

ACT Asbestos Health Study Q & A

Report 4: Data Linkage Study on the Risk of Mesothelioma and Other Cancers in Residents of Affected Residential Properties in the ACT

1. What is Report 4 about?

Report 4 describes the methods and results of research that examined whether the rates of mesothelioma and other cancers were higher in people who had lived at an affected residential property (ARP) than in people who had not.

To do this, Medicare enrolment data on residents of the ACT between November 1983 and December 2013 were linked to the ACT Asbestos Response Taskforce register of ARPs. These data were then linked to the Australian Cancer Database and the National Death Index.

There were 1 035 578 individuals registered with Medicare with an ACT address during the study period, 17 248 (1.67%) of whom had lived at an ARP. The data linkage allowed for a comparison of cancer rates between ACT residents who had lived at an ARP versus those who had not.

2. What are the main findings of Report 4?

There were 285 cases of mesothelioma diagnosed in people who had lived in the ACT at some point during the study period (1983–2013), with 152 of them being diagnosed outside the ACT. Mesothelioma was diagnosed in 7 people who had lived in an ARP sometime before their diagnosis.

The rate of mesothelioma was 2.5 times higher in men who had lived at an ARP than in men who had not. This corresponds to 4 extra cases of mesothelioma in male ARP residents between 1984 and 2013 (i.e., *additional* to the number expected to occur in this group, even if there had never been loose fill asbestos in these houses).

There were no cases of mesothelioma in women who had lived in an ARP. On average in Australia at present, the rate of mesothelioma in females is about a fifth of that in males.

The study also found that the rate of colorectal cancer was 1.3 times higher in male ARP residents and 1.7 times higher in female ARP residents than the corresponding rates in residents who did not live at ARPs. Prostate cancer rates were 1.3 times higher in male ARP residents.

3. What does this mean regarding the risk of mesothelioma?

Although the rate of mesothelioma was higher in men who had lived at ARPs than in men who had not, the risk of developing mesothelioma was very low even among ARP residents.

The increased risk of mesothelioma in men living at ARPs might reflect higher exposure to loose-fill asbestos through activities like entering roof spaces or doing renovations. These activities were reported more frequently by men than women in the cross sectional survey (Report 3 of the Asbestos Health Study).

These results should be interpreted with care, as there was: (1) no data prior to November 1983; (2) little information on other possible explanatory factors, such as occupational history of asbestos exposure; and (3) statistical uncertainty due to small numbers of some cancers.

4. What does this mean regarding the risk of other cancers?

The elevated rates of colorectal and prostate cancers in ARP residents were somewhat unexpected. Other studies have found, at most, weak associations between asbestos exposure and these cancers. Other explanations for these associations should be considered, including other risk factors that were unable to be measured, such as smoking or diet, and particularly in the case of prostate cancer, people seeking screening for cancer.

5. Why did the data linkage only start in 1983?

Data are not available before this date, as Medicare registrations only began in November 1983.

6. If it takes time to develop mesothelioma, wouldn't there be more cases in the future?

There may be more cases of mesothelioma over the next 20 years in people who have lived at an ARP. It would be possible to re-run the data linkage component of the study to include data beyond 2013. While no decision has been made to do that at this stage, the data sets are being preserved. Mesothelioma takes a long time to present and is very rare, so it may be useful to re-run the data linkage and analysis in several years time.

7. What are the symptoms of mesothelioma?

Mesothelioma is a cancer affecting the mesothelial cells which cover most internal organs. There are two main types of mesothelioma; pleural and peritoneal. Pleural mesothelioma is the most common type of mesothelioma, and accounts for about 90% of all mesotheliomas.

The main symptoms of pleural mesothelioma include:

- shortness of breath – which usually worsens with activity or when lying down
- chest pain or pain in the shoulder and upper arm
- loss of appetite, weight loss
- persistent cough or a change in a person's usual cough
- heavy sweating, particularly at night.

Early signs of pleural mesothelioma are similar to other conditions and diseases. If you are concerned about your health, you should seek advice from a qualified medical practitioner who can provide an assessment of your individual circumstances.

Further information can be found at <http://www.cancer.org.au/about-cancer/types-of-cancer/mesothelioma.html>

8. How can I find out more about the risks from asbestos?

The Department of Health document “A guide for householders and the general public” can be found at

[http://www.health.gov.au/internet/publications/publishing.nsf/Content/asbestos-toc/\\$FILE/asbestos-feb13.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/asbestos-toc/$FILE/asbestos-feb13.pdf)

9. What should I do if I am worried about my health?

People who are concerned about their health should seek advice from a medical practitioner who can provide an assessment of individual circumstance and exposure risks.

Face-to-face and phone support services are available through the Next Step program for those experiencing anxiety or depression — please call Capital Health Network on 6287 8066.

Additionally, support is available through Lifeline on 13 11 14 and Beyond Blue on 1300 224 636.

10. Is Report 4 publicly available?

The full Report is available on NCEPH’s website at

<http://nceph.anu.edu.au/research/projects/act-asbestos-health-study>.

Background

11. What was the purpose of the ACT Asbestos Health Study?

The Study’s purpose was to improve understanding of the health risks associated with living in an ACT house containing loose-fill asbestos insulation. There were four separate components of the Study:

1. An analysis of mesothelioma rates and distribution in the ACT (July 2015).
2. Focus groups held with current and recent residents of affected houses to discuss their health-related concerns (February 2016).
3. A study looking at the likely exposure levels and health-related concerns of current and recent residents in terms of years lived in an affected house and activities such as renovating (February 2017).
4. A study linking a number of data sets to estimate the risk of developing mesothelioma and other cancers in current and former residents of affected houses compared with people who have not lived in these houses (June 2017).

The unique nature of asbestos exposure caused by loose-fill asbestos meant that direct evidence was not available from scientific literature or from other countries about

potential health risks. This study will make an important contribution to knowledge of the risks of low-level domestic exposure to loose-fill asbestos.

12. Who conducted the study?

Independent researchers from the National Centre for Epidemiology and Population Health (NCEPH) at The Australian National University undertook the study in consultation with external cancer epidemiology experts from Sydney University and the Karolinska Institutet, Sweden. The research was overseen by a Steering Committee that included representation from ACT Health, the Asbestos Response Taskforce, NCEPH, a representative of the NSW Chief Health Officer and other experts as required.

13. Who paid for the study?

The ACT Government paid for the study. The cost for all components of the study was \$415,806.60 over two years.

14. Where can I find the study reports?

Reports from all parts of the study can be found at <http://nceph.anu.edu.au/research/projects/act-asbestos-health-study>.

15. Why has the study taken over two years?

The ACT Asbestos Health Study included four detailed components. All parts of the study required ethics committee clearance, data collection and analysis and writing of reports. This was a collaborative process involving people working in all states and territories, as well as the Commonwealth Government.

The final part of the study involved linking information from around Australia about people who may have lived in the ACT. This sort of research is tightly regulated in Australia to protect people's confidentiality, and this study has been ground-breaking in its use of some sources of information e.g. Medicare records of where people have lived since 1983.

The researchers needed to collate data from different Australian states and territories to minimise the chance of missing information on former residents of the ACT. Epidemiological studies require considerable refining and analysis of information before researchers can be sure that they have properly assessed the scale of a health risk.

16. Will any personal details be made public as a result of the study?

No, people are protected by privacy legislation and researchers' ethical codes, which together prevent any release or exposure of information that might identify any person. All researchers involved with the ACT Asbestos Health Study signed a confidentiality agreement prohibiting them from revealing any personal information.

17. Will the study be updated over time?

It would be possible to update component 4 of this study (data linkage) over time as the data will be stored securely at the Australian Institute of Health and Welfare for at least seven years.

18. What if I'm a tradesperson?

This study did not look at occupational exposure to loose-fill asbestos insulation. It may, however, provide useful information about the importance of appropriate management of asbestos during building work or repairs, including the use of protective equipment.

It would be difficult to specifically study the risk posed by loose filled asbestos to tradespersons who worked on Mr Fluffy houses over the forty or so years since it was installed. This is because, unlike residents, there are few records of work done on these houses, and who performed the work.

Tradespeople are encouraged to record any historical connections to affected properties on the National Asbestos Exposure Register at <https://asbestossafety.gov.au/national-asbestos-exposure-register> or at [https://www.accesscanberra.act.gov.au/app/forms/Mr Fluffy Record and Information Form](https://www.accesscanberra.act.gov.au/app/forms/Mr_Fluffy_Record_and_Information_Form).

19. Who can I contact about the research?

More information and contact details for NCEPH researchers can be found at <http://nceph.anu.edu.au/research/projects/act-asbestos-health-study>.

The ACT Asbestos Health Study team at NCEPH can be contacted on act.asbestos.health.study@anu.edu.au.