

The PFAS Health Study¹

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). We will analyse blood samples and survey responses from people in three towns that have high levels of PFAS contamination of the environment—Oakey (Qld), Williamtown (NSW) and Katherine (NT). We will compare the results with 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). We will analyse these blood samples for PFAS chemicals, and common blood chemicals (uric acid, creatinine and blood fats (e.g. cholesterol and triglycerides)). The survey will gather information about participants' potential exposure to PFAS and health conditions. You can complete the survey on behalf of your child online or in a paper format.

Your child has been invited to participate in this study because they previously participated in the Australian Government Voluntary Blood Testing Program for PFAS.

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, specifically cholesterol and uric acid.

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

The Study's findings will be made available through the Study's webpage (pfas.anu.edu.au) in mid-2020 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 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).

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

This is for you to keep

Participant Involvement

Here is what we would like you to do:

1. Read the enclosed Participant Information Sheet;
2. Read the enclosed consent form. You will only need to complete the copy of the consent form at the start of the online or paper survey, the enclosed copy is for you to keep;
3. Complete the health and lifestyle survey. It will ask you about health complaints and some background information. You can choose not to answer some questions if you wish. The survey will take 30 to 45 minutes to complete. To complete the survey online, type the web address into your browser and enter your unique username and password. **Please complete the survey before 20 December 2019.**

Blood tests

If you provide consent for additional testing on your child's blood sample that was sent to the ANU, your child's sample will be tested in early 2020 and your child's results will be reported to the PFAS Health Study team. We will send you a copy of your child's results in a letter with the normal range for blood chemicals (e.g. uric acid, creatinine, and blood fats). The blood chemicals check kidney function and cholesterol. High cholesterol is a risk factor for heart disease. If you do not wish to receive this information, you can indicate this on the consent form. With your consent, we will also send your child's results to their regular doctor if you provide us with their details on the consent form. We encourage you to have your child's results sent to their regular doctor.

If any of the blood chemical results are abnormal, the letter that you receive from the PFAS Health Study Team will include a recommendation for you and your child to attend their 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 child's 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.

While it is unlikely that your child, as an individual, will gain personal benefit from having their blood sample tested or in participating in the survey, there will be benefit to their wider community, and 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.

Your child's privacy

Your child's privacy is important to us. We will not tell other people that your child has 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 child's information is being analysed, people doing the analysis will not see any information that identifies your child.

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 any Australian Privacy Principle (APP) and how ANU will handle the complaint.

Data Storage

Your child's 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 your child will always be stored separately from anything that can identify them. Your child's data may be used for future ANU

This is for you to keep

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. Your child will not be identifiable in any archived data.

Blood Storage

Your child's blood sample will not be used for any other purpose than this Study without your consent. You can consent to have your child's blood sample stored and used in future PFAS Studies by indicating this on the consent 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 child's blood sample archived, their sample will be destroyed after testing. All study staff have made a written commitment to keep your child's 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. Dr Miranda Harris (ANU), 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 of the Study. Ms Sue Trevenar (ANU), Ms Kayla Smurthwaite (ANU), and Ms Anna Rafferty (ANU) will coordinate the Study's operations.

Questions and Answers

Ask us at pfas.anu.edu.au or 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

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

This is for you to keep