

Australian Mesothelioma Registry; Data Quality Statement

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Identifying and definitional attributes

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Data quality

Data quality statement summary:

The Australian Mesothelioma Registry (AMR) is a data collection held within the Australian Institute of Health and Welfare (AIHW), containing information on mesothelioma incidence, mortality and asbestos exposure from 1 July 2010 – present. The collection was established by the Cancer Institute of New South Wales (NSW) in 2011, but has been managed by the AIHW since mid-2017. The AMR is funded by [Safe Work Australia](#) (SWA).

All states and territories have legislation that makes cancer a notifiable disease. For the AMR, mesothelioma cases are ‘fast-tracked’ by each state and territory cancer registry. That is, extra resources are provided so that these records are processed and coded as quickly as possible. Each jurisdiction provides case notifications to the AMR on a regular basis. The case records include patient demographics, diagnosis details and, if applicable, death information.

The notifications are uploaded into the AMR database and used for reporting and research purposes. Using the data provided by the cancer registries, as well as annual linkages performed with the National Death Index (NDI) held by the AIHW, the AMR monitors national mesothelioma incidence and mortality. Information on potential asbestos exposure is also collected from consenting patients with mesothelioma, and their potential exposure source is assessed by the Monash Centre for Occupational and Environmental Health (MonCOEH) and used to identify patterns and trends of occupational and environmental asbestos exposure.

The AMR operates with ethical approval from the AIHW Ethics Committee and ethics committees within all states and territories. These arrangements allow the AMR to collect data in accordance with strict laws that protect patients’ privacy.

Key data quality issues

- Mesothelioma is a notifiable disease so it is mandatory for notifiers to provide information to state and territory cancer registries for all cases, which means that all cases of mesothelioma are recorded and subsequently provided to the AMR.
- The AIHW produces an annual publication which reports on the latest available information from the AMR. However, incidence and mortality data are likely to be an underestimate for the most recent years, as it is probable that not all mesothelioma cases are notified to the AMR at the time of publishing.
- Patients in the AMR can volunteer to participate in an asbestos exposure assessment, which has a participation rate of approximately 15%. While this may be considered low compared to other data collections, this represents 15% of **all mesothelioma cases** in Australia. Voluntary participation in the asbestos exposure component also has the potential to create bias in the data, for example, if the majority of participants are from WA and worked in a particular industry.
- Even though mesothelioma cases are fast-tracked by state and territory cancer registries, there are still delays with patient recruitment for a number of reasons. The AMR uses a passive consent model – clinicians are contacted to determine their patient’s eligibility, and have a 4-week period to advise if the patient shouldn’t be contacted to participate. If a response is not received during this period, patients are contacted by either state/territory cancer registries or the AMR, and invited to participate (noting that there are ethical approvals in place to allow this). Recruitment processes and timelines vary between state and territory cancer registries.
- There are limitations with reporting mesothelioma trends due to the lack of time series data in the AMR at this stage. However, mesothelioma incidence trends are reported using available data from two sources: the Australian Cancer Database (ACD) for the period 1982–2010, and the AMR for the period 2011–present.

Institutional environment:

The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the [Australian Institute of Health and Welfare Act 1987](#) to provide reliable, regular and relevant information and statistics on Australia’s health and welfare. It is an independent corporate Commonwealth entity established in 1987, governed by a [management Board](#), and accountable to the Australian Parliament through the Health and Ageing portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The Institute also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The Institute works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national datasets based on data from each jurisdiction, to analyse these datasets and disseminate information and statistics.

The Australian Institute of Health and Welfare Act 1987, in conjunction with compliance to the Privacy Act 1988, (Cth) ensures that the data collections managed by the AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality. For further information see the AIHW website www.aihw.gov.au

Mesothelioma notifications are provided to the AMR by the following state and territory cancer registries:

New South Wales Cancer Registry (NSW and ACT notifications):

<https://www.cancer.nsw.gov.au/data-research/data-held-by-cinsw/nsw-cancer-registry>

Queensland Cancer Register:

<https://cancerallianceqld.health.qld.gov.au/qcr/>

Western Australian Cancer Registry:

https://ww2.health.wa.gov.au/Articles/U_Z/Western-Australian-Cancer-Registry

Victorian Cancer Registry:

<https://www.cancervic.org.au/research/registry-statistics>

South Australian Cancer Registry:

<https://data.sa.gov.au/data/dataset/sa-cancer-registry>

Northern Territory Cancer Registry:

<https://health.nt.gov.au/professionals/health-gains/northern-territory-cancer-registry>

Tasmanian Cancer Registry:

<http://www.menzies.utas.edu.au/research/research-centres/tasmanian-cancer-registry>

The Monash Centre for Occupational and Environmental Health undertakes the asbestos exposure component of the AMR:

<https://www.monash.edu/medicine/sphpm/coeh>

Timeliness: The AMR has been operational since 2011, with AIHW taking over management of the registry from September 2017. The data collection contains all mesothelioma cases diagnosed in Australia from 1 July 2010–present.

State and territory cancer registries provide data files containing mesothelioma notifications on a regular basis, on a schedule agreed with each state and territory.

The AIHW is contracted by SWA to provide an annual report on mesothelioma in Australia.

Accessibility: The AMR website provides [annual reports](#) which can be downloaded free of charge – [Mesothelioma in Australia](#) was released on 13 November 2018. AMR data is also presented in the flagship AIHW publication, [Australia's health 2018](#) which is available on the AIHW website.

Users can request data tables not available online via the AMR information line on 1800 378 861, via email to amr@aihw.gov.au or using the [AIHW data request system](#). Requests that take longer than half an hour to compile are charged for on a cost-recovery basis. Requests may also require ethics and state and territory cancer registries approval for release.

General enquiries about AIHW publications can be made to the Communications, Media and Marketing Unit on (02) 6244 1032 or via email to info@aihw.gov.au.

Interpretability: There are three components to the AMR database.

Incidence data – Demographics and diagnosis information of people with mesothelioma that have been provided to the AMR by state and territory cancer registries

Mortality data – The AMR is linked with the AIHW National Death Index (NDI) database in Australia on an annual basis. This linkage provides more complete data on date of death and cause of death for AMR cases. The AIHW website provides additional information about the [NDI](#). The linked data are stored in the AMR database system and used for reporting. Data linkage between the AMR and NDI has not been undertaken since 2015, and will recommence in 2019.

Asbestos exposure data – Patients in the AMR can volunteer to participate in an asbestos exposure assessment. These data, analysed by MonCOEH staff, include estimated exposure profiles of people with mesothelioma. This involves patients completing a postal questionnaire and telephone interview about their residential and occupational history, as well as any potential family history of mesothelioma.

[Appendix A of Mesothelioma in Australia 2016: 6th Annual Report](#) provides more information about the assessment of asbestos exposure.

Relevance: The AMR contains all mesothelioma records that have been notified by state and territory cancer registries since 1 July 2010. This information is used to:

- better understand the relationship between asbestos exposure and mesothelioma, and the nature and levels of asbestos exposure that can result in mesothelioma.
- identify the circumstances under which groups of individuals are exposed to potentially dangerous levels of asbestos and to facilitate prevention, and to identify other exposures that may be associated with mesothelioma.
- assist the development of policies to best deal with the asbestos still present in our environment and inform the development of community education and awareness strategies.
- provide information to assist researchers in undertaking investigations with the aim of preventing mesothelioma in the future.
- monitor and report on longitudinal or geographic trends.

Accuracy:

Due to the complex nature of coding mesothelioma records and the time it takes for state and territory cancer registries to receive and code cases, the incidence and mortality data for the most recent years available are likely to be an underestimate, as it is probable that not all mesothelioma cases have been notified to the AMR at the time an annual report is published. The AMR data set is regularly updated back to 1 July 2010 and it would be expected that additional notifications will be reported in future publications.

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

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

The participation rate for the voluntary asbestos exposure assessment component of the AMR is around 15%. This is partially due to patients dying or being too unwell to participate. The results of the asbestos exposure assessments considers only the probability of asbestos exposure and doesn't take into account the duration, intensity or frequency of exposure. The information presented on potential exposure is for those who participate but may not be representative of everybody's asbestos exposure because a relatively high proportion of people diagnosed with mesothelioma don't participate in the asbestos exposure assessment component.

Coherence:

During the period, management of the registry transfer to AIHW, state and territory methodology for coding and notifying the AMR of mesothelioma cases remained consistent. Due to time required to set up ethical arrangement with each state and territory cancer registry to enable them to recruit patients and the aggressiveness of mesothelioma, it is expected there will be a decline in asbestos exposure participation for this period.

Data products

Implementation start date: 25/02/2019