

Expression of interest to be a member of the Consumer Advisory Board

What is the GOAL trial?

Frailty is high among older people with chronic kidney disease (CKD) and can be linked to disabilities and hospital admissions. Doctors who specialise in the care of older people, called geriatricians, routinely do a detailed medical review and care plan with older frail patients. This process is called a Comprehensive Geriatric Assessment (CGA). The benefits of a CGA in older frail patients with CKD have not been studied.

The GOAL trial aims to find out if CGAs help improve the health and wellbeing of frail older people with CKD. The trial will include 500 patients across 16 hospitals in Australia. Geriatricians at 8 of the hospitals will do a CGA for their frail older CKD patients, the other 8 hospitals will follow routine clinical care (no CGA). Patients will be asked to set some personal goals, and complete a quality of life questionnaire. After 3, 6 and 12 months, the goals will be reviewed to see if patients have achieved them and the questionnaire is repeated. The researchers will look at whether the patients who had a CGA are more able to achieve their goals and whether their quality of life is improved. The Australasian Kidney Trials Network is coordinating the trial.

Why do we need a consumer advisory board?

The researchers want to make sure that the trial is designed in a way that is meaningful to patients and carers, and focuses on outcomes that are important to them. The Consumer Advisory Board will help ensure the trial documents that are provided to patients are clear and useful, including when the trial results are shared with the kidney care community. Consumer engagement in research is expected by the National Health and Medical Research Council.

What time commitment is involved?

- A one hour meeting every 2-3 months, mostly via tele/videoconference, and
- One face to face meet per year held in a capital city, and
- A half-full day training workshop at the beginning
- Join meetings until December 2023
- Reasonable travel costs and time will be reimbursed according to Health Consumers NSW

Who are we looking for?

10-12 people, including:

- At least one caregiver of a patient who fits the trial eligibility criteria
- We will aim for at least 70% of the members to fit the trial eligibility criteria:
 - Aged 65 years or over
 - Moderate to severe CKD (eGFR below 59 ml/min/1.73m² i.e.: CKD stage 3-5)

To avoid a conflict of interest, Consumer Advisory Board members cannot be participants in the trial.

When does it all start?

Approximately August 2020

Will members be acknowledged for their input?

With permission, members will be acknowledged on the AKTN website and other trial documents.

How do I become involved?

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

- Chandana Guha (GOAL Project Officer) chandana.guha@sydney.edu.au Tel: 0414 703 870
- Professor Ruth Hubbard (GOAL Lead Researcher) r.hubbard1@uq.edu.au Tel: 07 3443 8043

Why are we asking the questions below?

It is important to the Australasian Kidney Trials Network (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 as many different backgrounds as possible.

Name:		Age:	
Home town:		State:	
Phone:		<input type="checkbox"/> Preferred contact	
Email:		<input type="checkbox"/> Preferred contact	
Gender:			
Ethnicity:			
Experience of chronic kidney disease or frailty condition(s):	<input type="checkbox"/> I have chronic kidney disease (Stages 3-5 / eGFR less than 59) <input type="checkbox"/> I am 65 years or over <input type="checkbox"/> I am a carer for someone with chronic kidney disease (stages 3-5) who is over 65 years of age <input type="checkbox"/> None of the above <input type="checkbox"/> Other, 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/other:			

Please email the completed form to chandana.guha@sydney.edu.au or post it to Chandana Guha, Children’s Hospital at Westmead NSW Australia, Level 2 Crn Hawkesbury Rd and Hainsworth St, Westmead NSW 2145. / Hand it to Chandana Guha.

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

Declaration

We would like to set up a register of people interested in being involved in improving the way we do research studies on Chronic Kidney Disease. Would you like the AKTN to keep your details securely on file so AKTN can contact you about any future consumer involvement or engagement opportunities?

Yes No

You can unsubscribe at any time by contacting us on the following number 0414 703 870.

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

Signature: _____

Date: _____