UNIVERSITY
OF WOLLONGONG
AUSTRALIA

Participant Information and Consent Form

Short Name of Project	DIET-GKD
Full Name of Project	Dietary Patterns in Kidney Disease: A longitudinal cohort study.
Principal Investigator	Associate Professor Kelly Lambert
Project Sponsor	University of Wollongong
Site Name	University of Wollongong

What am I being invited to do?

We, the School of Medicine, Indigenous and Health Sciences at the University of Wollongong (UOW), invite you to take part in a project that is investigating dietary intake and lifestyle habits of people with Genetic Kidney Disease. You have been invited to take part because you are aged 18 years or older, can read English, and have a genetic cause of kidney disease.

You will **not** be eligible to participate in this study if you:

- Have a significant cognitive impairment preventing you from being able to complete dietary and health surveys and give consent
- Have a life expectancy of less than 6 months.

We hope to recruit about 100 people from hospitals around Australia (including Blacktown Hospital, Wollongong Hospital, Liverpool Hospital, St George Hospital, Concord Hospital, Metro South Dialysis Brisbane and Hampstead Dialysis Centre Adelaide).

Please read this information and feel free to ask any questions. You can take some time to make up your mind and decide if this project is right for you. You can also talk to someone you trust, like a family member, friend, or your local doctor.

What is the purpose of this project?

Diet is important for improving health in many different types of diseases. The purpose of this study is to look at the role of diet in improving health in genetic kidney disease. We will collect information on diet and health from adults from Australia with genetic kidney disease. This will help researchers to see whether some diets are linked to better or worse

health outcomes. This study will provide important information for health professionals, and for people with genetic kidney disease.

Do I have to take part and can I change my mind?

Taking part is up to you

You get to decide whether you take part in this project. You can say yes or no.

Your decision won't affect your relationship with your doctor or the hospital.

You can change your mind at any time

If you do take part, you can stop at any time. You do not have to tell us the reason.

Once you stop taking part, we will not collect any more information about you. We will keep the information we have already collected to make sure the results of the project can be measured properly.

The project might stop for other reasons

We might need to stop the project while you are taking part. If this happens, we will explain the reasons to you.

We may also ask you to stop taking part in the project if it is no longer in your best interest. If this happens, we will discuss this with you.

What do I have to do if I take part?

If you take part in this project, you will be in it for 12 months.

We will ask you to complete some online questionnaires about your health and diet at the start of the study, and 12 months later. We will also ask you to share you most recent blood test results or visit your local pathology centre to provide a blood and urine sample at the start and end of the study. You will be provided with a pathology collection form for these samples.

This table below outlines what you need to do in this project. For more information, please contact Associate Professor Kelly Lambert on **(**02) 4221 5251.

What part of the project?	What do I have to do?
Consenting to take part in this project	If you are happy to take part in this project, you will be asked to sign a consent form.

When you start the project	Complete an online diet and health survey, which will take about 45 minutes to complete. Visit your local pathology collection centre to provide a blood and urine sample.
When you finish the project (12 months later).	Complete an online diet and health survey, which will take about 25 minutes to complete. Visit your local pathology collection centre to provide a blood and urine sample.

Payment for your time and expenses

You will be reimbursed for reasonable travel and study related expenses at the start and end of the study for your participation. You will also be given a report about your diet, with some tips to help you eat healthier.

What are the benefits of taking part?

By participating in this study you will receive a report about your diet and eating habits if you wish to receive a copy. By taking part, you will help the researchers understand more about how diet and lifestyle may impact health outcomes for people with genetic kidney diseases. This knowledge may help people in the future.

What are the risks and discomforts of taking part?

There are minimal risks to you from taking part in this project. The risks of participating in this project include the inconvenience of completing surveys. The online surveys and visit to your pathology centre may be time-consuming, and you may experience some slight discomfort when having your blood taken.

If I take part, what will happen to my information and samples?

Keeping your information safe

To keep your information safe, we will:

- follow all relevant privacy requirements
- keep it securely on an electronic database for 15 years at UOW.
- take steps to prevent anyone from accessing information that identifies you unless they need to, for example, to check it in an audit

- give it a code and keep it separate from anything that could easily identify you, like your name or contact information.

You can ask us to tell you what information we have collected about you as part of this project. If your information is not correct, you can also ask us to change it.

We will keep your information for 15 years. After this, we will destroy it.

Information collected from this study will be used in journal publications and presented in seminars. Data collected from this study may also be used in future analysis of this study, or future research related to this study area.

Who is running and paying for this project?

This project is being run by the University of Wollongong.

This project is being funded by an Alport Foundation of Australia grant and University of Wollongong Advancement and Equity Grant Scheme for Research.

Who has approved this project?

The Western Sydney Local Health District ethics committee has approved this project. This committee makes sure that this project meets Australian ethical standards for research that involves people.

Complaints about how this project is being run

If you have any complaints about how this project is being run, please contact:

A/Prof Kelly Lambert, Principal Researcher,

Contact details (4221 5251, klambert@uow.edu.au)

Where can I find more information?

Thank you for taking the time to read this information about our project. You can contact a member of the project team at any time to ask questions.

A/Prof Kelly Lambert, Principal Researcher,

Contact details (4221 5251, klambert@uow.edu.au