

ACT Asbestos Health Study: Component Two Focus Group Discussions

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Summary

The Australian Capital Territory (ACT) Government commissioned the Australian National University to undertake a study to improve understanding of the health risks of loose-fill asbestos insulation, which was installed in over 1,000 Canberra residences between 1968 and 1979. These residences are commonly referred to as 'Mr Fluffy' houses. This report on the *Focus Group Discussions* is the second component of the *ACT Asbestos Health Study*. It describes the discussions held with randomly selected Mr Fluffy residents.

A total of 19 residents participated in two focus groups held in two locations in Canberra in July 2015. The discussions centred on residents' health and financial concerns, their experiences of dealing with the practical issues that arose and the upheaval that occurred in people's lives, their perception of risk related to asbestos exposure and their perceptions of the public response to the issue.

Participants had some concerns about the physical health risks of their exposure to asbestos and about their children's risk of contracting mesothelioma in the future. However, their most immediate health concerns centred on the psychological distress associated with navigating the process of leaving their homes and relocating. Many participants described disruption to their plans for raising their children in a particular home and neighbourhood or their retirement plans. Participants found the uncertainty difficult to cope with and felt that it contributed to their anxiety and stress.

The focus group discussions allowed participants to raise issues and to interact with each other. People felt free to express both positive and negative opinions about the ways in which the ACT Government handled the Mr Fluffy issue and the flow on effects on their mental health.

On the whole, most participants seemed to have absorbed and understood the risks of asbestos exposure. This indicates that the risk communication strategy was successful, especially as asbestos can be categorised as a particularly alarming risk. Finally, the focus group discussions provided insights to inform the development of a subsequent survey questionnaire, which will include questions on psychological stress and social support.

Background

The focus group discussions are the second of four components of the ACT Asbestos Health Study. The ACT Government commissioned the Australian National University (ANU) to conduct the ACT Asbestos Health Study to improve the understanding by the researchers and Government of the health risks of living in a house containing loose-fill asbestos insulation (<http://nceph.anu.edu.au/research/projects/act-asbestos-health-study>). The focus group component of the overall study was designed to provide researchers with an understanding of the concerns of residents of Mr Fluffy houses in order to develop questionnaire items for the third component of the study—the cross sectional survey, and to provide feedback to the Government regarding risk communication provided to the residents.

Loose-fill asbestos insulation in the ACT

Between 1968 and 1979, a contractor commonly known as 'Mr Fluffy' insulated homes in the ACT, along with homes in southern New South Wales. The contractor blew asbestos in a ground raw form (loose-fill asbestos) into roof spaces.

Between 1988 and 1993, a Commonwealth Government audit visually checked some 65,000 houses in the ACT for the presence of loose-fill asbestos insulation. More than 1,000 houses were identified as containing this insulation and an extensive remediation program was undertaken, in which the loose-fill asbestos was removed from the roof spaces and efforts made to prevent any residual asbestos spreading inside the houses. In 2014, there were concerns about resident safety after asbestos fibres were found in living spaces of some remediated houses. In addition, news media have reported that at least one case of mesothelioma occurred in a present or former resident of an affected residential property (ARP) and in an electrician who worked on ARPs, although exposure histories have not been verified.

In June 2014, the ACT Government established The Asbestos Response Taskforce (<http://www.act.gov.au/asbestos-response-taskforce>) to respond to impacts of loose-fill asbestos insulation by providing assistance to affected residents, information to affected residents and the ACT community and a solution for removing the loose-fill asbestos insulation from the ARPs. (1) The Taskforce reports directly to the Chief Minister of the ACT and provides a single point of contact for ACT residents concerned about loose-fill asbestos insulation. The Taskforce provided guidance to the ACT Government on the long term management of this issue in the Territory and has subsequently administered the voluntary Buyback Program as well as providing wellbeing, financial and information support to those affected. The Taskforce is currently overseeing the Demolition Program of surrendered properties and continues its work in informing and engaging the community on this issue. The Taskforce is also recording contact details for those exposed to, or concerned about, loose-fill asbestos insulation in Canberra homes, including current and former home owners and tenants, tradespeople, real-estate and other professionals and members of the general community.

Objectives of the study

The primary objective of the ACT Asbestos Health Study was to improve researchers' understanding of the health risks of living in a house containing loose-fill asbestos insulation. This report concerns the second component of the study; the focus group discussions.

The overall aims of the focus group discussions were to:

1. examine the range of experiences and opinions of people living in, or owning, an ARP;
2. understand residents' perceptions of risk from exposure to asbestos in order to inform ways to assist affected residents (e.g. provide further information or mental, social or health services or other support);
3. inform policy responses regarding risk communication relating to environmental threats, to reduce anxiety where possible; and
4. contribute to the development of a questionnaire for a cross-sectional survey of residents.

This study was predicated on the understanding that health-related concerns are social in nature. The difficulties and concerns that residents may experience are likely to be due in large part to the social context in which they have to manage the situation. For example, moving houses, relocating children, talking with neighbours and being made aware of media-related information are all socially mediated interactions that may provoke feelings of stress, anxiety, or relief with potential health risks or benefits. In this report, we refer to the Mr Fluffy process; a term that we use to acknowledge that the ACT Government's Asbestos Response Taskforce has been operating since June 2014. Over this period, a number of activities have been announced prompting a range of responses in residents. In this sense our objectives and this report refer to an ongoing and changing process for residents.

Study design

Focus groups are designed to enable discussion of public circulating knowledge, underlying attitudes and opinions and are well suited to exploring a range of views on a topic. They are less suited to gaining information about personal sensitive matters. However, discussions may reveal concerns and issues that are often generated by the interaction within the group. Focus group discussions have been shown to contribute to health research and the development of social action programs. (2) Commonly, they are used in conjunction with other research methods, such as surveys. The exploratory, open-ended approach employed in focus group discussions is designed to gain new perspectives and generate hypotheses that typically contribute to a mixed method study. (3) In addition, they are associated with a range of theoretical approaches, although this study aligns most closely with a pragmatist and participatory paradigm by giving voice to Mr Fluffy residents and shaping the next stage of research. (3) It is problem focussed, demonstrating a real world practice orientation and was not aimed at generating mid- or high- level theory. In addition, it has a collaborative and change-oriented focus.

All research staff signed a Confidentiality Deed supplied by the Territory. The professional transcribing service staff signed an ANU deed poll agreeing to confidentiality. Data will be stored on secure servers at the ANU for five years.

Sampling and recruitment

The focus group study design followed protocols approved by ACT Health and ANU ethics committees. The ACT Asbestos Response Taskforce register of people owning or living in an ARP constitutes a purposive sampling frame. From within this, 80 people were randomly selected in order to gather information from people with different backgrounds that reflected the various experiences of residents. They were invited to participate in a focus group with the aim of obtaining 12 or more participants (an appropriate size for focus group discussions); at least 6 from each of North and South Canberra. Invitation letters (Appendix 1) asked residents to email or phone researchers to register their interest in participating in a group. Those who contacted researchers were provided with additional information about the location, the discussions, and information sheets (Appendix 2).

Both discussions were held in a community club venue; one discussion was held in North Canberra and the other in South Canberra, to ensure that they were easily accessible to those living all over Canberra. Participants provided consent (Appendix 3) after an explanation of the way in which discussions were going to be conducted was clearly explained. Participants were asked to use a pseudonym and any identifying information about participants was deleted before sending audio-recordings to professional transcribers.

Topics for discussion

Following the conventions of focus group discussions a list of open-ended, broad questions (a topic guide) aimed at generating discussion covered the following topics:

- Health (prompts—concerns for adults, for kids, over long and short-term, health checks, health knowledge);
- Risk perception and management (prompts—understanding of exposure, responses to exposure);
- Financial concerns (prompts—value of house, replacement, costs of living elsewhere, resale value);
- Stigma and other feelings generated by others;
- Practical issues (prompts—moving, schooling, work, replacement of belongings, rebuilding or replacing house - time costs, other issues);
- The public response (prompts—by government, media, others); and
- Other issues.

Invitees were provided with the list of topics to be discussed so the researchers could ensure participants would be comfortable with the topics during the session, some of these issues were potentially emotive, particularly for those with children. Invitees who were interested in attending one of the focus groups were asked to call the research team to register their

attendance, and to receive information about where and when the groups would be held. During these phone conversations participants were asked to read through the provided topics before the groups were held, and they were encouraged to consider raising issues that were not covered in this guide. They were asked to make notes of topics that they wished to discuss and to bring these notes along to the focus groups. Participants were also encouraged to discuss the topics with other adults in their household to see if there were other concerns that they would like raised. At the focus group sessions participants were provided with notepads and pens to make notes during the discussion, and were again reminded that they could raise issues that were not covered by the topic guide.

One researcher (CB) initiated discussion using these topics while also allowing discussion to follow the interests of the participants. Other researchers (GS, ST) took notes and facilitated the meetings. Participants were informed that the researchers were experts in conducting focus groups but not expert on the topic and were unable to provide information about the health risks or the process initiated by the ACT Government in response to the Mr Fluffy insulation in Canberra homes.

In addition to the focus group discussions, a brief one page questionnaire (Appendix 4) was distributed to study participants to collect basic socio-demographic data, such as age, gender, marital status, employment and number of children.

Data analysis

The focus group transcripts were read closely by team members and analysed according to a standard thematic analysis approach in which codes or categories are sorted and grouped into themes. (2) Deductive codes were derived from the topics presented for discussion to the focus groups while other inductive codes reflected additional issues or concerns raised by participants. As there were only two focus groups to be analysed it was not considered necessary to manage the data using a computer program. Due to the applied nature of the study and its pragmatist approach, the analysis has remained grounded in the content of the discussions rather than including additional interpretation. Following a mixed methods (inductive, exploratory) approach, we aimed, during the early phases of analysis, to provide insights or hypotheses that could be 'tested' through the subsequent cross sectional survey.

Ethics and funding

This project was approved by the ACT Health Human Research Ethics Committee (ETH.11.14.330) and the ANU Human Research Ethics Committee (Protocol no. 2015/209). The ACT Government provided funding for this study under the ACT Asbestos Health Study. Due to the sensitive nature of the discussions, this report does not include comments from study participants that are typical for many reports of focus group studies.

Results and discussion

Two focus groups were conducted: one at the Raiders Club, Weston and the other at the Canberra Southern Cross Club, Jamison. The groups were somewhat different in size and composition; the Northside group contained seven people, four women and three men, while the Southside group consisted of 12 people, eight men and three women (see Table 1).

Table 1: Focus Group Participants

Focus Group Participants	N= 19	%
Sex		
Male	11	58
Age range	32-80	Av. 56
English spoken at home	18	95
Education		
Tertiary	15	79
Certificate or Diploma	2	11
Completed secondary	2	11
Marital status		
Married	14	74
Single (widowed, divorced)	4	21
Co-habiting	1	5
Employment		
Employed	8	42
Not employed	8	42
Casual	3	16
Children		
Children living with you	12	63
Age range of children	1-31	Av 16
Owner of Mr Fluffy Home	18	95

Summary of the main themes

To initiate the conversation participants were asked in turn to state briefly their main or biggest issue, although some mentioned several. These issues were discussed in greater detail at a later stage often in response to very different prompts (see Table 2).

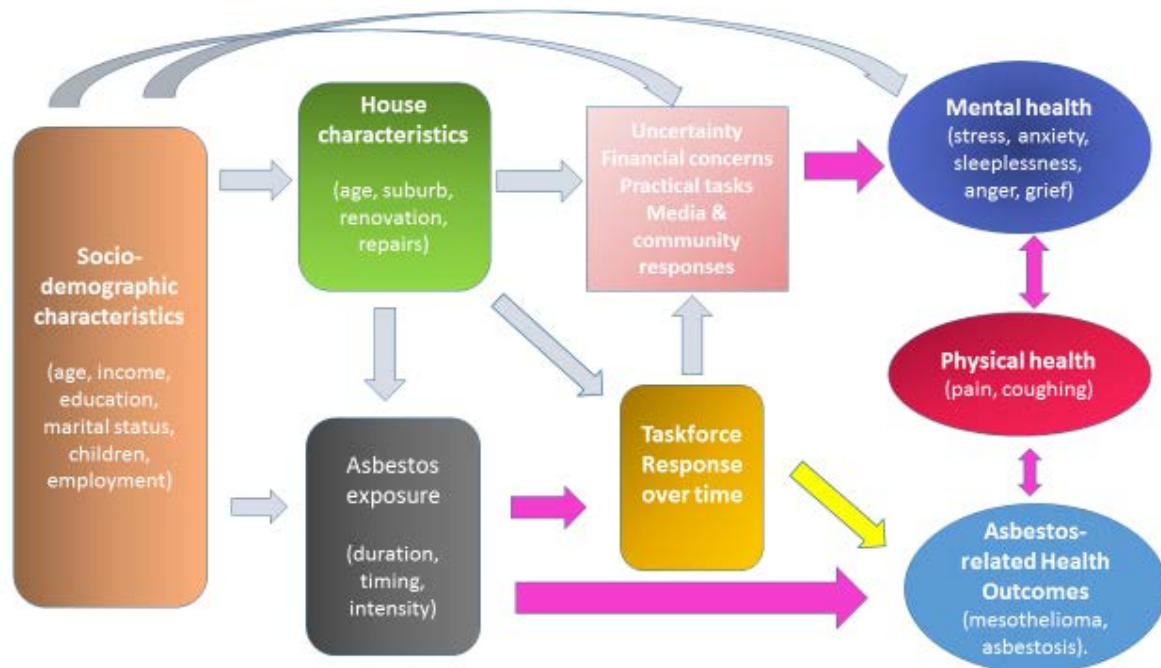
Table 2: Main issue for participants

Issues	No
Health – own and children’s due to asbestos exposure	5
Disrupted plans	4
Uncertainty and the unknown	3
No issues	2
Feeling victimised	1
Problem understanding the process	1
Time to move on	1
Regret, loss, grief	1
Mental health – stress, anxiety	1
Financial difficulties	1

*Note that at least one participant mentioned more than one issue, so the total number of issues is greater than the number of participants.

The discussions covered the topics in the following sections. As discussed by the participants, the themes were interconnected, particularly in relation to psychological health issues which they associated with many aspects of the Mr Fluffy process as Figure 1 illustrates (See Figure 1 for a conceptual diagram of the study).

Figure 1 A model of the perceived relationships between factors contributing to health outcomes



Pink arrows = a positive effect; yellow arrow = a mitigating effect; grey arrows = a mixed effect

Health

Physical health

Participants were aware of the dangers of asbestos exposure and the risk of contracting mesothelioma, although these fears were not overwhelming. However, a number of older men mentioned that they were likely to have been exposed because they had worked in ceilings and other spaces, or their homes had been renovated. They were more likely to be concerned about the health of their children who had grown up in Mr Fluffy homes rather than their own health. The smaller number of younger people who attended the discussions were concerned about their own young children's recent exposure.

Some participants were quite knowledgeable about asbestos and the risks of mesothelioma. They had clearly spent some time conducting research on the topic; others still had questions¹. Most participants understood that they would be unlikely to contract the disease until 30 to 40 years after exposure. Older people said that they were currently at the age when they were likely to have contracted the disease if they were going to get it. Because of their age, some were 'fatalistic' about it. A few provided additional information to other participants about the disease during the discussions. One person explained that there was an increased risk of mesothelioma due to exposure to Mr Fluffy interacting with the 'wrong

¹ At the focus groups, participants were informed that they would be able to gain further information about health risks at the public lecture given by Emeritus Professor Bruce Armstrong that was held in the week following the discussions.

genes'. Another recounted that they had read a book on pollution which put the risks from asbestos exposure into a less prominent perspective. It was observed that asbestos is 'everywhere' in Australia and that many people had been exposed at work or through everyday experiences.

Several wondered about asbestos getting into the water supply or the general atmosphere through demolition of ARPs. A woman noted that she and her children had a persistent cough that she thought might have been due to asbestos exposure while another was informed by a GP that his chest pains were due to asbestosis, although this diagnosis was later contradicted by another doctor. Another person had heard about a woman who had a disease in her kidneys or liver due to ingesting asbestos but acknowledged that this was 'not proven'.

Mental health

Participants discussed psychological distress and mental health concerns, such as stress and anxiety, related to uncertainty about what was going to happen. These psychological responses may have impacted on their physical wellbeing. One man admitted himself to hospital with chest pains related to stress and others relayed accounts of physical manifestations of stress and anxiety. Many economic and social concerns were related to participants' mental distress. Several participants mentioned that they were unsure whether they would be able to afford to rebuild on their properties and this was causing anxiety, others were experiencing stress over leaving their neighbourhoods as they had developed close relationships with their neighbours, and others were anxious about the prospect of their children needing to change schools, possibly several times if they had to rent housing out of area while waiting for their homes to be demolished and rebuilt.

A number of participants expressed emotions like sorrow and anger at feeling they needed to leave their house, their garden or their neighbours. People described the lengthy investment of time, energy and creativity which they had invested in their house and garden. Some mentioned that they were hoping to rebuild on their own block so that they could retain their neighbours and gardens but this was proving difficult. It was felt that these aspects of domestic living arrangements were not acknowledged sufficiently by the Taskforce response.

Financial concerns

Most people thought that they had been financially disadvantaged by owning and the process of selling a Mr Fluffy Home. The financial aspects of the process were complex and not always clear to study participants. Within the focus groups, people shared conflicting information about stamp duty for example.

They discussed that house valuations appeared to be inconsistent leading to perceptions of unfairness. House valuers and real estate agents were sometimes described in ways that made them sound predatory. Mr Fluffy residents thought that they were considered to be vulnerable. Participants observed that they were commonly called 'Fluffies' by real estate agents. Many said they could not afford to buy another property in the same suburb as the one in which they had previously lived. Leaving a suburb had a flow-on effect on other aspects

of their families' lives, such as children's schooling and friendships with neighbours. However, one person was pleased to have received a relocation grant. For some, financial concerns contributed to their stress.

Practical issues

Mr Fluffy residents represent a wide range of ages and life stages, so that their everyday experiences and the practical implications of the Mr Fluffy process were quite diverse. Some were concerned about children's schooling, others about long-term neighbourhood friendships. Others had very practical and immediate difficulties such as having to organise alternative housing quickly. Others described the difficulties or expense of getting tradesmen to work on Mr Fluffy houses, even though they had been supplied by the Taskforce with a list of the tradesmen who were able to carry out the repairs. Mr Fluffy residents were given the opportunity to have a case manager who were able to offer advice on practical issues and general support. Many said their manager was helpful which made the process less stressful but others did not find them helpful and some were unaware that a case manager was available. Overall, most were positive about the way their case managers were able to provide support during the time they were receiving valuations on their homes and negotiating moving to a new location.

The public response

Once again there were quite divergent views on the response of the government and media, in part reflecting the very different experiences and views of residents. People were concerned that negative reports about the danger of asbestos would drive down the value of their houses. Several mentioned a community perception that they had benefitted from owning a Mr Fluffy house. As with so much of the Mr Fluffy experience, the media response changed over the course of the Government's response so that participants themselves felt differently at various stages.

Participants' emotional responses to their treatment by others

Participants reported a range of feelings related to how they were treated by friends, neighbours and community members. Some said they felt stigmatised for owning a Mr Fluffy home. One person thought that because the Mr Fluffy problem had occurred in Canberra there was little national interest or concern.

Some people's attitudes to Mr Fluffy home owners were quite negative; they included people who would not visit a Mr Fluffy house or insisted on wearing a mask. However, other participants stated that friends and neighbours continued to visit. One person said that she avoided telling people that she lived in a Mr Fluffy house because she didn't want to be treated differently.

It became apparent throughout the two discussions that the amount of emotional support that participants received made a difference to their experience. Several talked about the support from partners and the way in which they shared the tasks of relocating. Others noted that they had a more difficult experience, in part, because they were already emotionally

upset due to other problems that had occurred in their lives. It is unfortunate that at the same time as the ACT Government response was occurring the Federal Government was downsizing so that some people experienced both job and housing disruptions. Several single mothers, in particular, expressed concern about their children's health as well as the difficulties of not having a partner with whom to share the emotional strain and the tasks.

Uncertainty

Participants expressed discomfort and stress related to uncertainty, the inability to make firm plans, or having their plans, for example for retirement, disrupted. The negative feelings of uncertainty related to the lengthy period of the Mr Fluffy process established by the Taskforce due to changes in advice received from the government. It should be noted that at the time the focus groups were held none of the participants had received instructions about when or how they could buy back the land and rebuild their homes.

Limitations of the study

We conducted only two focus groups as they were considered to be an exploratory phase of a study, that included a questionnaire based survey. The process of contacting and recruiting participants was designed to provide a randomly selected group of participants with an opportunity to participate. As in any research, those who agreed to participate in the study were ultimately self-selected. As is appropriate for a qualitative research design, the sample was not expected to be generalizable.

Final reflections

The groups were conducted so that participants had opportunities to raise issues and to interact with each other. The aims of the focus group discussions have been achieved in the following ways:

Aim 1: People felt free to express a range of opinions about the ways in which the Taskforce handled the Mr Fluffy process. Many acknowledged both positive and negative experiences, the difficulties that the ACT Government has been placed under and the efforts that it had made to remediate the situation.

Aim 2: Most people had a good understanding of the risks of asbestos-related disease and the lecture by Emeritus Professor Bruce Armstrong was promoted to provide people with further information. The health area that was of most concern was the risk of asbestos exposure to children, and whether children were particularly vulnerable to asbestos exposure due to their age. On the whole, most participants appeared to have absorbed and understood the risks of asbestos exposure which indicates that risk communication has been accomplished well, especially as asbestos exposure expresses some characteristics of a 'dread risk', which is one that is perceived to be uncontrollable, to be potentially fatal, and can affect future generations. (4) However, the discussion within focus groups indicated that despite efforts by the ACT government, people still experienced psychological stress and anxiety, particularly related to the uncertainty and lengthy duration of the Mr Fluffy process.

Aim 3: Findings from the focus group discussions have been provided to ACT Health to inform policy responses and will be combined with results from other components of the study to provide further information.

Aim 4: Finally, the focus group discussions have provided insights that have informed the development of the questionnaire for the cross sectional study (Component 3 of the overall study), including questions on psychological stress and social support, and have led to efforts to capture the changing experiences and emotions of those who have been involved in a lengthy process.

Acknowledgements

The researchers would like to thank the ACT Asbestos Health Study Steering Committee for their guidance and feedback on the study design.

They would also like to thank the ACT Asbestos Response Taskforce for their help in sending out invitations to residents to participate in the research.

Most importantly the study team thanks the focus groups participants for their time and willingness to speak about a range of health and social issues that have affected them in relation to living in a Mr Fluffy house.

References

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Appendices

Appendix 1: Invitation letter

ACT Asbestos Health Study: Focus Group Discussions

Dear Resident,

The National Centre Epidemiology and Population Health at the Australian National University is conducting a study funded by the ACT Government, on the health and other effects of living in a Mr Fluffy house. As part of this study we are conducting focus group discussions to gather the views of residents.

Your address has been selected at random by us from the list of affected houses provided to us by the Asbestos Response Taskforce. It is important to the overall study that we invite participants who are likely to have had a range of different experiences with their Mr Fluffy houses. We are writing to invite one person from your household to participate in a focus group discussion. This could either be you or another adult household member; this invitation cannot be passed on to a person who was not a resident of this household.

Information about focus group discussions:

We will hold two focus group discussions about your health-related experiences of living in a Mr Fluffy house. This is part of a larger study investigating the risks of living in a Mr Fluffy house. One focus group will be held on the northside and a similar one will be held on the southside. The discussions are likely to take between one and two hours. The venues and further details will be disclosed to those who agree to participate.

When: The focus group discussions will be within the next few weeks. Please notify us of your willingness to participate at your earliest convenience so we may advise you of the venue and date.

What are the focus group discussions about?

The discussion will cover the following topics related to living in a Mr Fluffy home:

- Health concerns
- Risk perception and management related to asbestos exposure
- Stress related to financial and other concerns due to circumstances related to living in an affected residence
- Social issues
- Practical issues — where to live, moving, schooling, work, replacement of belongings, rebuilding house — time costs, other barriers
- The response to the Mr Fluffy situation by government, media, other
- Other issues you or other participants raise.

What we will do after the group discussions:

The discussion material will be audio-recorded if permission is given, collated and analysed. The results of the analysis will contribute to the development of the questions to be used in a later survey sent to current and past residents of Mr Fluffy Houses. The de-identified findings from the study as a whole will be disseminated to participants, to the general public, and published in academic papers. You will not be identifiable in any of these outputs. Raw data will be safely stored on an ANU password protected computer for 5 years and then destroyed.

Are there any risks if you participate?

Your privacy is important to us. We ask that pseudonyms be used in the discussion and that participants refrain from supplying any identifying information during discussions. We will not identify you in research findings. We will not discuss with other people whether you participate or not. Your participation is voluntary and will not affect your position at work, or your use of any ACT Government service. There are no consequences of non-participation. You are free to withdraw from the discussion at any time and you can choose not to engage in discussion about any question that you perceive to be sensitive. It is possible that transcripts from the focus group discussions may be subpoenaed as part of legal actions related to Mr Fluffy litigations. However, transcripts will be de-identified. We ask that all discussion within the focus group remain confidential.

This is an opportunity for you to discuss issues related to living in a Mr Fluffy home and to shape the direction of the next phase of our research (the survey). We sincerely hope that you or another household member will join us.

Yours sincerely,

Cathy Banwell

To register your interest in participating or to seek further information please contact us by email or phone.

Ms Susan Trevenar	T: (02) 6125 6079	Susan.Trevenar@anu.edu.au
Dr Ginny Sargent	T: (02) 6125 5616	Ginny.Sargent@anu.edu.au
Dr Cathy Banwell	T: (02) 6125 0016	Cathy.Banwell@anu.edu.au

Concerns or complaints

The Australian National University and ACT Government Health Directorate Human Research Ethics Committees have approved the ethical conduct of this research (ANU HREC protocol 2015/209, ACT Health Ethics Committee ETH.11.14.330). If you have concerns regarding the way this research was conducted please contact either of the following:

Human Research Ethics Officer	Manager - Human Research Ethics
The Australian National University	ACT Health Directorate Research Office
Office of Research Integrity	Building 10 Level 6
Chancelry 10B, Lower Ground Floor	Canberra Hospital
T: (02) 6125 3427	T: (02) 6174 7968
E: Human.Ethics.Officer@anu.edu.au	E: acthealth-hrec@act.gov.au

ACT Asbestos Health Study

Participant Information Sheet for Focus Group discussions

What is the study about?

The focus group discussion study is part of a broader study concerning the health and related risks of living in a Mr Fluffy house. The focus groups are an opportunity for residents to express concerns about their health, and social impacts of living in a Mr Fluffy House and shape the direction of the broader study.

Who is funding the study?

ACT Health is funding the study.

Who can participate? / What will I be asked to do?

You have been randomly selected from the register of Asbestos Affected Premises to participate in one of two discussion groups. The groups will consist of between 10 to 15 people who will be invited to contribute to a general discussion. It is likely that the discussion will take between one and two hours. A small token of our appreciation (2 movies tickets) will be offered on completion of the discussion.

What are the focus group discussions about?

The discussion will cover the following topics related to living in a Mr Fluffy home:

- Health concerns
- Risk perception and management related to asbestos exposure
- Stress related to financial and other concerns due to circumstances related to living in an affected residence
- Social issues
- Practical issues – where to live, moving, schooling, work, replacement of belongings, rebuilding house - time costs, other barriers
- The response to the Mr Fluffy situation by government, media, other
- Other issues you or other participants raise.

What we will do after the group discussions?

The discussion material will be collated, and analysed and will then contribute to the findings from the broader study. The findings of the broader study will be disseminated to participants, to the general public and published in academic papers. The group discussion transcripts will not be available to individual participants.

Do I have to take part?

- We are asking all focus group attendees for their consent to collect their discussion via audio-recording. The recording of the discussions will not be attributed to individuals.
- Participants are free to withdraw from the research at any time without penalty and without providing a reason. If this occurs the researchers will dispose of any data already collected from you. However, it may not be possible to remove statements that you have made as part of the general discussion.
- At the group discussion individuals will be asked to sign a consent form presented to them at the time.

Are there any risks if I participate?

Your privacy is important to us. The identity of participants will not be collected except as a signature on the consent forms which are stored separately from data. We also ask that focus group members maintain the confidentiality of group discussions, and that participants in focus groups should refrain from making statements of a confidential nature or that are defamatory of any person. We ask that participants use pseudonyms. It is possible that transcripts from the focus group discussions may be subpoenaed as part of legal actions related to Mr Fluffy litigations. However, transcripts will be de-identified.

We will not be discussing whether you participated or not with other people. Only members of the research team will have access to the data. Your participation will not affect your position at work, or your use of any ACT Government service. It is entirely voluntary and there are no consequences for non-participation. The information you provide will not be linked to a name or phone number. Your data will be stored securely on ANU servers for five years and then destroyed.

What are the benefits to participants and the ACT community?

The focus group discussions provide residents with an opportunity to express concerns and describe experiences related to their health and their social circumstances. The findings from the focus groups will be used to shape the survey and contribute to the development of policy related to Mr Fluffy houses.

How will the focus group discussions findings be used?

These will be used to inform the development of a questionnaire to be sent to current and past residents. The findings, with other parts of the study findings, will be presented in a report to the ACT Government and to the general public and may be presented at scientific meetings and conferences, and published in academic books and journals. Information will be presented in such a way that individuals cannot be identified.

Questions

If you have any questions, do not hesitate to contact us (the researchers who are conducting the discussions) by email or phone.

Ms Susan Trevenar	T: (02) 6125 6079	Susan.Trevenar@anu.edu.au
Dr Ginny Sargent	T: (02) 6125 5616	Ginny.Sargent@anu.edu.au
Dr Cathy Banwell	T: (02) 6125 0016	Cathy.Banwell@anu.edu.au

Concerns or complaints

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Human Research Ethics Officer	Manager - Human Research Ethics
The Australian National University	ACT Health Directorate Research Office
Office of Research Integrity	Building 10 Level 6
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Appendix 3: Consent form

Participant Written Consent Form

ACT Asbestos Health Study

I have read and understood the Information Sheet you have given me about the research project, and I have had any questions and concerns about the project addressed to my satisfaction.

I have been informed that:

- The discussion will relate to health concerns of living in a Mr Fluffy House as detailed on the information sheet
- That I am free to withdraw at any time, that participation is voluntary and that there are no consequences for non-participation
- That all discussions are completely confidential
- That my data will be stored on ANU computers for 5 years and then destroyed
- That transcripts of the discussions may be subpoenaed if there were to be legal actions related to Mr Fluffy litigations.

I agree to participate in the project:

YES NO

I agree to this focus group discussion being audio-recorded:

YES NO

I agree that all discussions with the focus group are confidential

I (please sign) consent to take part in this research project.

Date

Appendix 4: Questionnaire

ACT Asbestos Health Study Questionnaire for Focus Group participants

1. Sex Male Female
2. Age _____ (in years)
3. Are you of Aboriginal or Torres Strait Islander heritage?
- No Yes, Aboriginal
- Yes, Torres Strait Islander Yes, both Aboriginal and Torres Strait Islander
4. Which language do you mainly speak at home?
- English Other – Please specify the language:

5. What is your highest completed level of education?
- Incomplete secondary Completed secondary
- Certificate or diploma Bachelor degree or above
6. Partnership status
- Single (Never Married) Single (Divorced/ Widowed) Married
- Cohabiting/De Facto
7. What is your employment status?
- Not employed Employed (casual) Employed (part-time)
- Employed (full-time) Student

8. Do you have any children living with you?

Yes No (if No, got to Q10)

9. If you have children living with you, what are their ages?

10. How many people (including children) lived in the Mr Fluffy house with you?

11. How long did you live in the Mr Fluffy house?

12. Did you own or rent the Mr Fluffy house?

Own Rent