

## Expression of interest to be a member of the Consumer Advisory Board for the Australasian Kidney Trials Network (AKTN)

### 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 focuses on outcomes that are important to them. The Consumer Advisory Board will help 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, including:

- patients and caregivers with lived experience of chronic kidney disease
- aged 18 years and over
- able to read and write English
- willing to participate and share your experience, opinions and suggestions about trials for the benefit of the kidney community

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 half-day reviewing trial documents and any webpages or mobile applications
- A one hour meeting every 2-3 months, mostly via Zoom (videoconference software)
- One face to face meeting per year, held in a capital city

The specific requirements of a trial with which you become involved will be outlined in the *Involvement & Communication Plan* for that trial, which may change over time. Please let us know if your availability changes over time.

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 are invited to become a Consumer Advisory Board member, there will be some training/information to read through. We'll contact you when there's a good fit between you and one of our trials!

Will members be acknowledged or reimbursed for their input?

With permission, members will be acknowledged on the AKTN website and other trial documents. Members are also entitled to reimbursement for reasonable travel costs and time, which will be paid in accordance with Health Consumers Queensland recommendations.

How do I become involved?

Please fill in all the boxes below. If you have any questions, please get in touch:

- Hayley Candler (Consumer Engagement Coordinator) [aktn.cec@uq.edu.au](mailto:aktn.cec@uq.edu.au) | 0419 614 798

***Why are we asking the questions below?***

It's important to the AKTN that we capture 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:		
Postcode:		
Phone:		<input type="checkbox"/> Preferred contact
Email:		<input type="checkbox"/> Preferred contact
Why would you like to be involved in kidney disease research?		
Gender identification:	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Non-binary / third gender	
Race/ethnicity:	<input type="checkbox"/> White / Caucasian <input type="checkbox"/> Australian Aboriginal or Torres Strait Islander <input type="checkbox"/> Indian subcontinent (e.g. India, Pakistan) <input type="checkbox"/> Asian, other than Indian subcontinent	

	<input type="checkbox"/> Other (specify):		
Is English your first language?	<input type="checkbox"/> Yes <input type="checkbox"/> No (please specify your first language: _____)		
What's the highest level of education you've completed?	<input type="checkbox"/> Did not attend High School <input type="checkbox"/> Some High School <input type="checkbox"/> Completed High School <input type="checkbox"/> Trade or vocational training <input type="checkbox"/> Degree <input type="checkbox"/> Postgraduate qualification		
What do you have experience with? <i>(please tick all that apply)</i>	<input type="checkbox"/> I have chronic kidney disease, OR <input type="checkbox"/> I am a caregiver to someone with chronic kidney disease <input type="checkbox"/> Haemodialysis <input type="checkbox"/> Peritoneal dialysis <input type="checkbox"/> Transplant <input type="checkbox"/> Acute Kidney Injury <input type="checkbox"/> Glomerulonephritis <input type="checkbox"/> Other, please specify: _____ _____		
Do you have any particular areas of interest in kidney disease research?	<input type="checkbox"/> No <input type="checkbox"/> Yes, please specify: _____ _____		
Have you participated in a clinical trial before?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Have you used Zoom (videoconference) before?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Occupation/area of study/particular skills:			

Please email the completed form to [aktn.cec@uq.edu.au](mailto:aktn.cec@uq.edu.au)

Your information will be stored electronically at the AKTN, 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](mailto: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: \_\_\_\_\_