

Introduction

This document is designed to clarify the role of the BEAT-CKD Consumer Advisory Board, the processes for their selection and succession, and their responsibilities.

For the purposes of this document, consumer is defined as any individual with a lived experience of kidney disease, including: people with CKD, receiving haemodialysis, peritoneal dialysis, kidney transplant recipients or family members/carers (including kidney donors) of a person with kidney disease.

Governance of the BEAT-CKD Consumer Advisory Board is provided by the BEAT-CKD Management and Operations Committees.

Funding of the BEAT-CKD Consumer Advisory Board is provided by the BEAT-CKD NHMRC Program Grant (APP1092957), which supports four national research and translation platforms:

- Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)
- Australasian Kidney Trials Network (AKTN)
- COCHRANE Kidney and Transplant
- KHA-CARI guidelines (Kidney Health Australia – Caring for Australians with Renal Impairment)

The BEAT-CKD Consumer Advisory Board oversees all consumer involvement activities for the BEAT-CKD research program.

Purpose

The primary responsibilities of the BEAT-CKD Consumer Advisory Board are to:

- Help set priorities for research topics and guidelines by providing direction and leadership to the BEAT-CKD program in relation to the needs and priorities of patients with chronic kidney disease and caregivers
- To work with the BEAT-CKD Management Committee to provide consumer insight and feedback to BEAT-CKD research activities, including the planning, conducting, disseminating and implementation of research. Specific tasks may include: reviewing research proposals/ideas, selecting and piloting data collection tools, reviewing research documents (such as consent forms and participant information sheets), developing lay-language summaries of reports and research findings, co-designing consumer events/sessions at scientific conferences
- To identify, promote and implement effective community involvement strategies in kidney disease research – developing resources and tools (both learning from other groups and developing our own relevant to our population)

Composition and terms

- The board will consist of a maximum of ~40 members from around Australia, with at least two from each state and territory
- Members will be selected via an Expression of Interest (EoI), circulated as a minimum through the contact lists collected from the BEAT-CKD Consumer Involvement workshops hosted in Sydney, Adelaide and Brisbane in 2017 and Kidney Health Australia consumer networks

- Sub-groups within the board will be formed, whereby board members contribute to research activities of the four BEAT-CKD groups based on their interests and preferences
- Board members wishing to have a high level of involvement may undertake the role of a co-chair – duration of these positions will be flexible and vary depending on the status and progress of the project or activity. Roles of co-chairs may include providing strategic direction to BEAT-CKD Chief Investigators, preparing meeting agendas for whole board meetings, and facilitating meetings
- Membership as a board member will be for 2 years, with an option to extend, after which an Expression of Interests (EOI) process will take place again

Meeting procedures

- Members will be invited to attend up to 2 meetings a year, with the entire board. Face-to-face (in some states) and electronic options will be provided. These meetings will be co-chaired by a BEAT-CKD researcher and consumer board member.
- Members will attend smaller meetings and participate in discussions (either in-person or via tele/videoconference) as required as part of individual research projects and activities, with informal electronic communication with the relevant BEAT-CKD researchers throughout the project's progress
- Where practicable, the meeting agenda and other relevant documents will be sent to meeting attendees with sufficient time for reading and consideration prior to meetings
- Being a member of the Board is voluntary, however expenses associated with meetings such as transport and parking will be reimbursed

Reporting:

- The BEAT-CKD Consumer Advisory Board has broad accountability and reporting lines to BEAT-CKD Management Committee
- Whilst BEAT-CKD Consumer Engagement initiatives may be in collaboration or partnership with Kidney Health Australia, BEAT-CKD consumer partners do not have direct reporting lines to Kidney Health Australia
- Consumers involved in BEAT-CKD research projects and initiatives will report to the researchers involved as required and agreed upon, by members of these specific groups