

# The PFAS Health Study

## Focus Groups Research Protocol

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For the Commonwealth Department of Health



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## 1. Project summary

The Per and Poly-Fluoroalkyl Substances (PFAS) Health Study: Phase II will investigate the exposure to and potential health effects of PFAS in areas of known contamination in the communities of Williamstown in New South Wales (NSW) and Oakey in Queensland (Qld), Australia.

In particular, this study will concentrate on the main chemical components of the firefighting foams used on Defence facilities in the townships of Williamstown and Oakey, which are perfluorohexane sulfonic acid (PFHxS), perfluorooctanoic acid (PFOA) and perfluorooctane sulfonic acid (PFOS). The applied research study will build on the results of a systematic review of the health effects of these chemicals.

The primary aim of the focus group discussion study is to gather a range of social and health-related experiences and views from current residents and workers exposed to PFAS from the two communities of Williamstown and Oakey. The difficulties and concerns that residents may experience are health risks related to exposure and others partly due to the social context in which they live. The study population is residents of the townships of Williamstown, NSW and Oakey, Qld. These focus group discussions will provide residents with the opportunity to express their concerns about living in a PFAS exposed area.

The general and scientific communities, the Local Governments and the Australian Government will be better informed about the perspectives of residents which can inform future research and policy responses. The results of these focus group discussions will influence the nature of subsequent surveys and may influence development of government policy.

## 2. General information

### 2.1. Protocol title

The PFAS Health Study Focus Groups Research Protocols

### 2.2. Protocol date

Thursday November 30 2017

### 2.3. Project funding

The Australian Government Department of Health<sup>1</sup> has commissioned the Australian National University to undertake the PFAS Health Study.

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### 2.4. Investigators

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### 3. 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] They have a wide range of industrial uses, including in protective coatings on furniture and textiles and non-stick coatings on cookware, and as flame retardants in fire-fighting foams. [2] These chemicals are highly inert thermally, chemically and biologically. [3] PFAS are environmentally persistent and can last for decades in water and soil, and they have been shown to accumulate in the environment (both soil and aquatic systems) of contaminated areas. [2, 4]

Human exposure to PFAS occurs primarily through consumption of contaminated food and water, which results in higher PFAS levels in the blood than background levels found in the general community. [5, 6] Some long-chain PFAS are biochemically stable and accumulate in the human body. [7, 8] Once absorbed through digestion and gas-exchange pathways, PFAS bind to plasma protein and accumulate in the blood stream. [9] In a Taiwanese, longitudinal birth cohort, it was found that prenatal exposure to PFAS can occur through the placental transfer of maternal blood to the foetus in utero. [10] Additionally, infants may be exposed to PFAS through contaminated breastmilk, although concentrations are lower than in the mother's blood. [11]

A range of possible health outcomes of exposure to PFAS have been investigated in epidemiological studies, particularly studies involving workers manufacturing these compounds. Despite correlations between exposure and disease or biomarkers for other PFAS compounds, the findings from epidemiological and biological studies have been inconsistent and subject to debate, specifically in regards to the relevance of animal studies to human health outcomes.

#### 3.1. PFAS in Williamstown, NSW and Oakey, QLD

In recent years, the environments of areas in Williamstown in NSW and Oakey in Qld have been identified as being contaminated due to Defence Force firefighting activities on nearby Defence bases. Use of aqueous film forming foam (AFFF) containing PFOS and PFOA as the main component on the Royal Australian Airforce base in Williamstown and the Army Aviation Centre in Oakey has been associated with detection of increased PFAS levels in ground water, soil, and biota. [12, 13] Since the initial use of the firefighting foams in the late 1970s, members of these communities have been exposed to potentially concerning concentrations of PFAS through the contamination of the local environment. Manufacturers have largely phased out PFOS and PFOA from AFFF due to toxicological concerns and have switched to alternative chemicals with similar properties. These often have a different fluorination that makes them less persistent. In 2004 the Australian Defence Force began phasing out the use of AFFF concentrates that contain PFOS and PFOA as active ingredients. [14] However, due to their environmental persistence, PFAS from AFFF used decades earlier still remain in ground water, sediment and soil in the local areas.

### 3.2. The PFAS Health Study

The public health significance of exposure to PFAS is unclear. Risk assessments of contaminated areas have evaluated likely exposure, but have not been clear about the health risk due to lack of consistent evidence about health outcomes of exposure. To date, there have been no well-designed epidemiological studies examining health effects of these chemicals in Australia, as the affected communities are often small and the levels of exposure highly variable.

The Australian Government Department of Health has commissioned the Australian National University to undertake the PFAS Health Study. The PFAS Health Study has five main parts, over two phases. Phase I involved the development of a draft Research Protocol for Phase II of the study, as well as a systematic review of the literature on the health effects of human exposure to PFAS. Phase II of the study is comprised of parts 2–5 below:

1. A systematic review of the published literature on the health effects of PFAS.
2. A focus group study to determine the concerns of individuals living in the vicinity of Williamtown and Oakey have in relation to exposure to PFAS and their health.
3. A blood serum study to define the serum concentrations (mean and range) of PFAS in Williamtown and Oakey residents living in the Investigation Areas and to compare the levels to those of people residing in non-contaminated areas in the townships and surrounding areas.
4. 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 Williamtown and Oakey communities.
5. 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 Williamtown and Oakey, compared to those living outside the Investigation Areas and in the general Australian population.

This Protocol is for the Focus Group Study.

#### 4. Study goals and objectives

The primary aim of the focus group discussion study is to gather a range of social and health-related experiences and views from current residents and workers exposed to PFAS from the two communities of Williamstown and Oakey, particularly in the Investigation Areas as defined by the NSW Environmental Protection Agency (EPA) and the Department of Defence, respectively. The focus groups are designed to elicit experiences of people living in the communities.

The specific objectives of the focus group discussions are 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.

## 5. Study design

Focus group discussions are a valuable method for collecting qualitative data, as they enable discussion of public knowledge, and underlying attitudes and opinions. They are well suited to exploring a range of views on topics in the public domain although they are less appropriate for gathering information about highly personal and sensitive matters. Discussions may reveal concerns and issues that are often generated by the interaction within the group. As a consequence, focus group discussions are commonly used in health research and the development of social action programs often in conjunction with other research methods such as surveys.

A focus group study, such as this, is predicated on the understanding that health-related concerns are social in nature. The difficulties and concerns that residents may experience are health risks related to exposure and others partly due to the social context in which they live. For example, selling property, moving residence, relocating children and awareness of media-related information are all socially mediated interactions that may provoke feelings of stress, anxiety, or relief and have potential health risks.

## 6. Methodology

### 6.1. Study population

The study population is residents and workers of the Investigation Areas of Williamtown, NSW and Oakey, Qld. Residents living outside the areas of investigation, but within the townships will also be invited to participate as they will have concerns about their health and the impact the contamination is having on their lives. Previous residents will not be actively sought to participate in the focus groups, but will not be excluded if they want to participate.

### 6.2. Study procedure

#### Recruitment

There will be five focus groups held in Oakey and five held in Williamtown at different times of the day to ensure that people can attend. To ensure that there is a balance of people attending these sessions, the study team will ask people to register their attendance.

As these group discussions will focus on a community issue, participants will be invited to take part through a range of community-based groups and media outlets, including local radio and newspapers. This will include displaying posters in shops and community centres advertising focus group discussion dates and contact details for registration with the study team. We will consult with local 'experts', such as local general practitioners, government representatives and community health workers on the best ways to recruit participants in each location.

#### Participants

In total, between 8 and 10 focus groups will be recruited from the two towns. Focus groups are not expected to be representative and instead are used to gather an array of views on issues of community importance; in this case PFAS contamination. Ideally, a focus group consists of about 6-12 people although they may be larger.

We will aim to ensure that the groups will contain a mix of men and women with a range of interests (e.g. property owners, townspeople, farmers). In small communities, it is likely that some focus group participants may know each other. As the topic of the discussions is of considerable concern to the communities, we expect that people will be keen to attend. The venues selected for the meetings should be easily accessible for community members (e.g. local halls, community centres) and politically neutral. Each focus group discussion will be conducted by at least two experienced researchers; one to moderate and the other to observe, take notes and assist in other ways.

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

## Study conduct

The manner in which the focus groups discussions are conducted will be clearly explained to participants (face-to-face at the time and through information sheets, see Appendix 1) who will be required to give consent, see Appendix 2. The focus groups discussions will be conducted in a way that minimises concerns about privacy and confidentiality. They will be audio-recorded and participants will be asked to provide a pseudonym at the beginning of the discussion that will be recorded and used by participants during the discussions. Any identifying information about participants will be deleted before sending recordings to transcribers. All research staff and staff from the transcribing service will sign a Confidentiality Deed. A brief one page questionnaire will be distributed to participants to collect basic socio-demographic data, such as age, gender, marital status, area of residence (rural/urban), employment, number of children (see Appendix 3). These data can be used describe the composition of the groups, although it is not expected that group participants will be representative.

The audio-recordings will be professionally transcribed by a service previously used by the researchers. Experienced qualitative researchers will read the transcriptions closely several times before developing a coding manual. A specialised computer program will be used to assist in data management. Inductive and deductive codes, reflecting the questions asked and concepts that arise during the discussions will be used to build broader themes following the standard approach of thematic analysis.

Participants will be informed that they can withdraw while the discussion is taking place or choose not to answer any question that they perceive to be sensitive. Study investigators conducting the group discussions are trained and sensitive to potential issues. They will manage the group to avoid one person dominating the discussion and provide space for less forthright members to voice their opinions. If study participants become distressed discussing the impact of living in an affected area on their lives more broadly, they will be referred to free mental health and counselling services available through their GP, the local Primary Health Network or through Support Now.

Data will be stored on secure servers at the ANU for a minimum of five years following completion of the study.

## Study method

Following the conventions of focus group discussions a list of open-ended, broad questions (a topic guide and potential prompts) aimed at generating discussion will be 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 financial and other concerns—value of house replacement, costs of living elsewhere, resale value, sorrow at 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
- Perceptions of the response to the PFAS situation reported in the media
- Other issues

It is anticipated that group participants will provide varying responses to these open-ended discussion topics depending on their circumstances (e.g. whether they work in a contaminated area or reside in the area).

The key outcomes of the focus group study would be an understanding of the health (including social) concerns of residents and their perceptions of the risks of PFAS contamination.

## 7. Follow-up

There will be no follow-up of focus group participants. However, participants will be eligible to participate in the cross-sectional survey.

## 8. Data management, statistical analysis and quality assurance

Focus groups transcriptions will be read several times by experienced qualitative researchers who will then develop a coding manual using ATLAS.ti software to assist in this task and with data management. The codes, reflecting the questions asked and concepts that arise during the discussions, will be used to build broad themes, following a general thematic analysis approach.

The focus group data will be analysed for common themes following standard procedures and will not identify individuals. [15] The facilitators of the focus groups are qualitative researchers experienced in conducting focus group discussions. The audio files will be checked by the researchers to remove identifying information that people may supply during discussions (i.e. previous residence etc.). The focus group transcripts will be stored on a password protected server at the ANU and will only be accessible to study investigators involved in the data analysis. The data from each focus group will not be reported on separately.

## 9. Expected outcomes of the study

These focus group discussions will provide residents with the opportunity to express their concerns about living and/or working in a PFAS exposed area. Their participation will contribute to their concerns being addressed through the overall study. The general and scientific communities, the Local Governments and the Australian Government will be better informed about the perspectives of residents that can inform future research and policy responses. The results of these focus group discussions will influence the nature of subsequent surveys and may influence development of government policy. There will also be scientific benefit and benefit to the broader general community.

## 10. Dissemination of results and publication policy

The results from each component of the PFAS Health Study will be detailed in a report provided to the Commonwealth Department of Health. The study team will also prepare articles for publication in peer-reviewed journals. All reports and publications will acknowledge funding from the Department and input from the community and other experts. Authorship of peer reviewed articles will be determined in accordance with the Uniform Requirements for Manuscripts Submitted to Biomedical Journals produced and endorsed by the International Committee of Medical Journal Editors, specifically those considerations set out under heading IIA 'Ethical Considerations in the Conduct and Reporting of Research: Authorship and Contributorship'.

The results, which are a thematic analysis of community views expressed in the focus groups, will be summarised in a format suitable for lay-people and the report for each component of the study will be made available to community members via the study webpage. Additionally, after the acceptance of the report the study team will hold a community consultation in each of the two communities at which time the findings of the report will be presented, and the next stages of the study will be reported.

The first report, due in April 2018, will present the results of the focus group discussions and provide give feedback to the Department and the communities on the issues that were raised by participants. It is expected that community consultations will be held in both townships in May 2018. These community consultations will be particularly important, as people who did not attend the focus group discussions will be able to provide feedback about other relevant issues not picked up during the group discussions. At this time the study team will be able to discuss the types of questions that will be included in the Cross-sectional Survey and the timing of both the Cross-sectional Survey and the Blood Serum Study.

## 11. Duration of the project

The project is expected to take five months. The final report for this study is due to be completed by the end of April 2018.

## 12. Project management

Martyn Kirk is the Principal Investigator of the overall PFAS Health Study, and will be involved in the planning of the focus group study, as well as in editing the final report to be submitted to the Department of Health.

Cathy Banwell is a Co-Investigator on the PFAS Health Study and will lead the focus group study. Cathy will design the study, lead the planning, facilitate the discussions, perform the data analysis, and write the report for the focus groups. Cathy will also be involved in the communication of the study to both communities and will be available to talk to media regarding the study.

Tambri Housen is a Co-Investigator on the PFAS Health Study and will assist Cathy Banwell in the focus group study. Tambri will be involved in the planning, assist with the discussions, perform the data analysis, and co-write the report for the focus groups. Tambri will also be involved in the communication of the study to both communities and will be available to talk to media regarding the study.

Susan Trevenar is a Research Officer on the PFAS Health Study and will assist Cathy Banwell in the focus group study. Susan will be involved in the planning, assist with the discussions, and edit the report for the focus groups. Susan will also be involved in the communication of the study to both communities and will assist in all administrative duties including booking travel, accommodation, venues, and responding to enquiries from participants.

Kayla Smurthwaite is a Research Assistant on the PFAS Health Study and will assist Cathy Banwell in the focus group study. Kayla will be involved in the planning, assist with the discussions, and edit the report for the focus groups. Kayla will also be involved in the communication of the study to both communities and will assist in all administrative duties including booking travel, accommodation, venues, and responding to enquiries from participants.

### 13. Ethics

Ethical issues relate to the risks and benefits of participating in a focus group. These usually include concerns about anonymity and protection of privacy and the potential harms associated with participation. The study has obtained approval and oversight from the Human Research Ethics Committees of the DDVA and ANU (DDVA HREC Protocol 024-17, ANU HREC Protocol 2017/816).

Participants will be informed that they can withdraw while the discussion is taking place or choose not to answer any question that they perceive to be sensitive. If study participants become upset discussing the impact of living in an affected area on their lives more broadly, they will be referred to their GP or local mental health support services..

## 14. References

1. Kissa E: **Fluorinated surfactants and repellents**, vol. 97: CRC Press; 2001.
2. Buck RC, Franklin J, Berger U, Conder JM, Cousins IT, de Voogt P, Jensen AA, Kannan K, Mabury SA, van Leeuwen SPJ: **Perfluoroalkyl and polyfluoroalkyl substances in the environment: Terminology, classification, and origins**. *Integrated Environmental Assessment and Management* 2011, **7**(4):513-541.
3. Smart B: **Characteristics of C-F systems**. In: *Organofluorine Chemistry: Principles and commercial applications*. Edited by Banks R, Smart B, Tatlow J. Boston, MA: Springer; 1994: 57-88.
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**. *Archives of Environmental Contamination and Toxicology* 2005, **48**(4):559-566.
5. Trudel D, Horowitz L, Wormuth M, Scheringer M, Cousins IT, Hungerbühler K: **Estimating consumer exposure to PFOS and PFOA**. *Risk Anal* 2008, **28**(2):251-269.
6. Fromme H, Tittlemier SA, Volkel W, Wilhelm M, Twardella D: **Perfluorinated compounds--exposure assessment for the general population in Western countries**. *Int J Hyg Environ Health* 2009, **212**(3):239-270.
7. Steenland K, Fletcher T, Savitz DA: **Epidemiologic evidence on the health effects of perfluorooctanoic acid (PFOA)**. *Environmental Health Perspectives* 2010, **118**(8):1100-1108.
8. Olsen GW, Burris 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**. *Environmental health perspectives* 2007:1298-1305.
9. Faniband M, Lindh CH, Jönsson BA: **Human biological monitoring of suspected endocrine-disrupting compounds**. *Asian journal of andrology* 2014, **16**(1):5.
10. Chen MH, Ha EH, Wen TW, Su YN, Lien GW, Chen CY, Chen PC, Hsieh WS: **Perfluorinated compounds in umbilical cord blood and adverse birth outcomes**. *PLoS one* 2012, **7**(8):e42474.
11. Services USDoHaH: **Toxicological profile for perfluoroalkyls**. In.: Agency for Toxic Substances and Disease Registry; 2015: 574.
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. AECOM Services Pty Ltd: **Preliminary Ecological Risk Assessment December 2016 - RAAF Base Williamtown Stage 2B Environmental Investigation**. In. Edited by Department of Defence; 2016: 1.
14. [PFAS Investigation and Management Program](#)
15. Braun V, Clarke V: **Using thematic analysis in psychology**. *Qualitative Research in Psychology* 2006, **3**(2):77-101.

## 15. Appendices

### 15.1. Appendix 1 Focus group discussions: participation information sheet

#### **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.

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

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 [here](#) 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](mailto:Cathy.Banwell@anu.edu.au) [Tambri.Housen@anu.edu.au](mailto: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: <a href="mailto:ddva.hrec@defence.gov.au">ddva.hrec@defence.gov.au</a>	Human Research Ethics Officer The Australian National University Office of Research Integrity Chancelry 10B, T: (02) 6125 3427 E: <a href="mailto:Human.Ethics.Officer@anu.edu.au">Human.Ethics.Officer@anu.edu.au</a>
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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).

15.2. Appendix 2 Focus group discussions: consent form

## 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:

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The Australian National University  
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Chancelry 10B,  
T: (02) 6125 3427  
E: [Human.Ethics.Officer@anu.edu.au](mailto:Human.Ethics.Officer@anu.edu.au)

15.3. Appendix 3 Focus group discussions: questionnaire

**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**

## **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](mailto: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.**

<b>Contact name</b>	<b>Telephone</b>	<b>Email</b>
Ms Susan Trevenar	T: (02) 6125 6079	<a href="mailto:Susan.Trevenar@anu.edu.au">Susan.Trevenar@anu.edu.au</a>
Dr Tambri Housen	T: (02) 6125 0460	<a href="mailto:Tambri.Housen@anu.edu.au">Tambri.Housen@anu.edu.au</a>
Dr Cathy Banwell	T: (02) 6125 0016	<a href="mailto:Cathy.Banwell@anu.edu.au">Cathy.Banwell@anu.edu.au</a>