

Participant Information Statement

People with chronic kidney disease

Research study: Health Behaviours and substance use in people with CKD

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1. What is this study about?

We are conducting an interview study on health behaviours and substance use. The study aims to understand the perspectives of people with chronic kidney disease (CKD) on health behaviours and substance use. Little is known about substance use, including alcohol, tobacco, vapes, and other substances such as illicit substances, in people with CKD. We want to understand the perspectives and experiences of substance use, as well as preferences for support and interventions for people with CKD. This knowledge is needed to help improve outcomes and care.

In this study, substance use will be defined as alcohol, tobacco, e-cigarettes/vapes, illicit drugs or any other substance that is consumed, inhaled or injected into the body. A substance is something that changes a person's mental or physical state, how someone behaves or feels.

Taking part in this study is voluntary.

Please read this sheet carefully and feel free to ask any questions about anything you don't understand or want to know more about.

2. Who is running this study?

The study is being carried out by the following researchers:

Anastasia Hughes (Responsible Researcher) affiliated with the University of Sydney and Centre for Kidney Research, is conducting this study as part of her PhD through the University of Sydney under the supervision of the following researchers:

Professor Allison Jaure (Co-investigator)

Affiliated with the University of Sydney and Centre for Kidney Research.

Professor Becky Freeman (Co-investigator)

Affiliated with the University of Sydney.

Dr Karine Manera (Co-investigator)

Affiliated with the University of Sydney and Centre for Kidney Research.

Professor Germaine Wong (Co-investigator)

Affiliated with the University of Sydney, Centre for Kidney Research and Westmead Hospital.

Dr Nicole Scholes-Robertson (Co-investigator)

Affiliated with the University of Sydney and Centre for Kidney Research.

No conflicts of interest.

No financial disclosures.

This study is supported by a NHMRC Centre of Excellence Grant (CRE-PACT APP207026), and The Elizabeth and Henry Hamilton-Browne Scholarship at the University of Sydney.

3. Who can take part in the study?

We are looking for people who have chronic kidney disease, including CKD not yet requiring kidney replacement therapy, those receiving dialysis or have received a kidney transplant. You must be 18 years or older to join and usually reside in Australia or New Zealand. You do not need to have engaged with substances to take part in this study. We are interested in hearing all perspectives and experiences.

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to take part in an interview. Before the interview you will sign a consent form and then be asked to complete a short survey to collect basic information about you and your health. During the interview you will be asked about your perspectives on substance use in people with CKD, and any impacts on social relationships and life participation. We also want to discuss strategies and interventions for substance use in people with CKD. The interview will take about 30-45 minutes and be held either in-person or online via Zoom based on practicality and your preference. The interview will be recorded and transcribed by the researcher conducting the interviews.

5. Can I withdraw once I have started?

Participating in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney, Centre for Kidney Research, Westmead Hospital, or your healthcare providers.

If you decide to take part in the study and then change your mind, you can withdraw at any time. You can let the project team know by contacting Anastasia Hughes by email at anastasia.hughes@sydney.edu.au

If you take part in an interview you may refuse to answer any questions that you do not wish to answer. If you choose to withdraw, we will stop collecting information from you. Your information and answers collected up to the time you withdraw will be included in the results. If you don't want the information already collected to be in the study results, please tell us at the time you withdraw.

This research project may be stopped unexpectedly. This may be because of a lack of participants, a lack of resources, or enough information received within the set time of the study. The research team will inform you if this occurs.

6. Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. The data will be de-identified and coded to remove any links between names and data collected, particularly in the case of any illegal activity that is shared. Confidentiality will also be protected by storing consent forms and transcripts separately. We aim to only obtain information directly necessary for the research project and only record information which is relevant to the research project; and we will protect the confidentiality of participants by ensuring identities are not ascertainable as outlined above.

The researcher may be required to disclose certain information obtained during the study, and may have a duty to report to the police or other appropriate authorities the details of certain specific criminal offences disclosed in the interview. The researcher will stop the interview and caution you, if you begin to disclose details of any criminal offence. If you wish to discuss offences you should only do so if you understand this caution, and only discuss such offences in general terms.

You can withdraw consent at any time without the need to provide a reason or incur any penalties. You may skip questions if you feel distressed or uncomfortable or stop at any time. Researchers will check in with you if they notice distress throughout the interview to ensure you are comfortable and wish to continue. The research team are available to assist you arrange appropriate, please contact Anastasia Hughes (anastasia.hughes@sydney.edu.au). You can also contact the following support services.

<u>Who to contact for immediate help</u>	
Australia	
NSW Mental Health Line	1800 011 511
Beyond Blue	1800 51 23 48
Lifeline Australia	13 11 14
Domestic Violence Line	1800 65 64 63
1800RESPECT	1800 73 77 32
Quitline	13 78 48
Alcoholics Anonymous (AA)	1300 222 222
Narcotics Anonymous (NA)	1300 652 820

National Alcohol & Other Drug Hotline	1800 250 015
Butterfly Foundation	1800 33 4673
New Zealand	
Healthline	0800 611 116
Depression Helpline	0800 111 757 free text 4202
Samaritans	0800 726 666
Lifeline	0800543 354
Youthline	0800 376 633
Alcohol and Drug Helpline	0800 787 797
1737 Peer Support	1737
0508 TAUTOKO Suicide Crisis Helpline	0508 828 865

7. Are there any benefits?

You will not receive any direct benefits from being in the study. However, your involvement will help us understand the perspectives of people with CKD on health behaviours and substance use. By sharing your perspectives and experiences, you will help us understand how to improve care for people with CKD with the aim to achieve better health outcomes.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information from or about you for the purposes of this study.

Any identifiable information you provide us will be stored securely and will only be disclosed with your permission unless we are required by law to release information. We plan to publish the study findings. You will not be individually identifiable in these publications. Information collected as part of this study will include basic demographic information, clinical characteristics and the interview data (recording and transcription).

This data will be stored securely on the University of Sydney OneDrive for 5 years as required by the National Health and Medical Research Council (NHMRC) guidelines. Then it will be deleted. We will obtain additional ethics approval if we use the research for additional purposes or with additional researchers. We will store this information and dispose of it securely following the University's Recordkeeping Policy. For more details about how your information will be handled please see the University's [privacy webpage](#).

9. Will I be told the results of the study?

You have the right to receive feedback about the overall results of this study. The results of this study will be published in a peer-reviewed journal and shared to participants as a plain language summary. If you wish to receive a summary of the results, please email Anastasia Hughes (anastasia.hughes@sydney.edu.au).

10. What if I would like more information?

When you have read this information, the following researcher will be available to discuss it with you further and answer any questions you may have:

Anastasia Hughes (Responsible Researcher, PhD Candidate):

anastasia.hughes@sydney.edu.au

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [ethics reference: [2025/HE001136](#)] according to the National Statement on Ethical Conduct in Human Research.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager

human.ethics@sydney.edu.au

+61 2 8627 8176

This information sheet is for you to keep