Australian Government Australian Institute of Health and Welfare





# Mesothelioma in Australia 2021

#### Published April 2023

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. In the 2019–20 financial year, the estimated health system expenditure for mesothelioma cases was \$32.1 million (total cancers \$12.1 billion) (AIHW 2022a).

Men were more likely to be diagnosed with mesothelioma than women across all age groups, and the number of cases diagnosed each year for both men and women has steadily increased over the past 40 years. There is no cure for mesothelioma with the main cause being from exposure to asbestos – a material that has been banned in Australia since the end of 2003. It can take many years after being exposed to asbestos (between 20 and 60 years) for mesothelioma to develop (Cancer Council 2019a).

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

Note that in this report, incidence data primarily comprises those notified cases of mesothelioma that had been received up until 1 November 2022 by the AMR, diagnosed between 1 January 2021 and 31 December 2021. This extraction date differs from previous reports. For further information see *Mesothelioma in Australia 2021: methodology paper*.



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 2021: 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 2021, 93% of cases reported to the AMR were pleural mesothelioma – that is, the cancer occurred in the mesothelial lining around the lungs. In the other 7% of cases, mesothelioma arose in other mesothelial-lined surfaces around the heart (pericardial), abdomen (peritoneal) and scrotal sac. More information on the diagnostic characteristics of cases of mesothelioma diagnosed in 2021 is available in Table A10 of *Mesothelioma in Australia 2021 – 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).

While 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 with fibres invisible to the naked eye that can be inhaled into the lungs (enHealth 2013) 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 2018; 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 totally banned in Australia since December 2003, and it is now illegal to make, use or import them 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 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, lung cancer and asbestosis.

## How have the number of cases changed over time?

The AMR is the most up-to-date source of national 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 about the challenges of collecting mesothelioma data and AMR processes, see page 17 of this report and *Mesothelioma in Australia 2021 – 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 752 cases of mesothelioma diagnosed in 2015 to date and notified to the AMR, 67% of notifications were received in the year they were diagnosed (2015), 22% in 2016, and 11% were received from 2017 onwards.

## Figure 1: Difference in number of mesothelioma cases between originally published data<sup>1</sup> and current report during 2011 to 2020



2022; Table A1 in *Mesothelioma in Australia 2021 – data tables*.

As at 1 November 2022, 722 cases of mesothelioma diagnosed in 2021 had been reported to the AMR (Figure 2). Men have been consistently more likely to be diagnosed with mesothelioma than women – this is expected because the majority of cases are from exposure to asbestos in the type of environments in which men more commonly worked, 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 averaged around 2.7 cases per 100,000 people between 2011 and 2021; for men, it averaged 4.7 per 100,000, and for women, it averaged 1.0 per 100,000.



## Figure 2: Number and age-standardised rate (ASR) (per 100,000 population) of people diagnosed with mesothelioma, by year and sex, 2011 to 2021

Note: Rates have been age-standardised to the 2001 Australian Standard Population. Source: AIHW analysis of AMR data as at 1 November 2022; Table A2 in *Mesothelioma in Australia 2021 – data tables*.

## Long-term trend

Reporting using AMR data is only possible for the period since July 2010 as that is when the data collection began. However, longer-term 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 2011–2021.

Between 1982 and 2021, the number of new cases of mesothelioma reported annually steadily increased – from 135 to 577 for men and from 22 to 145 for women (Figure 3). To date, the year in which the highest overall number of cases (824) were diagnosed is 2017. It is important to note that the apparent fall in cases in 2021 is likely due to delays in the AMR receiving notifications – the number of cases for 2021 are expected to rise after 1 November 2022 (date these data were extracted). Also note that the number of cases may continue to increase slightly for all years, and particularly from 2016 onwards, as more cases are notified to the AMR (see Table A1 in *Mesothelioma in Australia 2021 – data tables* for further information).



Mesothelioma in Australia 2021 – data tables.

Between 1982 and 2007, the crude incidence rate rose for men from 1.8 to 5.5 cases per 100,000 population. For women, the rate rose from 0.3 in 1982 to 1.4 cases per 100,000 population in 2015 (Figure 4). The crude incidence rate for persons rose from 1.0 in 1982 to a peak of 3.3 cases per 100,000 population in 2003 and has since remained at around 3.2 cases per 100,000 population.

## Figure 4: Crude rate (per 100,000 population) of people diagnosed with mesothelioma, by year and sex, 1982 to 2018



After adjusting for differences in the age structure of the populations, the age-standardised incidence rate rose between 1982 and 2003 for both men (2.3 to 5.9 cases per 100,000 population) and women (0.3 to 1.0 cases per 100,000 population) (Figure 5). The incidence rate for persons rose from 1.2 in 1982 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.



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

Sources: 1982–2010 (dotted line): AIHW 2022b; 2011–2021 (solid line): AIHW analysis of AMR data as at 1 November 2022; Table A3 in *Mesothelioma in Australia 2021 – data tables.* 

## How does mesothelioma diagnosis vary by age and sex?

The age of people in the AMR who were diagnosed in 2021 ranged from 19 to 100 (Figure 6). The median age at diagnosis was 77, and a greater number of men than women were diagnosed across all 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. An Australian 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 2021, age-specific mesothelioma incidence rates (the number of new mesothelioma cases per 100,000 population in specific age groups) generally increased with increasing age – for age 85 and over, the rates for men were 50.8 cases per 100,000 population and for women were 9.5 cases per 100,000 population. Men consistently had higher rates than women across all age groups, with men aged 75 to 79 being over 6 times as likely to be diagnosed as women (Figure 7).

## Figure 7: Rate (per 100,000 population) of people diagnosed with mesothelioma, by age and sex, 2021



## 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 2018–2021. 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 2018–2021, age-standardised rates of mesothelioma ranged from 1.1 cases per 100,000 people in the Northern Territory to 3.4 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 2014–2017 in Table 1 in *Mesothelioma in Australia 2021 – data tables*.

		Males		Females		People		
State	No.	Rate	No.	Rate	No.	Rate		
NSW	805	4.2	184	0.8	989	2.4		
Vic	530	3.6	144	0.8	674	2.1		
Qld	523	4.4	142	1.1	665	2.6		
WA	338	5.8	91	1.3	429	3.4		
SA	183	3.9	55	1.0	238	2.3		
Tas	68	4.3	11	0.6	79	2.3		
ACT	23	2.9	10	1.0	33	1.8		
NT	5	2.0	1	0.2	6	1.1		
Australia	2,475	4.2	638	0.9	3,113	2.4		

## Table 1: Number and age-standardised rate (per 100,000 population) of people diagnosed with mesothelioma, by sex and state/territory, 2018–2021

Note: Due to small counts in some states and territories, data have been grouped into the years 2018–2021, to enable rates to be directly age-standardised to the 2001 Australian Standard Population.

Source: AIHW analysis of AMR data as at 1 November 2022.

#### What is relative survival?

Relative survival is a measure of the survival of people with mesothelioma compared with that of the general population. It is calculated by dividing the observed survival of people with mesothelioma 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 2021 (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. An analysis of mesothelioma using ACD data shows that median age at diagnosis has increased from 63 years in 1982 to 77 years in 2018 (AIHW 2022b). By age-adjusting to a group with a consistent age structure, such as those people with mesothelioma in 2014–2018, age-adjusted relative survival rates account for the impact different age structure can have on comparisons over time in relative survival rates.

For further information see Mesothelioma in Australia 2021 - methodology paper.

Due to its aggressive nature, mesothelioma has a very low survival rate compared to other cancers (AIHW 2022b). The condition is often diagnosed at advanced stages, because early symptoms can go unnoticed or be mistaken as symptoms for other conditions or diseases (ADRI 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 and Damhuis 2004).

Linked data from the ACD and National Death Index (NDI), shows that the average length of time that people survive after being diagnosed with mesothelioma is gradually improving over time. Figure 8 shows the 1, 3 and 5-year age-adjusted relative survival of people with mesothelioma from 1989–1993 to 2014–2018 – all survival rates have increased over this period, most notably the 1-year survival. This apparent improvement in survival may be due to factors such as diagnosing mesothelioma at an earlier stage and improvements over time in how patients are treated.

## Figure 8: 1, 3 and 5-year age-adjusted relative survival of people diagnosed with mesothelioma, 1989–1993 to 2014–2018



#### Notes

 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 2014–2018 relative survival reporting population diagnosed with mesothelioma (that is, the group diagnosed with mesothelioma and used to calculate the 2014–2018 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 2022b; Table A5 in Mesothelioma in Australia 2021 - data tables.

### How many people die from mesothelioma?

Using the NMD to report on long-term mortality trends, the number of mesothelioma deaths has increased from 416 in 1997 to 701 in 2020. Deaths from mesothelioma increased generally but with fluctuations over the period among both men and women. For men, the number of deaths in 2020 was 1.6 times higher than in 1997, while for women there were over twice as many deaths in 2020 compared to 1997 (Figure 9).



1. Figures are presented by year of death for 1997–2019 and year of registration of death for 2020.

2. Deaths registered in 2018 and earlier are based on the final version of Cause of Death Unit Record Files (CODURF). Deaths registered in 2019 are based on the revised version and deaths registered in 2020 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the Australian Bureau of Statistics (ABS). For further information see *Mesothelioma in Australia 2021 – methodology paper*.

Source: AIHW 2022b; Table A6 in Mesothelioma in Australia 2021 - data tables.

Although the number of deaths has increased over time, the age standardised rate of deaths has remained fairly stable (Figure 10). 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).

From 1997 to 2020, age-standardised mesothelioma mortality rates fluctuated between 2.1 and 2.7 deaths per 100,000 population (Figure 10). Rates for men ranged from 3.7 deaths per 100,000 in 2020 to 5.0 deaths per 100,000 population in 2001 and 2004. Rates for women fluctuated around 0.8 deaths per 100,000 over the period.

## Figure 10: Age-standardised rate (per 100,000 population) of deaths from mesothelioma, by year and sex, 1997 to 2020



2. Deaths registered in 2018 and earlier are based on the final version of Cause of Death Unit Record Files (CODURF). Deaths registered in 2019 are based on the revised version and deaths registered in 2020 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the Australian Bureau of Statistics (ABS). For further information see *Mesothelioma in Australia 2021 – methodology paper.* 

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

Source: AIHW 2022b; Table A6 in Mesothelioma in Australia 2021 - 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 probably 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.

In total, 1,328 people (1,070 men and 258 women) diagnosed with mesothelioma since 1 July 2010 consented to participate in the voluntary asbestos exposure assessments as at 30 October 2022. Of these, 1,139 people (899 men and 240 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 2021 – methodology paper*.

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

More than 9 in 10 (94% or 1,067) people were assessed as having possible or probable exposure to asbestos (Table 2). For men, this exposure most commonly occurred in their jobs. Occupational exposure to asbestos is typically associated with greater exposure and frequency than non-occupational exposure.

Of the 1,067 people for whom exposure was detected, most men had some form of occupational exposure, whereas very few women did:

- 79% (671) of men provided information indicating possible or probable occupational exposure ('occupational exposure only' and 'both occupational and non-occupational exposure'), compared with 6.6% (14) of women (Table 2).
- 99% (211) of women provided information indicating non-occupational exposure ('non occupational exposure only' and 'both occupational and non-occupational exposure'), compared with 85% (732) of men (Table 2).

#### Table 2: Occupational and non-occupational exposure assessment, by sex, 2010–2021

Any exposure indicated	Men		Women		People	
	No.	%	No.	%	No.	%
Occupational exposure only	126	14.7	1	0.5	127	11.9
Non-occupational exposure only	184	21.5	198	93.4	382	35.8
Both occupational and non-occupational exposure	545	63.7	13	6.1	558	52.3
Total	855	100	212	100	1,067	100

Note: Of the 1,139 participants, 72 (6.3%) participants (44 men and 28 women) were assessed as having neither occupational nor nonoccupational 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 exposure above background was obtained by the exposure assessment methods used.

Source: AIHW analysis of AMR data as at 1 November 2022, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2021.

Table 3 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 Northern Territory, Australian Capital Territory and Tasmania, so these were excluded.

Table 3 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 43% across states
- 'both occupational and non-occupational exposure' ranged from 45% 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 3: Occupational and non-occupational exposure assessment, by state, 2010–2021

Any exposure indicated				State						
	NSW		Vic		Qld		WA		SA	
	No.	%	No.	%	No.	%	No.	%	No.	%
Occupational exposure only	46	13	27	13	20	11	18	11	10	13
Non-occupational exposure only	128	35	91	43	55	29	58	34	33	41
Both occupational and non-occupational exposure	191	52	95	45	113	60	96	56	37	46
Total	365	100	213	100	188	100	172	100	80	100

Notes

1. Of the 1,139 participants, 72 (6.3%) participants (44 men and 28 women) were assessed as having neither occupational nor nonoccupational asbestos 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 exposure above background was obtained by the exposure assessment methods used.

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

3. There were insufficient numbers of participants to present results for NT, ACT and Tasmania.

Source: AIHW analysis of AMR data as at 1 November 2022, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2021.

### **Occupational asbestos exposure**

Figure 11 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, 82% of participants who received the 'Trades' module, 73% of those who received the 'Water transport' module, and 39% of participants 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.

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## Figure 11: Exposure assessment results by most commonly used job-specific modules, 2010–2021



Source: AIHW analysis of AMR data as at 1 November 2022, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2021; Table A7 in *Mesothelioma in Australia 2021 – 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 2013, Version 1.3).

Among participants who received the 'Trades' module, 'possible or probable' exposure to asbestos was assessed in:

- 96% of the 82 people in electrical trade jobs
- 90% of the 245 people in building trade jobs
- 90% of the 58 people in metal production and fabrication jobs
- 85% of the 52 people in plumber/gasfitter jobs
- 78% of the 94 people in metal fitter/turner and toolmaker jobs

In contrast, only 40% of the 15 people in telecommunication technician jobs and 65% of the 17 people in engineer jobs were assessed as 'possible or probable' exposure to asbestos (see Figure 12).





Among participants who received the 'Land or Water transport' modules, 'possible or probable' exposure to asbestos was assessed in:

- All of the 29 people in marine engineer jobs
- 90% of the 29 people in shipwright/boatbuilder jobs
- 80% of the 5 people in stevedore/waterside worker jobs
- 71% of the 59 people in automotive maintenance jobs

In contrast, only 17% of the 53 people in other land transport jobs were assessed as 'possible or probable' exposure to asbestos (see Figure 13).

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## Figure 13: Occupational asbestos exposure by job title for the 'Water transport' and 'Land transport' modules, 2010–2021



Source: AIHW analysis of AMR data as at 1 November 2022, based on interviews completed among people who were diagnosed with mesothelioma between 1 July 2010–31 December 2021; Table A8 in *Mesothelioma in Australia 2021 – data tables*.

#### Non-occupational asbestos exposure

All 1,139 participants completed the non-occupational questionnaire module. Of those where exposure was indicated, 940 (83%) were assessed as having had 'possible or probable' exposure in non-occupational contexts. Non-occupational exposure to asbestos is typically associated with lower exposure and frequency than occupational exposure. 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 (excluding paid work) (51% assessed as possible or probable exposure)
- lived in a house undergoing renovations (38% assessed as possible or probable exposure)
- serviced car brakes/clutch (excluding paid work) (30% assessed as possible or probable exposure)
- lived in the same home as someone with a job where they were exposed to asbestos and who came home dusty (20% assessed as possible or probable exposure).
- lived in a house made of fibro that was built between 1947 and 1987 (12% assessed as possible or probable exposure).

See Table A9 in *Mesothelioma in Australia 2021 – data tables* for further information on sources of nonoccupational exposure.

#### No asbestos exposure

For 72 participants (6.3% of all 1,139 participants – 44 men and 28 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 and associated asbestos exposure?

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 and 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 https://mesothelioma-australia.com/home. This report and previous annual reports are available at https://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.

For more information about the regulation and eradication of asbestos in Australia visit the Safe Work Australia website at https://www.swa.gov.au and the Asbestos Safety and Eradication Agency website Asbestos Safety and Eradication Agency: https://www.asbestossafety.gov.au/.

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### Glossary

**age-adjusted survival:** A method to remove the influence of changes in the ages of those diagnosed with a specific cancer type (or group) over time when considering changes in relative survival rates over time. The population used in this report is people diagnosed with mesothelioma in the latest year, which was used to adjust the survival rates for all the previous years.

**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. The population used in this report is the 2001 standard population.

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

**Australian and New Zealand Standard Classification of Occupations (ANZSCO):** is primarily a statistical classification designed to aggregate and organise data collected about jobs or individuals and is based on the skill level and specialisation usually necessary to perform the tasks of the specific occupation, or of most occupations in the 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.

**Cause of death unit record file (CODURF):** Is a dataset containing information relating to all deaths registered in Australia for a given reference year.

**crude rate:** the number of events in a given period divided by the size of the population at risk in a specified time period.

**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.

### References

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### Acknowledgments

This report was prepared by Mr Tom Watson, Ms Sue Barker and Mr Brett Davis from the AMR team at the AIHW. The AMR team would also like to acknowledge the valuable guidance and advice from Mr Justin Harvey and Mr Richard Juckes. The AMR Expert Advisory Group also provided valuable advice: Professor Tim Driscoll (Chair), Associate Professor Fraser Brims, Ms Elizabeth Chalker, Dr Claire Cooke Yarborough, Ms Justine Ross, Professor Karen Walker-Bone, Associate Professor Sonja Klebe and Mr Trevor Torrens.

The AIHW acknowledges the data and assistance provided by all state and territory cancer registries, and thanks staff at the Monash Centre for Occupational and Environmental Health for undertaking and reporting on the asbestos exposure component of the AMR, and staff at the Social Research Centre for their work interviewing people diagnosed with mesothelioma.

The AMR is funded by Safe Work Australia.

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#### Suggested citation

Australian Institute of Health and Welfare 2023. Mesothelioma in Australia 2021. Cat. no. CAN 152. Canberra: AIHW.

ISBN 978-1-922802-69-9 (Online) ISBN 978-1-922802-70-5 (Print) DOI: 10.25816/bgvs-g016

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