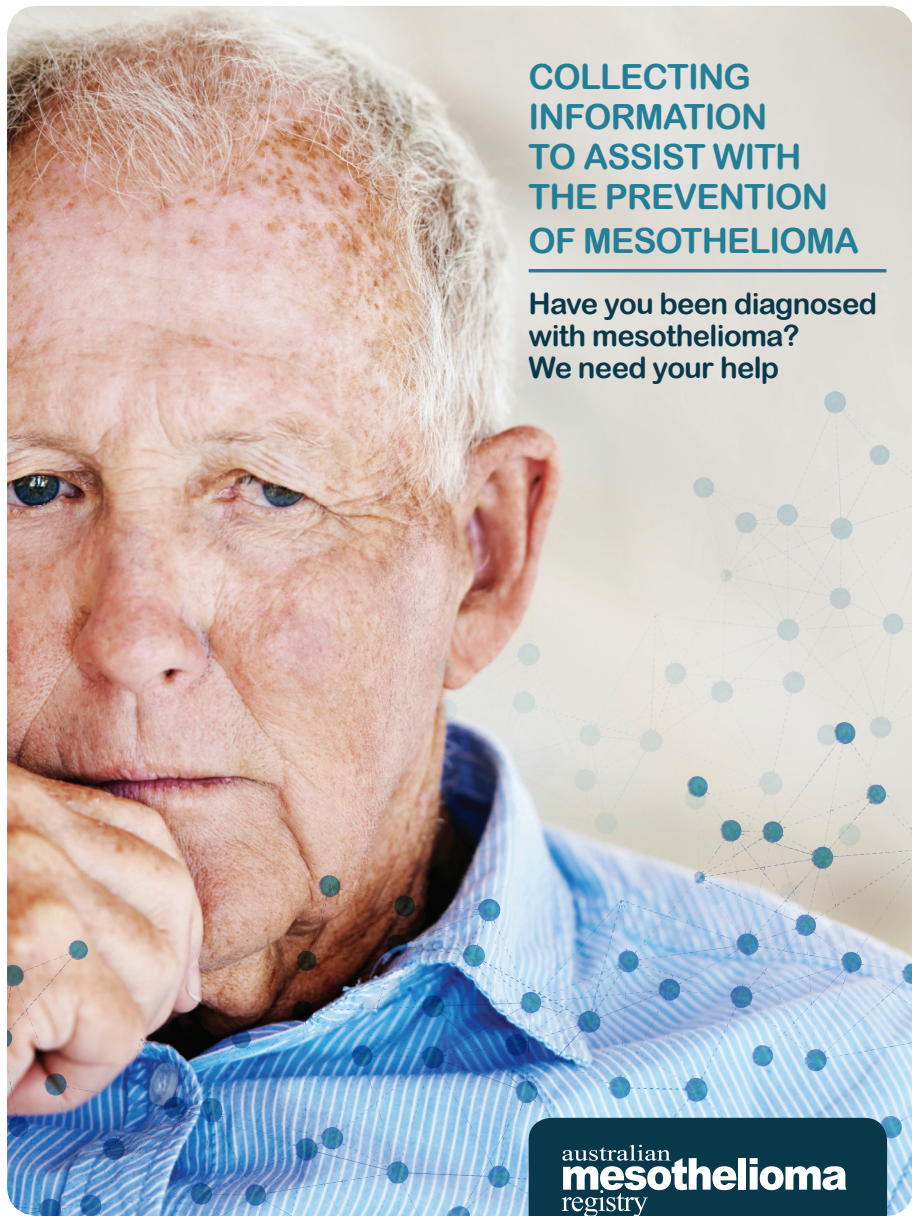


COLLECTING
INFORMATION
TO ASSIST WITH
THE PREVENTION
OF MESOTHELIOMA

Have you been diagnosed
with mesothelioma?
We need your help



australian
mesothelioma
registry

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

 AMR information line
1800 378 861

 Email
amr@aihw.gov.au

 Website
mesothelioma-australia.com

 Write to (no stamp required):
Australian Mesothelioma
Registry Australian Institute of
Health and Welfare

Reply Paid 570
Canberra ACT 2601



PEOPLE WITH
MESOTHELIOMA
WE NEED YOUR HELP

Delivery Address:
GPO Box 570
CANBERRA ACT 2601



No stamp required
if posted in Australia




Australian Mesothelioma Registry
Australian Institute of Health and Welfare
Reply Paid 570
CANBERRA ACT 2601

What is the Australian Mesothelioma Registry (AMR)?

The AMR is a government initiative funded by *Safe Work Australia* that collects information about people diagnosed with mesothelioma from 1st July 2010, including history on people's asbestos exposure. The information collected helps the Australian Government develop policies, with the aim of reducing mesothelioma in the future.

The AMR collects information about cases of mesothelioma to:

- Better understand 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.
- 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.

What does participation involve?

If you choose to participate, you will receive an information pack containing a:

- Patient Information Sheet
- Consent Form
- Questionnaire

Participation involves completing a questionnaire and taking part in a short telephone interview about your:

- Occupational and residential history;
- Family mesothelioma history (if any).

The information you supply will help to improve the understanding of mesothelioma and asbestos exposure. Participation is voluntary and you can withdraw at any time by contacting the AMR. When completing the Questionnaire, don't worry if you can't remember something about your history. Any information that you provide is valuable. The purpose of the Questionnaire is to help identify when you may have come into contact with asbestos during your life. Once the questionnaire is completed and returned, you will be asked to take part in a short telephone interview involving more detailed questions about your potential asbestos exposure.

There are two ways you can participate in the AMR:

SELF
NOTIFY

If you have been diagnosed with mesothelioma you can self-notify to the AMR by:

- completing the attached form and returning via the **self-stick prepaid envelope** provided
- calling our information line on **1800 378 861**
- registering online at the AMR website **mesothelioma-australia.com**.

DOCTORS
CONSENT

When the mesothelioma diagnosis is first made, the doctor may be approached to check you meet the AMR eligibility criteria and are well enough to participate. If eligible, you will receive an AMR information pack.

Why should I participate?

We need your help to increase participation in the patient questionnaire and interview component which is around 20%. All information is useful and you will be taking part in something that really helps to make a difference. **Let's work together towards the prevention of mesothelioma.**

How will my personal information be used?

Your personal information will only be used for research purposes that are expected to contribute to mesothelioma control or improvements in care of people with mesothelioma. Data may be linked to other data collections, including those containing health or treatment information such as hospital, pathology, emergency department, Births, Deaths and Marriages registry records and cancer registry records.

How is my privacy protected?

As part of the Australian Institute of Health and Welfare (AIHW), the AMR observes the Australian Privacy Principles set out in the Privacy Act 1988 when collecting and dealing with any personal information, meaning that data are stored strictly to protect people's privacy. The AMR does not allow the publication of information that identifies individuals, or might potentially identify them.

The Australian Institute of Health and Welfare Act 1987 has some additional protections to the Privacy Act 1988. Most importantly, information about identified individuals, including deceased individuals, is not required to be released in response to court orders, including subpoenas. In addition, this information is protected from release under the Freedom of Information (FOI) Act, except if the information sought is about the FOI applicant.

If you have been diagnosed with mesothelioma, we need your help.

The AMR assists with research and prevention of mesothelioma. Your participation will help towards preventing mesothelioma in the future. If you have recently been diagnosed with mesothelioma, please notify the AMR by providing your details below. We will be in touch.

✉ **MAIL:** Complete this form and return via this prepaid envelope slip
☎ **PHONE:** Call AMR on 1800 378 861 (toll-free)
🌐 **ONLINE:** mesothelioma-australia.com

Fields marked with an * are mandatory.

*FIRST NAME:

*LAST NAME:

DATE OF BIRTH:

SELECT:

Male

Female

ADDRESS:

SUBURB/TOWN:

*STATE/TERRITORY: POSTCODE:

*CONTACT PHONE:

EMAIL ADDRESS:

COMMENTS:

The information collected is stored in accordance with laws that protect people's privacy. Data will only ever be published in a format that does not identify individuals. The AMR respects your privacy and will ensure that your information is kept confidential at all times.