

The PFAS Health Study

Component One:

Oakey, Williamtown and Katherine Focus Groups Study

Cathy Banwell,¹ Tambri Housen,¹ Kayla Smurthwaite,¹ Susan Trevenar,¹ Liz Walker,¹ Katherine Todd,¹ May Rosas,² Martyn Kirk¹

¹National Centre for Epidemiology and Population Health, Research School of Population Health, The Australian National University, Canberra, ACT, Australia.

²Ngaigu-Mulu Aboriginal Corporation, Katherine, NT, Australia.

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National
University

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Abbreviations

Abbreviation	Full Text
AFFF	Aqueous film-forming foam
ANU	Australian National University
DDVA	Departments of Defence and Veterans' Affairs
GPs	General practitioners
NSW	New South Wales
NT	Northern Territory
NTDoH and MSHR	Northern Territory Department of Health and Menzies School of Health Research
PFAS	Per- and poly-fluoroalkyl substances
PFHxS	Perfluorohexane sulfonic acid
PFOA	Perfluorooctanoic acid
PFOS	Perfluorooctane sulfonic acid
Qld	Queensland
VBTP	Voluntary Blood Testing Program

Plain language summary

This report details the findings from a series of focus group discussions held in Oakey (Qld), Williamstown (NSW), and Katherine (NT) between January and August 2018. The main aim of this study was to understand participants' views and experiences of PFAS (per- and poly-fluoroalkyl substances) contamination in their local area, with a focus on participants' health concerns.

Residents in these communities have been potentially exposed to PFAS chemicals. Potential exposure pathways varied between communities but include the use of contaminated water, including bore and river water on their properties, as well as town water. Less important potential exposure sources were eating locally produced foods and bush foods, through work activities, and in some instances through direct contact with firefighting foams.

The study team advertised the focus groups in all the communities in the four weeks before the discussions. Four focus group discussions were held in each community, with 46, 36 and 29 participants attending in each of Williamstown, Oakey and Katherine respectively. One focus group discussion in each of the three communities was dedicated to Defence staff, contractors and family members. In Oakey, there were slightly more men than women, Williamstown focus groups contained roughly the same number of men and women, and in Katherine, there were predominately more women who attended the focus groups. Overall, the non-Aboriginal community groups contained slightly more people over the age of 50, more people who owned their own properties, and more who had lived in the area for longer than ten years. In Katherine, an additional three focus groups of 69 participants were held in local Aboriginal communities. The Aboriginal focus groups were larger, included more women who were often accompanied by children, and were held on community land.

Participants voiced concerns related to their health and PFAS exposure. Children were considered more vulnerable due to their young age and exposure from growing up in affected areas. Participants were particularly concerned about the onset of cancers and the deterioration of existing health conditions. Another major concern for many participants was the stress and anxiety related to the duration of the PFAS contamination and uncertainty with respect to the long-term impact on health, specifically for their children. In addition to the above concerns, Aboriginal participants were also worried about the health of their children, contamination of river foods and bush tucker, and the overall impacts on country. Many participants were concerned about continuation of uncertainty and feeling unable to sell their property, being "*stuck*" in their community and lacking options to "*move on*". Participants in the group discussions asked for greater transparency and consistency in the information they received. They discussed options that they thought would reduce their anxiety and provide information or pathways that could lead them out of their current situation soon.

The findings from the focus group discussions have been used to contribute to the questionnaire design for a cross-sectional survey on health effects of PFAS. This report details the experiences and emotions of people who have been affected by the PFAS contamination.

These findings are one aspect of the PFAS Health Study. All research components will be released separately as each component is completed. In addition, findings will be combined with results from other parts of the PFAS Health Study at a later date, to provide further information to the communities and to Government.

Executive summary

The communities of Williamtown in New South Wales (NSW), Oakey in Queensland (Qld), and Katherine in the Northern Territory (NT) have been contaminated with PFAS due to firefighting activities on nearby Defence Force bases. Members of these communities have been potentially exposed to PFAS primarily through the use of contaminated water including bore and river water on their properties, and via eating locally grown foods.

In December 2016 the Australian Government Department of Health (Department of Health) commissioned the Australian National University (ANU) to undertake an independent study on the health effects of PFAS in the Williamtown and Oakey communities—the PFAS Health Study. In May 2018, Katherine in the Northern Territory (NT) was added to the epidemiological study. Katherine residents were also potentially exposed to PFAS through contaminated water, including town water, and other similar routes. This report details findings from a Focus Groups Study to determine the concerns of individuals living in the vicinity of Williamtown, Oakey and Katherine in relation to exposure to PFAS and their health.

The primary aim of the Focus Groups Study was to gather a range of social and health-related experiences and perceptions from current residents and workers exposed to PFAS in the three communities. Four focus groups were conducted among general community members in each of Oakey, Williamtown and Katherine, giving a total of 12 focus groups containing 111 participants. Overall, the non-Aboriginal community groups contained slightly more people over the age of 50, more people who owned their own properties, and more who had lived in the area for longer than 10 years. In Oakey, there were slightly more men than women, Williamtown focus groups contained roughly the same number of men and women, and in Katherine, there were predominately more women who attended the focus groups. In Katherine an additional three focus groups of 69 participants were held in local Aboriginal communities. The Aboriginal focus groups were larger, included more women who were often accompanied by children, and were held on community land.

Most focus group participants were concerned about the potential health risks of exposure to PFAS for their families and specifically for their children, who may be particularly vulnerable due to their young age and exposure while growing up in affected areas. Participants were worried about the onset of cancers and the aggravation of existing health conditions. Many referred to psychological stress and anxiety related to the lengthy duration of PFAS contamination and uncertainty with respect to health outcomes, as well as implications for their current and future financial status. Focus group participants reported that they would like greater transparency and support in their interactions with government representatives at all levels, and some clear guidance or pathways out of their current situation in a timely fashion. Many referred to feeling “trapped” or “stuck”.

The findings from the focus group discussions have contributed to the development of a questionnaire for a cross-sectional study, including questions on psychological stress and social support. They have captured the changing experiences and emotions of those who have been involved and may inform policy responses regarding risk communication in the future for any organisation dealing with a contamination event. Ultimately, the results of this focus group study will be combined with results from other components of the PFAS Health Study to provide a comprehensive overview of the impact of PFAS contamination on health.

1. Study information

1.1. Report title

The PFAS Health Study: Focus Groups Research Report

1.2. Report date

February 2019

1.3. Project funding

The Australian Government Department of Health¹ has commissioned the Australian National University to undertake the PFAS Health Study.

¹Department of Health
GPO Box 9848
Canberra ACT 2601, Australia

1.4. Investigators

Principal Investigator

Professor Martyn Kirk, Australian National University¹

Co-Investigators

Associate Professor Cathy Banwell, Australian National University¹

Dr Tambri Housen, Australian National University¹

Ms May Rosas, Ngaigu-Mulu Aboriginal Corporation²

Dr Katherine Todd, Australian National University¹

Professor Adrian Miller, Central Queensland University³

Research Officer

Ms Susan Trevenar, Australian National University¹

Research Assistants

Ms Kayla Smurthwaite, Australian National University¹

Ms Liz Walker, Australian National University¹

¹National Centre for Epidemiology and Population Health
Research School of Population Health
College of Health and Medicine
Building 62, Cnr of Eggleston and Mills Roads
The Australian National University
Acton ACT 2601, Australia

²Ngaigu-Mulu Aboriginal Corporation
PO Box 1876
Katherine NT 0851

³Office of the Pro Vice-Chancellor (Aboriginal Engagement)
Central Queensland University
538 Flinders Street
Townsville Qld 4810

Study Management

Professor Martyn Kirk
National Centre for Epidemiology and Population Health
Research School of Population Health
The Australian National University
ACT 2601 AUSTRALIA
Telephone: +61 2 6125 5609
Mobile: +61 4 2613 2181
Email: pfas.health.study@anu.edu.au

2. Rationale and background information

Per- and poly-fluoroalkyl substances (PFAS), including perfluorooctane sulfonic acid (PFOS), perfluorooctanoic acid (PFOA) and perfluorohexane sulfonic acid (PFHxS) are man-made chemicals. [1] These chemicals are highly inert—thermally, chemically and biologically. [2] PFAS are environmentally persistent, can last for decades in water and soil, and have been shown to accumulate in soil and aquatic environments of contaminated areas. [3, 4]

PFAS can also accumulate in the human body, tending to favour tissues with a large blood supply, including the liver, kidneys and lungs. [5] One of the concerns with PFAS chemicals is the length of time they remain in the human body. The half-life of a substance in the body is defined as the length of time required to eliminate half of the substance from the body by normal physiological processes. The biological half-life in human serum varies with the type of PFAS, with estimates of 3.8 years for PFOA, 5.4 years for PFOS and 8.5 years for PFHxS. [6] Due to these characteristics, PFAS are regarded as ‘emerging contaminants’, with potential to threaten the environment and human health. [7]

2.1. Potential health effects of PFAS exposure

There have been many epidemiological studies reported in the literature that examine the health effects of exposure to PFAS. The people studied have included those who worked in plants manufacturing these chemicals, firefighters, people with higher than usual exposure because of contamination of water supplies and people in the general community. The *PFAS Health Study – Systematic Literature Review* examined 221 separate scientific publications, identifying 148 individual health outcomes. [8] These published studies covered effects on reproduction, on pregnant women and their newborn babies, on body metabolism, on major body systems (including brain and nerves, heart and blood vessels, airways and lungs and the immune system), on specific conditions (such as obesity, diabetes and cancer), and on thyroid gland function.

The systematic review identified a sufficient level of evidence to indicate that PFOA and PFOS were associated with elevated total cholesterol levels in the blood stream (hypercholesterolaemia). The review also found limited evidence that exposure to PFAS in the blood was associated with higher levels of uric acid in the blood (hyperuricaemia), kidney and testicular cancers and lower levels of antibodies than usual following vaccination against some vaccine preventable infections. [8]

There remains much uncertainty as to the health effects of PFAS exposure. In the few areas in which there is evidence for a possibly causal association of PFAS with an effect on human health, the association is either uncertain, or weak. Despite this, there is considerable community concern about the potential long-term health effects of these chemicals in the environment.

2.2. PFAS in Australia

PFAS chemicals have been manufactured since the 1950s and used in a wide variety of applications and consumer goods such as non-stick cookware, fabric, furniture and carpet stain protection. [9] They were also an ingredient in aqueous film-forming foam (AFFF) used for firefighting activities. [10] Manufacturers have largely phased out PFOA and PFOS from AFFF and have switched to alternative chemicals with a shorter fluoroalkyl chain. [10] However, due to the environmental stability of PFAS in AFFF used decades earlier, the chemicals still remain in ground water, sediment and soil in the local areas. [10]

2.3. PFAS in Williamstown, Oakey and Katherine

In 2015, the Australian Government announced that areas of Williamstown, NSW and Oakey, Qld were contaminated due to firefighting activities on nearby Defence Force bases. In 2017, it was announced that the town of Katherine, NT was also contaminated. Use of AFFF on Defence bases has resulted in detection of increased PFAS levels in ground water, soil, and biota. [11-13] Members of these communities have been potentially exposed to PFAS primarily through the use of contaminated water including bore and river water on their properties, and via eating locally grown foods. Bioaccumulation of PFAS in the food chain has led to concerns about the consumption of animal products from the local farming regions, including livestock raised on contaminated land and fish and crustaceans sourced from local waterways. Communities have raised concerns about the uncertainty of their future due to the physical health effects that may arise after living in a PFAS contaminated region, and to the financial effects on the local farming industry and properties. [14]

2.4. The PFAS Health Study

The Australian Government Department of Health (Department of Health) commissioned the Australian National University (ANU) to undertake an independent study on the health effects of PFAS in Australian communities– the PFAS Health Study. The study is described below:

1. a focus group study to determine the concerns of individuals living in the vicinity of Williamstown, Oakey and Katherine have in relation to exposure to PFAS and their health;
2. a blood serum study to define the serum concentrations (mean and range) of PFAS in Williamstown, Oakey and Katherine residents living in the Investigation Areas and to compare the levels to those of people residing in the townships and surrounding areas;
3. a cross-sectional survey to investigate the exposure and risk factors for high serum PFAS levels, including sociodemographic (e.g. age, sex, location) and other factors (e.g. duration of residence in the area, water source), and associations of high serum PFAS

levels with common symptoms, signs and diagnosed illnesses in the Williamstown, Oakey and Katherine communities; and

4. a data linkage study to examine whether sex-specific age adjusted rates of diseases potentially associated with PFAS are higher among people who have lived in the Investigation Areas of Williamstown, Oakey and Katherine, compared to those living outside the Investigation Areas and in the general Australian population.

This report provides a summary of the findings from the Focus Groups Study conducted in Williamstown, Oakey and Katherine between January and August 2018.

3. Objectives of the study

The primary aim of the Focus Groups Study, which consisted of a number of focus group discussions, was to gather a range of social and health-related experiences and perceptions from current residents and workers in the Williamstown, Oakey, and Katherine Investigation Areas. The target population was residents living or working in the Investigation Areas as defined by the NSW Environmental Protection Agency and the Department of Defence, respectively.

The specific objectives of the focus group discussions were to:

1. Examine the range of experiences and opinions of people living, working or owning property in a PFAS affected area;
2. Understand residents' perceptions of health and other risks from exposure to PFAS in order to inform ways to assist affected residents (e.g. provide mental, social and health services or support);
3. Inform policy responses regarding risk communication relating to environmental threats, to reduce suffering and unnecessary anxiety; and
4. Inform the development of a questionnaire for a future cross-sectional survey of residents.

3.1. Study design

In order to address the specific objectives of this component of the PFAS Health Study, we adopted an inductive exploratory methodology for collecting qualitative data. [15] Focus group discussions facilitate discussion of public knowledge, underlying attitudes, perceptions and opinions and are well suited to exploring a range of views on community topics. [16] Discussions may reveal concerns and issues that are often generated by interactions within the group. Consequently, focus group discussions are commonly used in health research and in the development of health programs, often in conjunction with other research methods such as surveys. [15, 17] The focus groups were not intended to statistically represent the communities although we aimed to capture a range of community views and experiences related to PFAS. The focus group discussions were conducted in the affected communities of Williamstown, Oakey and Katherine.

3.2. Sampling and recruitment

Our aim was to hold between four and five focus group discussions in all three study sites with 6–12 participants in each group (an appropriate size for focus group discussions). The research team posted advertisements in local newspapers, flyers in local shopping centres and community facilities, and organised a letterbox drop in Williamstown and Oakey. In Katherine, the focus groups were advertised through print and digital advertisements in the local newspaper, via a

specific story in the *Katherine Times*, via dissemination of information to community reference groups, and via a post on a community Facebook group. For all three communities the study team contacted community members who had previously registered their interest in the study. The advertising material (Appendices 1 and 2) invited people living and/or working in the PFAS Investigation Areas to participate in a focus group and asked residents to email or phone researchers to register their interest in participating in a group. Potential participants who contacted researchers were provided with additional information about the location, the discussions, and were pre-sent the information sheet (Appendices 3 and 4). To recruit participants in Aboriginal communities in Katherine, an Aboriginal Elder notified community members when the team would be visiting their community, enabled access to communities, and assisted in facilitating the discussions.

3.3. Data collection

Discussion groups were held at the Returned and Services League Club in Oakey, the Mercure Hotel in Newcastle, Knott's Crossing Resort in Katherine, and in three outdoor settings in the Aboriginal communities in Katherine. In all groups, participants provided written consent (Appendices 5 and 6) following a clear explanation of the purpose of the study and format of the focus group discussions. Consent was also sought for audio-recording of the focus group discussions. Participants were asked to use a pseudonym throughout the discussions and no identifying information has been used in this report. A brief one page questionnaire (Appendices 7 and 8) was distributed to the general community study participants to collect basic sociodemographic data, such as age, gender, marital status, employment and number of children. Due to the less formal nature of the Aboriginal groups and their use of several different Aboriginal languages, we did not ask them to complete these questionnaires. Following the conventions of focus group discussion, a list of open-ended questions and potential prompts aimed at generating discussion was developed to cover the following topics:

- Health—concerns for adults, for children, over long and short-term, health checks, health knowledge;
- Risk perception and management, and understanding of PFAS exposure;
- Emotional stress related to uncertainty and other concerns—value of house replacement, costs of living elsewhere, resale value, feelings about leaving long-term residence;
- Stigma—how are exposed people viewed by others in community;
- Practical issues—alternative living arrangements, moving, schooling, work, replacement of belongings, rebuilding house—time costs, other barriers;
- Changes in connection to local land and water sources – changes in farming and fishing activities, use of local produce, Aboriginal connection to land;
- Perceptions of the response to the PFAS situation reported in the media; and

- Other issues.

In the general community groups, participants were provided with the list of topics to be discussed, prior to consenting to the study to ensure that they were comfortable with the areas that would be covered. Participants were also encouraged to highlight issues not mentioned on the list that they felt were important in relation to their perceptions of the health impacts of PFAS. The primary researcher (CB) initiated discussion using these topics while also allowing discussion to follow the interests of the participants. Other researchers (TH, KS, ST, and LW) took notes and facilitated the meetings. Where appropriate, participants were informed that the researchers were experienced in conducting focus groups but not experts on the impacts of PFAS on human health.

The Aboriginal focus group discussions in Katherine were conducted differently from the others. An Aboriginal Elder from Katherine was contracted to organise and facilitate the groups. She visited the communities first to inform them about the study and we later visited the communities with her to conduct the discussions. In each community, we set up a table with fruit, biscuits and juice in the community structure and invited community members to join us. The Elder introduced us and the study and we then obtained signed consent forms and consent to record the conversations. Participants were given tags showing their self-chosen pseudonyms to safeguard anonymity. The Elder facilitated discussion in these groups, often repeating questions using local Aboriginal language. Team members located themselves around the site to capture side conversations as the groups were large, and somewhat dispersed, with men and women sitting separately. Community members moved in and out of the group and children played around the groups or sat with relatives.

3.4. Data analysis

The audio-recorded discussions were saved in secure files and transcribed by a professional transcribing service. The professional transcribing services staff signed an ANU deed poll agreeing to confidentiality. Data will be stored on secure servers at the ANU for five years.

To conduct thematic analysis which has been described “as a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data” the lead author adopted semi-realist frame which aimed to reflect the participants’ experiences, and meanings. [18] The preliminary level of analysis occurred when facilitators met after each focus group to discuss and take note of the mood of the discussions and significant statements that had been made in the groups. The lead author then followed the recommended steps for thematic analysis by familiarising herself with the content of the transcripts through repeated readings, and developing an inductive and deductive coding matrix. [18] Code word or phrases were applied manually to the transcripts that were later entered into a computer software package (Atlas ti

version 8) for management. Coded segments of text were grouped into broader level themes and then described under the headings in this report. Participants' experiences of living in a PFAS area, and their perceptions of health and other risks, were organised under theme headings that align mainly with the first two objectives of the study. The communication of risk is relevant at various points in the document and is referred to in the discussion. Material from the focus group report has informed the development of the questionnaire for the cross-sectional survey of residents.

3.5. Ethics and funding

This project was approved by the ANU Human Research Ethics Committee (Protocol 2017/816, 2018/151), the Departments of Defence and Veterans Affairs (DDVA) Human Research Ethics Committee (Protocol 024-17, 055-018) and the Northern Territory Department of Health and Menzies School of Health Research (NTDoH and MSHR) Human Research Ethics Committee (Protocol 2018-3121). The Department of Health provided funding for this study under the PFAS Health Study.

4. Results

4.1. Local Settings

As we describe below, there are many similarities in residents' experiences of living in PFAS Investigation Areas. However, it is also important to recognise that the differing geospatial and social conditions in each of the affected communities has shaped residents' views of PFAS in particular ways.

The small township of Oakey is located on the Oakey Creek, which stems from the Condamine River. Town residents were concerned about the economic viability of the township as a separate issue from the management of land and agricultural produce. For these Oakey residents the discussion about PFAS echoed the larger struggle that many small rural communities experience to remain viable in a period where rural communities were suffering from a loss of population and services. They were keen to attract new enterprises and residents to their town. Many local houses had signs on the front fence supporting new coalmines. On the town outskirts, rural producers were concerned with financial problems related to managing their property. These varied perspectives and interests contributed to intense debate within the community about how they should respond to the PFAS contamination. Oakey residents saw PFAS as a problem that had been imposed upon them but they differed about whether the story should be broadcast to attract a government response or compensation, or suppressed to attract businesses and new residents.

Williamstown has no obvious town centre and consists of ribbon commercial development, a few large agricultural producers and many small acreages. While some participants were members of longstanding farming families that had lived in the district for several generations, many residents had chosen to move to the area in the last few decades because of its location, proximity to the coast, and pleasant climate. Despite these differences, the Williamstown community appeared relatively united in their concern about PFAS contamination. They had attracted considerable media and were 'well-known' by other PFAS-affected communities for their outspoken statements about PFAS.

Katherine is a rural centre lying at the margin between the semi-tropical north and the desert region to the south. The town is located next to the Katherine River that runs through the Katherine Gorge—an international tourist attraction. The commercial centre of the town is small, although the suburbs are quite extensive extending to rural properties on the outskirts. Similar to Williamstown, many of Katherine's residents had moved to the area for the 'lifestyle' it offered and proximity to nature. Non-Aboriginal and Aboriginal residents expressed a strong attachment to land, country and the river in particular. Concern for the reputation of the town and potential

impact on tourism (on which many Katherine residents rely) has led to differences of opinion in the community about how vocal they should be about the PFAS contamination. Katherine residents have access to the Tindal Aquifer that supplies bore water to properties and is used to supply water to public amenities and the township parks. In some rural areas, residents used bore water to irrigate their produce. The Katherine River is of major cultural significance and a resource for the local Aboriginal communities, with the symbolic and utilitarian value of the river alluded to by both general community and Aboriginal participants. The river provides swimming, other recreational activities, and hunting for local inhabitants.

All three communities were similarly located on low-lying, flat areas near rivers or waterways that are prone to flooding. Despite the resemblance, the flows of contaminated groundwater and the spatial and social organisations of the communities differed. One Williamstown participant described Oakey and Williamstown as “*two completely different areas*”. These two communities contained long-standing residents and farmers who claimed they had a detailed knowledge of local conditions based upon their families’ connections to the land. Several participants felt that experts from outside did not understand local geographic and climatic conditions and water flows, in relation to PFAS contamination and had not sufficiently consulted the local experts such as themselves. In one community, some long-term residents commented that recent council planning decisions to build new housing developments had contributed to flooding by disrupting natural water flows. Local specialised knowledge of the water system in the Katherine area, which is part of the Daly River Catchment, is recognised to have been developed by Aboriginal traditional owners over thousands of years of connection to country. [19] Despite differences between the three communities, some residents recognised that they have a common problem and they have provided information and support to each other.

4.2. General Community and Defence Force Focus Groups in Oakey, Williamstown and Katherine

The purpose of the focus groups was not to determine the ‘truth’ of participants’ views but instead to represent their experiences and perceptions to the best of our ability. In our role as group facilitators, we did not ascertain the correctness of participants’ statements concerning the complex technical facts about PFAS, nor did we adjudicate when divergent views were raised or participants proffered conflicting information.

Four focus group discussions were conducted among general community members of Oakey, Williamstown and Katherine. In each of these locations, one of these focus groups comprised of people who were connected to the local Defence Force base in some capacity (workers or family members). The three separate focus group discussions conducted in Aboriginal communities in

Katherine will be reported separately as they were substantially different in the way in which they were conducted and in their findings (see 4.4).

As Table 1 shows, the majority of participants in the general community focus groups were over 50 years of age. The focus group discussions in Oakey included a higher proportion of male participants than those in Williamtown and Katherine. Most participants had completed secondary school and many had further qualifications. At least one-third of all participants described themselves as retired. Participants tended to be married, own their own home and to have lived in the area for over ten years and often much longer. In several groups, both partners in a relationship attended. Of the 111 self-completed questionnaires that we used to collect these data, less than 10% were not filled in completely.

Table 1. General Community Focus Group Composition, PFAS Health Study

	Oakey 4 Focus Groups	Williamtown 4 Focus Groups	Katherine 4 Focus Groups
Number of Participants	36	46	29
% male	58%	46%	34%
Aged 50 plus	75%	65%	66%
Aboriginal or Torres Strait Islander	-	-	14%
Education			
Incomplete secondary	22%	6%	10%
Secondary	30%	41%	10%
Certificate/Diploma	25%	37%	34%
Bachelor or above	22%	15%	45%
Married or co-habiting	83%	74%	55%
Employment			
Casual employment	3%	4%	11%
Part-time employment	6%	4%	0%
Full-time employment	50%	39%	43%
Retired	35%	46%	39%
Unemployed	6%	7%	7%
Have children living with you	36%	65%	34%
Own home	92%	80%	72%
Lived in area 10 or more years	72%	65%	89%

Physical health concerns

Participants in all groups discussed their own and their family's current and future physical health. Participants in the three communities were deeply concerned that they had increased their children's risk of developing diseases, including cancer, in the future. They were also worried about contracting serious health conditions themselves in the future through exposure

with PFAS. Some questioned whether their own or their family members' current health problems were caused, or exacerbated, by exposure to PFAS. Williamtown participants referred to what they suspected was a "cancer cluster" several times, which had occurred in a specific geographical location in the PFAS Investigation Area. There was a strongly voiced perception among participants that this cluster was due to PFAS exposure. Male participants in Williamtown mentioned testicular cancer as a risk of PFAS exposure, with several reports of the disease in the community. Participants in all communities were also concerned about cases of other cancers, including bowel cancer and prostate cancer, but some questioned the uncertainty of attributing disease to exposure.

Is there a spike in bowel cancer in the area because people have got it in their family? Prostate cancer, it's an aging disease, is that why we've got so much of it around, we're living longer, or is it something to do with the PFAS exposure? Nobody knows.

The Katherine focus group discussions were conducted after the systematic review of the health effects of PFAS was released, allowing these participants to reflect on the findings. One person commented "I think they call PFAS the golden magnet or something for cholesterol". They also questioned whether PFAS had contributed to the high prevalence of diseases like diabetes.

Participants who were associated with the Defence Force bases concentrated on long-term health outcomes. They described high levels of exposure among people who had worked or had lived on the bases. They said they had been exposed to PFAS contaminated bore water through activities on the bases in the past, including drinking the water, bathing and swimming in the water and using the water to complete common household chores, including washing dishes. Defence personnel had been exposed to PFAS directly through the firefighting foams used on the base, and through occupational and recreational use. Participants recalled past skin symptoms in themselves and their children as "itchiness", "hives" and "skin crawling" after direct exposure to the foams or bore water on the bases.

In Katherine, participants were also concerned about contact with Katherine River water. A number of them mentioned swimming in the hot spring that was described as a "direct discharge from the Tindal aquifer". Some people particularly enjoyed this and often took their children to the spring. They also described the common practice of drinking water directly from the river.

During the discussions, participants further described the methods they had used to obtain information about the physical health impacts of PFAS. They noted that the information found on the internet could be used to buttress their existing views. However, participants also acknowledge that internet-derived information, as well as information from other sources, was varied and often contradictory, which contributed to confusion and frustration in the community.

Participants also reported that they did not usually consult the Department of Health website for health related information.

Despite government efforts to assist people to obtain blood tests and provide medical advice, focus group participants said that did not always feel they had received useful information about these tests or the health effects. Some participants reported that they were unaware they could access blood testing for PFAS for free. Others said they were confused by the results of their blood tests and did not always feel they received a helpful explanation from their general practitioners (GPs). According to some participants, not all GPs in the PFAS Investigation Areas were well informed about PFAS and human health. As an example, participants recounted how a local doctor had advised them that PFAS was good for their cholesterol levels. Others felt that local GPs had been extremely supportive of their concerns.

Participants perceived that information around the potential health effects of PFAS on physical health was contradictory and was reported by them to contribute to their mental anguish and stress. The “*not knowing*” what impact exposure will have on their health and in the long-term their children’s and grandchildren’s health was a common concern in all three communities.

Mental health concerns

Although most people were worried about their physical health, their immediate focus was on their stress, anger and negativity related to their current situation. A participant said; “*we talk about stress of health and mental stress*” and another group member from the same town thought that their community was brought together by “*the anger and negativity*”. Furthermore, group members discussed the difficulty of separating physical and mental health.

That’s the mental side of it is that you don’t know, you get sick and you don’t know whether to [attribute] it to the pollution here ... and there’s that psychological side that you sort of is what I’ve got caused by this or is it something else?

This discussion continued with participants acknowledging that although it is “*very difficult to prove*” the link between PFAS and physical health “*it’s still there in your mind*”. In another discussion group, participants commented that local residents are “*stressing, are angry ... about their house*”, prompting another participant to ask if someone could “*check their blood pressure*”. Some participants mentioned that their experiences in obtaining health support aggravated their negative feelings. For example, one person said that getting pre-test counselling had resulted in them feeling in “*worse shape*” afterwards. Another person said that “*fragile*” older members of their community had difficulty understanding medical information related to the blood testing.

Parents reported feeling guilt related to exposing their children to the PFAS chemicals. One person said: “*I don’t have the right to contaminate my grandkids*”. They were concerned about

the potential long-term effects this could have on their health and future lives. Another participant explained:

We've got two teenage kids and the unknown of they've been eating our fruit and vegetables that we've been growing up until recently and we were told that it was safe to do so.

Counselling and support services to residents of Williamstown, Oakey and Katherine were provided through their local Primary Health Networks. Members of a Williamstown focus group expressed a preference for using a locally organised informal support group because the advice they received from the professional services was considered impractical, and did not recognise the complexities and demands of their everyday lives. As an example, participants were encouraged to take a holiday away from the Investigation Area to reduce stress after expressing financial concerns to a counsellor. They said they did not have the time or money to do so.

Because of these deficiencies many participants reported spending considerable time monitoring for and obtaining information about PFAS themselves; time, which they felt, could have been better spent working or in leisure activities. Participants primarily associated their stress, anxiety and anger with uncertainty over long-term health prospects, and with disruptions to their social relationships and their financial circumstances.

[Ambiguity concerning PFAS measures in the environment](#)

Although most people were concerned about the physical health risks of PFAS, others did not think that the evidence was strong. Several participants suggested that PFAS may not be harmful or could even be beneficial for human health. Participants' uncertainty about their health was linked to the difficulty in determining their degree of exposure to PFAS. The direction and severity of the PFAS contamination at the sites was changeable and contested. Several participants in Oakey and Williamstown brought maps to the focus groups that showed the boundaries of Investigation Areas and indicated the direction of water flows and location of contaminated bores. However, there was uncertainty and anxiety about these areas marked on the map because they had shifted over time.

The movement, and use, of water in Katherine was particularly confusing to, and contested by, focus group participants, with people questioning and contradicting each other in the groups over the treatment and management of water. We were told that the Department of Defence had funded the installation of rain water tanks on some rural properties close to the base, while town residents were drinking town tap water, but were uncertain of its safety. Participants recounted that some town water came from the river upstream from the contamination site and some from the bore that was being treated to remove PFAS. This mix of water sources was

sometimes referred to as a “shandy” and was affected by seasonal variation in river water levels. Participants questioned the wisdom of this approach, the location of treatment sites, and the drilling of new bores. The complications of these various water sources and mitigation strategies left many residents uncertain about the safety of their tap water despite reassurances from the Department of Defence.

Participants in all three locations questioned the measurements of PFAS levels in water and soil, along with the way in which the tests were conducted. Based on their extensive local knowledge of water distribution, some participants queried the locations of the Investigation Area. They observed that the spread of PFAS contamination was patchy, and the boundaries of the PFAS Investigation Areas seemed arbitrary, particularly when a person living on one side of a street could be in an Investigation Area and a neighbour on the other side was not, even though water flowed in that direction.

Participants recognised that the Defence Force bases in each Investigation Area were the original source of PFAS contaminated water. They observed that most local residents had come into contact with it through bores on their properties. They recounted how in Williamstown and Oakey subsequently, rural and semi-rural residents were transferred to “town water” sourced from nearby dams. However, they then observed that using town water for agricultural purposes was expensive, increasing the property’s operating costs. In Katherine, residents had lost access to the Tindal Aquifer which they described as one of the best sources of water in Australia. Severe flooding in the three sites had occurred in recent years, which some participants attributed to topsoil becoming contaminated on land where PFAS contaminated bore water had not been used, or land outside of the Investigation Area. Participants were also concerned that the floods had affected produce and livestock raised on flooded land.

Blood testing for PFAS

Blood testing and a lack of clarity around the meaning of the results led to confusion, uncertainty and distress. Participants said that test results were not explained to them by some GPs and results varied between people in ways that did not make sense to them. They discussed how the PFAS levels in affected residents’ blood did not always seem to align with the measures of PFAS in environmental tests. Some people found that the produce from their property showed high PFAS measures, while their own blood tests were low or *vice versa*. They reported that these discrepancies added a further layer of confusion. Furthermore, members of community action groups and other community members compared their results and discussed discrepancies among themselves, thus amplifying uncertainty in the community. A repeated concern was how to interpret and respond to the results of blood tests particularly if they showed high levels of PFAS. Some participants said that they chose not to get their children tested because they did

not want to have the worry if the results showed high PFAS levels. One of the great sources of stress expressed by participants was high PFAS blood levels in children and themselves and not knowing what this meant for future health outcomes.

Health risk and uncertainty

Discrepancies between scientific evidence and personal experience intensified participants' confusion and uncertainty. One person said that there were a "*lot of unknowns*", and a "*lot of misinformation*". The focus group discussions gave the sense that almost any aspect of PFAS contamination and exposure in these communities was steeped in doubt, with the result that people had felt that they had no clear way of moving forward. Participants described how living with this level of uncertainty over a period of several years had contributed to the own and other residents' negative mental health.

Participants rationalised the complexity of assessing health risks and uncertainty in several ways. Some said that they were reassured because local wildlife and livestock living in contaminated areas were apparently healthy. A participant explained that, "*animals would know what is good water and what is not*". This observation gave them respite from worry and permitted them to focus on everyday issues, although it also led them to question the expert advice they received, including not to consume their own agricultural produce. Some livestock producers reported that there had been a significant reduction in the fertility in their animals and an increase in stillbirths and other health problems in their animals, which they surmised was due to exposure to PFAS.

Another approach for participants was to acknowledge the uncertainty of risk. They recognised that the health effects of PFAS would develop slowly over time and it was therefore almost impossible to know whether future poor health was due to PFAS exposures. Participants reported that one way of managing the uncertainty of their situation would be to sell their property and leave their community to reduce their PFAS exposure.

The uncertainty regarding health risks, exposed another level of difficulty in responding to the issue. Participants felt misinformed if they received information that was less worrying than the information they had collected themselves on the internet.

I spoke to [expert] on the phone.... And he – it was a little bit disappointing to be honest because he gave me the same spiel that the doctor gave me. But he said I shouldn't be alarmed by those levels in my child.

Financial concerns

Financial uncertainty was a major contributor to participants' stress and anxiety. Participants said that there had been a major decline in property and house prices due to PFAS. One person commented:

20 acres, \$100,000 four bedroom house. I don't know anywhere else in Australia that you'd get something like that, maybe [the other PFAS affected sites].

People who lived in or near Investigation Areas reported that they were unable to sell or improve their properties because they said that banks would not lend money on the properties, thus reducing the pool of potential buyers to those who did not require a mortgage. The banks were described as being “way out in front” on the issue meaning that they had rapidly realised the financial implications of PFAS and had stopped lending on properties in or near the Investigation Areas before there was an assessment of the health risks. Banks were reported to be unwilling to distinguish between residential or business properties, suggesting that their lending policies were based primarily on financial risks irrespective of the health risks. In one focus group, a participant speculated that banks could not lend money on contaminated land because they risk being sued. Another person recounted how a bank would not lend on a domestic residence that was in a non-contaminated area because the owner's business was located in the Investigation Area. Some participants said that banks and real estate agents would not even inspect properties to provide valuations.

Some participants had bought properties as a strategy for managing their retirement. They had previously planned to sell their properties to finance their retirement lifestyle and/or aged care in the future. These people were particularly anxious about their future, as they contemplated loss of financial independence simultaneously with the burdens of ill-health and aging.

We're caught. If I spend my super and buy another house I won't have any money to live. Certainly, I'm not happy. I was happy here for a long time, or reasonably happy but since this started, I don't want to live here anymore.

Because banks had devalued affected properties, participants felt that it was a waste to spend money maintaining and improving them. They felt quite distressed to see their previously well-maintained properties becoming run down and neglected but they could not afford to invest money that would not be returned. Participants were also concerned about their children inheriting their properties due to the potential health risks. What had previously been seen as a gift had been transformed into a potential burden.

I've got a property there that my kids wouldn't be able to sell and they don't want it, they sure don't want it.

Due to health concerns and general levels of anxiety and discord in affected communities, many, but not all, participants were keen to move elsewhere but said that they could not move because they were unable to sell their properties. Frequently, participants said that they felt “*stuck*”.

Attempts to ameliorate the potential health effects of PFAS imposed additional financial burdens. In Katherine, people were buying bottled water despite assurances that town water was now safe. In some communities, those living on acreages were forced to purchase town water rather than using free bore water. Consequently, they were spending considerably more than previously to water their livestock and grow fruit and vegetables on their properties. In addition, participants had been provided with precautionary advice that they should not consume products from their property due to the potential health risks associated with PFAS contamination of the soil, leading them to incur additional costs purchasing food. This was important to participants who did not have a high disposable income or had chosen a sustainable and self-sufficient lifestyle. Participants were confused about the safety of produce grown on contaminated land, as this person explains.

I wanted [Defence] to shut my bore down and compensate for my cost of the bore and then to pay my excess water and use town water. And they said no but yet they told me don't drink the water and don't put it on your veggie patch.

A number of focus group participants described themselves as producers who ran rural businesses of various sizes and types. Some raised livestock while others grew fresh produce that they either sold commercially or consumed themselves. Commercial producers were concerned about reputational damage and loss of business income. Participants felt guilty about selling livestock products produced in the Investigation Area, despite receiving advice that it was safe. Several livestock producers said that raising livestock on affected land had made their businesses unviable or their property “*not fit for purpose*”. Participants had given up raising animals because of financial losses. Some had put their livestock down, and replaced contaminated soil.

Some participants owned properties that had been in their family for several generations which they were planning to hand down to the next generation. These properties had both economic and emotional value and represented family connections to identity and place.

We've been there 30 years and you can't walk away and where do you live?

Another participant added:

We built the place. We dug it from the ground up and brought our kids up there and there's a lot of emotional attachment to it. It is not just financial.

Perceived impact on community cohesion

Participants expressed concern that the reputational damage to their town or area was driving away investment and other commercial interests. Some argued that town businesses and other commercial interests were damaged by negative publicity about PFAS. They related how visitors from out of town would ring ahead to ask whether the water was safe to drink before they stopped in the town. These concerns were part of a broader interest in the economic development of their towns and region. They described how the positive aspects of living in their community had been negatively affected by PFAS publicity. The participants who held these views generally supported new developments in the area such as mines and roads and did not want the PFAS issue to stand in the way of this change. They argued that because health risks from PFAS were low or uncertain they should be de-emphasised and the positive aspects of living in these areas should be promoted instead.

Katherine residents were concerned that PFAS had impacted negatively on the local tourism industry, which is a major contributor to the Katherine economy. A woman who had worked in the industry said that tourism had *“gone downhill in the last three years”* and that tourists preferred to stay in Darwin rather than Katherine. She would advise tourists not to drink tap water because she would not drink it herself.

Levels of community trust

High levels of suspicion and mistrust in communities had been generated around the PFAS issue and its relationship to health. The process of informing communities about PFAS through community consultations appeared to have undermined trust, with focus group participants reporting that they felt that they had been deliberately misinformed or fobbed off during consultations. They said that their questions were avoided or left unanswered, and that the information they received was insufficient or contradictory. One person reported he became angry after attending a meeting, even though he had merely been curious initially, because of the way a community information meeting was conducted and how community members were spoken to by the experts. Others described the use of *“smoke and mirrors [by] State Government, Local Council, [and] Federal Government. None of them will claim responsibility for anything”*. Another said the process had the *“appearance of deception”*. Participants were particularly suspicious of the Department of Defence. One person was concerned that members of the affected bases had been involved in managing the response to PFAS, arguing that this was a conflict of interest. Others differentiated between the Defence Force as an institution based in the seat of government, and locally located Defence Force personnel who were not held responsible for the contamination. However, several Defence Force personnel commented that they felt as if they were viewed negatively by some community members. Some participants

observed that the focus group discussions were the first time that they had an opportunity to express their opinions and concerns.

Frequent changes to the way the possible health effects from PFAS, level of associated risk and advice provided to communities, were described raised participants' sense of mistrust and confusion. Various bodies made statements about the science of PFAS that were then contradicted or replaced by other statements. While the evidence remained ambiguous, participants felt that this gave outside agencies the opportunity to downplay the health effects of PFAS by stating that findings were inconclusive. It was observed that there had been a senate enquiry into PFOS/PFOA that had made nine recommendations, but they had not been adopted.

Other interest groups were also viewed suspiciously. Real estate agents were accused of selling properties without disclosing the PFAS problem to buyers. One person who had recently purchased property said that she would not have moved to the area if she had been told about the contamination. An ongoing class action lawsuit appeared to exacerbate the tensions between community groups. In Williamstown, some people claimed that boundary lines of the Investigation Area had been drawn to exclude "*big businesses that are worth millions*".

Members of the three communities had differing views on the role of the media in reporting health effects and the scale of contamination. Generally, some participants viewed the media as a useful tool for attracting attention to their concerns and providing a mechanism to nudge government. Others thought the media was purely interested in using the PFAS story to sell papers or attract followers, irrespective of whether the story was true and whether it damaged the community. Some distrusted the media almost as much as government representatives, bureaucrats and other experts. Many felt that the stigma associated with affected communities was due to the media's scare-mongering and sensational reporting. A number of participants were positive about ABC's Four Corners program on PFAS aired in October 2017 although others thought it was biased and exaggerated. [20]

The level of suspicion in the affected communities meant that information that was provided by almost any government agency or other organisation associated with PFAS was disputed. It also affected the conduct of our research and potentially how future research findings will be received by community members. For example, a few participants were initially reluctant to sign consent forms due to their general levels of suspicion around the government's response to PFAS and potential access to personal information. Some also felt that the financial outlay on PFAS research could be better spent on finding a solution for them or that research on the health effects of PFAS would allow the government to avoid responding to the issue appropriately or in a timely fashion.

Distrust appeared to be linked with feelings of injustice. Participants perceived themselves as hard-working Australians who had paid their taxes and contributed to their country. They

suggested that if they were to contaminate their neighbour's land they would suffer the consequences, but because a government agency was the source of the contamination there would be no accountability; in other words, there were two sets of rules. Furthermore, participants argued that they had done nothing to create the problem and perceived the current situation as acutely unfair. They thought that the government was failing in its role to protect its citizens. A further reflection on government came from a participant who observed the experts and bureaucrats who visited them:

...don't have to live here you see, they can breeze in and breeze out, the same with the pollies. I've seen dozens of them, they come in and promise you this and that and they're gone, never see them again.

Members of all three communities commented on how they thought that their geographic distance from seats of government diminished their influence on the outcomes they sought on PFAS.

4.3. Defence Force participants

As noted above, Defence Force members had somewhat different experiences and perceptions from general community residents. Defence Force members and their families described high levels of exposure to PFAS in the past when they lived on-base. They were also more aware of the potential health risks of chemical exposures due to their professional training than the general public and they tended to contextualise and diminish the immediate risks. They reported they had been exposed to a range of potentially toxic chemicals while working on bases. Some had a good knowledge of health concepts (e.g. dose-response relationships) related to exposure and the nature of PFAS. Many, but not all, were concerned about their long-term health and strongly supported the idea of conducting epidemiological studies on Defence Force personnel.

PFAS raised a difficult situation for some Defence Force personnel who were concerned because they felt they were viewed negatively by the affected communities or treated as a “*bad neighbour*”. They were concerned that PFAS contamination had damaged the reputation of Defence Force personnel. Some Defence Force members said community members avoided them in public while others felt that their position in the communities was unaffected. Some Defence Force members considered that they were as negatively affected by PFAS as community members because they had higher levels of exposure, but felt that they received less sympathy and understanding. However, they also recognised that they were unaffected by financial problems that community members were experiencing, and that if they were to develop health problems that could be attributed to their work, these would be covered financially.

Though they had an allegiance to fellow Defence Force members and took pride in their work, Defence Force members were critical about a *“lack of information”* about PFAS and poor communication from senior Defence Force members. Several group members said they were *“cynical”* about the Defence Force response to PFAS and suggested that transparency was not part of the organisational culture. Nevertheless, they strenuously defended their base commanders and the use of PFAS on bases in previous decades because the health effects were unknown at the time and it was a very effective product.

Some civilian members of the communities were resentful that their Defence Force neighbours avoided many of the negative effects of PFAS. One person mentioned that the Defence Force members have access to loans via a Defence Force bank, while others highlighted that Defence Force members were previously relocated to housing outside Investigation Areas. This sense of unfairness was heightened because, as participants observed, town businesses did not always reap economic benefits from the presence of the Defence Force base because most members lived elsewhere and did not shop locally.

4.4. Aboriginal Focus Groups

The three Aboriginal Focus group discussions were conducted over two days in three communities on the outskirts of Katherine, and consisted of 69 adult participants, composed of approximately 80% women. They were facilitated by a local Aboriginal elder who alerted community members to our approaching visit and then took us into the communities. All the group discussions, in contrast to the general community groups, were held in open air structures in an open grassed area in the centre of the communities. The communities varied somewhat in size and distance from Katherine and represented the three main Aboriginal groups in the area; the Dagoman, Jawoyn and Wardaman communities.

Health concerns

Participants in all three groups were concerned about the potential impact of PFAS on their own health, and particularly on the health of their children *“and their future”*. This concern or *“worry”* was exacerbated by high levels of existing illness in the communities, which left participants wondering if PFAS had contributed. One person observed that a *“lot of people die ... too young”* and another said *“there’s a lot of sick people in the community”*. A woman questioned whether the recent death of a child was due to sickness from PFAS while another person said *“when I water [plants], if it touches your skin, I’m thinking about you might get cancer the long way round”*.

Participants sometimes linked PFAS to a general concern about the health of people and the health of country. One person observed *“we’ve still got country, but it will be lost with our Elders”*

referring to the numbers of people who had died in the past. Another person who came from interstate, observed: *“This brings back memories of the Maralinga.... People are still dying today from Maralinga”*, referring to the location where Aboriginal people lost their land and health due to nuclear contamination. There was little discussion of mental health concerns in these groups, except for general statements about being *“worried”*, a term used by the Aboriginal Elder who jointly facilitated the groups. Apart from these comments, participants generally did not link specific health conditions with PFAS. Aboriginal members’ perceptions of poor health in their communities appeared to contribute to their feelings of vulnerability to PFAS. However, PFAS seemed less immediate to them than their other health concerns.

Most participants had not participated in the Voluntary Blood Testing Program for PFAS that was freely available to the Aboriginal population through the Wurli-Wurlinjang Aboriginal Health Service. The service had previously reported that a small but steady trickle of people were obtaining blood tests. There were suggestions from some participants that the health service should visit the communities to organise blood testing because some people wanted to know their PFAS levels, though found the journey to town difficult.

Possible pathways to PFAS exposure

In the Aboriginal communities, participants appeared confused and uncertain about PFAS on their environment. The one item of information that most people were aware of, was that they should only eat one fish a day because the river and the fish in it were contaminated by PFAS. They understood that it may be detrimental to their health if they consumed greater quantities than this. Participants described PFAS as though it was an infection that people could catch from contact with river water or river food products. The advice to consume only one fish a day had considerable cultural and economic significance. People said that previously they had fished frequently in the river and often consumed large quantities and varieties of fish (mullet, brim, barramundi, jewfish, and catfish), turtles and their eggs, mussels, crocodiles and eggs. The advice to limit their consumption was confusing in light of their understanding of PFAS as something like an infection meaning they thought that fish were either contaminated or not, *“If we eat the fish that’s infected, do you think that we’ll get infected too?”* Some asked if by examining the fish they could tell if it *“had this PFAS”*. They were also unaware that some fish seemed to retain lower levels of PFAS in their tissues than others (i.e. barramundi compared to mullet) and were therefore safer to eat. They wanted information about the safety of other river foods such as eggs, shellfish and crocodiles. Furthermore, they were aware that aquamarine life may well move up or down stream and in or out of affected areas. In addition, some participants said they used river water to make medicine with native plants. They also sought information about the effect of PFAS on bush tucker, bush meat and local plants that would have been in contact with river or bore water. They sometimes ate organ meat from local animals and were concerned that these

types of meats were more contaminated than muscle meat. Participants were also unclear about whether their tap water was safe to drink.

Financial and other Concerns

Most Aboriginal focus group discussion participants did not plan to move elsewhere because of PFAS—as one person said, *“This is our home”*. They were unsure about whether their land had been contaminated during floods in 1998 and 2006, and whether it had been tested for PFAS. They had a strong attachment to, and concern for, their country with one person observing: *“They damaged the country, yeah, they poisoned the river”*. The river was central to many of their activities and recreation with a person commenting that: *“the river is our life”*. Someone wondered why *“they say that you can go swimming and that, but don’t drink the water”*. Nevertheless, people were uncertain about the safety of swimming in the river particularly for children, with concerns such as whether it was safe to open their eyes under water.

There were financial implications from restricted access to river foods. Although we were unable to provide a clear estimation, participants said that they spent more of their income than previously, or a *“lot of money”*, on supermarket food to replace foods such as fish and game, since they had been told they should eat these only in limited quantities. Many also bought bottled water. Participants also reported that the bush tucker bought in the shops *“like kangaroo, crocodile, whatever doesn’t taste the same like the bush one”*, because *“it comes from different parts of Australia”*. While some people now bought fish, others said they had replaced game and fish with bought red meat, suggesting that PFAS may be contributing to a transition away from more traditional diets.

Information received about PFAS

Members of the Aboriginal communities said that because they did not feel comfortable attending community information sessions run by the Departments of Defence and Health, at Knotts Crossing Resort and in a shopfront at the local mall in the centre of Katherine, they had not received the information disseminated in these settings. Overall, they did not appear to have the same level of detailed and specific knowledge that many general community members had obtained. Some members of the Aboriginal groups remembered receiving information about PFAS from either one or two women who were perhaps from government although they were unclear which level of government. Others mentioned that they heard about it from the media or from other people. They were upset that the dangers of PFAS had been known about long before they were informed. They asked:

But why we weren't told back then, you know, in the '80s, we weren't told. And we had, our old people were still alive, and they didn't speak and tell our Elders while they were still alive.

This statement suggests that they considered that Elders were best able to respond to a problem that affected the health of country. Another person added “*Yeah, they're only just telling us, I think last year we got told about this*”. One person said that the government is “*not being fair.*” However, they thought that they had received information about PFAS at the same time as the rest of the Katherine community.

4.5. Ways forward

It was unsurprising given the diversity of views expressed in the focus groups that participants expressed a variety of aspirations for the future. Many participants who said they felt stuck were worried about PFAS health effects. Participants reported that they felt high levels of anxiety and stress because of being unable to move from their current location, and they felt as though their lives were on hold in other ways. They wanted to extricate themselves from their connection to contaminated land and be able to make plans to move on but they could not afford to because of the drop in property values.

Other people felt that they had everything that they had wanted where they currently lived, but because of the potential health risks, they could not make the most of the land they live on for financial gain or enjoy the lifestyle they had planned for:

My main concern is the, the long term health of the people who are well above the average PFAS content in their blood. And the second main concern is the mental health of the people ... that have been subjected to extreme pressure. Not only of the blood tests, but also of their property values and their lifestyle.

These people wanted the health risk removed so that they could continue with the life that they had anticipated. For example, one resident said:

I want them to decontaminate my property, to make it liveable. I have sheep and they are contaminated. So, yeah, my bores are contaminated, we are contaminated.

Some participants took a similar view but argued that if they could have certainty or proof about the health effects of PFAS they would be able to act accordingly. They hoped that high quality research into the problem would provide greater certainty. More immediately, participants wanted greater transparency in government's response to PFAS and clearer information. They

wanted to feel as though government agencies were listening to them and treating them with respect.

Participants in the Katherine Focus Groups were more likely than others to say that they did not want to move. They expressed a strong connection to the place with one person observing that:

I've loved living in Katherine you know. This block of land has been my home, it's where I brought up my kids, its everything to me and yet at the same time it's a contaminated piece of land and you're holding these two things in your hand, and the confusion of it, these two opposing truths, it drives you nuts.

Part of this attachment was the lifestyle offered by the Katherine River that was widely used for recreational activities. Members of the general community resented that they were advised not to fish or swim in the river. Signs posted along the banks advising this were near some Aboriginal communities but not near the river close to the main parts of town. They were also concerned that the town pool had been closed down temporarily, although it had since been re-opened. They repeated and reinforced the accounts we heard in the Aboriginal communities of the impact of contamination of country and on traditional hunting and food gathering areas.

5. Discussion

The primary aim of this focus group study was to gather a range of social and health-related experiences and perceptions from current residents and workers exposed to PFAS in the three communities of Oakey, Williamtown and Katherine. A total of 15 focus group discussions were held with 180 participants. A number of major themes emerged from the focus group discussions.

Community perceptions of health and other risks associated with exposure to PFAS was similar across all three study sites and for Aboriginal and non-Aboriginal communities. Specifically, communities were concerned about the health effects of exposure to PFAS, particularly on their children. Parents expressed feelings of “*guilt*” at having exposed their children to a toxic chemical, while they had thought they were giving them a wholesome upbringing. Commonly mentioned health concerns attributed to exposure to PFAS included; the presence of unusual cancers in their communities, ‘cancer clusters’ in the Investigation Areas, thyroid problems, unexplained deaths in the community and concern with respect to PFAS having the potential to aggravate existing health conditions. According to participants the plethora of contradictory evidence available through the internet caused confusion and stress as people attempted to navigate the available information to inform themselves about the potential risks associated with exposure.

Participants in all communities discussed the Voluntary Blood Testing Program. They reported that high levels of PFAS in blood tests contributed to increased anxiety in individuals and among parents of children with high blood levels. Many experienced a high level of confusion when attempting to interpret their blood test results and take decisions on what action was required. This suggests that there may be detrimental mental health effects associated with blood testing for an environmental contaminant where there is no treatment on offer.

Throughout the focus group discussions it appeared that the contamination of the environment with the PFAS chemicals, and the subsequent prolonged and complex response from authorities, may have had a pronounced psychological impact on members of the community. Participants observed that they experienced substantial stress and anxiety related to the duration of the PFAS contamination, delay in notification, perceived lack of transparency and poor communication of risk, and uncertainty of potential health effects.

Participants’ perceptions that the PFAS contamination and the associated disruption and uncertainty has contributed to physical and mental health effects will inform the development of a questionnaire for a future cross-sectional survey of residents and can be measured through the use of standardised instruments.

Some members of the Aboriginal, as well as, the general community in Katherine perceived that not enough had been done by relevant government agencies to engage Aboriginal communities,

or to consider and take account of their unique dietary and cultural practices in risk assessments and risk communication. Consultation and information meetings had been held in locations where Aboriginal people did not feel comfortable attending. Aboriginal people's understanding of PFAS being limited compared to general residents due to what they saw as poor engagement at the community level. They were particularly concerned with the potential impact of PFAS with respect to their traditional practices tied to the river such as hunting, eating bush foods and fishing. Better engagement with Aboriginal communities, through community visits, among other activities, is needed to improve their knowledge and understanding of the PFAS contamination and what this means for them and their relationship with country.

Contributing to participants' reported feelings of psychological distress was the uncertainty they experienced in relation to their futures. The financial impact that the contamination had on individuals living in affected communities was discussed in all focus group discussions. The devaluation of land and inability to sell contaminated properties led to the loss of financial security and the loss of control over their financial futures. Participants commonly reported feeling "*stuck*" as their plans for retirement, travel, holidays, financial security and a legacy to leave their children were put on hold. The financial problems associated with PFAS contamination was probably the most immediate issue on which participants sought guidance and support.

Food producers are particularly affected by the environmental contamination in affected communities. They have been instructed not to eat their own produce but are faced with the tension of still being able to sell contaminated produce in the market place. Some producers made the decision to remove their products from market, at great financial cost. Others struggle with what they perceive as an ethical dilemma of selling contaminated food that they have been instructed not to eat themselves, and being no longer able to maintain the self-sustainable lifestyle they had set up for themselves and their families.

The environmental contamination has also had a detrimental impact on community cohesion and led to communities feeling stigmatised. High levels of distrust by community members of all levels of government, government officials and in some cases other community members was expressed. This distrust has coloured community perspectives of risk communication. The health and environmental complexities of PFAS exemplify a 'wicked problem' with interactive dynamic elements that make it challenging for experts and community members alike to explain and understand. An additional challenge for community members is the pervasiveness of the impact of PFAS in their everyday lives leading them to express a desire for clarity and certainty. Some participants sought to simplify their difficulties by trying to identify individual components that could lead to easy, quick solutions.

The focus groups attracted a range of community members. The discussions provided an appropriate forum in which participants felt free to express a range of opinions about the ways

in which PFAS contamination has impacted on them; they were often outspoken and quite critical. Some said this was the first time they had the opportunity to talk about PFAS and for their opinions and concerns to be heard.

PFAS is an example of a “man-made, slowly-evolving environmental disaster” [21] because it is difficult to detect, it involves human casualty, has a slow evolution and creates existential uncertainty. Such environmental contamination events are complex and uneasily span the scientific world of risk assessment and that of lay expertise and lived experience. [22] They “often are characterized by ambiguity and conflict regarding their nature and impact, as well as about criteria defining ‘victims’ and their needs”. [21] The uncertainty about risk, mistrust and confusion appears to be a common community response to these types of events. This current study, along with several others on asbestos mining at Wittenoom, coal mining in the Hunter Valley, and community perceptions of environmental studies [23-25] may contribute to a better understanding of people’s experiences and lead to improved responses in terms of risk communication. This study highlights the vital importance of transparent, clear and empathetic communication. [23-25] It also highlights the importance of engaging communities early and providing them with an opportunity to have their voices heard in a neutral environment. It is hoped that the results of these focus group discussions will serve to inform risk communication strategies for communities affected by environmental contamination in the future with a focus on reducing suffering and unnecessary anxiety.

The focus group discussions have informed the development of the questionnaire for the cross-sectional study. The cross-sectional study will include questions on psychological stress, perceptions of stigma, coping strategies, access to mental health services, and adherence to advice to reduce PFAS exposure.

5.1. Limitations of the study

The process of contacting and recruiting participants was not designed to select a random group of participants. Those who agreed to participate in the study were ultimately self-selected. The groups were not expected to be generalisable to the wider community, as is typical for qualitative research design. It was also difficult to obtain complete high quality audio-recording of the Aboriginal focus groups due to the outdoor setting and the presence of children.

6. Conclusion

In conclusion, both the health and social effects of PFAS contamination were of significant concern for residents living in these communities. The experiences of communities have been coloured by ongoing uncertainty which has fuelled mistrust and further compounded the psychological distress. Participants sought greater transparency and clarity regarding their future.

7. Acknowledgements

The research 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 or working in a PFAS contaminated area.

The PFAS Health Study is funded by the Department of Health.

8. References

1. Kissa E: **Fluorinated surfactants and repellents**, Second edn. New York: CRC Press; 2001.
2. Smart BE: **Characteristics of C-F systems**. In: *Organofluorine Chemistry: Principles and commercial applications*. edn. Edited by Banks R, Smart B, Tatlow J. Boston, MA: Springer; 1994: 57-88.
3. Buck RC, Franklin J, Berger U, Conder JM, Cousins IT, de Voogt P, Jensen AA, Kannan K, Mabury SA, van Leeuwen SP: **Perfluoroalkyl and polyfluoroalkyl substances in the environment: Terminology, classification, and origins**. *Integr Environ Assess Manag* 2011, **7**(4):513-541.
4. Kannan K, Tao L, Sinclair E, Pastva SD, Jude DJ, Giesy JP: **Perfluorinated compounds in aquatic organisms at various trophic levels in a Great Lakes food chain**. *Arch Environ Contam Toxicol* 2005, **48**(4):559-566.
5. Perez F, Nadal M, Navarro-Ortega A, Fabrega F, Domingo JL, Barcelo D, Farre M: **Accumulation of perfluoroalkyl substances in human tissues**. *Environ Int* 2013, **59**:354-362.
6. Olsen GW, Burriss JM, Ehresman DJ, Froehlich JW, Seacat AM, Butenhoff JL, Zobel LR: **Half-life of serum elimination of perfluorooctanesulfonate, perfluorohexanesulfonate, and perfluorooctanoate in retired fluorochemical production workers**. *Environ Health Perspect* 2007, **115**(9):1298-1305.
7. US EPA: **Emerging contaminants – Perfluorooctane sulfonate (PFOS) and perfluorooctanoic acid (PFOA)** In. Washington, DC.; 2014.
8. Kirk M, Smurthwaite K, Bräunig J, Trevenar S, D'Este C, Lucas R, Lal A, Korda R, Clements A, Mueller J *et al*: **The PFAS Health Study: Systematic literature review**. In. Canberra: The Australian National University; 2018.
9. HEPA: **PFAS national environment management plan**. In. Canberra, ACT; 2018.
10. Braunig J, Baduel C, Heffernan A, Rotander A, Donaldson E, Mueller JF: **Fate and redistribution of perfluoroalkyl acids through AFFF-impacted groundwater**. *Sci Total Environ* 2017, **596-597**:360-368.
11. AECOM Services Pty Ltd: **Preliminary ecological risk assessment December 2016 - RAAF Base Williamstown Stage 2B environmental investigation**. In. Edited by Department of Defence; 2016: 1.
12. AECOM Services Pty Ltd: **Stage 2C environmental investigation - Preliminary ecological risk assessment, Army Aviation Centre Oakey**. In. Edited by Department of Defence; 2016: 2.
13. Coffey: **Detailed Site Investigation Report RAAF Base Tindal**. In. Edited by Department of Defence. Victoria, Australia; 2018: 164.
14. **Impacts on the affected community** [https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Foreign_Affairs_Defence_and_Trade/ADF_facilities/Report%20part%20A/c03]
15. Creswell JW: **Research design: Qualitative, quantitative, and mixed methods approaches**, 2nd edition edn. Thousand Oaks, California: Sage; 2003.
16. Krueger RA: **Focus groups : a practical guide for applied research**, 2nd Edition edn. Thousand Oaks, California: Sage; 1994.
17. Wong LP: **Focus group discussion: a tool for health and medical research**. *Singapore medical journal* 2008, **49**(3):256-260; quiz 261.
18. Braun V, Clarke V: **Using thematic analysis in psychology**. *Qualitative Research in Psychology* 2006, **3**(2):77-101.
19. Ayre M, Mackenzie J: **“Unwritten, unsaid, just known”: the role of Indigenous knowledge(s) in water planning in Australia**. *Local Environment* 2013, **18**(7):753-768.
20. Four Corners: **Contamination**. In.: ABC, Australia; 2017: 46m 52s.

21. Cline RJ, Orom H, Child JT, Hernandez T, Black B: **Social support functions during a slowly-evolving environmental disaster: The case of amphibole asbestos exposure in Libby, Montana.** *Health Commun* 2015, **30**(11):1135-1148.
22. Clapp JT, Roberts JA, Dahlberg B, Berry LS, Jacobs LM, Emmett EA, Barg FK: **Realities of environmental toxicity and their ramifications for community engagement.** *Soc Sci Med* 2016, **170**:143-151.
23. Cappelletto F, Merler E: **Perceptions of health hazards in the narratives of Italian migrant workers at an Australian asbestos mine (1943–1966).** *Social Science & Medicine* 2003, **56**(5):1047-1059.
24. Scammell MK, Senier L, Darrah-Okike J, Brown P, Santos S: **Tangible evidence, trust and power: public perceptions of community environmental health studies.** *Soc Sci Med* 2009, **68**(1):143-153.
25. Higginbotham N, Freeman S, Connor L, Albrecht G: **Environmental injustice and air pollution in coal affected communities, Hunter Valley, Australia.** *Health Place* 2010, **16**(2):259-266.

9. Appendices

9.1. Appendix 1 Focus group discussions: flyer for Williamstown and Oakey

The PFAS Health Study: Focus Group Discussions

Have your say about living in a PFAS affected area.

This is an opportunity to share your views and contribute to future research and policy.

Please come along and join focus group discussion to be held in your community. We are keen to include participants who have a range of experiences with, and views of, PFAS health risks.

Information about focus group discussions:

We will hold five focus group discussions in your community. This is part of a larger study investigating the health risks of living in a PFAS Investigation Area. The discussions are likely to take between one and two hours. A small token of our appreciation (\$50 EFTPOS voucher) will be offered on completion of the discussion.

When: The focus group discussions will be within the next few weeks in your community.

Please ring or email **Ms Susan Trevenar on 02 6125 6079 or pfas.health.study@anu.edu.au**

She will inform you of the times and venues and send you an information sheet.

This is an opportunity for you to discuss issues related to living in a PFAS affected area and to shape the direction of the next phase of our research (the survey). We sincerely hope that you will join us.

Cathy Banwell and the research team.

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

Contact name	Telephone	Email
Ms Susan Trevenar	T: (02) 6125 6079	Susan.Trevenar@anu.edu.au
Dr Tambri Housen	T: (02) 6125 0460	Tambri.Housen@anu.edu.au
Dr Cathy Banwell	T: (02) 6125 0016	Cathy.Banwell@anu.edu.au

9.2. Appendix 2 Focus group discussions: flyer for Katherine

The PFAS Health Study: Focus Groups Study

Have your say about living in a PFAS affected area.

Please come along and join focus group discussion to be held in your community. We are keen to include people who have a range of experiences with, and views of, PFAS health risks.

Information about focus group discussions:

We will hold five focus group discussions in your community. This is part of a larger study investigating the health risks of living in a PFAS Investigation Area. The discussions are likely to take between one and two hours. A small token of our appreciation (\$50 EFTPOS voucher) will be offered on completion of the discussion.

The focus group discussions will be within the next few weeks in your community.

Please contact Ms Liz Walker on 02 6125 7840 or email pfas.health.study@anu.edu.au to receive information on focus group times and location.

This is an opportunity for you to discuss your experience living or working in a PFAS Investigation Area and to help guide the next phase of our research (the survey).

We sincerely hope that you will join us.

Cathy Banwell and the research team.

Contact

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

Ms Liz Walker	Dr Tambri Housen	Dr Cathy Banwell
T 02 6125 7840	T 02 6125 0460	T 02 6125 0016
E liz.walker@anu.edu.au	E tambri.housen@anu.edu.au	E cathy.banwell@anu.edu.au
ANU HREC Protocol 2018/151 NTDoH and MSHR HREC Protocol 2018-3121 DDVA HREC Protocol 055-18		

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Health and Medicine

9.3. Appendix 3 Focus group discussions: participation information sheet for Williamstown and Oakey

PFAS Health Study

Participant Information Sheet for Focus Group Discussions

Project Title:

The PFAS Health Study: A Focus Group Study

The Australian Government Department of Health is funding the study.

Researcher Team	Contact Details
Professor Martyn Kirk	E: martyn.kirk@anu.edu.au
Associate-Professor Cathy Banwell	E: cathy.banwell@anu.edu.au
Dr Tambri Housen	E: tambri.housen@anu.edu.au
Ms Susan Trevenar	E: susan.trevenar@anu.edu.au
Ms Kayla Smurthwaite	E: kayla.smurthwaite@anu.edu.au

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is entirely voluntary; there is no obligation to take part in the study, and if you choose not to participate there will be no detriment to your career or future health care.

If you decide you want to take part in the research project, you will be asked to sign the consent section.

You will be given a copy of this Participant Information and Consent Form to keep.

Project Title: The PFAS Health Study: A Focus Group Study

This study is being conducted by researchers from the National Centre for Epidemiology and Population Health in the Research School of Population Health at The Australian National University. Professor Martyn Kirk is the primary investigator of the PFAS Health Study. Associate-Professor Cathy Banwell will lead the focus group discussion study with Dr Tambri Housen, Ms Sue Trevenar, and Ms Kayla Smurthwaite.

General Outline of the Study:

The focus group discussion study is part of a broader study concerning the health and related risks of living in a PFAS affected area. The focus groups are an opportunity for residents to express concerns about their health and the social impacts of living in the area and to shape the direction of the broader study. Anyone living in a PFAS affected area is invited to participate in a discussion group. We expect to hold five group discussions in your area in public locations, such as town halls or community centres. The groups will consist of up to 12 people who will be invited to contribute to a general discussion. It is likely that the discussion will last between one and two hours.

The Australian Government has commissioned this study. No identifiable personal information will be provided to the Australian Government in the course of this study.

Participant Involvement:

Participation in the study is entirely voluntary; there is no obligation to take part in the study, and if you choose not to participate there will be no detriment to your career or future health care. 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.

We are asking all focus group attendees for their consent to collect their discussion via audio-recording so we can accurately record everything everyone tells us. As people talk quickly it is difficult to write everything down and we do not want to miss anything anyone tells us. Your contribution to the discussion will be confidential beyond the group in which you participated. Your name will not be recorded anywhere on the recorder and if it is mentioned it will not be transcribed. If anyone does not wish to be recorded, the person may withdraw from the discussion.

During the focus group discussions, participants will be asked to discuss the following topics related to living in a PFAS affected area:

- Health concerns
- Risk perception and management related to potential PFAS exposure
- Stress related to financial concerns due to living in the area
- Social issues
- Practical issues – where to live, moving, schooling, work, replacement of belongings, rebuilding house - time costs, other barriers
- The response to the PFAS situation by government, media, other
- And other issues that participants raise

Participants will be asked to fill out a short form collecting demographic information. With consent, the focus group discussions will be recorded. The discussions will last about an hour and the total time will be about two hours.

After the study the discussion material will be transcribed, 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.

Risks of Participating:

These discussions may raise some feelings of distress as they concern potential threats to health and well-being. The Australian Government has funded dedicated mental health and counselling services to provide support during this time. If you should become distressed, free counselling services are available and can be accessed through your GP, the local Primary Health Network or through Support Now. If you are a currently serving member of the ADF, you can access services through your usual Defence Health Centre.

A small token of our appreciation, a \$50 EFTPOS voucher, will be offered on completion of the discussion.

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 design a survey to be conducted in PFAS affected communities in 2018 and will contribute to the development of policy related to PFAS contamination. These will be used to inform the development of a survey 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 Australian Government Department of Health 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.

Confidentiality:

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 privacy is important to us. The identity of participants will not be collected except as a signature on the consent forms that 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 PFAS litigations. However, participants in focus groups will be anonymous, in the situation a participant's name is mentioned during interview, it will not be

transcribed. Your participation will not affect your position at work, or your use of any local or state 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. It will not be used in future studies.

Privacy Notice:

The ANU Privacy Policy is located https://policies.anu.edu.au/ppl/document/ANUP_010007 and contains information about how you can

- Have access or seek correction to your personal information; and
- Complain about a breach of an Australian Privacy Principle (APP) by ANU and how ANU will handle the complaint.

Questions:

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

Dr Cathy Banwell

Dr Tambri Housen

T: 02 6125 0016

T: 02 6125 0460

Cathy.Banwell@anu.edu.au Tambri.Housen@anu.edu.au

Concerns or complaints:

The Australian National University Human Research Ethics Committee and the DDVA Human Research Ethics Committee (ANU HREC protocol 2017/816 and DDVA HREC protocol 024-17). If you have concerns regarding the way this research was conducted please not hesitate to contact the researchers or the following:

Executive Officer DDVA HREC CP3-6-037 PO Box 7911 Canberra BC ACT 2610 T: (02) 62663807 E: ddva.hrec@defence.gov.au	Human Research Ethics Officer The Australian National University Office of Research Integrity Chancelry 10B, T: (02) 6125 3427 E: Human.Ethics.Officer@anu.edu.au
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No member of the research team will receive a personal financial benefit from involvement in this research project (other than their ordinary wages).

9.4. Appendix 4 Focus group discussions: participation information sheet for Katherine

The PFAS Health Study

This Is For You To Keep

Participant Information Sheet for Focus Group Discussions

Project Title: The PFAS Health Study: A Focus Groups Study, Katherine, NT

The Australian Government Department of Health is funding the study.

Researcher Team	Contact Details
Professor Martyn Kirk	E: martyn.kirk@anu.edu.au
Associate-Professor Cathy Banwell	E: cathy.banwell@anu.edu.au
Dr Tambri Housen	E: tambri.housen@anu.edu.au
Professor Adrian Miller	E: adrian.miller@cdu.edu.au
Dr Katherine Todd	E: katherine.todd@anu.edu.au
Ms Susan Trevenar	E: susan.trevenar@anu.edu.au
Ms Kayla Smurthwaite	E: kayla.smurthwaite@anu.edu.au
Ms Liz Walker	E: liz.walker@anu.edu.au

This Participant Information Sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is entirely voluntary; there is no obligation to take part in the study, and if you choose not to participate there will be no negative consequences.

If you decide you want to take part in the research project, you will be asked to sign the consent form.

You will be given a copy of this Participant Information and Consent Form to keep.

Project Title: The PFAS Health Study: A Focus Groups Study, Katherine, NT

This study is being conducted by researchers from the National Centre for Epidemiology and Population Health in the Research School of Population Health at The Australian National University. Professor Martyn Kirk is the primary investigator of the PFAS Health Study. Professor Adrian Miller will provide advice on working with Aboriginal communities. Associate-Professor Cathy Banwell will lead the focus group discussion study with support from Dr Tambri Housen, Dr Katherine Todd, Ms Sue Trevenar, Ms Kayla Smurthwaite, and Ms Liz Walker.

General Outline of the Study:

The focus group discussion study is part of a broader study concerning the health and related risks of living in a PFAS Investigation Area. The focus groups are an opportunity for residents to express concerns about their health and the social impacts of living in the area and to shape the direction of the broader study. Anyone living in a PFAS Investigation Area is invited to participate in a discussion group. We expect to hold seven group discussions in your area in public locations, such as town halls or community centres. The groups will consist of up to 12 people who will be invited to contribute to a general discussion. It is likely that the discussion will last between one and two hours.

The Australian Government has commissioned this study. No identifiable personal information will be provided to the Australian Government in the course of this study.

Participant Involvement:

Participation in the study is entirely voluntary; there is no obligation to take part in the study, and if you choose not to participate there will be no detriment to your career or future health care. 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.

We are asking all focus group attendees for their consent to collect their discussion via audio-recording so we can accurately record everything everyone tells us. As people talk quickly it is difficult to write everything down and we do not want to miss anything anyone tells us. Your contribution to the discussion will be confidential beyond the group in which you participated. Your name will not be recorded anywhere on the recorder and if it is mentioned it will not be transcribed. If anyone does not wish to be recorded, the person may withdraw from the discussion.

During the focus group discussions, participants will be asked to discuss the following topics related to living in a PFAS Investigation Area:

- Health concerns
- Risk perception and management related to potential PFAS exposure
- Stress related to financial concerns due to living in the area
- Social issues
- Practical issues – where to live, moving, schooling, work, replacement of belongings, rebuilding house - time costs, other barriers
- Changes in connection to local land and water sources – changes in farming and fishing activities, use of local produce, Aboriginal connection to land
- The response to the PFAS situation by government, media, other
- And other issues that participants raise

Participants will be asked to fill out a short form collecting demographic information. With consent, the focus group discussions will be recorded. The discussions will last about an hour and the total time will be about two hours.

After the study the discussion material will be transcribed, 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.

Risks of Participating:

These discussions may raise some feelings of distress as they concern potential threats to health and well-being. The Australian Government has funded dedicated mental health and counselling services to provide support during this time. If you should become distressed, free counselling services are available and can be accessed through your local GP, the local primary health network or through Support Now. If you are a currently serving member of the ADF, you can access services through your usual Defence Health Centre.

Due to the content being discussed in the focus groups there is the potential for the transcripts to be subpoenaed as part of legal actions related to PFAS litigations. As we ask all participants to use a pseudonym for the discussions, real names will not appear on the transcripts. Additionally, the transcripts themselves will not identify specific participants, but will note whether the speaker was a facilitator or a participant only.

A small token of our appreciation, a Woolworths Essential gift card, will be offered the instructions for participants and before the discussion begins.

The focus group discussions provide residents with an opportunity to express concerns and describe experiences related to their health and their social circumstances. The results from the discussion groups will be combined with the results from similar discussion held in Williamstown and Oahey in January and February 2018. The findings from the focus groups will also be used to design a survey to be conducted in PFAS affected communities in 2018 and will contribute to the development of policy related to PFAS contamination. These will be used to inform the development of a survey 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 Australian Government Department of Health 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.

Confidentiality:

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 privacy is important to us. The identity of participants will not be collected except as a signature on the consent forms that 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 PFAS litigations. However, participants in focus groups will be anonymous, in the situation a participant's name is mentioned during interview, it will not be transcribed. Your participation will not affect your position at work, or your use of any local or state 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. Your personal contact information will not be used in future studies.

Privacy Notice:

The ANU Privacy Policy can be found at https://policies.anu.edu.au/ppl/document/ANUP_010007 and contains information about how you can

- Have access or seek correction to your personal information; and
- Complain about a breach of an Australian Privacy Principle (APP) by ANU and how ANU will handle the complaint.

Questions:

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

Dr Cathy Banwell

T: 6125 0016

Cathy.Banwell@anu.edu.au

Dr Tambri Housen

(02) 6125 0460

Tambri.Housen@anu.edu.au

Concerns or complaints:

The Australian National University Human Research Ethics Committee, Northern Territory Department of Health and Menzies School of Health Research Human Research Ethics Committee, and the DDVA Human Research Ethics Committee (ANU HREC protocol 2018/151, NTDoH and MSHR protocol 2018-3121, and DDVA HREC protocol 055-18). If you have concerns regarding the way this research was conducted please do not hesitate to contact the researchers or the following:

<p>Human Research Ethics Officer The Australian National University T: (02) 6125 3427 E: Human.Ethics.Officer@anu.edu.au</p>	<p>Ethics Administration Human Research Ethics Committee of the NT Department of Health and Menzies School of Health Research T: +08 8946 8600 E: ethics@menzies.edu.au</p>	<p>Executive Officer DDVA HREC CP3-6-037 PO Box 7911 Canberra BC ACT 2610 T: (02) 62663807 E: ddva.hrec@defence.gov.au</p>
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No member of the research team will receive a personal financial benefit from involvement in this research project (other than their ordinary wages).

Participant Written Consent Form

Title: The PFAS Health Study: Focus Group Discussions

I, give my consent to participate in the project mentioned above on the following basis:

I have had explained to me the aims of this research project, how it will be conducted and my role in it.

I understand the risks involved as described in the Participant Information Sheet.

I am cooperating in this project on condition that:

- the information I provide will be kept confidential
- the information will be used only for this project. The research results will be made available to me at my request and any published reports of this study will preserve my anonymity
- I have been given a copy of the 'Departments of Defence and Veterans' Affairs Human Research Ethics Committee (DDVA HREC) Guidelines for Volunteers'.

I understand that:

- there is no obligation to take part in this study
- I am free to withdraw at any time

I have been given a copy of the participant information sheet and consent form, signed by me and by the principal investigator Martyn Kirk to keep.

_____ Signature of participant

_____ Name in full

_____ Date

_____ Signature of Principal Investigator

_____ Name in full

_____ Date

Concerns or complaints to:

The Australian National University Human Research Ethics Committee and the DDVA Human Research Ethics Committee (ANU HREC protocol 2017/816 and DDVA HREC protocol 024-17). If you have concerns regarding the way this research was conducted please do not hesitate to contact the researchers or the following:

Executive Officer
DDVA HREC
CP3-6-037
PO Box 7911
Canberra BC ACT 2610
T: (02) 62663807
E: ddva.hrec@defence.gov.au

Human Research Ethics Officer
The Australian National University
Office of Research Integrity
Chancelry 10B,
T: (02) 6125 3427
E: Human.Ethics.Officer@anu.edu.au

9.6. Appendix 6 Focus group discussions: consent form for Katherine

Consent Form

Title: The PFAS Health Study: Focus Groups Study, Katherine, NT

I, give my consent to participate in the project mentioned above on the following basis:

I have had explained to me the aims of this research project, how it will be conducted and my role in it.

I understand the risks involved as described in the Participant Information Sheet.

I am cooperating in this project on condition that:

- the information I provide will be kept confidential
- the information will be used for the Per and poly-fluoroalkyl substances (PFAS): a focus group study, including combining results with the Williamtown and Oakey focus groups results. Themes emerging from the focus groups discussions will be used to develop questions for the future PFAS Health Study cross-sectional study.
- the research results will be made available to me at my request and any published reports of this study will preserve my anonymity
- I have been given a copy of the 'Departments of Defence and Veterans' Affairs Human Research Ethics Committee (DDVA HREC) Guidelines for Volunteers'.

I understand that:

- there is no obligation to take part in this study
- I am free to withdraw at any time
- the focus groups discussion is being audio recorded
- the transcript from the focus group discussion may be subpoenaed as part of legal actions related to PFAS litigations, but that the transcripts will not identify me in any way.

I have been given a copy of the participant information sheet and consent form, signed by me and by the principal investigator Cathy Banwell to keep.

_____ Signature of participant

_____ Name in full

_____ Date

_____ Signature of witness

_____ Name in full

_____ Date

_____ Signature of interpreter

_____ Name in full

_____ Date

_____ Signature of Principal Investigator

_____ Associate Professor Cathy Banwell

_____ Date

Concerns or complaints to:

The Australian National University Human Research Ethics Committee, Northern Territory Department of Health and Menzies School of Health Research Human Research Ethics Committee, and the DDVA Human Research Ethics Committee (ANU HREC protocol 2018/151, NTDoH and MSHR protocol 2018-3121, and DDVA HREC protocol 055-18). If you have concerns regarding the way this research was conducted please do not hesitate to contact the researchers or the following:

Human Research Ethics Officer

The Australian National University
Office of Research Integrity

Chancelry 10B,

T: (02) 6125 3427

E: Human.Ethics.Officer@anu.edu.au

Ethics Administration

Human Research Ethics
Committee of the NT
Department of Health and
Menzies School of Health
Research

T: +08 8946 8600

E: ethics@menzies.edu.au

Executive Officer

DDVA HREC

CP3-6-037

PO Box 7911

Canberra BC ACT 2610

T: (02) 62663807

E: ddva.hrec@defence.gov.au

9.7. Appendix 7 Focus group discussions: questionnaire for Williamstown and Oakey

PFAS Health Study
Questionnaire for Focus Group participants

1. Sex

Male Female Other

2. Age

25-29 30-34 35-39 40-44
 45-49 50-54 55-59 60+

3. What is your highest completed level of education?

Incomplete secondary Completed secondary
 Certificate or diploma Bachelor degree or above

4. Partnership status

Single (Never Married) Single (Separated/Divorced/ Widowed)
 Married Cohabiting/De Facto

5. What is your employment status?

Not employed Retired Employed (casual))
 Employed (part-time) Employed (full-time)

6. What is your current job?

7. Do you have any children living with you?

Yes No

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

9. Did you own or rent your home?

Own Rent

10. Where do you live?

In town Outskirts of town Rural property

11. How long have you lived in this area? _____Years

9.8. Appendix 8 Focus group discussions: questionnaire for Katherine

PFAS Health Study

Questionnaire for Focus Groups Study, Katherine, NT participants

1. Sex

Male Female Other

2. Age

18-24 25-29 30-34 35-39
 40-44 45-49 50-54 55-59 60+

3. Are you of Aboriginal or Torres Strait Islander origin?

No Yes, Aboriginal Yes, Torres Strait Islander
 Yes, both Aboriginal and Torres Strait Islander

4. What is your highest completed level of education?

Incomplete secondary Completed secondary
 Certificate or diploma Bachelor degree or above

5. Partnership status

Single (Never Married) Single (Separated/Divorced/ Widowed)
 Married Cohabiting/De Facto

6. What is your employment status?

Not employed Retired Employed (casual))
 Employed (part-time) Employed (full-time)

7. What is your current job?

Please turn over

8. Do you have any children living with you?

Yes No

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

10. Did you own or rent your home?

Own Rent

11. Where do you live?

In town Outskirts of town Rural property

12. How long have you lived in this area? _____ Years