

# Moving beyond tokenism: Past, present and the future of consumer engagement in kidney disease research

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## Primer

In September 2016, the National Health and Medical Research Council (NHMRC) and the Consumer Health Forum of Australia released a *Statement on consumer and community involvement in health and medical research*. The purpose of the document is to guide research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research. They define 'consumers' as patients, potential patients, carers and people who use healthcare services. This significant document by the NHMRC recognises that involving consumers and community members adds value to health and medical research, and that they have a right and responsibility to do so.

From a kidney disease perspective, the lack of patient involvement in research can limit the relevance of research to patients and their caregivers, with a recent study showing that 80% of clinical research did not address the top 10 priorities identified by patients with chronic kidney disease (CKD) (Jun et al., 2015). Involving consumers in kidney disease research as equal partners provides enormous benefits not only to researchers to avoid research waste and increase patient recruitment/retention, but also for patients to develop a better understanding of their illness and health systems, and also to strengthen relationships with clinicians, leading to improved engagement in their care and better outcomes.

## The spark that began the patient revolution

Involving consumers (patients, carers and family members) across all stages of kidney research has been gaining

momentum among the nephrology community over the last decade. Nephrologists and researchers proactively involved in this space successfully secured an NHMRC grant that addressed the patient priorities across the research cycle. The Better Evidence And Translation – Chronic Kidney Disease (BEAT-CKD) research collaboration program linked four national kidney disease research and translational platforms – the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), the Australasian Kidney Trials Network (AKTN), the Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) guidelines, and Cochrane Kidney and Transplant.

This program aimed to improve the lives of people with CKD both in Australia and globally by generating reliable evidence to inform healthcare decisions made by clinicians, policymakers and patients. This new program was comprised of academic kidney specialists with a broad range of research skills, clinical expertise and internationally recognised networks. More importantly, it also included consumers with lived experience of kidney disease and their carers as a part of the BEAT-CKD consumer advisory board. The group has embedded consumers in the governance structure of the four national kidney disease research and translational platforms. Members of this advisory board have also been responsible for onboarding and mentoring new consumer research partners at a project level. Currently, most of its members are still involved in tactical capacities as research partners and advisors in all BEAT-CKD research projects through a process of based on interests and expertise.

The BEAT-CKD program was a key paradigm shift in addressing how research is done in Australia and New Zealand, as the investigators conducted three consumer workshops

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held in Adelaide, Brisbane and Sydney which were attended by more than 105 patients and carers and 43 researchers and clinicians. From these workshops, the investigators identified key principles to inform a consumer engagement strategy in kidney disease research. In this research space, the BEAT-CKD program turned into a consumer movement that empowered patients and their caregivers to have their voices heard and included in all aspects of care, policy and research that impacts them as end users; it fittingly echoed the slogan “Nothing about us without us”.

## A domino effect

The success of the BEAT-CKD program created a domino effect and addressed some of the other key areas in terms of opening avenues for consumers. For example, involving consumers in nephrology conferences as plenary speakers, conducting dedicated pre-conference workshops, and providing consumers with complimentary registrations to attend scientific symposiums were considered aspirational and unrealistic before BEAT-CKD. The generous support from the leadership and the Scientific Program and Awards Committee of the Australian and New Zealand Society of Nephrology (ANZSN) developed and implemented its consumer engagement framework.

Since the implementation of the framework, consumers have been appointed to the Society’s key advisory committees and been welcomed to all sessions of the Society’s scientific and policy meetings. Specific consumer plenary sessions have also been created within the main body of the society’s Annual Scientific Meeting, the Dialysis Nephrology and Transplantation Workshop, and the Home Dialysis Conference.

## Not just an Indigenous tick box approach

*Every which way you look at renal disease in Aboriginal people, the only solutions that will work in the long term are those that are Aboriginal-led, culturally responsive, located in Aboriginal organisations and evaluated through an Aboriginal lens – Pat Turner, CEO, National Aboriginal Community Controlled Health Organisation.*

Whether it be the National Indigenous Kidney Transplantation Taskforce (NIKTT), established in 2019, the Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project, or the recent MRFF Indigenous Health Research Grant on Patient Navigators, all of these programs have a strong Aboriginal community reference group which works alongside an enthusiastic research team of clinicians and key decision-makers. All these projects work on the mantra that nothing can be achieved without the explicit involvement of Aboriginal and Torres Strait Islander people, and that Aboriginal patient experts are positioned as chief investigators throughout all research processes. Indeed, in a first of its kind, the latest MRFF grant investigating the best way to integrate patient navigators into

the kidney transplant system is led by a kidney transplant recipient and involves numerous transplant recipients and patient navigators on the core research team. These groups strive hard to deliver equity in kidney care for Aboriginal people across areas such as the delivery of outreach kidney transplant education and assessment in rural and remote areas, the establishment of transplant-focused patient mentor projects and Indigenous Reference Groups, and the strengthening of the Aboriginal and Torres Strait Islander health workforce in kidney transplant settings. The recent launch of the KHA-CARI guideline *Recommendations for culturally safe kidney care for First Nations Australians* is a testament to the Aboriginal consumer-led and co-designed approach in action.

## Current developments

BEAT-CKD investigators were recently awarded \$2.5 million in funding to establish a Centre of Research Excellence: Partnering with patients with CKD to transform care and outcomes (CRE-PACT). A core strategy of CRE-PACT is to train and mentor a minimum of 30 patients/caregivers to participate in research as equal and confident partners. Patient partners are empowered to initiate, design and implement research. One of the key successes of this grant enabled consumers with lived experience of kidney disease to be embedded across the four organisations in a paid role as patient engagement officers.

The mission of the CRE-PACT is to transform the care and health of people with CKD by answering patient-prioritised research questions and addressing outcomes that are critically important to patients. In CRE-PACT, patients will play central roles in prioritising, designing, conducting and translating research. CRE-PACT is by no means a revolution in consumer engagement in kidney disease research but a natural evolution to make consumer engagement more sustainable and to empower consumers as confident partners in kidney research. For example, consumer involvement in the pregnancy and parenthood in kidney disease research project is already at a mature phase, thanks to proactive researchers and an active consumer advisory group who were engaged early in the research cycle.

## Are renal clinical research nurses the future of consumer engagement?

Up until recently in the kidney disease research area, consumer engagement often happened by choice rather than chance, a conscious choice made by champion nephrologists, researchers and advocates. Currently, renal nurses are not only at the coalface of delivery of care to kidney patients, but they also play a significant role in translating research into practice. They have the power to make or break any novel clinical intervention and the ability to recruit and retain consumers in clinical trials. Renal nurses across Australian and New Zealand renal units are already involved as champions to conduct

consumer feedback surveys, recruit and retain consumers in clinical trials, and disseminate study results to participants.

However, it is incredibly important to have more than goodwill in engaging consumers and there is a need for substantive funding to aid the nursing force to upskill or recruit as renal clinical research nurses (RCRNs). A clinical research nurse (CRN) is a specialised registered nurse who combines clinical nursing expertise with research knowledge and skills. A RCRN will deliver rigorous, high-quality clinical research to improve healthcare outcomes, the research participant/consumer experience, and treatment pathways, acting as a consumer champion to ensure ethical and efficient care. Consumer engagement is a deliberate practice by the few visionaries who challenge the status quo by involving consumers in kidney research. Who else is better suited to challenge the status quo than the renal nurses?

## Reference

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## Chief investigators of the research projects mentioned in the editorial

Professor Jeremy Chapman, Professor Allison Jauré (née Tong), Professor Jonathan Craig, Professor Carmel Hawley, Associate Professor Germaine Wong, Professor David Johnson, Dr Nicole Scholes Robertson, Professor Stephen McDonald, Professor Kirsten Howard, Associate Professor Shilpanjali Jesudason, Professor Armando Teixeira-Pinto, Professor Jaqui Hughes, Dr Kim O'Donnell, Dr Janet Kelly, Ms Kelli Owen, Ms Rhanee Tsetsakos, Ms Nari Sinclair, Dr Samantha Bateman, Dr J Lavoie, Ms Kate Tyrell, Mr Neil Wilkshire, Ms Cedrina Algy, Mr David Crocker, Mr Lachlan Ross, Ms Amy Graham, Ms Heather Hall, Mr Peter Henwood.