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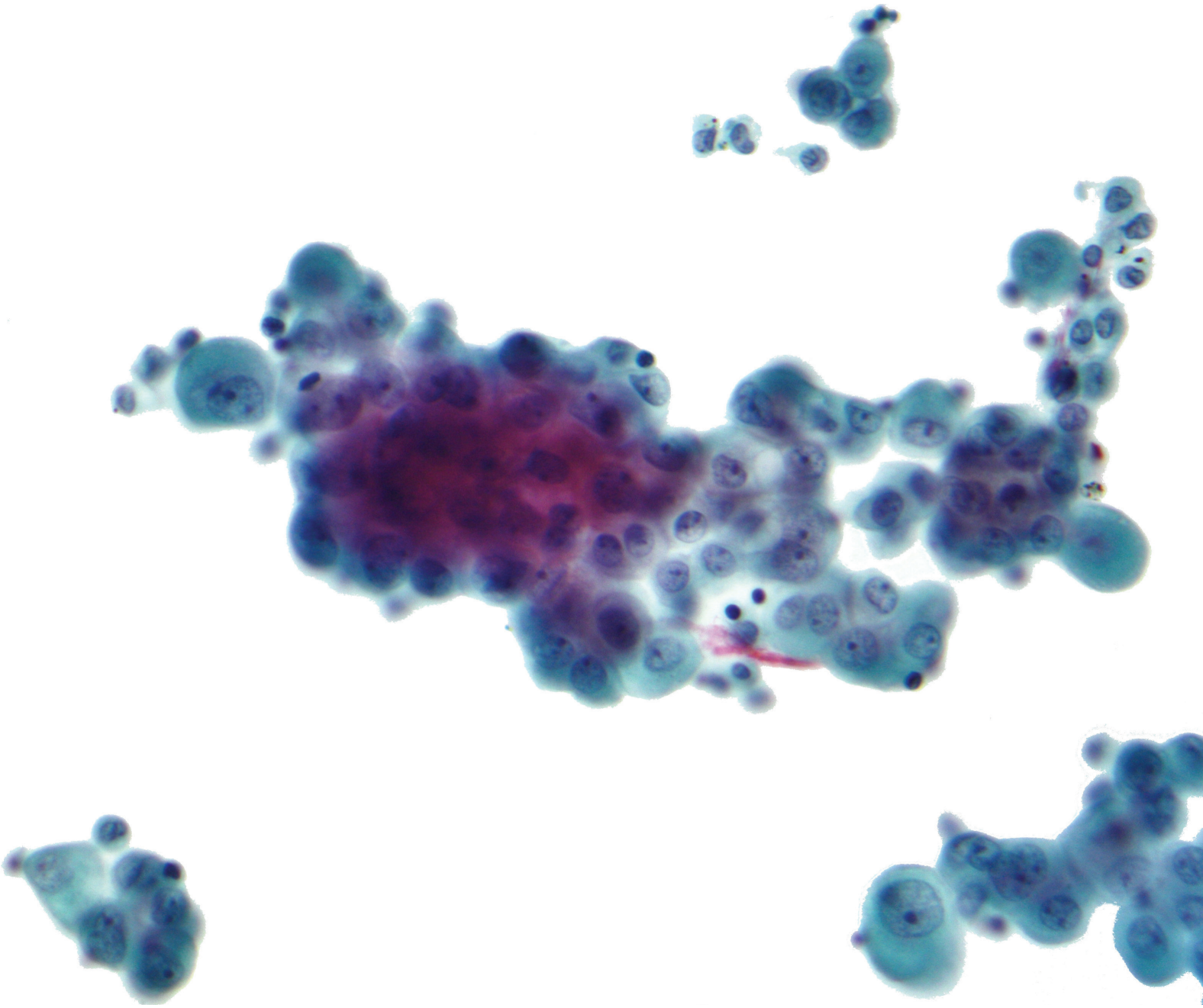

2nd Annual Report
Mesothelioma in Australia 2012

safe work australia

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Comcare

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Monash Centre for Occupational and Environmental Health, Monash University

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Cancer Epidemiology and Health Services Research Group, University of Sydney

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Abbreviations and acronyms

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
CINSW	Cancer Institute NSW
HVRF	Hunter Valley Research Foundation
JSM	Job-specific module
MonCOEH	Monash Centre for Occupational and Environmental Health
NDI	National Death Index
NOHSC	National Occupational Health and Safety Commission
NSW	New South Wales
NT	Northern Territory
OccIDEAS	Occupational Integrated Database Exposure Assessment System
Qld	Queensland
SA	South Australia
Tas	Tasmania
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 to collect details of asbestos exposure directly from people who have mesothelioma.

The AMR report published in September 2012 reported on people diagnosed with mesothelioma in 2011.

This report focuses on data for the 2012 calendar year using data available at 30 June 2013.

Number of new cases

As at 30 June 2013, the AMR had received 619 notifications of people newly diagnosed with mesothelioma between 1 January and 31 December 2012. Of these people, 511 were males and 108 were females, and the majority (79.6%) were aged 65 years or over at the time of diagnosis. The annual age-specific incidence rates of mesothelioma peaked at 7.9 per 100,000 in females 75–79 years of age and 44.8 per 100,000 in males 80–84 years of age.

For 2012 diagnoses, the most common subtype of mesothelioma was the epithelioid subtype (49.4%). The most common location was the pleura (93.7%).

An additional 27 people with mesothelioma were notified to the AMR since the publication of the AMR's 2011 report. This has increased the previously reported number of diagnoses for 2011 from 612 to 639. A similar increase is likely to be seen in the reported number of patients diagnosed in 2012.

Age-standardised incidence rates

The age-standardised mesothelioma incidence rate in 2012 for males and females together was 2.4 cases per 100,000 person-years.

The male age-standardised incidence rate declined between 2011 and 2012, from 4.8 per 100,000 to 4.3 per 100,000, while there was a slight increase in the female age-standardised incidence rate from 0.7 per 100,000 to 0.8 per 100,000.

The 2001 Australian standard population (the population most commonly used in routine reporting of cancer incidence in Australia) was used in calculating the 2011 and 2012 age-standardised rates shown in this report.

Number of deaths

By 10 April 2013, 290 (46.8%) mesothelioma patients diagnosed in 2012 were recorded as having died. Where cause of death was known, 95.7% were recorded as being due to mesothelioma in the data available at 30 June 2013.

Asbestos exposure

The AMR's data on asbestos exposure are based on the estimated exposure profiles of people with mesothelioma diagnosed from 1 July 2010 to 31 December 2012.

Of the 256 people (205 males and 51 females) with mesothelioma who completed the asbestos exposure questionnaire, 229 (89.5% representing 182 males and 47 females) also completed the telephone interview.

Of the 229 who were interviewed:

- 144 (62.9%) respondents (142 males and 2 females) were found to have 'possible' or 'probable' occupational asbestos exposure.
- 85 (37.1%) respondents (40 males and 45 females) provided no information to suggest they had occupational exposure. Of those, 70 people (31 males and 39 females) were found to have asbestos exposure in non-occupational contexts and 15 people provided no information to suggest they had asbestos exposure above background levels in either occupational or non-occupational spheres.

These assessments consider only the probability of asbestos exposure and do not provide information about the duration, intensity or frequency of exposure, if exposure had occurred.

1. Introduction

Purpose

This is the second report of the Australian Mesothelioma Registry (AMR), a new national registry, which became operational in 2011. The AMR contains information about people diagnosed with mesothelioma in Australia from 1 July 2010 onwards. This report primarily presents data for the period from 1 January 2012 to 31 December 2012. Data from the period 1 January 2011 to 31 December 2011 are also shown in the Appendix 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, which are composed of fibres that do not readily break down within the human body and are resistant to fire and chemical corrosion. Asbestos fibres are so small that they are invisible to the naked eye and can be inhaled into the lungs.

Until the mid-1980s, Australia was a producer of asbestos and one of the world's highest users per capita of asbestos (Leigh et al 2002). Asbestos containing materials (ACMs) were used extensively in Australia due to their qualities of durability, 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 exceptions were granted for specialised use in the Australian Armed Forces. The legacy is a large amount of asbestos in buildings and other infrastructure, and thousands of different products containing asbestos are still in use today. Many homes built in Australia before the late 1980s contain some ACMs.

Asbestos exposure can cause cancers such as lung cancer (in interaction with tobacco smoking) and is the predominant cause of mesothelioma, an aggressive form of cancer that arises in the mesothelium–the membranous tissue that surrounds the heart, lungs, gastrointestinal and urogenital organs, and lines the chest and abdominal cavities. The exact 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 has one of the highest incidence rates of malignant mesothelioma in the world. The incidence of mesothelioma increased in Australia from at least 1982, when data on new cases first became available nationally (Safe Work Australia 2012), but appears to have stopped increasing in incidence since the early 2000s (AIHW 2012). 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.

The AMR

The AMR became operational in 2011 and includes new cases of mesothelioma diagnosed from 1 July 2010 in Australia. The Registry replaces the previous Australian Mesothelioma Register managed by the National Occupational Health and Safety Commission (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 were enacted. As a result, the incidence of mesothelioma

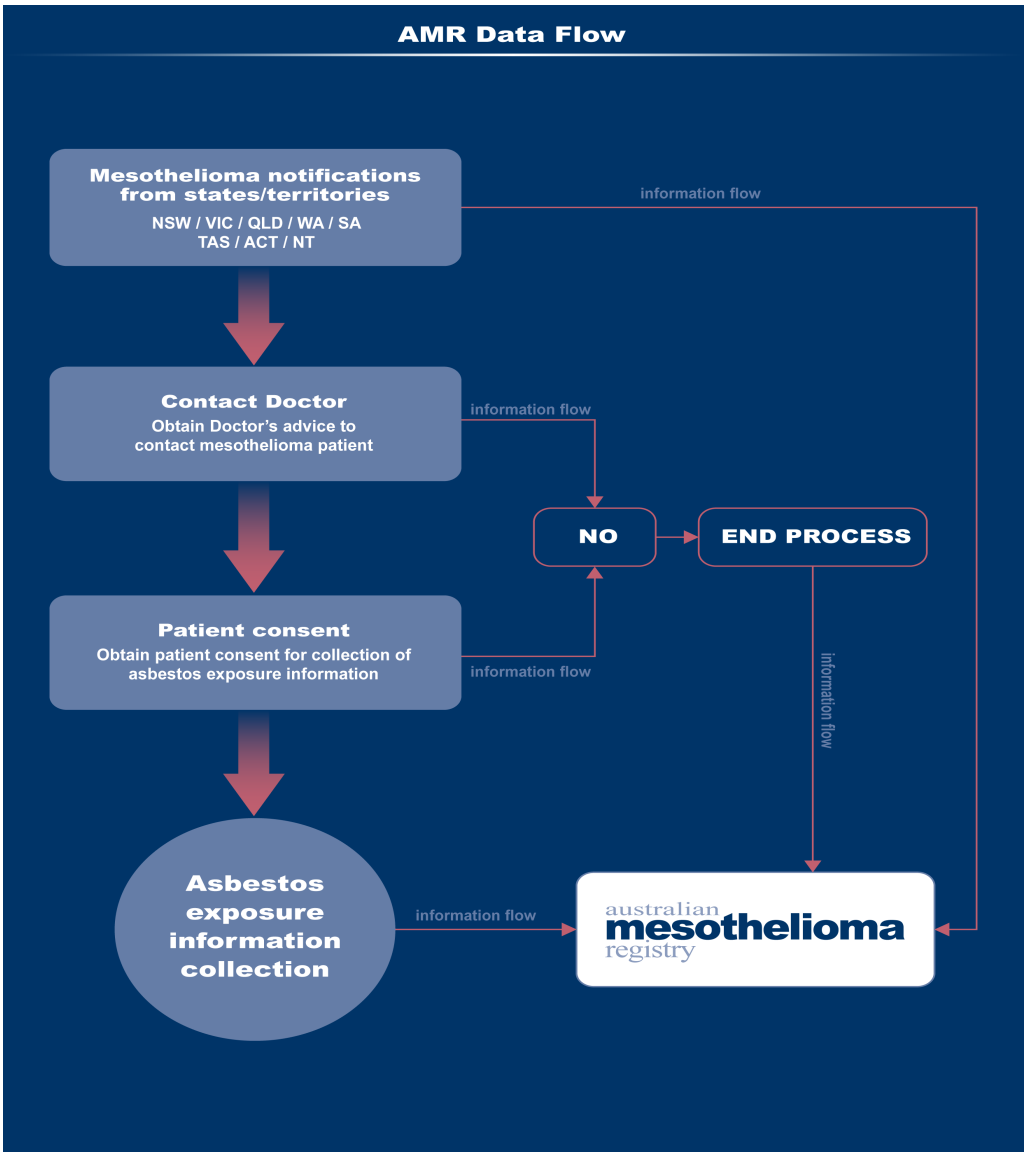
was dramatically under-reported and the reporting of asbestos exposure information dropped to less than 50%of new cases reported. Due to incompleteness of data, published reports ceased in 2004 and the Register was suspended in December 2007.

The new AMR collects information about cases of mesothelioma to:

- accurately measure the incidence of mesothelioma in Australia for the purposes of
    - monitoring changes in the incidence of mesothelioma following the ban on all uses of asbestos
    - identifying increases in the incidence of mesothelioma that may result from ongoing or possibly increasing non-workplace exposure to asbestos already in the wider environment (the postulated third wave), or 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 process of obtaining mesothelioma notifications and asbestos exposure data by the AMR.

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; that is, these records are given priority and are processed and coded as quickly as possible. The state and territory cancer registries submit notifications to the AMR on a regular basis. Notified records include demographic information and details of the diagnosis and death.

Asbestos exposure information

Once a notification of mesothelioma is received, the state or territory cancer registry contacts the patient's clinician 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

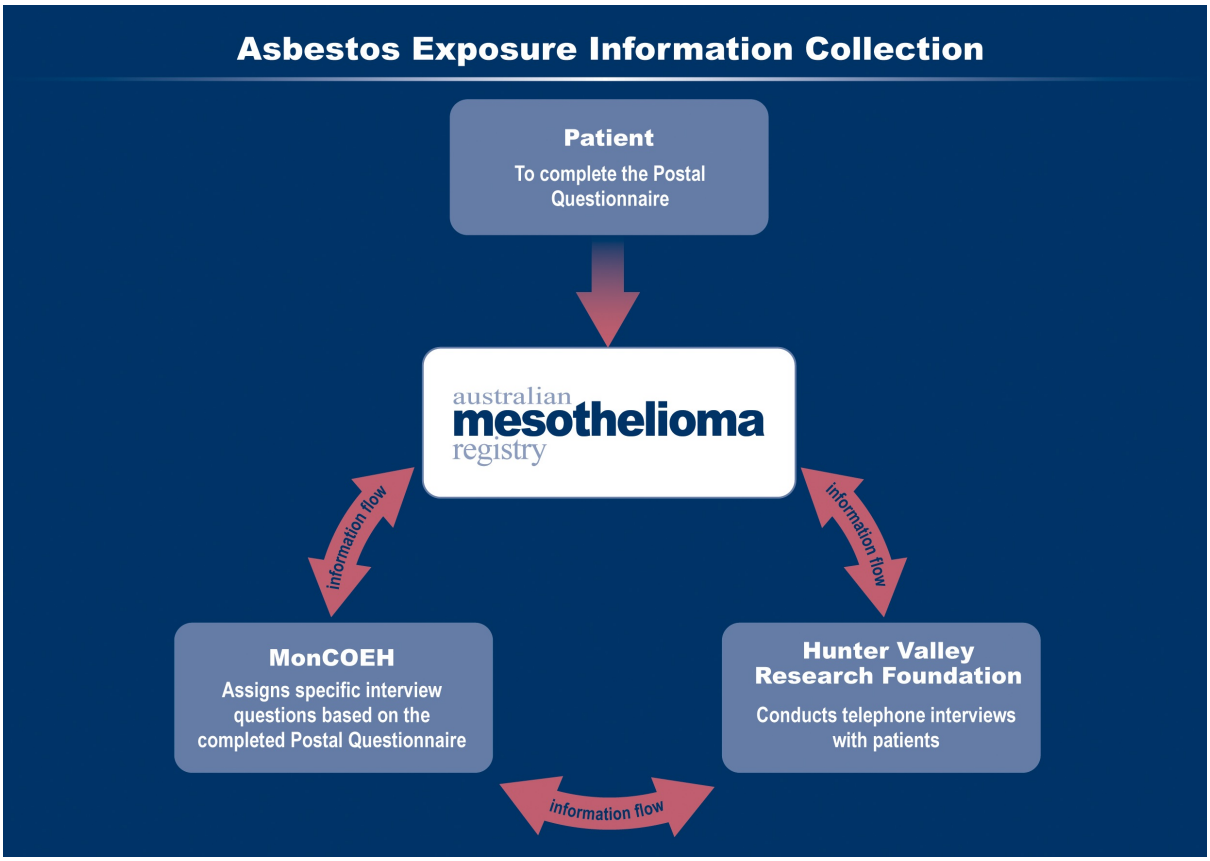
the patient is well enough to be contacted about their exposure to asbestos. Following this, the state and territory cancer registries contact the patient.

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 unless a notification is received from the respective state or territory cancer registry to confirm their mesothelioma diagnosis.

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

- In the postal questionnaire, patients list their residence, school and occupation histories. 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 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 had asbestos exposure. This means the telephone interview is tailored to the participant. The Hunter Valley Research Foundation (HVRF) conducts the telephone interviews.

Figure 1.2: AMR asbestos exposure information collection



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

This report

This is the second report presenting data collected from the AMR, including mesothelioma notifications and asbestos exposure information. In this report, data for patients diagnosed during the calendar year 1 January 2012–31 December 2012 are presented.

Since the publication of the AMR's 2011 data (AMR 2012), an additional 27 people newly diagnosed with mesothelioma in 2011 have been notified to the AMR. A similar increase is likely to be seen in the reported number of patients diagnosed in 2012. 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 difficult 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 1.1 shows the differences in AMR reports over time.

Table 1.1: 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	31 August 2012	Number of Deaths & Cause of Death – State and Territory Cancer Registries & National Death Index
Mesothelioma in Australia 2012	2013	30 June 2013	Australian estimated resident population at 30 June 2012	Australian 2001 standard population World Standard Population (Segi 1960)	10 April 2013 30 June 2013	Number of Deaths– National Death Index Cause of Death – State and Territory Cancer Registries

The report includes the following additional sections:

2. Incidence
3. Mortality
4. Asbestos exposure

Appendix A details methods used for collating the data and Appendix B contains the tables underlying figures.

2. Incidence

Number of cases

In total, 619 people diagnosed with mesothelioma from 1 January 2012 to 31 December 2012 had been notified to the AMR at 30 June 2013 (Table 2.1). This compares to 639 cases reported for 2011 at 30 June 2013.

Table 2.1: People in Australia newly diagnosed with mesothelioma by sex and six-month period, 1 January 2012–31 December 2012

	1 Jan–30 June 2012	1 Jul–31 Dec 2012	Total
Males	274	237	511
Females	52	56	108
Persons	**326**	**293**	**619**

Since the previous publication there have been additional notifications of people diagnosed with mesothelioma reported to the AMR: seven for 2010 (2.1% increase), and 27 for 2011 (4.4% increase). A similar increase is anticipated in the reported number of patients diagnosed in 2012.

Table 2.2 shows the number of males and females newly diagnosed with mesothelioma by state and territory in 2012 for the year 2012. The incidence rate for males and females combined was 2.4 per

100,000 person-years overall and ranged from 0.0 in Northern Territory to 4.3 in Western Australia. The rate for males was higher than for females in all jurisdictions and overall (4.3 and 0.8, respectively).

The 2001 Australian standard population (the population most commonly used in routine reporting of cancer incidence in Australia), was used in calculating the 2011 and 2012 age-standardised rates shown in this report.

The incidence rate age-standardised to the World Standard Population (Segi 1960) was 1.4 per 100,000 (Table A3). This is the figure that should be used when comparing incidence rates in Australia to those in other countries.

The overall 2012 age-standardised mesothelioma incidence rates differed minimally from those in 2011 (Table A4).

Table 2.2: New cases of mesothelioma and age-standardised incidence rates by sex and state and territory, 2012

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Males	133	123	121	82	n.p.	n.p.	n.p.	0	511
Females	29	22	29	22	<5	<5	<5	0	108
Persons	**162**	**145**	**150**	**104**	**35**	**14**	**9**	**0**	**619**
				Rate per 100,000 person-years[(a)]					
Males	3.4	4.3	5.4	7.2	n.p.	n.p.	n.p.	0.0	4.3
Females	0.6	0.6	1.1	1.8	n.p.	n.p.	n.p.	0.0	0.8
Persons	**1.9**	**2.2**	**3.1**	**4.3**	**1.7**	**1.9**	**n.p.**	**0.0**	**2.4**

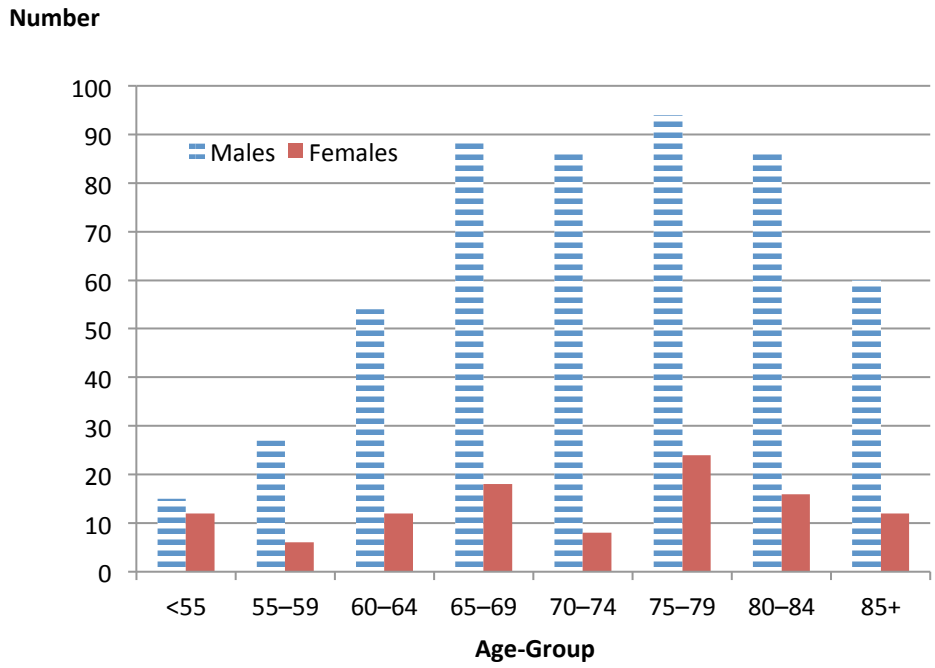
(a) Directly age-standardised using the 2001 Australian standard population.

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

Age at diagnosis for patients diagnosed in 2012 ranged from 32–94 years. The largest proportions were in the age groups ranging from 65 years to 84 years (Table A5).

Figure 2.1 shows the distribution by age and sex of new cases of mesothelioma diagnosed in 2012. There were 511 males diagnosed with mesothelioma (see Table 2.1) with the largest number in the 75–79 year age group (94 patients). The 108 females diagnosed with mesothelioma were more evenly spread across age groups.

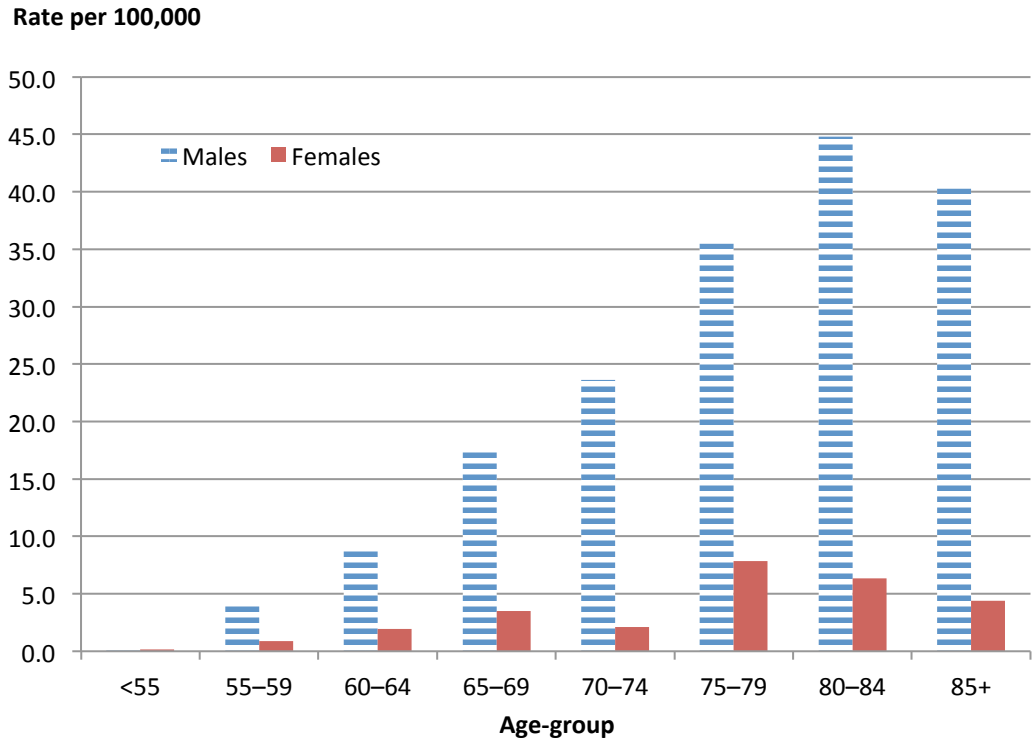
Figure 2.1: New cases of mesothelioma by age-group and sex, 2012



Source: Table A6.

Age-specific incidence rates of mesothelioma (Figure 2.2) generally increased with age. The rates were highest at 44.8 per 100,000 among males aged 80–84 years, and 7.9 per 100,000 females 75–79 years (Table A7).

Figure 2.2: Age-specific incidence rates of mesothelioma by sex, 2012



Source: Table A8.

Diagnosis information

In 2012, epithelioid mesothelioma was the most common subtype (49.4%) of mesothelioma notified to the cancer registries. Sarcomatoid mesothelioma, which includes desmoplastic mesothelioma, accounted for 14.7%. Biphasic mesothelioma, where a combination of epithelioid and sarcomatoid cells are present, represented 9.9% , while unspecified types of malignant mesothelioma accounted for a quarter (26.0%) of cases (Table 2.3). The tumour location was the pleura for 93.7% of patients (Table 2.4).

Table 2.3: New cases of mesothelioma by histological type, 2012

Type of mesothelioma	Number	Per cent
Epithelioid	306	49.4
Sarcomatoid[(a)]	91	14.7
Biphasic	61	9.9
Malignant–not otherwise specified	161	26.0
Total	**619**	**100.0**

(a) Includes desmoplastic mesothelioma

Table 2.4: New cases of mesothelioma by location of tumour, 2012

Tumour location	Number	Per cent
Pleura[(a)]	580	93.7
Peritoneum[(b)]	35	5.7
Other[(c)]	0	0.0
Not stated	4	0.6
Total	**619**	**100.0**

(a) Includes pericardium, pleura and overlapping lesion of heart, mediastinum and pleura.
(b) Includes peritoneum, specified parts of peritoneum, malignant neoplasm of retroperitoneum and peritoneum and overlapping lesion of retroperitoneum.
(c) Includes malignant neoplasm of ovary and tunica vaginalis.

Table 2.5 presents laterality information, excluding 23 cases for non-paired organs where this was not applicable. None of the reported tumours was bilateral.

Table 2.5: New cases of mesothelioma by laterality (where applicable), 2012

Laterality	Number	Per cent
Right	217	36.4
Left	180	30.2
Bilateral	0	0.0
Not stated	199	33.4
Total	**596**	**100.0**

The most common basis for diagnosis was histology (87.9%). There was only one case for this period where diagnosis was based on the death certificate only (Table 2.6). National death data for 2012 have not yet been received by all cancer registries and therefore the total number of mesothelioma deaths reported here 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 certificates only.

Table 2.6: New cases of mesothelioma by best basis of diagnosis, 2012

Best basis	Number	Per cent
Death certificate only	1	0.2
Clinical, no investigation[(a)]	8	1.3
Clinical investigation[(b)]	16	2.6
Specific tumour markers	0	0.0
Cytology	49	7.9
Histology[(c)]	544	87.9
Not stated	1	0.2
Total	**619**	**100.0**

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

There are limitations with reporting mesothelioma trends and projections due to the lack of time series data in the AMR at this stage. These will be reported in the future. The annual Safe Work Australia report presents trends in mesothelioma incidence and mortality using available data from the Australian Cancer Database (ACD) (for example, Safe Work Australia 2012).

3. Mortality

Mortality figures are obtained using data linkage of AMR cases to National Death Index (NDI) and cause of death data were from state and territory cancer registry data (See Appendix A: Methods).

Number of deaths

Of the 619 people diagnosed with mesothelioma in 2012 and notified to the AMR, there were 290 (46.8%) deaths nationally (Table 3.1).

Table 3.1: Deaths of people diagnosed with mesothelioma in 2012 by state and territory

Deaths	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	77	72	81	45	0	8	7	0	290
Per cent of patients diagnosed	47.5	49.7	54.0	43.3	0.0	57.1	77.8	0.0	46.8

Since the publication of the AMR's 2011 report, an increase in deaths from 310 to 437 (41%), was recorded for people diagnosed with mesothelioma in 2011 (Table A8). Similarly, the 2012 death figures are likely to be an underestimate as death information would not yet be available for all relevant cases.

Cause of death

Cause of death information from state and territory cancer registries was available for 163 of the 290 (56.2 %) deaths recorded in this period. Where cause of death was known, mesothelioma was the cause of death in 95.7% of cases (in seven cases, mesothelioma was not listed as the cause of death).

Table 3.2: Cause of death known for people diagnosed with mesothelioma in 2012

Cause of death	Number	Per cent
Mesothelioma	156	95.7
Not mesothelioma	7	4.3
Total	**163**	**100.0**

Cause of death information from the NDI linkage was known for 155 of the 437 (35.5%) deaths recorded for people diagnosed with mesothelioma in 2011 (Table A8 and Table A9). Cause of death information is not yet available for the majority of people diagnosed in 2011 and 2012 as cases are yet to be coded.

There are as yet insufficient data to report trends in incidence and mortality, and survival, and to provide future projections of incidence and mortality.

4. Asbestos exposure

This section describes the results of exposure assessment for participants diagnosed from 1 July 2010 and before 31 December 2012.

Table 4.1 presents the numbers of people diagnosed between 1 July 2010 and 31 December 2012 who completed the recruitment process or were in the process of being recruited at 31 May 2013. This table should be interpreted in the context of Table A2, which outlines the patient recruitment models used by the state and territory cancer registries.

The overall number of people diagnosed in 2010, 2011 and 2012 who consented to participate in the asbestos exposure assessment was 256 at 31 May 2013. Of these, 229 people (89.5%) had completed both the questionnaire and telephone interview components of the assessment (Table 4.1).

Table 4.1: Recruitment for asbestos exposure data collection for patients diagnosed in 2010, 2011 and 2012 by state and territory, at 31 May 2013

	NSW/ACT	Vic	Qld	WA	SA	Tas	NT	Total
				Consenting patients/Postal questionnaires completed				
2010–2011	34	41	16	12	10	6	1	120
2012	52	30	18	26	5	5	0	134
Total	**86**	**71**	**34**	**38**	**15**	**11**	**1**	**256**
				Interviews conducted				
2010–2011	30	35	15	12	8	5	1	106
2012	50	25	14	24	5	5	0	123
Total	**80**	**60**	**29**	**36**	**13**	**10**	**1**	**229**

Of the 256 participants who completed the postal questionnaire, seven reported a family member who also had mesothelioma. However, 44 (17.2%) of respondents did not answer this question.

The remainder of the section includes information on the 229 individuals who were diagnosed before the end of 2012 and who completed both a questionnaire and a telephone interview.

Asbestos exposure assessment: overview of results

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. The methodologies used to assess occupational and non-occupational exposures to asbestos are described in more detail in the sections below.

The jobs held by each participant were assessed for likelihood of asbestos exposure. 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 4.2). Jobs where there is information to indicate that exposure above background levels was

likely were assessed as 'probably exposed'. 'Possibly exposed' indicates that the available information suggests 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'.

Table 4.2: Classification of assessments of exposure probability

Level	Description
Probable	Convincing information from JSM interview data that exposure was more likely than not.
Possible	Information, usually from JSM interview, indicated that exposure may have occurred.
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.

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

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.

Figure 4.1 gives an overview of the exposure assessment of the 229 participants who were diagnosed prior to the end of 2012. JSMs were used in telephone interviews for 161 participants to collect additional data about particular jobs of interest. For 129 of these participants, data from JSM interviews suggested that occupational exposure was possible or probable. A further seven participants provided other information that was judged by the exposure assessment team to be sufficient to indicate that occupational exposure was at least possible.

Sixty-eight participants did not receive any JSMs (however, these participants did receive the non-occupational module: see below). These individuals had either had no paid jobs ever (two participants) or their job history included no jobs indicative of possible asbestos exposure. Females comprised 59% of this group.

Within the group that received no JSMs, eight participants (all males) provided other information at the interview that was sufficient to demonstrate possible occupational exposure to asbestos, although this had not been apparent on the basis of their job histories alone. The additional information these participants provided varied, but for these eight participants the information was assessed as sufficient to indicate at least possible occupational exposure.

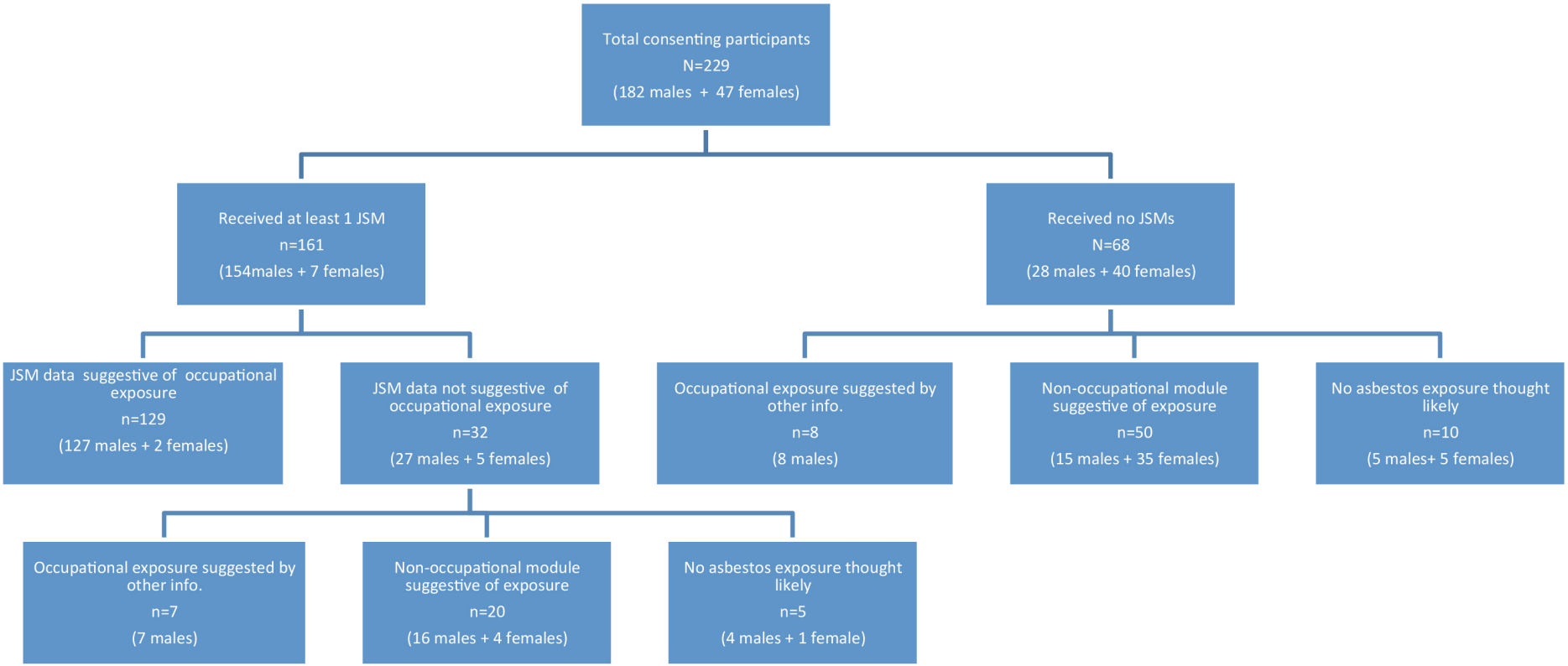
All participants received the non-occupational asbestos exposure questionnaire module. Of the 60 for whom occupational exposure was assessed as unlikely, 50 were assessed as having had possible or probable asbestos exposure in non-occupational contexts, based on information collected by the non-occupational questionnaire module.

For 10 participants (5 males and 5 females), no asbestos information could be retrieved. These 10 participants are classified as 'exposure unlikely'. It should be noted that although it has not been possible to identify asbestos exposure among these 10 participants using the AMR exposure, this does not mean that they have never been exposed to asbestos. It means that no evidence of above background exposure was obtained by the ascertainment methods used.

In summary, a total of 144 (62.9%) participants were found to have evidence of possible or probable occupational asbestos exposure (including two females). Of those for whom no occupational exposure was thought likely, 70 (31 males and 39 females) were found to have information indicative of possible or probable exposure in non-occupational contexts. For a total of 15 (6.6%) participants, no information was found to indicate asbestos exposure above background levels in either occupational or non-occupational spheres.

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 mesothelioma cases only. Because comparable exposure data from the general population are not available at this time, estimates of risk of mesothelioma associated with particular exposure circumstances ascertained cannot be made.

Figure 4.1: Occupational exposure assessment process by stage



Note: JSM = Job-specific module

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

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 with very low probability of exposure were not allocated JSMs and where a participant had many similar jobs, JSMs were allocated to a representative selection.

Table 4.3 shows how many participants received each of the most commonly used JSMs at least once. A single participant could receive a particular JSM more than once for different jobs and a single participant could receive JSMs of different types for different jobs. Each single job could only receive one JSM; therefore, the totals in Table 4.3 do not add up to the total number of participants.

The most frequently administered JSM was the Trades module, which was intended to capture asbestos exposures in a wide range of trades and related jobs. This module was most frequently given to 36 participants with construction-related jobs, 16 participants with electrician-related, 13 participants with plumbing and 24 with metal-related trades. JSMs for land and water transport-related jobs were used for 38 and seven participants respectively. The Land Transport module was most frequently used for driver jobs and jobs associated with maintenance of land vehicles (including heavy and light road vehicles as well as railway trains). The Asbestos Users N.E.C. module was intended to capture asbestos exposure in a range of miscellaneous jobs and it was administered to 13 participants, five of whom were given this JSM for laundry-related jobs. Ten participants were given other JSMs.

The Asbestos Mine/Mill JSM was administered only once for a job in an asbestos mill (and exposure was assessed as probable for this job). No participants reported jobs as asbestos removalists.

Table 4.3: Job-specific modules (JSMs) assigned to participants by types of jobs

JSM name	For which types of jobs was this JSM allocated?	No. participants allocated this JSM at least once[a]
Trades	Construction (carpenter, joiner, builder, bricklayer etc.)	36
	Electrician	16
	Plumbing	13
	Boilermaker, welder	10
	Other metal & mechanical trades (including fitters, turners, machinists)	24
	Engineering	8
	Labouring & general maintenance	6
	Telecommunications technician	4
	Painter	4
	Other	8
	Total participants given Trades JSM	**129**
Land Transport	Driver	14
	Mechanic/fitter/panel beater	21
	Other	3
	Total participants given Land Transport JSM	**38**
Water Transport	Marine engineer/mechanic	12
	Other seagoing jobs (including military navy)	6
	Ship/boat building	4
	Waterside worker/stevedore	2
	Other	1
	Total participants given Water Transport JSM	**25**
Asbestos Users N.E.C.	Laundry work	5
	Other	8
	Total participants given Asbestos users N.E.C. JSM	**13**
Other JSMs[b]	**Total participants given other JSMs**	**10**

(a) Individuals can be allocated more than one JSM and therefore the totals in this table do not equal the total number of participating cases. 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 4.4 shows how many participants received each of the most commonly reported JSMs and what the resultant exposure probability assessment was for these individuals based on these modules. 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, 98 (76.0%) were classified as probably exposed on the basis of the information they provided in response to that module. For 23 (17.8%) of the recipients of the Trades JSM, asbestos exposure was considered unlikely based on this JSM. For the majority (68.4%) of those who received the Land Transport JSM, exposure was considered unlikely based on that JSM and for the majority (68.0%) of those who received the Water Transport JSM, evidence suggested exposure was probable.

Table 4.4: Job-specific module (JSM) exposure assessment results (probability of exposure only) by JSM types (for JSMs used sufficiently often for meaningful interpretation)

JSM name	No. participants allocated this JSM at least once	Assessed probability of exposure (participants)		
		Probable	Possible	Unlikely
Trades	129	98	8	23
Land Transport	38	9	3	26
Water Transport	25	17	5	3
Asbestos users N.E.C.	13	5	2	6
All other JSMs[(a)]	10	5	1	4

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

Table 4.5 shows exposure assessment results for the 129 participants who received the Trades JSM, by the most common job types reported by these participants. The majority of individuals given the Trades JSM for construction, electrical, plumbing, metal trades or other trade-related jobs were classified as having had probable asbestos exposure.

Table 4.5: Trades JSM exposure assessment results (probability of exposure only) for five largest categories of job titles

	No. participants allocated this JSM at least once	Assessed probability of exposure (No. participants for whom asbestos exposure was assessed as possible, probable, undetected)		
		Probable	Possible	Unlikely
Construction (carpenter, joiner, builder, bricklayer etc)	36	34	0	2
Electrician	16	11	1	4
Plumbing	13	13	0	0
Boilermaker, welder	10	9	1	0
Other metal & mechanical trades (incl fitters, turners, machinists & refrigeration trades)	24	18	2	4
All other Trades JSM recipients	30	13	4	13
Total participants given Trades JSM	**129**	**98**	**8**	**23**

Non-occupational exposure

All participants received a common questionnaire module to assess their non-occupational exposure. This non-occupational module was administered to all participants, regardless of occupational history and irrespective of whether JSMs were also administered to that individual. Information from the non-occupational module was used to assess exposure probability for each participant in the same way as occupational exposure probability was assessed. The analysis was undertaken using a three-level exposure scheme: asbestos exposure 'probable', 'possible' or 'unlikely'. It is important to note that the classification used for this report is based only on the probability of any exposure to asbestos and does not take into account intensity, duration or frequency of exposure.

For 85 participants (45 females and 40 males), no evidence of occupational asbestos exposure was detected using the methodology designed for the use in the AMR. Of these, JSMs yielded no information to suggest occupational exposure for 32 participants. Additionally, 60 participants did not receive JSMs because their job histories did not contain jobs likely to have exposure above background level.

Of those without evidence of occupational exposure, 70 (82.4%) were assessed as having had possible or probable exposure in non-occupational contexts based on data collected from the non-occupational questionnaire module. Table 4.6 shows the contexts of non-occupational asbestos exposure that were reported by these 70 participants.

Table 4.6: Context of non-occupational exposure among 70 participants without evidence of occupational exposure

Non-occupational module section	Total
Ever lived in a house made mainly of fibro (built 1947–1987)	19
Ever lived near asbestos mine or asbestos products factory	8
Ever did major home renovations which involved asbestos products (excluding paid work)	37
Ever lived in a house during major renovations (where house was built and the work undertaken during relevant periods)	35
Ever serviced car brakes/clutch (excluding paid work)	12
Ever lived in same home as someone with asbestos-exposed job who came home dusty	19
Ever visited Wittenoom in Western Australia (excluding paid work)	10
Ever visited another Australian asbestos mining town (excluding paid work)	0
Other credible evidence of non-occupational exposure	3

It should be noted that a number of respondents answered the question about living in a house during renovations and undertaking major home renovations apparently in relation to the same renovation event: of the 37 home renovators, 18 also answered 'yes' to living in a house during renovations. Of the 37 who reported having done home renovations, 16 were females.

Of the 10 participants in Table 4.6 who answered 'yes' to having visited Wittenoom, two were females who had lived at Wittenoom for a period, but were not employed there. Of the remaining eight who had been visitors to Wittenoom, most visited only once and stays were generally for only one day. All of the eight Wittenoom visitors reported first visiting after the closure of the Wittenoom asbestos mine in 1966 and two did not visit until after 1990. Of the five Wittenoom visitors who provided a reason for their visit, all reported that they had visited for recreation and/or visiting family/friends.

There is overlap between categories of exposure in Table 4.6. Among the 70 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 totals do not add up to 70.

Appendix A: Methods

This report focuses on data for people diagnosed with mesothelioma during the period 1 January 2012–31 December 2012 and notified to the AMR. All data presented in the report represent those that had been received by the Australian Mesothelioma Registry at 31 May 2013 for exposure data, and 30 June 2013 for incidence data. Mortality data are reported at 10 April 2013 for number of deaths, and 30 June 2013 for cause of death.

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 numbers of cases by the Australian estimated population of the same sex and age group at 30 June 2012.

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

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

Completeness

Notification data were complete for the majority of data items. However, the percentage of missing mandatory fields ranged from 0.0% to 36.8%.

There were 290 cases with either a date of death, cause of death, or both. Of these, the cause of death was unknown for 43.8% of the cases.

For South Australia, the following data items are not provided unless the patient consented to participate: Indigenous status, full date of birth (month and year are provided), full date of diagnosis (month and year are provided), address, and all names. In Table A1, 29 of the missing cases for these fields are from South Australia.

Table A1: AMR notification fields and per cent of missing records, 2012

Field	Mandatory field	No. of records	No. missing/ not stated	Per cent missing
Cancer registry ID/unique identifier	Yes	619	0	0.0
Record status	Yes	619	0	0.0
State/territory	Yes	619	0	0.0
Title	No	619	503	81.3
Last name	Yes	619	29	4.7
First name	Yes	619	29	4.7
Other names	No	619	258	41.7
Case address	Yes	619	29	4.7
Date of birth[(a)]	Yes	619	29	4.7
Sex	Yes	619	0	0.0
Indigenous status	Yes	619	228	36.8
Country of birth	No	619	178	28.8
Diagnosis date[(b)]	Yes	619	0	0.0
Best basis of diagnosis	Yes	619	1	0.2
Topography	Yes	619	4	0.6
Morphology	Yes	619	0	0.0
Laterality	No	596	199	33.4
Date of death	No	290	0	0.0
Cause of death code	No	290	127	43.8

(a) The 29 missing cases are for SA where only MM/YYYY has been provided, although full dates are recorded by SA.

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

New South Wales reported receiving mesothelioma notifications without pathological confirmation. At 31 May 2013, there were 10 reported cases of mesothelioma yet to be confirmed for NSW for 2012. For these cases, there is some evidence to suggest mesothelioma, but not enough to satisfy the criteria of the state's internal coding policy. This may be a likely case for other state and territory cancer registries. These additional diagnoses have not been included in figures for this report.

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

Data linkage with the National Death Index

All records in the AMR at 10 April 2013 were sent to the Australian Institute of Health and Welfare (AIHW) for linkage with the NDI. The purpose of the linkage was to obtain death data, including date of death and cause of death, for all records on the AMR.

For patients diagnosed in 2012, there were 290 successful record linkages with updates to include date of death. Cases notified to the AMR after 10 April 2013 were not included in the data linkage and therefore, death figures are an underestimate. Due to the 2012 AMR data being relatively recent, cause of death information was not yet available for most linked records. Subsequently, provisional data from states and territories were used for cause of death information in this report. A

further data linkage will be carried out by AIHW later in 2013 to obtain cause of death information for more records. Death data obtained from the NDI will be updated to reported death information in previous years in subsequent AMR reports.

The AMR data is linked with the NDI on an annual basis and the linkage provides updates to all previously linked cases and those not successfully linked. 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 ABS. 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, as well as death certificates, to ascertain deaths for mesothelioma cases.

Small cells

Small cells of less than five cases have been presented in some tables in this report. Exceptions are state/territory tables disaggregated by more than one demographic factor, such as sex and age group, and where rates are based on cells of less than 10 cases. The data in the asbestos exposure section are based on exposure judgements made by MonCOEH, and not solely on demographic characteristics, so 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 received, contacting the patient to see if they are interested in participating.

The patient recruitment processes vary across the states and territories in line with the state or territory ethics approval or patient recruitment protocols. In NT, SA and Queensland, doctors need to return a completed consent form to the relevant cancer registry to indicate consent. All other jurisdictions (Victoria, Tasmania, NSW/ACT and WA) are operating on a 'passive consent' (opt out) model. A passive consent model is where doctors do not respond within three or four weeks respectively, consent is assumed and the patient is contacted.

NSW/ACT moved to the passive consent model from 1 May 2012. WA also adopted the new model from October 2012; however, the majority of patients diagnosed in 2012 and recruited to the AMR would have been recruited via the previous patient recruitment model. Table A2 presents some characteristics of the different processes.

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

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

Coding of occupations

All occupations reported by patients via the AMR postal questionnaire are coded according to the Australian and New Zealand Standard Classification of Occupations (ANZSCO) (ABS 2006). 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 which the participant has reported, based on judgement by MonCOEH of possible asbestos exposure. The purpose of a JSM is to ask a systematic series of questions about a possible asbestos-exposed job, in a standardised way, to elicit task and exposure information which can then be used to estimate that individual's occupational asbestos exposure. 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 so many jobs of interest, it is not feasible to administer JSMs for all jobs. 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 relevant for a proportion of participants, 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 the present report, exposure has been assessed as probability of any exposure. The classification of exposure probability uses a three-level scheme: 'probable', 'possible' and 'unlikely'.

Appendix B: Tables underlying figures

Table A3: Age-standardised incidence rates (World Standard Population) by sex and state and territory, 2012

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
				Rate per 100,000 person-years[(a)]					
Males	1.9	2.2	2.9	4.2	n.p.	n.p.	n.p.	0.0	2.4
Females	0.3	0.4	0.7	1.1	n.p.	n.p.	n.p.	0.0	0.5
Persons	**1.1**	**1.2**	**1.8**	**2.6**	**1.0**	**1.3**	n.p.	**0.0**	**1.4**

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

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

Table A4: New cases of mesothelioma and age-standardised incidence rates by sex and state and territory, 2011

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Males	159	102	113	91	48	n.p.	9	n.p.	540
Females	26	28	21	12	10	<5	0	<5	99
Persons	**185**	**130**	**134**	**103**	**58**	**14**	**9**	**6**	**639**
				Rate per 100,000 person-years[(a)]					
Males	4.2	3.6	5.3	8.5	5.1	n.p.	n.p.	n.p.	4.8
Females	0.6	0.8	0.8	0.9	0.9	n.p.	n.p.	n.p.	0.7
Persons	**2.2**	**2.1**	**2.9**	**4.4**	**2.8**	**2.1**	n.p.	n.p.	**2.6**

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

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

Table A5: New cases of mesothelioma by age-group, 2012

Age Group	Number
Less than 40	3
40–44	2
45–49	6
50–54	16
55–59	33
60–64	66
65–69	107
70–74	94
75–79	118
80–84	102
85–89	54
90 and over	18
Total	**619**

Table A6: New cases of mesothelioma by sex and age-group, 2012

	<55	55–59	60–64	65–69	70–74	75–79	80–84	85+
Males	15	27	54	89	86	94	86	60
Females	12	6	12	18	8	24	16	12
Persons	**27**	**33**	**66**	**107**	**94**	**118**	**102**	**72**

Table A7: Age-specific incidence rates of mesothelioma, 2012

	<55	55–59	60–64	65–69	70–74	75–79	80–84	85+
Males	0.2	4.0	8.8	17.5	23.6	35.5	44.8	40.3
Females	0.1	n.p.	1.9	3.5	n.p.	7.9	6.3	4.4
Persons	**0.16**	**2.43**	**5.33**	**10.44**	**12.57**	**20.71**	**22.95**	**16.99**

Note: Age-specific rates using the Australian estimated population at June 2012.

n.p. Rates not published due to small numbers.

Table A8: Deaths of people diagnosed with mesothelioma in 2011 by state and territory

Deaths	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	142	104	99	71	0	12	5	<5	437
Per cent of patients diagnosed	76.8	80.0	73.9	68.9	0.0	85.7	55.6	n.p.	68.4

Note: Death information from the NDI.

Table A9: Cause of death known for people diagnosed with mesothelioma in 2011

Cause of death	Number	Per cent
Mesothelioma	140	90.3
Not mesothelioma	15	9.7
Total	**155**	**100.0**

Note: Cause of death information from the NDI

Glossary

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

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

Histology Microscopic examination of cells and tissues.

Job-specific module (JSM) Telephone questionnaire modules 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 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.

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

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

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

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

OccIDEAS (Occupational Integrated Database Exposure Assessment System) a secure, web-based survey tool used in research projects where accurate, subject-specific exposure assessment is needed. It is a computerised interview tool for collecting exposure data from individual subjects. OccIDEAS also manages and organises the exposure information and is 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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