An introductory note for the Minister and for the Asbestos Response Taskforce in relation to the Mr Fluffy Legacy Project Report

The ACT Government in 2014, with Katy Gallagher as Chief Minister, made the courageous commitment to tackle the inherited problem of Mr Fluffy loose fill asbestos insulation in ACT homes for once and for all.

This decision was made when further evidence emerged of persisting asbestos contamination in some previously remediated homes. The basis of this decision was the unacceptable ongoing risk of mesothelioma –a fatal cancer related to asbestos exposure- despite the measures already taken.

The Asbestos Response Taskforce was formed to determine how this might be done most effectively to ensure a permanent solution.

It was recognised from the outset that the only certain solution was to identify and permanently remove all Mr Fluffy insulation, including the unknowable spread of and contamination by asbestos in an uncertain number of homes. However, the use of loose fill asbestos insulation in homes was not an asbestos problem which had previously been encountered, so there was no tested solution available to inform the Taskforce.

Consultation with experts in management of asbestos contamination was unanimous that the only sure way to get rid of all the asbestos was to demolish all affected homes and permanently dispose of all potential contamination within the homes and the land on which they stood. This was recognised from the outset as a daunting prospect.

The logistics of doing this were also untested and evolved during the earlier stages of the Loose Fill Asbestos Insulation Eradication Scheme. Not to trivialise the gravity of the situation, it had much in common with being required to build a plane and fly it at the same time.

There had to be a capacity for flexibility and re-thinking at a time those affected needed certainty.

CERG (Community and Expert Reference Group) was set up at this time to assist the Taskforce to test their proposals with this group and wherever possible within the many existing regulations. Modifications continued to be made to the plans as new evidence and information emerged.

This meant that the Taskforce, a government entity, had to mediate between those affected and those responsible for regulations, and guide a traumatised group of home owners in a direction they had never envisaged and did not want to go.

In this challenging environment, the Taskforce is to be commended for the many ways it continued to learn and modify its plans as a result of this learning. Much it has accomplished has been done in a more considered and flexible way than more generally happens in routine government interventions. Particularly noteworthy accomplishments have included:

- the evolution and maintenance of the Personal Support Team;
- the particular expectations for the demolition and land auction teams; with those involved being encouraged to recognise their intrusion into distressed communities; and
- the Taskforce's regular involving and informing of the wider communities where the homes were situated.

Also, the linking of this project to ongoing training for those tradespeople involved in building and maintaining homes in the ACT means that they are now well informed about recognition and management when asbestos is discovered in a building.

However importantly, as in all natural and man-made environmental disasters, the powerless people affected by the calamity are not in a position to comprehend the complexities of the ongoing decision-making processes. Consequently, all the inevitable frustration and dissatisfaction with their distressing and uncertain circumstances tend to be focused on the agency they are forced to deal with, with no ready means of knowing the underlying source of their particular woes at that time. The bearer of bad news is so often held to be accountable for the intolerable situation.

Most affected homeowners did not participate in the consultation process and many of these told us they preferred to put it all behind them and move on in their lives. In all similar situations, people are more likely to respond when they have unresolved issues, but their experiences are still very relevant, even if raw in their expression.

However, with Mr Fluffy, the uncertain threat of future health disaster in the form of mesothelioma remains a threat and cannot be ignored. I believe it is imperative that we ensure, as stated in the consultation report, that the ANU Public Health Survey related to exposure to asbestos in these homes is continued into the future, when the consequences will emerge. It is a unique opportunity to contribute to our general knowledge of this terrible disease as well as recognising those locally affected.

Similarly, the medical profession, and GPs in particular, must have ongoing opportunities to keep learning about the best ways of monitoring all those involved who come for advice so that they are appropriately supported and get relevant assessment, and avoid unnecessary and potentially harmful investigations.

The overwhelming message from the people who generously gave their time to be involved in the legacy project consultation is *there should never be another Mr Fluffy*. Hence, recommendation one addresses how the ACT Government and community can learn lessons from the Mr Fluffy experience.

Other recommendation themes include:

- tracking health impacts;
- supporting families;
- recording the stories;
- establishing a place of reflection; and
- education.

Remembering this experience as a community may seem less relevant to some at this time, when the eradication scheme is still in progress. But if we do not begin to implement what we have learned at this time, the whole saga will become buried as we get immersed in more immediate everyday issues and this major and formative event in the development of Canberra will be misremembered and undervalued to the detriment of this very special city. On behalf of my fellow CERG members I commend this report to you.

We request you budget appropriate funds in the 2020-21 and future ACT budgets to implement the recommendations with appropriate urgency, respect and focus.

We collectively offer our support to assist you in this task.

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Dr Sue Packer AM 2019 Senior Australian of the Year Chair of CERG



Community and Expert Reference Group

Mr Fluffy Legacy Project

Consultation Outcomes Report and Recommendations



Prepared by

Mr Fluffy Community and Expert Reference Group Sue Packer Chair

Prepared for

ACT Government Asbestos Response Taskforce

Photo credit

Many of the images used in this report were supplied to the project team by Mr Fluffy homeowners from their personal libraries.

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Foreword from the Community and Expert Reference Group

The purpose of this Mr Fluffy Legacy Project is similar to a legacy left to a family – to enable the handing on of memories, lessons and objects to inform those coming afterwards and help them to understand the lives and experiences of those who went before and strengthen us all to learn from them.

The Mr Fluffy saga is a clear example of an evolving and enduring catastrophe, which initially emerged when the Commonwealth government of the day allowed loose fill asbestos insulation to be installed in over 1,000 Canberra homes against the advice of the then health department. Further poor decisions intended to correct the error finally led, after nearly 50 years, to the decision to demolish all affected homes.

No affected individual or household has emerged from this experience unscathed and some have been so traumatised by this unforeseen burden in their lives that they will never fully recover.

When I attended the drop-in consultations, I was again reminded that this has affected an exceptional group of people, characterised as independent and conscientious providers for their families. Their careful choice of homes and caring for their homes and families had been the cornerstone of their lives, only to discover that their care and plans have been overturned by asbestos, leaving them with dangerous, worthless homes and their beloved families at risk of fatal disease. Not only that, but the ensuing unexpected need for most to have to participate in the government's solution to the asbestos problem has been an additional burden and galling experience.

All are living with the possibility of developing mesothelioma, a fatal, asbestos-caused cancer, for themselves and others exposed to the asbestos in their homes. Indeed, some loved ones and tradespeople have. The huge uncertainty of whether or when this dread might become a reality, (which might not be for many years), is the enduring nightmare for many and the reason for this massively expensive and traumatic demolition of 979 homes to date.

The demolitions are almost completed, but the process is far from over, so why think of acknowledging legacies at this time? The impetus comes because communities forget and mis-remember catastrophes so quickly, particularly as governments move on and priorities shift. This project is only the starting point, undertaken when the experiences are fresh and raw. The intention is to develop it in such a way that it can evolve, as the story evolves. We cannot risk having it put aside and forgotten as we do with many things we would rather not remember. None of the collective lessons emerging from its progress should be lost or ignored. That is why acknowledging Mr Fluffy's legacies is essential.

The consultation process has provided many suggestions for tangible ways of acknowledging these legacies. I believe we have scope for many different aspects of them to be incorporated into the recommendations for the legacy project.

This whole loose fill asbestos saga was entirely preventable, had the then known dangers of asbestos and the advice given at the outset been heeded. The intention of the legacy project is to acknowledge this and the accompanying trauma and to promote thinking and behaviour that will prevent any similar avoidable disaster in the future. Given that collectively the suggestions are of relatively modest cost, I urge the government to commit to the implementation of the final report's recommendations, to help ensure that this intention is achieved.

There should never be another Mr Fluffy.

Dr Sue Packer CERG Chair

Executive summary

A consultation and engagement strategy was developed to deliver a coordinated, timely and focussed program to engage a wide range of stakeholders about the Mr Fluffy Legacy Project. The consultation and engagement process played a key role in capturing the community's ideas and views on the type of projects they wish to see realised that acknowledge the legacies of Mr Fluffy.

In eliciting feedback on the multiple legacies of Mr Fluffy in Canberra, three engagement themes were developed to guide respondents. These themes sought to gain a deeper appreciation of; the feelings and reflections of people about their homes and lived experiences, the types and scope of legacies that should be acknowledged, and what sorts of projects or programs would be the most appropriate form of acknowledgement.

Throughout the consultation we heard a diverse range of views and feedback from people who were directly affected by Mr Fluffy, people who had friends and family who were affected, and people who worked in industries that dealt with Mr Fluffy and the Loose Fill Asbestos Insulation Eradication (the scheme).

From 14th August to 11th September a draft copy of the Mr Fluffy Legacy Project Discussion Paper was made available for review and comment. The additional views and feedback expressed have been incorporated into the final report and recommendations.





Ongoing health issues are a factor for members of the Mr Fluffy community and access to adequate services is needed, including mental health services, health screening, practitioner training and research.

A single submission received during consultation on the draft Mr Fluffy Legacy Project Discussion paper stated that they were very satisfied with the actions of the ACT government but were not supportive of the majority of recommendations presented. The respondent also felt the views expressed during the consultation were not representative of the whole.

In seeking to determine the appropriate legacies of Mr Fluffy, there is universal support among respondents to document and reflect on the lessons learned, and that these lessons are shared widely to inform future governments and community programs and policies. It is also broadly recognised that the Mr Fluffy story is an important part of Canberra's history and should be recorded as such.

The collegiality of the Mr Fluffy community is evident at every gathering and there is a recognition that a place or space to come together to share experiences, to connect and to reflect is also supported.

Many respondents expressed concern about the timing of the legacy project and there is by no means universal support for a legacy project at this time. However, for those respondents who did share their views and ideas recommendations are made under the following six key themes.

- 1. Learning lessons and documenting knowledge
- 2. Tracking the ongoing health impacts
- 3. Supporting families now and in the future
- 4. Recording the stories and personal experiences
- 5. Establishing a place of reflection
- 6. Supporting education and research

Recommendations

Throughout the consultation we heard a diverse range of views and feedback from people who were directly affected by Mr Fluffy, people who had friends and family who were affected, and people who worked in industries that dealt with Mr Fluffy and the scheme.

Many respondents expressed concern about the timing of the legacy project and there is by no means universal support for a legacy project at this time. However, for those respondents who did share their views and ideas about how to acknowledge the decades long history of Mr Fluffy, the following recommendations are made under six key themes.

1. Learning lessons

- 1.1 A board of inquiry be established to document the chronology of decisions and how policy and program responses were developed
- 1.2 Lessons learned be documented and shared with other jurisdictions to ensure this does not happen again when a new issue or contaminant emerges, including clear and consistent procedures to guide any future response
- 1.3 Research to understand the factors that enabled, delayed or prevented people from 'moving on' this information to be used to better ensure, more targeted support for people affected by similar disasters in the future
- 1.4 That an independent evaluation of the ACT Government's response to the impacts of the Mr Fluffy insulation be conducted. The evaluation should include both qualitative and quantitative assessments, and seek feedback from Mr Fluffy homeowners, tradespeople, contractors, healthcare providers and others about their experiences.

2. Tracking health impacts

2.1 Support for the ACT Asbestos Health Study conducted by the Australian National University to monitor the ongoing health impacts of Mr Fluffy homeowners and potentially expanded to include those who rented, visited, or at any time worked on Mr Fluffy homes

3. Supporting families

- 3.1 Ongoing support for families and access to mental health services as well as GP services tailored and bespoke for Mr Fluffy homeowners rather than just a generic referral to GP or Lifeline or other such resources.
- 3.2 Training for health practitioners to understand and be able to respond to patients with issues related to Mr Fluffy including a snapshot of the history and issues faced so that patients do not have to re-tell their stories at each visit, and improved and specialised palliative care for those with asbestos-related diseases

4. Recording the stories

- 4.1 Curate a collection for Canberra Museum and Gallery including stories, poetry, art, interviews, photographs, songs and the like.
- 4.2 Ensure Mr Fluffy homeowner impact statements tabled in the House of Representatives and the ACT Legislative Assembly in 2014 and the 'More than Bricks and Mortar' book are included in the ACT archives collections/library
- 4.3 An accurately researched and publicly available history and chronology of all Mr Fluffy events starting from the 1960s be prepared

5. Establishing a place of reflection

- 5.1 Establish a small pocket park or place of reflection to be planted with cuttings or selected species representing their lost homes and gardens
- 5.2 Park to also include an interpretive plaque or signage acknowledging the My Fluffy story

6. Education

- 6.1 Establishment of a PhD scholarship for research or coursework related to a theme resulting from Mr Fluffy including (but not limited to);
- 6.1.1 Public administration and decision making in responding to crisis
- 6.1.2 History or biographies
- 6.1.3 Architecture and design
- 6.1.4 Treating ongoing and/or long-term mental illness and stress in people exposed to asbestos



Community and Expert Reference Group