

AMR UPDATE

THE AUSTRALIAN MESOTHELIOMA
REGISTRY NEWSLETTER
1st Edition - October 2012

australian
mesothelioma
registry

WELCOME TO THE FIRST EDITION of AMR UPDATE.

This newsletter is designed to keep you up to date on the Australian Mesothelioma Registry (AMR) and our efforts to understand the relationship between asbestos exposure and mesothelioma.

Introduction

The Australian Mesothelioma Registry (AMR) is a new National Registry which became operational in 2011. The Registry includes all patients diagnosed with mesothelioma in Australia from 1 July 2010. In addition, information about asbestos exposure is collected from people with mesothelioma through a Postal Questionnaire and telephone interview.

The Registry replaces the previous Australian Mesothelioma Register managed by the National Occupational Health and Safety Commission. 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.

Announcement: Our 1st Annual Data Report - Released in September 2012

The Australian Mesothelioma Registry in conjunction with Safe Work Australia has recently published its first annual report Mesothelioma in Australia 2011. This report presents data from the new AMR. It includes data collected from both mesothelioma notifications, and from the asbestos exposure information collection. In this report, data for patients diagnosed during the calendar year 1 January–31 December 2011 are presented.

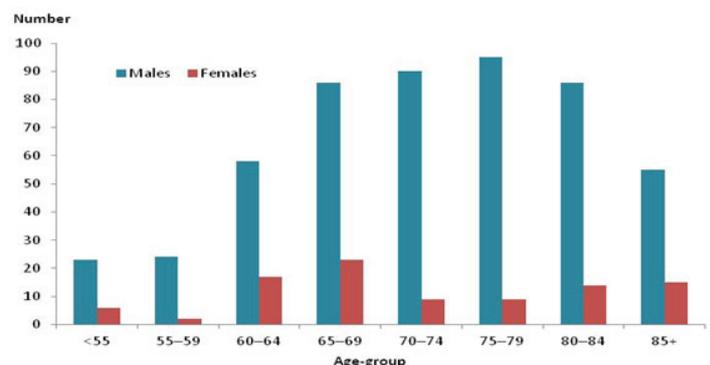
The report includes the following sections:

1. Incidence
2. Mortality
3. Asbestos exposure

Did you know?

- The incidence rate for mesothelioma is 2.7 per 100,000 population
- 612 cases of mesothelioma were reported to the AMR for 2011
- Males accounted for 85% of notified cases
- 79% of patients were aged 65 years or over
- The most common type of mesothelioma was the epithelioid subtype (44%)
- Most common location was the pleura (92%)
- There were 310 deaths of patients diagnosed in 2011 (51%)
- Job types with highest asbestos exposure likelihood:
 - Construction and building trades
 - Electrical and related trades
- Most common circumstances of non-occupational asbestos exposure:
 - Home renovation-related activities
 - Car maintenance

New cases of mesothelioma by age-groups and sex, 2011



The above and many more interesting facts and figures can be found in our [2011 Annual Data Report](#).

The report is available on the [AMR website](#).

Cancer Direct

Read about lung cancer resources in the launch issue of [Cancer Direct](#), the Cancer Institute NSW quarterly cancer resource for General Practitioners.

Support Services

We understand the diagnosis of mesothelioma has a big impact on a person and their family members, friends or carers. The AMR doesn't have the skills or expertise to provide a specialised counselling service or give professional medical advice. We encourage patients to talk to their doctors if they are concerned about their diagnosis. They may also find the [support sites](#) on the AMR website useful.

Staff Profile: Paula Laws, Manager Australian Mesothelioma Registry

Paula became Manager of the AMR at the Cancer Institute NSW in January 2011. Paula has worked in the field of national health data for over 10 years, previously working at the Australian Institute of Health and Welfare and managing the National Perinatal Data Collection. Her experience includes management of large datasets, national data collection and reporting, and development of data standards. Paula has also been an investigator on several research projects.

Paula's role is to oversee the operation of the Registry, to manage partnerships with participating organisations and to provide advice on the Registry.

The AMR Data Manager, **Grace Kwaan**, compiles the AMR data both from states and territories and from patients, ensuring data quality to allow a high standard of reporting.

You can contact Paula via the AMR Helpline on 1800 378 861.

The role of the doctor in the recruitment of patient to the AMR

When a notification of a mesothelioma diagnosis is made to the AMR, the relevant state or territory cancer registry will approach the patient's doctor to obtain their advice on whether their patient meets various eligibility criteria. Participation in the AMR involves the patient completing a postal questionnaire and telephone interview.

Criteria to confirm patient's eligibility:

- *Diagnosed with mesothelioma on or after 1st July 2010*
- *Physically and mentally able to complete a written survey*
- *Able to participate in a telephone interview (10–30 mins, can be split if necessary)*
- *Aware of their mesothelioma diagnosis*
- *A life expectancy of at least 2–3 months*
- *Diagnosed within Australia*

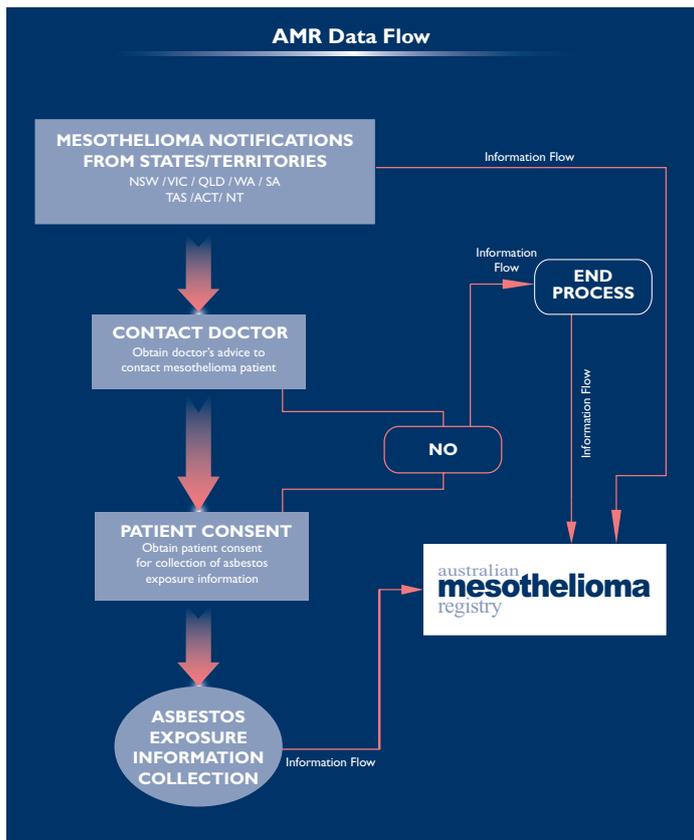
Doctors play a vital role in the recruitment process and the AMR rely on the assistance of clinicians to ensure the timeliness of data collection. The prompt completion and return of the clinician consent form would greatly assist with patient recruitment and undertaking of the telephone interview.

Important occupational and environmental asbestos exposure information cannot be collected from the patients without a general practitioner or treating doctor considering each patient's suitability.

Please refer to the diagrams below regarding the flow of information from state and territory registries, doctors and patients to the AMR (Figure 1). Figure 2 below depicts the relationship of how asbestos exposure information is collected for the AMR.

For more information on patient recruitment process and asbestos exposure information collection, please visit [our website](#).

Figure 1: Patient recruitment process and data flow for AMR:



Promoting the AMR to patients diagnosed with mesothelioma

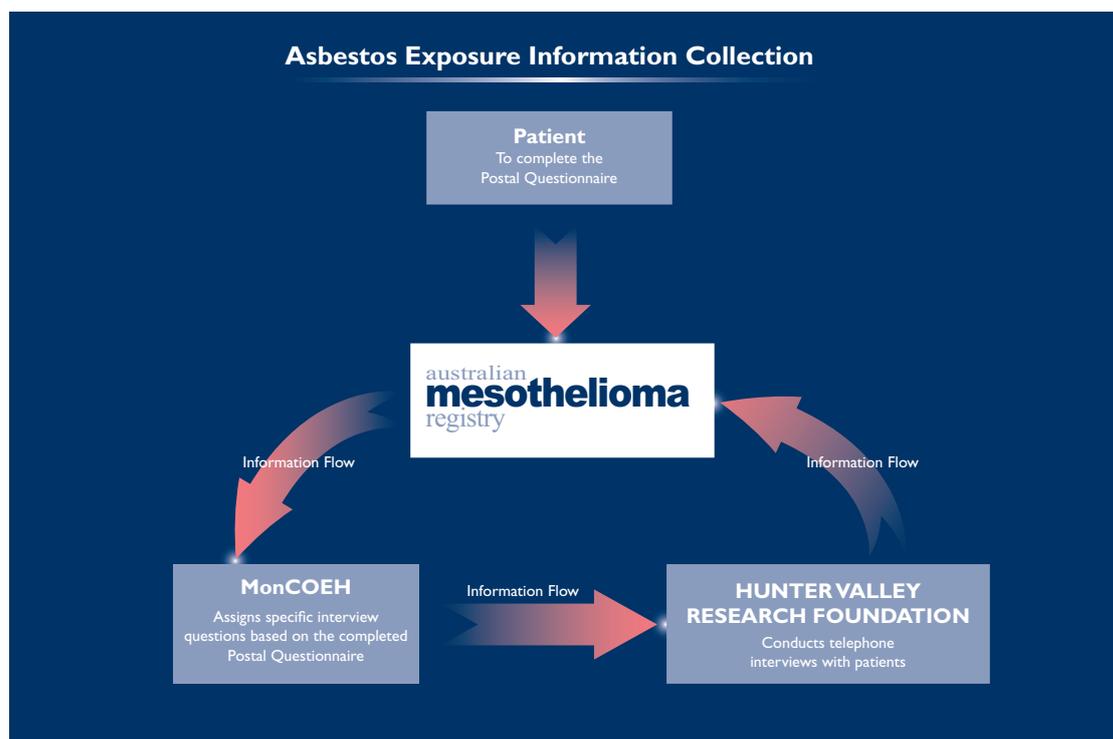
Support of clinicians, lung cancer nurses and others in contact with mesothelioma patients is needed to promote knowledge of the AMR to people diagnosed with mesothelioma to encourage patient participation.

AMR information will aid federal and state governments to develop policies to deal with asbestos in buildings and other infrastructure. It provides a national resource for researchers to identify preventable risk factors to assist in reducing mesothelioma in the future. Exposure assessments provide detailed information not previously available.

So why should patients participate?

- Results will be more representative of all patients with mesothelioma and will be more meaningful
- Information obtained about the relationship between asbestos exposure and the causes of mesothelioma will aid research and prevention of mesothelioma in the future.

Figure 2: Process of asbestos exposure information collection.



Newsletter feedback

We are interested in your feedback. Please send your comments, questions and suggestions for our newsletter to us using the contact details on this page.

Contact Us

Helpline (toll-free):

1800 378 861
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(Eastern Standard Time)
(excludes NSW Public Holidays)

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Website: www.mesothelioma-australia.com

Our partners

Safe Work Australia:
safeworkaustralia.gov.au

Comcare:
www.comcare.gov.au

Cancer Institute NSW
www.cancerinstitute.org.au

Monash Centre for Occupational and Environmental Health
www.coeh.monash.org

Hunter Valley Research Foundation
www.hvrf.com.au

The Asbestos Diseases Research Institute
www.adri.org.au

Cancer Epidemiology and Health Services Research Group of the University of Sydney
sydney.edu.au

University of Western Australia
www.uwa.edu.au

Dust Diseases Board
www.ddb.nsw.gov.au