

# The PFAS Health Study<sup>1</sup>

## Participant Information Sheet

Researchers at the National Centre for Epidemiology and Population Health, Research School of Population Health, The Australian National University (ANU) are conducting The PFAS Health Study.

### Information about The Study

This Study is part of a larger research project about health effects of living in a PFAS contaminated area ([pfas.anu.edu.au](http://pfas.anu.edu.au)). We will analyse survey responses and blood samples from people in three towns that have high levels of PFAS contamination of the environment—Oakey (Qld), Williamstown (NSW) and Katherine (NT). We will compare the results with information from people who live in similar towns that do not have high levels of PFAS in the environment—Dalby (QLD), Kiama and Shellharbour (NSW), and Alice Springs (NT). The survey will gather information about participants' potential exposure to PFAS and health conditions. You can complete the survey online or in a paper format. We will analyse all of the blood samples for PFAS chemicals and blood chemicals that measure blood fats (e.g. cholesterol) and show how well your liver, kidneys and thyroid are working.

You have been invited to participate in this study because you were randomly selected from the Medicare enrolment file by the Services Australia, previously called Australian Government Department of Human Services, based on where you live. The ANU-led research team has not been provided with contact details of people and are not aware of who has been selected for this study.

We aim to find out what factors might influence a person's PFAS level, what health concerns might be linked with blood PFAS levels and how blood PFAS levels influence other chemicals in blood, particularly those that measure how well your liver, kidneys and thyroid are working and also blood fats, e.g. cholesterol.

Taking part in the Study is entirely voluntary; you are not obliged to take part, and choosing not to will be no disadvantage to you. You can withdraw from the Study at any time without disadvantage and without giving a reason. If you choose to withdraw we will destroy data already collected from you if you ask us to.

The Study's findings will be made available through the Study's webpage ([pfas.anu.edu.au](http://pfas.anu.edu.au)) in mid-2021 and published in scientific journals. The results will give a broad overview of health impacts, if any, of living in a PFAS Investigation or Management Area.

The Australian Government Department of Health has commissioned this Study. No personal information we collect will be given to the Australian Government or any other third party.

### More information on PFAS

PFAS (per- and polyfluoroalkyl substances) are a group of manufactured chemicals that have been used in aqueous film forming (firefighting) foams. Environmental contamination by PFAS is a relatively new problem, and evidence about its possible effects on the human body is limited. Everyone has been exposed to PFAS to some degree through food, makeup, sunscreen, clothes, paints, leather coatings, household products such as protective coatings on furniture, and non-stick surfaces on some cookware and food packaging. This exposure is low and probably harmless. PFAS are very stable chemicals and persist for a long time in the environment and human body (if absorbed). Detailed information on what is currently known about the health effects of exposure to PFAS is available on our website ([pfas.anu.edu.au](http://pfas.anu.edu.au)).

1 Official Project Title: The Per- and Polyfluoroalkyl Substances (PFAS) Health Study: Cross-sectional Survey and Blood Serum Study

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## Participant Involvement

Here is what we would like you to do:

1. Complete the enclosed consent form. You only need to complete the consent form that is inside the survey, the other copy is for you to keep;
2. Complete the health and lifestyle survey. It will ask you for some background about yourself, and about past and current health. You can choose not to answer some questions if you wish. The survey will take 20 to 30 minutes to complete. To complete the survey online, type the web address from your instruction letter into your browser and use the unique username and password from your instruction letter.
3. Complete your details on the pathology form. Please ensure that the bottom half of the pathology form has been completed.
4. Make an appointment with one of the collection centres listed on the pathology form; present form to the pathology collection facility. You do not need to fast for this blood test.

## Blood tests

All of the blood samples will be analysed together when all participants have completed the data collection phase of the study. We will send you a copy of your results in a letter, once those results are available. We will include a comparison of your PFAS levels to those of the Australian population, and also the range of values considered to be normal for the other chemicals that are measured in your blood. If you do not wish to receive this information, you can indicate this on the pathology form. With your consent, we will also send your results to your regular doctor if you provide us with their details on the pathology form. We encourage you to have your results sent to your regular doctor.

If any of the blood chemical results are outside the normal range, the PFAS Health Study Team recommend that you attend your usual medical provider to discuss these results. The PFAS Health Study Team will not be able to provide a clinical interpretation of any results because it is beyond the scope of this study and because interpretation of results may require a full medical history and examination. Your usual medical provider will be best placed to interpret this information for you. It will be your responsibility to seek further medical follow-up of any results and there may be costs associated with this. It will be your responsibility to fund all costs related to any medical or clinical follow-up after you receive these results.

All Australians are expected to have some level of PFAS in their blood. There is no 'normal' range of PFAS blood levels for an individual but individual levels can be compared with levels from the Australian general population. There are some important points to be aware of with PFAS testing<sup>2</sup>:

- PFAS blood levels cannot predict health problems and cannot tell you whether a current health problem is related to PFAS levels. This is because evidence about the possible effects of PFAS on health is limited.
- There is no practical treatment available to lower levels of PFAS in blood.
- A PFAS blood test will only tell you the current level of PFAS in your blood. It will not tell you when you were exposed to PFAS or what you were exposed to. The blood level will usually reflect exposure to PFAS over a long period of time.
- The PFAS blood test does not measure the level of PFAS precisely. This means that if you were to have two samples taken at the same time, there may be a difference in the results due to the way the test is conducted.

While it is unlikely that you, as an individual, will gain personal benefit from having your blood tested or in completing the survey, there will be benefit to other communities in Australia and worldwide that are concerned about PFAS contamination in their environment. Health effects will be documented and the results will be provided to government, and freely available to participants, the general community, and other researchers.

2 Voluntary Blood Testing Program for PFAS Pre-Test Consultation Advice for GPs. Canberra (ACT): Department of Health.

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## Your privacy

Your privacy is important to us. We will not tell other people that you have taken part. Only members of the research team will have access to the information you give us. Personal identifying information will not appear in any reports, it will only be used to contact you about future studies relating to the PFAS Health Study, if you agree to us doing this. When your information is being analysed, people doing the analysis will not see any information that identifies you.

The ANU Privacy Policy can be found at [https://policies.anu.edu.au/ppl/document/ANUP\\_010007](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 any Australian Privacy Principle (APP) and how ANU will handle the complaint.

## Data Storage

Your data will be stored securely on password protected ANU data servers during the collection and analysis stages of the Study. It will be stored on password protected ANU servers for five years from the date of any publication resulting from the research, and then archived (stored) at the ANU. Information about you will always be stored separately from anything that can identify you. Your data may be used for future ANU analyses of the health effects of PFAS exposure. Any future analyses would require additional ethical review and clearance. Access to the archived data will be limited to named staff working on the Study. You will not be identifiable in any archived data.

## Blood Storage

Your blood sample will not be used for any other purpose than this Study without your consent. You can consent to have your blood sample stored and used in future PFAS Studies by indicating this on the pathology form. These blood samples will be stored in a secure freezer at ANU. Future research **will not** include genetic research. If used in future research, we are not planning to report the individual test results to you as we do not expect the results of any additional tests to be clinically important to your health. If you choose not to have your blood sample archived, your sample will be destroyed after testing. All study staff have made a written commitment to keep your information secure at all times.

## Research Team

Professor Martyn Kirk (ANU) leads the PFAS Health Study. Professor Adrian Miller from Central Queensland University provides advice on working with Aboriginal communities. Emeritus Professor Bruce Armstrong (Universities of Sydney and WA), Professor Jochen Mueller (University of Queensland), Professor Cate D'Este (ANU), Professor Robyn Lucas (ANU), Professor Archie Clements (Curtin University), Associate Professor Rosemary Korda (ANU), Associate Professor Philip Batterham (ANU), Dr Jennifer Bräunig (University of Queensland), Professor Cathy Banwell (ANU), Dr Tambri Housen (ANU) and Dr Aparna Lal (ANU) advise on the content and methods of the Study. Dr Jo Lane (ANU) will provide clinical support to the research team in identifying participants in distress, and will refer participants to local crisis support services if required. Ms Hsei Di Law (ANU) advises on data analysis and Ms Imogen Gad is responsible for data management, of the Study. Ms Sue Trevenar (ANU), Ms Kayla Smurthwaite (ANU), and Ms Anna Rafferty (ANU) will coordinate the Study's operations.

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## Questions and Answers

Ask us at [pfas.anu.edu.au](https://pfas.anu.edu.au) or [pfas.health.study@anu.edu.au](mailto:pfas.health.study@anu.edu.au). If you have questions about how to complete the survey, you can call us on 1800 430 903.

## Concerns or complaints

The Human Research Ethics Committees (HREC) of the Australian National University (ANU), the Northern Territory Department of Health and Menzies School of Health Research (NTDoH and MSHR) have approved the Study (ANU HREC protocol 2018/651, NTDoH and MSHR HREC protocol 2018-3226). If you have concerns regarding the way this research is conducted please do not hesitate to contact the researchers or the ANU Ethics Administration:

### Human Research Ethics Officer

The Australian National University

**T:** (02) 6125 3427

**E:** [Human.Ethics.Officer@anu.edu.au](mailto: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](mailto:Ethics@menzies.edu.au)

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