Submission to the PFAS Sub-committee of the Joint Standing Committee on Foreign Affairs, Defence and Trade (JSCFADT)

Reducing the mental health burden of being a member of a PFAS-affected community requires participatory community interventions

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We make this submission on behalf of a multi-centre collaboration comprising academics and public health practitioners associated with the University of Newcastle, Australian National University, the University of Queensland and Griffith University.[*] Members of our research team have worked in the field of environmental health for over two decades and have been heavily involved in the PFAS response in Australia to date.

Members of the team have variously worked on the National PFAS Epidemiological Study, contributed to the Australian Expert Panel on PFAS Health Effects, performed a recent review of the enHealth Community Engagement Handbook, worked with the Community Reference Group in Williamtown and are involved in a current study assessing the effectiveness of PFAS exposure control in exposed communities and among firefighters.

We believe that, to date, insufficient focus has been given to remediating the mental health and community impacts of PFAS contamination in affected Australian communities. A novel, multi-disciplinary approach to research and implementation, one taken in partnership with residents in affected communities, is required and needs to be supported.

1. Stress and poor mental health are major known health impacts of PFAS contamination

The discovery of PFAS contamination in a community leads to stress and potential mental health impacts. Concerns regarding psychological impact have been raised repeatedly by affected residents through parliamentary submissions, social and mainstream media, and community forums, and it is evident in research on PFAS and its community impacts. The public consultation for the 2018 Australian Expert Panel review on the Health Effects of PFAS found that twenty of 189 respondents reported that they were concerned about the effect that PFAS exposure was having on their mental health. Focus groups conducted in 2019 in Katherine, Oakey and Williamtown as part of the ongoing ANU PFAS Epidemiological study found that many residents experienced psychological stress and anxiety related to the prolonged duration of PFAS contamination and uncertainty with respect to health outcomes.

[*] *The team includes, aside from those listed above, Associate Professor Kelly Fielding and Dr Kylie Morphett of the University of Queensland and Associate Professor Anne Roiko of Griffith University, who are making a separate submission on their survey research*.

The mental health impacts are articulated in terms of a fear of long term health effects, such as cancer, concern about the loss in value of homes and businesses, a lack of trust in government or other departments who are meant to fix the problem, and feelings of not having a voice or of being treated unfairly.

Government responses to PFAS may also compound the stress experienced by communities, through the effectiveness of communication and support provided. The resulting loss of trust in government information can in turn lead to excessive fear or disregard for recommended strategies to mitigate risks. The Australian Expert Panel review on PFAS about found that many residents were worried about skin and air absorption, despite these exposure pathways being comparatively minor contributors to total PFAS burden. Research by members of our group (Fielding and Moffett - who have provided a separate submission) has also found that risk messages are perceived differently by residents of affected communities compared to those living in other areas.

2. The impact of PFAS contamination on stress is cumulative

Research conducted by members of our team has found that the stress experienced by affected residents resulted from a number of factors. Focus group participants in Katherine, Williamtown and Oakey were primarily concerned about the potential health risks of PFAS exposure for their families and specifically their children. Concerns about uncertainty and future health effects was worsened by concerns about their current and future financial status.

A common theme articulated by residents was the feeling of being “trapped” or “stuck”. In addition to an estimated loss in property value of approximately 15%, residents reported experiencing stigmatisation from financial institutions when applying for business and personal loans. Stigma also led to isolation of community members – some reporting stories where grandchildren and family would not visit them for fear of the PFAS contamination in the environment.

Additionally, stress generally is cumulative. Ongoing social or economic marginalisation, pre-existing health concerns and localised impacts from drought, fire or flooding, for example, are exacerbated by the effects of nearby environmental contamination, frustrations with government departments and a diminution in internal community support.

3. PFAS contamination erodes social support structures affecting family and community resilience, prolonging time needed for recovery and increasing vulnerability to future impacts

Australia knows of the mental health effects of droughts, flooding and bushfires in rural and regional areas. The effects of human-imposed impacts – such as PFAS contamination, climate change and economic downturns (including those due to shutdowns associated with COVID-19) - are less well understood and not as effectively addressed. Evidence from other man-made environmental disasters, such as Libby amphibole asbestos, suggests that individual psychological impacts may trigger secondary social effects, such as relationship and family breakdown, and substance misuse. Communities may be divided due to differing interests

and aspirations among industry and social groups in relation to the impact and the responsibility to respond to contamination.

Researchers from our team found that residents of the PFAS affected townships were simultaneously brought together and divided by the issue. Those articulating concern about the impacts of PFAS on the environment, or health, bonded to voice their concerns and lobby for what they considered to be an appropriate government response. Others expressed concern that negative publicity about the impact of PFAS was damaging the reputation of their town and driving away investment and other commercial opportunities. They argued that, because health risks from PFAS were unclear or low, they should be downplayed, and the positive aspects of their town should be promoted instead. Katherine residents explained that PFAS had had a negative impact on the local tourism industry, which is a major contributor to the Katherine economy.

These different perspectives contributed to a sense of discord and disunity, which was stronger in some communities than others. The collective trauma that can be experienced within such communities can have intergenerational consequences. PFAS contamination in residential areas will be longstanding, as remediation is addressed primarily at source removal.

4. Research into PFAS and mental health to date has focused on the immediate individual effects rather than long-term and community level impacts

There is a relative dearth of literature on the mental health impacts of PFAS in communities Australian and overseas. Research to date has taken a strongly biomedical approach, with the link between PFAS exposure levels and neurodevelopmental outcomes in children examined in several studies. A recent literature review found no published studies in the peer reviewed literature on the mental health impacts of perceived PFAS contamination.

Members of our group are currently undertaking research in this area as a component of the Australian National University's PFAS Epidemiological study. This research will investigate a cross-sectional sample of the community using validated screening tools for mental illness, such as the DASS-21 and Kessler 10 (K10) scale.

While this effort represents a much-needed first step, we argue that the research is required to address a broad array of topics. The relationships among emotional, health, social and economic factors for community-level impacts must be investigated. Ways to alleviate the negative impacts on mental health have to be identified, tested and rolled out across PFAS-affected communities in Australia, ideally involving residents in the process of design and implementation.

5. Participatory approaches in other contexts have been shown to remediate the community level impacts of contamination and restore trust between residents and government departments

Evidence related to other contested environmental issues suggests that participatory approaches can restore agency and hope to communities affected by contamination. PFAS focus group participants reported they would like greater transparency and support in their interactions with government representatives. Participatory approaches, such as co-design of

scientific research between community members and representatives of government departments, have been shown to be successful in examples, such as the establishment of the Latrobe Valley Air Quality monitoring network following the Hazelwood mine fires in Morwell, Victoria. Another example of a successful partnership that has been undertaken in Williamtown, NSW is the "Community Helping Community" program established by PFAS-affected residents, the University of Newcastle Family Action Centre, and the Department of Human Services.

These factors suggest the value in participatory approaches that inform, consult, involve, collaborate, and empower (Council on Environmental Quality, 2007)[34]. Such an approach addresses the lack of control that community members often experience in risk assessments (Cline *et al*., 2014)[5], where a complex relationship exists between "knowledge insufficiency", "worry" (Griffith *et al*., 2004)[35] and lack of trust in institutions.

These sorts of intervention elements are informed by a widely accepted, best practice model of care developed by the Council of Environmental Quality (CEQ) for the National Environmental Policy Act (NEPA, USA) (Council on Environmental Quality, 2007)[34].

The PFAS focus group study shows that each community has its own needs and expectations as well as requiring specific strategies to disseminate information, given the community's structure and history. These factors need to inform the participatory, co-design phase of an intervention.

The investigation and implementation of any such programs has to be undertaken in partnership with residents and other stakeholders. Residents have had their health endangered, but they can also be seen as victims of an alienating system of responses by government, however well-intentioned those responses may have been.

Australian and international data highlight that there is a significant level of concern within PFAS affected communities regarding both the potential health effects of PFAS and the communication strategies employed by government departments to date. These levels of concern are in some situations not well aligned with the level of PFAS exposure. That is, some who have not faced much exposure may be highly concerned. However, such concerns and associated social and mental health impacts are harmful in their own right.

6. No studies examining mental health impact were funded in the recent NH&MRC Targeted Call for Research, despite its priority among community members

A proposal to initiate this engagement, investigation and testing was submitted by our team in response to a special call for research on health impacts of PFAS contamination. This one-off round of grant funding was handled by the National Health and Medical Research Council in 2019 (NH&MRC). The terms of reference for the special call (*see below*) responded to input from residents in affected communities by identifying 'stress, anxiety and trauma' among a short list of the impacts to be addressed, and that is where our multi-disciplinary team focused its attention.

> Applications are invited that address one or more of the following:
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> a) **Advancement of existing understanding of human health outcomes** that may arise from acute and long term exposure to PFAS, **including** either direct health and/or **indirect health outcomes such as stress, anxiety and trauma**.

b) Investigation of the biological mechanisms by which the different per- and poly-fluoroalkyl chemicals may affect human health and whether there are differences in potencies that could inform human health risk assessments.

c) Investigation of the various potential exposure pathways, including through the ingestion of products from animals exposed to PFAS, and identification of factors that can mitigate/exacerbate an individual's susceptibility to health outcomes.

d) Evaluation and/or advancement of the reliability of biomonitoring of human PFAS exposure in Australia.

e) Development and/or evaluation of methods for analysis of human health data where exposure is to multiple per- and poly-fluoroalkyl chemicals.

f) Development and/or evaluation of methods to minimise human environmental exposure to PFAS, or enhance elimination following environmental exposure.

(NHMRC TARGETED CALL FOR RESEARCH into Per- and Poly-Fluoroalkylated Substances Call-Specific Funding Rules, Dec. 2018.)

However, none of the nine projects funded in that special call focused on understanding or addressing mental health impacts. In addition to our own proposal addressing mental health impacts, one led by Prof Jason Prior of UTS, also failed to gain funding in this special call.

The inability for these projects to win such support suggests how challenging it can be for assessors to weigh up the quality of proposed efforts that fall at the intersection of environmental health, mental health and applied social science. Regardless, the outcome of this funding round has left a yawning gap – an area in need of attention that has implications across dozens of PFAS-affected communities in Australia.

7. A broad approach is required as part of a holistic remediation program, considering the mental health and wellbeing impacts of PFAS contamination at an individual, family and community level.

Mental health impacts in communities around Australia that are affected by PFAS contamination remain to be addressed. Those impacts are compounded by the uncertainty and economic effects resulting from shutdowns and social distancing associated with the COVID-19 pandemic and long-term shifts attributed to climate change. The impacts can be exacerbated by feelings of marginalisation, the passage of time and sustained uncertainty about health outcomes related to the expected latency period before feared cancers might surface among residents and their children.

On these grounds, our broadly experienced, multi-centre, interdisciplinary team recommends identifying what is happening, why it seems to be happening, what can done about it and by whom. Specifically, we recommend:

A. **Long-term studies** of mental health impacts of PFAS contamination in high profile communities, such as Oakey, Katherine and Williamtown;

B. **Employing partnerships** of researchers, public health practitioners and community members to develop understanding of physical health risks and to enable the creation, piloting and implementation of tools to address socio-economic and mental health impacts;

C. **Establishment of a program** of research and application directed at the nexus of environmental health, community mental health and socio-economic wellbeing to address the legacies of PFAS contamination.

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