

Australasian Kidney Trials Network (AKTN) Consumer Advisory Board

Membership Expression of Interest



What is the AKTN?

The Australasian Kidney Trials Network (AKTN), based in Brisbane, Australia:

- Is a not-for-profit research organisation.
- Designs, conducts and supports clinical trials with the aim of improving life for people living with kidney disease.
- Aims to run clinical trials in the most practical ways possible.

Why do we need a Consumer Advisory Board?

The researchers want to make sure that the AKTN trials are designed and run in a way that is meaningful to patients and caregivers, and focus on outcomes that are important to them. The Consumer Advisory Board helps ensure that trial designs and documents provided to the kidney community are clear and useful, including when the trial results are shared with the kidney care community.

Consumer engagement in research is also expected by the National Health and Medical Research Council.

Who are we looking for?

People from Australia and New Zealand who are:

- patients and/or caregivers with lived experience of chronic kidney disease,
- aged 18 years and over,
- able to read and write English,
- willing to participate and share their experiences, opinions, and suggestions about trials for the benefit of the kidney community, and
- willing to participate in meetings via free videoconference software, such as Zoom.

Please note that Consumer Advisory Board members cannot review trial documents etc. that are related to a trial they are already participating in.

What time commitment is involved?

This is very much up to you and will be supported by any guidance you need, which could range from an hour's introductory meeting to a half- to full-day training workshop when you're ready to start. This will depend upon the type and level of involvement you choose. Some of our most common consumer involvement activities are below and if you indicate your availability for them **(please tick all that apply)**, we'll start to get an idea about what type of involvement you would like:

- A one-hour meeting every 3 months, held via Zoom (free videoconference software) ☐
- One- to two-hour review of trial materials (e.g. documents, webpages, mobile applications) a few times a year ☐
- One face to face meeting per year, held in a capital city ☐

When does it start?

Hayley Candler, the AKTN Consumer Engagement Coordinator, will be in touch within a month of her receiving this completed form. If you're invited to become a Consumer Advisory Board member, there will be some training / information to read through and a Terms of Reference document to complete.

Will members be acknowledged or reimbursed for their input?

With permission, members will be acknowledged on the AKTN website and / or trial documents. Members are also entitled to reimbursement for the time they dedicate to Board activities and reasonable travel costs (where applicable). These are paid in accordance with Health Consumers Queensland guidelines.

How do I become involved?

Please respond to the questions below and await a response from Consumer Engagement Coordinator, Hayley Candler. If you'd like to get in touch in the meantime, feel free to email Hayley at aktn.cec@uq.edu.au or call her on 0419 614 798.

Why are we asking the questions below?

It's important to the AKTN that we capture the views and opinions from people of a variety of backgrounds and experiences. The information you provide below will help us ensure we include people from as many different backgrounds as possible.

First and Last Name:		
Year of Birth:		
Suburb & Postcode:		
Phone:		☐ Preferred contact
Email:		☐ Preferred contact
Why would you like to be involved in shaping kidney disease research?		
Gender identification:	☐ Male ☐ Female ☐ Non-binary / third gender ☐ I prefer not to answer ☐ Other:	
Race / ethnicity:	☐ White / Caucasian ☐ Australian Aboriginal or Torres Strait Islander ☐ Indian subcontinent (e.g. India, Pakistan) ☐ Asian, other than Indian subcontinent ☐ Other:	

What's the highest level of education you've completed?	☐ Did not attend high school ☐ Some high school ☐ Completed high school ☐ Trade or vocational training ☐ Degree ☐ Postgraduate qualification
In what capacity do you have experience with chronic kidney disease?	☐ I have chronic kidney disease ☐ I am a caregiver to someone with chronic kidney disease
With which condition/s do you have experience? <i>(please tick all that apply)</i>	☐ Acute Kidney Injury (AKI) ☐ Polycystic Kidney Disease (PKD) ☐ Glomerulonephritis (GN) ☐ Autosomal Dominant Polycystic Kidney Disease (ADPKD) ☐ Other, please specify: _____ _____
With which treatment/s have you had experience? <i>(please tick all that apply)</i>	☐ Haemodialysis ☐ Peritoneal dialysis ☐ Transplant (as recipient) ☐ Transplant (as donor) ☐ Other, please specify: _____ _____
Please describe any prior experience you've had with consumer / health advisory groups and/or clinical trials:	
Occupation / area of study / particular interests and skills (optional):	

Please email the completed form to aktn.cec@uq.edu.au

Your information will be stored electronically at the AKTN, The University of Queensland, on a secure server.

Declaration

We have a register of people interested in being involved in improving the way we do research studies on kidney disease. May the AKTN keep your details securely on file so they can contact you about any future consumer involvement or engagement opportunities?

☐ Yes ☐ No

You can unsubscribe at any time by contacting Hayley Candler at aktn.cec@uq.edu.au or by phone, on 0419 614 798.

You confirm that all information given in this form is accurate.

Signature: _____

Date: _____