advanced stages, because early symptoms can go unnoticed or be mistaken as symptoms for similar conditions or diseases (Asbestos Diseases Research Institute 2019; Cancer Council 2019a). Many factors can affect a person's chances of survival, including their age at diagnosis and overall health status, the type of mesothelioma they have, and level of exposure to asbestos (such as whether it was occupational or non-occupational and the duration of exposure) (Burgers & Damhuis 2004).

This section, which presents linked data from the ACD and NDI, shows that the amount of time that people survive after being diagnosed with mesothelioma is gradually improving over time. Figure 7 shows the 1, 3 and 5-year age-adjusted relative survival of people with mesothelioma from 1987-1991 to 2012-2016—all survival rates have increased over this period, most notably the 1-year survival. This improvement in survival may be due to factors such as earlier diagnosis and improved treatment (Musk et al. 2011).

Figure 7: 1, 3 and 5-year age-adjusted relative survival of people diagnosed with mesothelioma, 1987–1991 to 2012–2016



Notes

1. Age-adjusted relative survival rates: use a single population (the base population) and apply the survival rates (by age) for the respective time periods to this population; the base population is the 1987–1991 relative survival reporting population diagnosed with mesothelioma (that is, the group diagnosed with mesothelioma and used to calculate the 1987–1991 mesothelioma relative survival rates). These age-adjusted relative survival rates are not directly comparable with survival rates for other sexes or cancers.
2. The error bars presented in this figure represent 95% confidence intervals. A 95% confidence interval (CI) implies that there is 95% confidence that the true value will be included in this interval.

Sources: AIHW Australian Cancer Database 2016; National Death Index; Table A5 in *Mesothelioma in Australia 2019—data tables*.

Death rate continues to rise

The AMR is linked to the NDI to determine how many people registered on the AMR had subsequently died. Date and cause of death information from state and territory cancer registries was used where NDI data was not available. In 2019, 724 deaths of people with mesothelioma (with any cause of death) were recorded on the AMR—a rate of 2.9 deaths per 100,000 population (Table 2). This rate has increased from 1.9 deaths per 100,000 in 2012. The number of recorded deaths is expected to increase as more information becomes available over time. Where cause of death information was available for 2012–2019, mesothelioma was recorded as the primary (or ‘underlying’) cause of more than 90% of deaths among people with mesothelioma each year.

Table 2: Number and age-standardised rate (per 100,000 population) of deaths among people with mesothelioma, by year and sex, 2012 to 2019

Year of death	Males		Females		People	
	No.	Rate	No.	Rate	No.	Rate
2012	491	3.5	93	0.6	584	1.9
2013	545	4.0	98	0.6	643	2.2
2014	579	4.5	118	0.8	697	2.5
2015	550	4.3	146	1.0	696	2.5
2016	574	4.7	120	0.8	694	2.1
2017	608	5.1	131	0.9	739	2.8
2018	592	5.2	135	1.0	727	2.9
2019	586	5.3	138	1.1	724	2.9

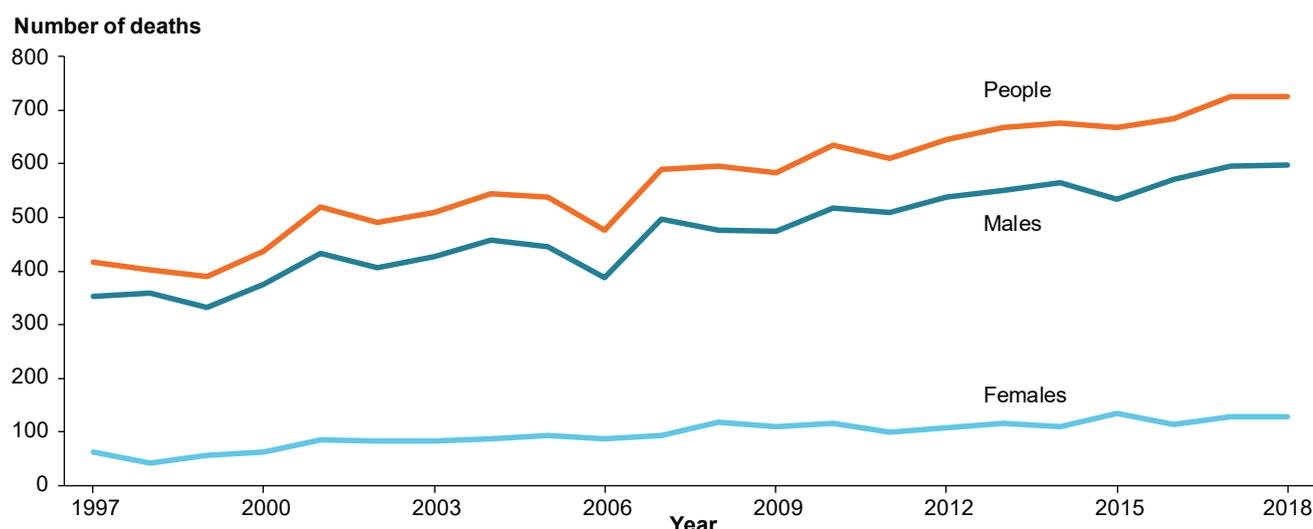
- Notes*
1. The total number of deaths for 2019 is preliminary and are expected to rise as more information becomes available.
 2. Due to delays with data linkage, results exclude any deaths from SA that occurred between 1 May 2019–31 December 2019 that were included in the National Death Index (NDI). However, any deaths reported to the AMR directly from the South Australian Cancer Registry that occurred during this period have been included.
 3. Rates have been age-standardised to the 2001 Australian Standard Population.

Source: AMR data at 1 April 2020.

This report uses the NMD to report on long-term mortality trends. The number of mesothelioma deaths has increased from 416 in 1997 to 726 in 2018—the highest number of deaths during that period. Deaths from mesothelioma increased generally but with fluctuations over the period among both males and females. For males, the number of deaths in 2018 was 1.7 times higher than in 1997, while for females there were over twice as many deaths in 2018 compared to 1997 (Figure 8).

Although the number of deaths has increased over time, the age standardised rate of deaths has remained fairly stable. The most likely reason for this is Australia’s increasing and ageing population (whereby older Australians are accounting for an increasing proportion of the population) (ABS 2019).

Figure 8: Number of deaths from mesothelioma, by year and sex, 1997 to 2018

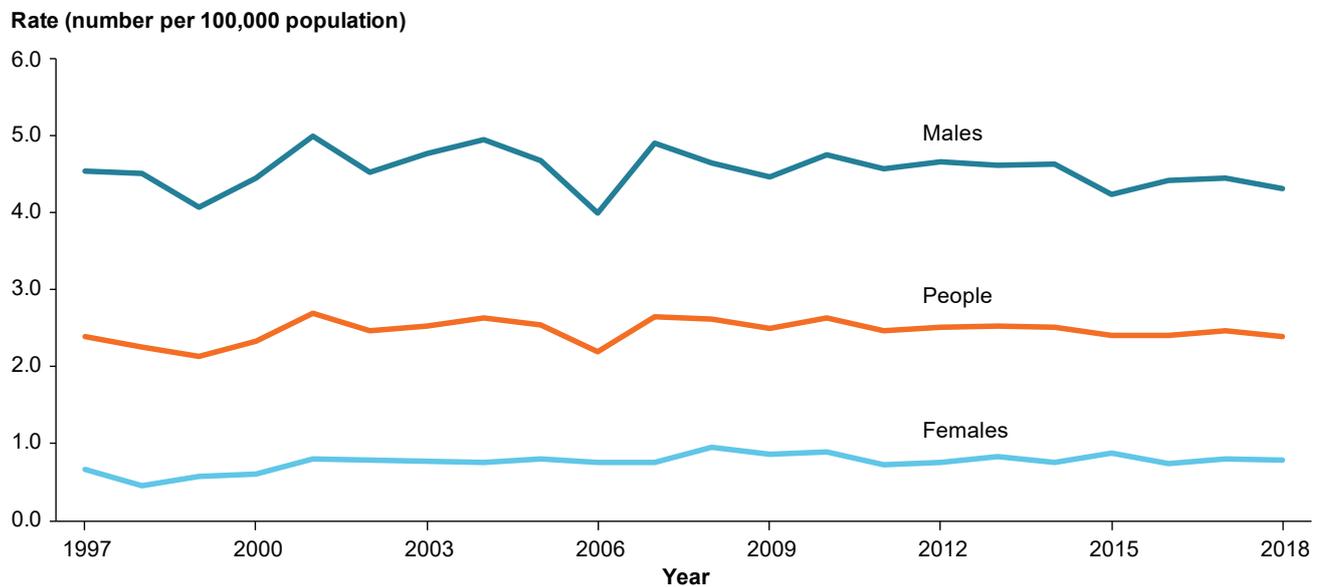


- Notes*
1. Figures are presented by year of death for 1997–2017 and year of registration of death for 2018.
 2. Deaths registered in 2015 and earlier are based on the final version of the Cause of Death Unit Record File (CODURF), deaths registered in 2016 are based on the revised version and deaths registered in 2017 and 2018 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the Australian Bureau of Statistics (ABS).
 3. The CODURF is provided to the AIHW by the Registries of Births, Deaths and Marriages and the National Coronial Information System (managed by the Victorian Department of Justice) and includes cause of death as coded by the ABS. The data are maintained by the AIHW in the National Mortality Database.

Sources: AIHW National Mortality Database; Table A6 in *Mesothelioma in Australia 2019—data tables*.

From 1997 to 2018, age-standardised mesothelioma mortality rates fluctuated between 2.1 and 2.7 deaths per 100,000 population (Figure 9). Rates for males ranged from 4.0 deaths per 100,000 in 2006 to 5.0 deaths per 100,000 population in 2001 and 2004. Rates for females fluctuated around 0.8 deaths per 100,000 over the period.

Figure 9: Age-standardised rate (per 100,000 population) of deaths from mesothelioma, by year and sex, 1997 to 2018



Notes

1. Figures are presented by year of death for 1997–2017 and year of registration of death for 2018.
2. Deaths registered in 2015 and earlier are based on the final version of the Cause of Death Unit Record File (CODURF), deaths registered in 2016 are based on the revised version and deaths registered in 2017 and 2018 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the Australian Bureau of Statistics (ABS).
3. The CODURF is provided to the AIHW by the Registries of Births, Deaths and Marriages and the National Coronial Information System (managed by the Victorian Department of Justice) and includes cause of death as coded by the ABS. The data are maintained by the AIHW in the National Mortality Database.
4. Rates have been age-standardised to the 2001 Australian Standard Population.

Source: AIHW National Mortality Database; Table A6 in *Mesothelioma in Australia 2019—data tables*.

Asbestos exposure among people with mesothelioma

Previous research has shown mesothelioma can be associated with occupational and non occupational exposure to asbestos; historically, occupational exposure has been dominated by asbestos mining, manufacturing and use of asbestos-containing materials (enHealth 2013; Safe Work Australia 2014). Because mesothelioma typically develops a long time after exposure, the majority of current cases in this report are likely related to occupational exposure in workplaces that occurred before current occupational asbestos regulations and practices came into effect. The results here should not be interpreted as indicative of current risk in workplaces today.

Over 1,100 people (904 men and 228 women) diagnosed with mesothelioma since 1 July 2010 consented to participate in the voluntary asbestos exposure assessments at 1 April 2020. Of these, 1,015 (802 men and 213 women) completed both the questionnaire and telephone interview components of the assessment.

Based on the jobs held by the participant during their working life, relevant job-specific questionnaire modules were allocated for the participant's telephone interview. For example, participants who have worked in jobs such as electrician, plumber and carpenter may be allocated the 'Trades' module. Participants could be allocated multiple job-specific modules for different jobs. Participants' lifetime exposure in non-occupational settings (such as their home) was also evaluated with a non-occupational module. For the purposes of this assessment, potential exposures to asbestos were then classified according to the likelihood that they were above background levels of 0.0001 f/ml (fibres of asbestos per millilitre) (Brown 2001). Probability of exposure was assessed as either 'probable', 'possible' or 'unlikely', and level of exposure as either 'high', 'medium' or 'low'. For more information, see *Mesothelioma in Australia 2019—methodology paper*.

Nine in ten participants were assessed as having some exposure to asbestos

More than 9 in 10 (94% or 952) people were assessed as having possible or probable exposure to asbestos (Table 3). For men, this exposure most commonly occurred in their jobs. Occupational exposure to asbestos is typically associated with higher frequency, dose and duration of exposure than non-occupational exposure.

Of the 952 people for whom exposure was detected:

- 78% (597) of men provided information indicating possible or probable occupational exposure ('occupational exposure only' and 'both occupational and non-occupational exposure'), compared with 6.8% (13) of women (Table 3).
- 99% (188) of women provided information indicating non-occupational exposure ('non occupational exposure only' and 'both occupational and non-occupational exposure'), compared with 85% (648) of men (Table 3).

Table 3: Occupational and non-occupational exposure assessment, by sex, 2010–2019

Any exposure indicated	Men		Women		People	
	No.	%	No.	%	No.	%
Occupational exposure only	115	15.1	1	0.5	116	12.2
Non-occupational exposure only	166	21.8	176	93.1	342	35.9
Both occupational and non-occupational exposure	482	63.2	12	6.3	494	51.9
Total	763	100	189	100	952	100

Note: Of the 1,015 participants, 63 (6% of) participants (39 males and 24 females) were assessed as having neither occupational nor non-occupational exposure. Although it was not 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.

Source: AIHW analysis of AMR data at 1 April 2020, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2019.

Table 4 shows the results from the asbestos exposure assessment among the 5 states and territories with the largest number of participants; New South Wales, Victoria, Queensland, Western Australia and South Australia. There were insufficient numbers of participants to present results for NT, ACT and Tasmania, so these were excluded.

Table 4 shows that the proportion of participants assessed as having:

- 'occupational exposure only' ranged from 11% to 13% across states
- 'non-occupational exposure only' ranged from 29% to 44% across states
- 'both occupational and non-occupational exposure' ranged from 43% to 60% across states.

As these percentages are based on small numbers of participants, drawing conclusions about apparent differences between states is not recommended.

Table 4: Occupational and non-occupational exposure assessment, by state, 2010–2019

Any exposure indicated	State									
	NSW		Vic		Qld		WA		SA	
	No.	%	No.	%	No.	%	No.	%	No.	%
Occupational exposure only	42	12.9	27	13.4	16	10.6	18	11.1	8	11.3
Non-occupational exposure only	113	34.8	88	43.6	44	29.1	54	33.3	29	40.8
Both occupational and non-occupational exposure	170	52.3	87	43.1	91	60.3	90	55.6	34	47.9
Total	325	100	202	100	151	100	162	100	71	100

Notes

1. Of the 1,015 participants, 63 (6% of) participants (39 males and 24 females) were assessed as having neither occupational nor non-occupational exposure. Although it was not 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.
2. There were insufficient numbers of participants to present results for NT, ACT and Tasmania to present results for those states which were precluded to ensure confidentiality.

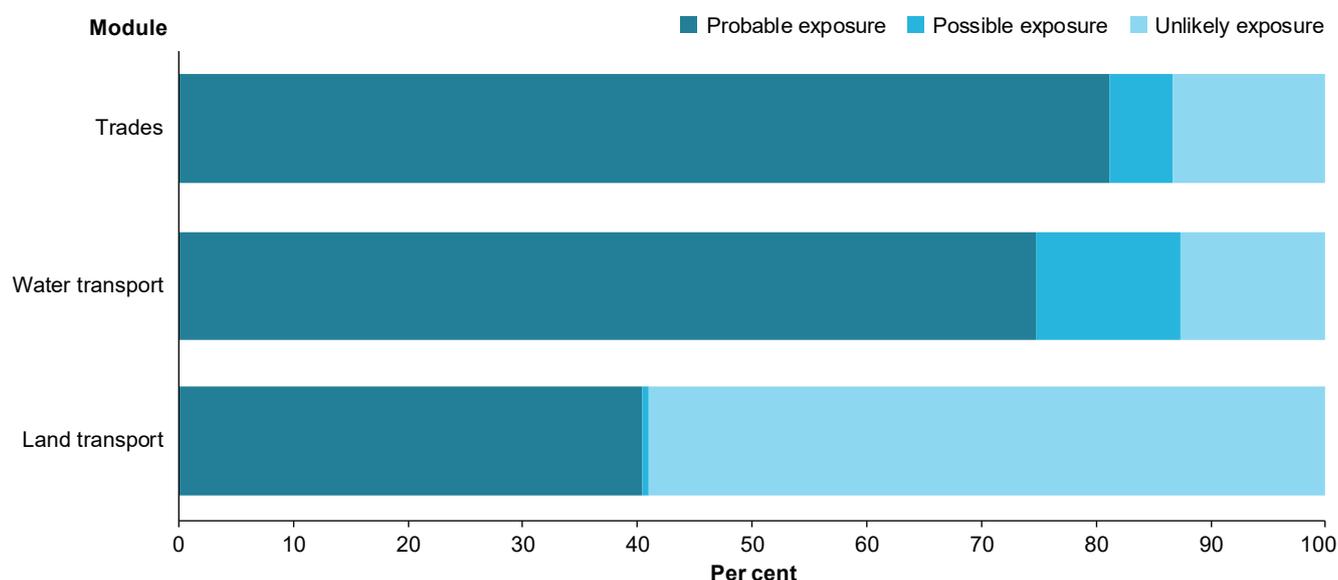
Source: AIHW analysis of AMR data at 1 April 2020, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2019.

Occupational asbestos exposure

Figure 10 shows the estimated likelihood of exposure among jobs assessed using the three most commonly allocated job-specific interview modules. Based on the interview data collected, 81% of participants who received the ‘Trades’ module, 75% of participants who received the ‘Water transport’ module, and 40% of those who received the ‘Land transport’ module, were assessed as having had ‘probable’ exposure to asbestos for jobs in those categories.

Results are based on the responses people gave to each specific module - participants are typically assigned multiple job-specific modules for different jobs, so the sum of respondents assigned to each module does not equal the total number of participants. Because questionnaire modules are assigned only to jobs with some likelihood of exposure, the finding of exposure in a high proportion of the jobs that respondents were questioned about is to be expected.

Figure 10: Exposure assessment results by most commonly used job-specific modules, 2010–2019



Source: AIHW analysis of AMR data at 1 April 2020, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2019; Table A7 in *Mesothelioma in Australia 2019—data tables*.

Occupational exposure by job type

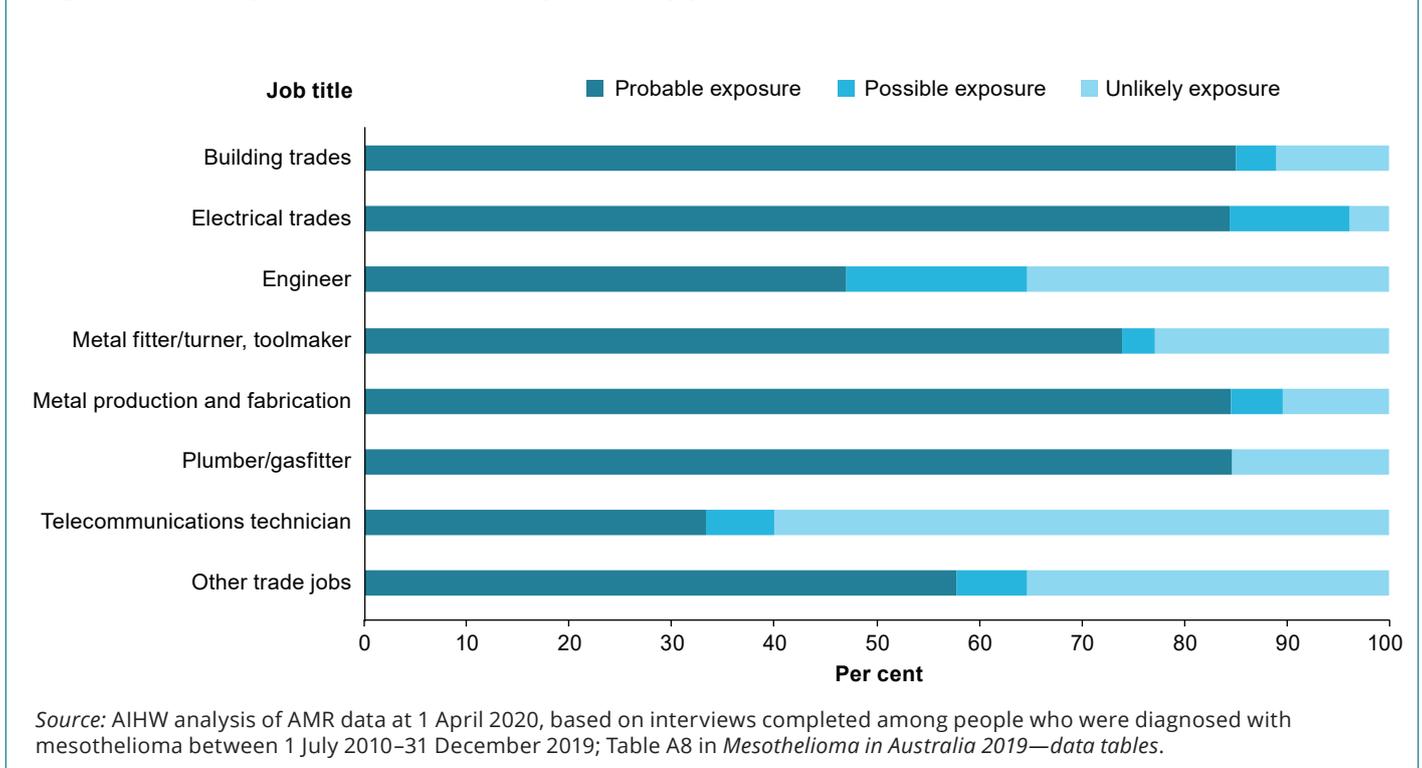
For participants who received the same module for more than one job, the results presented are based on a participant's highest exposed job in that job category. Because participants can have different exposure probabilities and/or levels for different jobs, the exposure estimate reported here is the maximum exposure likely in that job category for each individual. For example, if a participant had two trade-related jobs which were assessed as having a different probability and/or level of exposure, the higher of the two would be reported for that participant in that job category. Participants may be assigned different modules for different types of jobs, so the sum of respondents assigned to each module does not equal the total number of participants.

Jobs are coded according to the Australian and New Zealand Standard Classification of Occupations (ANZSCO).

Among participants who received the Trades module (Figure 11):

- 74% of people who had metal fitter/turner/toolmaker jobs were assessed as having had probable exposure in those jobs. For 99% of those with probable exposure, the level of exposure to asbestos was classified as 'high'.
- 85% of people who had plumber/gasfitter jobs, 84% of those who had electrical trade jobs, and 85% who had jobs in building trades, were assessed as having had probable exposure in those jobs. For the majority of these, the level of exposure was classified as 'high'.
- 60% of people who had telecommunications technician jobs and 35% who worked in engineer jobs were assessed as unlikely to have been exposed in those jobs.

Figure 11: Occupational asbestos exposure by job title for the 'Trades' module, 2010–2019

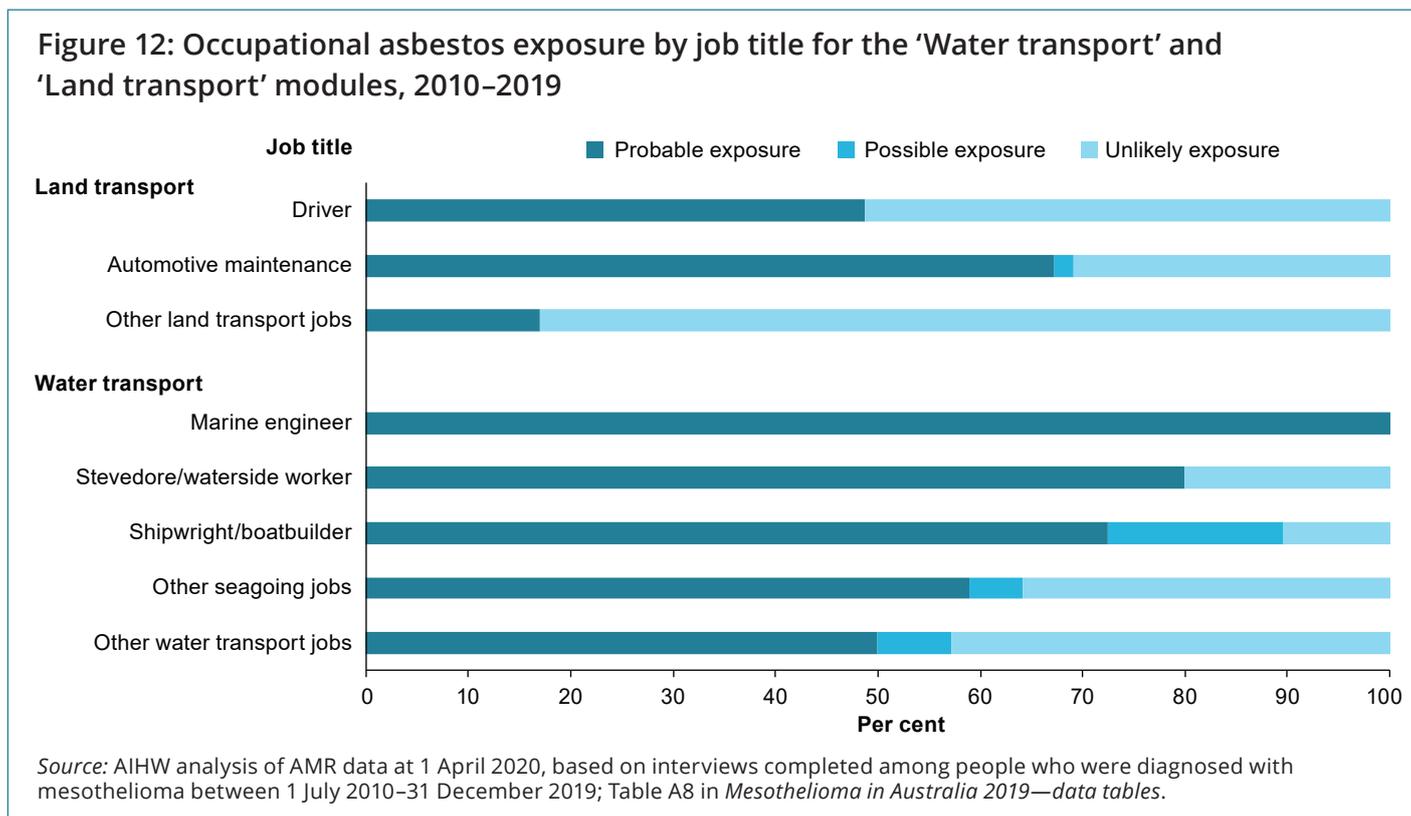


Among participants who received the water transport module (Figure 12):

- 100% of people with marine engineer jobs were assessed as having had probable exposure, with the level of exposure estimated as 'high' for 79% of these. 52% of participants with shipwright/boat builder jobs were estimated to have had probable exposure at a 'high' level.

Among participants who received the land transport module (Figure 12):

- 67% of people who had jobs in automotive maintenance, and 49% of those with driving jobs, were assessed as having had probable exposure—among those assessed as probably exposed in these jobs, the level of exposure was estimated as 'high' for most.



Non-occupational asbestos exposure

All 1,015 participants completed the non-occupational questionnaire module. Of these, 836 (82%) were assessed as having had possible or probable exposure in non-occupational contexts. It was common to have indications of exposure in more than one non-occupational context, so a number of participants are counted in more than one category. Therefore, the sum of participants in each category does not add up to the total number of participants. The most common contexts in which non-occupational asbestos exposure was assessed as possible or probable were among those who reported ever having:

- undertaken major home renovations that involved asbestos products (including paid work) (43% assessed as possible exposure, 7.9% assessed as probable exposure)
- lived in a house undergoing renovations (39% assessed as possible exposure)
- serviced car brakes/clutch (excluding paid work) (30% assessed as probable exposure)
- lived in the same home as someone with a job where they were exposed to asbestos and who came home dusty (14% assessed as possible exposure, 6.2% assessed as probable exposure)
- lived in a house made of fibro that was built between 1947 and 1987 (10% assessed as probable exposure).

See Table A9 in *Mesothelioma in Australia 2019—data tables* for further information on sources of non-occupational exposure.

No asbestos exposure

For 63 participants (6.0% of all 1,015 participants—39 men and 24 women), there was no indication of asbestos exposure above background levels in either occupational or non-occupational contexts. This does not mean that these participants have never been exposed to asbestos; rather it means that no evidence of exposure above background levels was obtained using the exposure assessment methods.

What are the challenges in collecting data and reporting on mesothelioma?

Confirming a diagnosis of mesothelioma is often very challenging for a variety of reasons:

- Symptoms of mesothelioma are common to many other conditions, and mesothelioma cells can often look similar to cells of other cancers (Cancer Council 2019b).
- Because mesothelioma symptoms are not specific to the condition, diagnosis is often complicated. Diagnostic confirmation of mesothelioma generally involves a number of clinical investigations, including biopsies, radiology and clinical examinations conducted by a multidisciplinary team (van Zandwijk et al. 2013).
- Diagnostic and treatment practices for mesothelioma are not equally distributed across Australia (van Zandwijk et al. 2013).

If a mesothelioma diagnosis is uncertain for any reason, the AMR is not notified and the case remains unrecorded, until such a time as the diagnosis is confirmed. Other challenges in collecting data and reporting on mesothelioma include:

- Although state and territory cancer registries fast-track mesothelioma notifications, there is still a time lag between a person's diagnosis, their inclusion in the AMR data set and (if consent is given) when they are interviewed for the AMR's asbestos exposure collection. Reasons for this lag include the time it takes to make a definitive diagnosis, the time between diagnosis and notification to cancer registries and to the AMR. Case verification and recruitment processes also vary between state and territory cancer registries.
- The participation rate in the asbestos exposure assessment of the AMR is low, at around 15% of people with mesothelioma. This is partially due to people dying or being too unwell to participate.

Where do I go for more information?

More information on the AMR is available at www.mesothelioma-australia.com/home.

The report *Mesothelioma in Australia 2019* and previous annual reports are available at www.mesothelioma-australia.com/publications-and-data/publications. People diagnosed with mesothelioma can choose to self-notify by contacting the AMR via email at amr@aihw.gov.au or via the toll-free information line on 1800 378 861.

Glossary

age-adjusted rate: See age-standardised rate.

age standardisation: A way to remove the influence of age when comparing populations with different age structures. This is usually necessary because the rates of many diseases vary strongly with age (usually increasing with increasing age). The age structures of the different populations are converted to the same 'standard' structure and then the disease rates that would have occurred with that structure are calculated and compared. This report uses the direct method of age standardisation.

age standardised rate: A rate that results from removing the influence of age by converting the age structures of the different populations to the same 'standard' structure, providing a more valid way of comparing rates from populations with different age structures.

age-specific rate: The rate for a specific age-group. The numerator and denominator pertain to the same age group.

Australian Cancer Database (ACD): Contains data on all new cases of cancer diagnosed in Australia (except basal and squamous cell carcinomas of the skin) since 1982.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period, often expressed as a rate (number per population).

mortality: The number or rate of deaths in a population during a given time period.

National Death Index (NDI): A catalogue of death records used in data linkage for epidemiological studies.

National Mortality Database (NMD): Holds records for all deaths in Australia since 1964.

non-occupational exposures: Chemical, biological, psychosocial, physical and other factors from places other than the workplace that can potentially cause harm. Examples include contact with asbestos during private house renovations and living in the same home as someone with an asbestos-exposed occupation who came home dusty.

occupational exposures: Chemical, biological, psychosocial, physical and other factors in the workplace that can potentially cause harm.

relative survival: the probability of being alive for a given amount of time after diagnosis compared with the general population. A 5-year relative survival figure of 100% means that the cancer has no impact on the person's chance of still being alive 5 years after diagnosis, whereas a figure of 50% means that the cancer has halved that chance.

underlying cause of death: The disease or injury that initiated the sequence of events leading directly to death.

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