

How will patient information be used?

- The data collected is stored in accordance with strict laws that protect people's privacy.
- Information will only be published in a format that does not identify individuals.
- Any research undertaken using registry data will require approval from a Human Research Ethics Committee and all requests for information are expected to contribute to mesothelioma control and improvements in care for people with mesothelioma.
- Data may be linked to other data collections, including those containing health or treatment information such as Hospital, pathology, emergency department, and Births, Deaths and Marriages registry records; Cancer registry records.


Who is involved?


- Safe Work Australia
- Cancer Institute NSW
- Comcare
- Hunter Research Foundation
- University of Sydney
- University of Western Australia
- Asbestos Disease Research Institute
- State & Territory Cancer Registries
- Monash Centre for Occupational and Environmental Health at Monash University

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

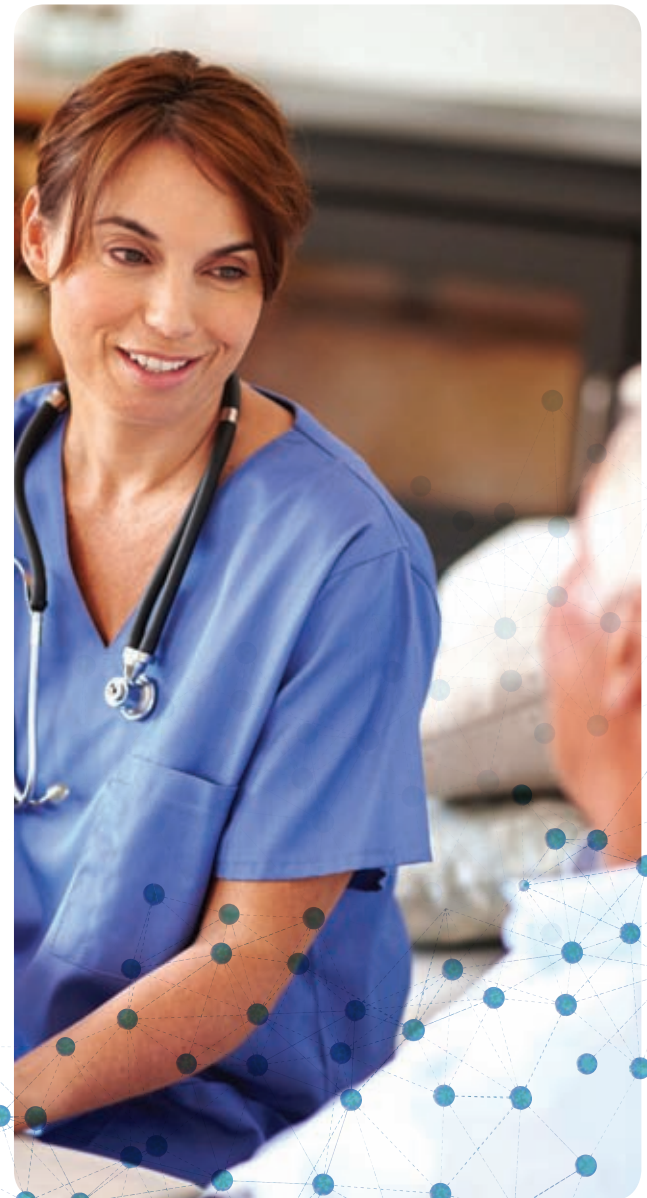
 **Helpline:** 1800 378 861

 **Email:** amr@cancerinstitute.org.au

 **Website:** mesothelioma-australia.com

 **Mail:** Australian Mesothelioma Registry, Cancer Institute NSW, Reply Paid 41, Alexandria NSW 1435

WORKING ON THE PREVENTION OF MESOTHELIOMA IN THE FUTURE FOR HEALTH PROFESSIONALS:



What is the Australian Mesothelioma Registry (AMR)?

Australia has one of the world's highest rates of mesothelioma and it is estimated that this is yet to peak. As a response to the increasing incidence of mesothelioma the AMR was established and collects information about people diagnosed with mesothelioma from 1st July 2010, including history on people's asbestos exposure.

This information helps the Australian Government develop policies to best deal with the asbestos still present in Australia's buildings and environment, with the aim of reducing mesothelioma in the future.

What is the role of the doctor?

Patient participation in the AMR is currently only 20%. To help improve this we ask that Doctors and Health Professionals assist with the following:

1. Educate patients

We strongly encourage you to educate your patients on the AMR and the opportunity to self notify. Patients can self notify via the AMR website, by calling the AMR or by completing the form in the Patient Self-Notify Brochure.

2. Doctors consent

We ask that doctors complete the consent form promptly to advise on the eligibility of their patient. The consent form will be sent to Doctors from the state/territory cancer registries upon notification of a mesothelioma case.

To be eligible patients must be:

- Physically and mentally able to complete a written survey
- Able to participate in a telephone interview
- Aware of their mesothelioma diagnosis

What does participation involve?

Eligible patients will receive an information pack including:

- Patient information sheet
- Consent form
- Postal questionnaire

Participation involves patients completing the questionnaire and taking part in a short telephone interview about their occupational and residential history; and family mesothelioma history (if any). The purpose of the Questionnaire is to help identify when patients may have come into contact with asbestos. Once the questionnaire is completed and returned patients will be asked to take part in a short telephone interview involving more detailed questions about their potential asbestos exposure. This information will help to improve understanding about mesothelioma and asbestos exposure.

The AMR collections information about mesothelioma cases to:

- Better understand the relationship between asbestos exposure and mesothelioma.
- Identify the circumstances under which groups of individuals are exposed to potentially dangerous levels of asbestos and to facilitate prevention.
- Better understand the nature and levels of asbestos exposure that can result in mesothelioma.
- Assist the development of policies to best deal with the asbestos still present in our environment.
- Provide information to assist researchers in undertaking investigations with the aim of preventing mesothelioma in the future.