

Patient Engagement in Kidney Research – Workshop Invitation

We need patients with kidney disease and their carers to become involved in shaping future kidney research in Australasia by taking part in a patient engagement project.

Background and purpose

The purpose of the patient engagement project is to strengthen the engagement between patients, health professionals and policy makers who are leading kidney research.

The Better Evidence and Translation – Chronic Kidney Disease (BEAT-CKD) research program (<http://beatckd.org/>) aims to improve the lives of people living with chronic kidney disease in Australia by generating high-quality research evidence to inform healthcare decisions made by patients, health professionals and policy makers. It includes:

- the Australasian Kidney Trials Network (AKTN) – which leads trials of new treatments for kidney disease;
- the ANZDATA Registry – which coordinates the data collections used for planning health services and quality assurance programs for dialysis and transplant units; and
- the CARI guidelines – these are the clinical practice guidelines, which kidney specialists use to guide treatment choices for patients.

Involvement of patients and carers is important to make sure research addresses the most relevant problems, and to make sure that results are communicated back.

We are hosting one-day workshops in different Australian states specifically for PATIENTS and their CARERS (FAMILY MEMBERS) to have a voice in kidney research. We invite you to attend, hear about kidney research and share your thoughts and experiences – help us to shape the kidney research of the future!

The patient engagement workshop will:

1. Give you information about what is going on in the research world for kidney patients
2. Discuss ways for more patients to have a voice and help researchers decide what to study and how to go about it
3. Help set up new pathways for getting patients and their communities involved in research
4. Enable patients to have a say in existing research programs, including BEAT CKD

You don't have to have any research experience or qualifications.

WE need patients and carers who are living with kidney disease to come along and give us your perspectives and ideas. Help us develop the best research for YOUR future!

What will be required of you if you participate in the consumer engagement workshop?

The first consumer engagement workshop is being held on **Friday the 18th of August** at the **Mercure Hotel Sydney**. The workshop will run from 9:00am to 4:15pm.

Participants are engaged in a volunteer capacity, and will be considered part of the BEAT CKD research group. There is no payment for involvement in the Patient Engagement Workshop. However, for those driving, parking expenses will be covered. Refreshments and lunch will be provided.

The workshop will involve some presentations and interactive workshops to describe current kidney research taking place in Australia and what patient and community involvement looks like in this environment. The presentations will cover barriers to patient participation, and are designed to help break these down and increase ways you can become involved. There will also be discussions which will enable you to voice your priorities for kidney research and talk about what ongoing participation following on from the workshop would look like.

Program*

*May be subject to change

Time	Session
9.00 am	Registration & Coffee
9.15 am	Welcome and introductions <i>Anne McKenzie</i>
9.30 am	Overview of Chronic Kidney Disease Research in Australia ⁽¹⁾ <i>Carol Pollock (TBC)</i>
10.00 am	Morning tea
10.15 am	What is consumer & community participation? <i>Anne McKenzie</i> <ul style="list-style-type: none"> • Definitions • Why is important and what are the benefits? • The principles • Where does it fit within the research cycle? • Levels of participation
11.15 am	Effective consumer engagement – presentations and panel discussion <ul style="list-style-type: none"> • Consumer perspective <i>Jo Watson – Health Consumer Advocate, Deputy Chair of the Consumers Health Forum of Australia.</i> • CKD consumer perspective <i>Fabian Marsden (TBC)</i> • Researcher perspective <i>Shilpa Jesudason (TBC)</i>
12.30 pm	Lunch
1.15 pm	Methods for consumer and community participation <i>Anne McKenzie</i>
1.45 pm	Putting the theory into practice – Models of engagement
2.30 pm	Break
2.45 pm	Putting the theory into practice – Getting involved in kidney research initiatives e.g. registries (ANZDATA), clinical trials (AKTN), guidelines (KHA-CARI)
4.00 pm	Review, evaluation and next steps
4.15 pm	Close

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