



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 survey responses and blood samples 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 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, which has now closed, gathered information about participants' potential exposure to PFAS and health conditions. 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 the liver, kidneys, and thyroid are working.

You have been invited to participate in this Study because your child previously participated in the PFAS Health Study Blood Serum Study and Cross-sectional Survey. **You provided consent for us to test your child's blood sample, and to use your child's blood sample for future PFAS research.**

We aim to find out how blood PFAS levels influence other chemicals in blood, particularly those that measure how well your child's liver, kidneys, and thyroid are working, and also blood fats, e.g. cholesterol.

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 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) 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.

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

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. PFAS are very stable chemicals and persist for a long time in the environment and human body (if absorbed). They may have harmful effects on human health. Detailed information on what is currently known about the health effects of exposure to PFAS is available on our website (pfas.anu.edu.au).

Participant Involvement:

Here is what we would like you to do:

If you would like to receive a copy of the results for your child's liver and thyroid function tests you will need to complete the online consent form. **Please complete the consent process before 5 February 2021.** If you are unable to complete the consent form online please contact the Study team on 1800 430 903 during business hours to complete the consent form via telephone. Alternatively, you can email the team at pfas.health.study@anu.edu.au to arrange a time for the Study team to contact you.

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 child's results in a letter, once those results are available. We will include the range of values considered to be normal for the blood chemicals that are measured in your child's blood. If you do not wish to receive this information, you can indicate this by not contacting the study team. With your consent, we will also send your child's results to their regular doctor that you previously provided details for in the PFAS Health Study. We encourage you to have your child's results sent to their regular doctor.

If any of the blood chemical results are outside the normal range, the PFAS Health Study Team recommends that you attend your child's 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 you, as an individual, will gain personal benefit from having your child's blood sample tested, there will be benefit to your 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 privacy:

Your child's 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 your child's blood test results, 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 you.

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 initials and consent preferences will be stored on the Qualtrics website during the data collection stage of the Study. All additional 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 child's 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 child's blood sample will not be used for any other purpose than this Study without your consent. 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. Emeritus Professor Bruce Armstrong (Universities of Sydney and Western Australia), 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) and Ms Kayla Smurthwaite (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 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
---	---