

Consumer Involvement Workshops

Overview of workshops across Australia

In 2017, BEAT-CKD and Kidney Health Australia (KHA) hosted 3 Consumer Involvement Workshops across Australia in Sydney, Adelaide and Brisbane.

A total of 148 people attended, including 105 patients and carers.

The workshops included:

- Presentations from researchers about what is currently happening in Chronic Kidney Disease research
- Presentations from patients and researchers about their perspectives of consumer involvement in research
- Discussions about important research topics



Why did we host the workshops?

To make research relevant and important to patients, we want to involve them in all stages of the research process. Patient and carer opinions are critical in deciding important topics for kidney research and how research should be conducted.

The purpose of the Consumer Involvement Workshops held in 2017 was to take the first step in this process – to reach out to patients and carers and ask them how they would like to be involved in research and what research they would like to see. The information we collected from the workshops via surveys and focus groups have helped us to understand how consumers would like to be involved and what issues are most important to them.

What happens next?

For workshop attendees who indicated they would like to have a high level of involvement in kidney disease research:

- We are establishing a BEAT-CKD Consumer Advisory Board with 3 arms based in Brisbane, Sydney and Adelaide (but available online to people everywhere).
- This board will meet regularly in person or via video/teleconference to discuss issues relating to Chronic Kidney Disease research
- There is currently an expression of interest for this group on the BEAT-CKD website <http://beatckd.org/consumeradvisoryboard/> and it will be sent out to you by email as well

For workshop attendees who said they would like to complete surveys or attend research conferences from time to time:

- Conference invitations and surveys will be sent to you from either BEAT-CKD or KHA as they arise – BEAT-CKD and KHA will first approve that this is high quality

Thank you

On behalf of BEAT-CKD and Kidney Health Australia, we would like to thank everyone who attended the workshops or who expressed interest in being on our contact lists. Your time and enthusiasm are our greatest resources for improving kidney disease research in Australia.

The Better Evidence and Translation – Chronic Kidney Disease group (BEAT-CKD): a partnership between researchers across Australia looking at Chronic Kidney Disease (www.beatckd.org)

Kidney Health Australia (KHA): a not-for-profit organisation dedicated to improving the health outcomes and quality of life for people living with kidney disease (www.kidney.org.au)

