



Participant Information and Consent Form

Full Name of Project	Experiences of World Transplant Game participants regarding exercise after kidney transplantation
Principal Investigator	Assoc Prof Kelly Lambert
Project Sponsor	University of Wollongong
Research team	Eden Rothnie White, student dietitian, University of Wollongong



What am I being invited to do?

As principal investigator I would like to invite you to take part in a project that is exploring the motivation and inspiration for commencement of exercise after kidney transplantation and to understand the barriers and enablers to exercise.

You have been invited to take part because you are aged 18 years or older, can read English, have had a kidney transplant and have or will compete in the world Transplant Games.

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

- Are aged less than 18 years or
- Have another type of organ transplant eg lung, heart or liver or
- Cannot converse in English or
- Do not consent to the audio recording of an interview with a member of the research team

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?

Work by our research team has found that people who have had a kidney transplant often struggle to start or get back to being active. We want to know more about what may help or hinder this.

We thought who best to ask – than people who have or are training to compete at the highest level – the World Transplant Games.

We will collect some basic information from you about your age, gender, and when you had a transplant. We will then ask a series of questions about your motivations for undertaking exercise and for competition. We will ask you about what has helped or hindered you on this journey and ask if you have any suggestions to help others get back or to start being active.

This research will provide useful information for health professionals, and also for people on who have had a transplant.

Part of the research will be used by Eden Rothnie White in her research studies at the University of Wollongong.



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 interviewed on Zoom or Microsoft Teams by a member of the research team. This will be at a time convenient to you.

We expect this to take about 30 minutes but feel free to talk for longer if you wish.

This table below outlines what you need to do in this project. For more information, please contact: Assoc Professor Kelly Lambert, klambert@uow.edu.au

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. You will also be asked again verbally on the day of the interview before you start
When you start the project	You will have an interview with a member of the research team. You will be given the opportunity to check the interview transcript after the interview. If you wish to do so you will be provided with a copy by the interviewer via email.
When you finish the project	After the interview, we will contact you to ask if you would like to see the preliminary themes from the interview as well as read the transcript of your own interview. After this you have completed the study

 **Payment for your time and expenses**

You will not be reimbursed for study related expenses. However, we anticipate the only burden will be the time you take to be interviewed.

 **What are the benefits of taking part?**

You will not directly benefit from taking part in this project. By taking part, you will help the researchers understand more about how to help others become more active. This knowledge may help other people in the future who will have a kidney transplant.

 **What are the risks and discomforts of taking part?**

There are minimal risks to you from taking part in this project. It is a possible that you may be inconvenienced by participating in this project. However, we will try and arrange a time to talk that is suitable to you.

There is a slight risk that some people may become emotional talking about your transplant. If this is the case, you are free to stop anytime and or withdraw from the study. In the event

of emotional distress we may refer you to a relevant support organisations such as Beyond Blue, to your treating Physician, GP, or Nurse Practitioner. The Principal investigator is also a health professional with extensive experience and training in counselling and will provide participants with the opportunity to debrief if desired. In case of severe distress, we will provide appropriate mental health first aid.



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 5 years at the University of Wollongong.
- 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.

You can ask to withdraw your information from the study. This is possible until the point of analysis. After this, all information will be in a de-identified format and not possible to withdraw.

We may choose to include quotes from your interview in any future publications or presentations. However, these quotations will be in an anonymous fashion and not identifiable.

All data collected will be securely stored at the University of Wollongong. The data will be retained securely on MS teams for 5 years after the study has ended and may be accessed in future studies related to this topic. Audio recordings of the interview will be deleted once the transcription of the interview has been occurred. The information you share during the interview may be used to help develop programs to assist and support other kidney transplant recipients, as well as published by the research team and or presented at professional conferences



Who is running and paying for this project?

This project is being run by the University of Wollongong.

There is no funding to conduct this project.



Who has approved this project?

The University of Wollongong Human Research Ethics Committee has approved this project (Ethics approval number 2024/338). 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 the UOW Ethics Officer, +61 2 4239 2191 or email uow-humanethics@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 the Principal Investigator Kelly Lambert at any time to ask questions via email klambert@uow.edu.au or +61 2 4221 5251