

Centre of Research Excellence – Partnering with Patients with Chronic Kidney Disease to Transform Care and Outcomes

Annual Forum & Workshop

Preliminary Program

Monday 20th November 2023, 11:30am-3:00pm AEST

Primary venue: Translational Research Institute, Brisbane

Satellite sites: Sydney (USyd) and Adelaide (SAHMRI & Flinders Centre for Innovation in Cancer)

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Information

Date: Monday 20th November 2023

Venues:

Primary

- Translational Research Institute, Auditorium and Seminar Rooms, 37 Kent Street, Woolloongabba 4102, Brisbane.

Satellite sites

- South Australian Health and Medical Research Institute, North Terrace, Adelaide.
- Flinders Centre for Innovation in Cancer, Flinders Medical Precinct, Bedford Park, Adelaide.
- The Susan Wakil Health Building, The University of Sydney, Camperdown, Sydney.
- Zoom: Facilitation details TBC.

Format:

The forum will begin with an internal operations meeting, which will include the Management team, members of the CRE-PACT sub-committees (training, research, partnership) and the Patient Advisory Group (PAG). This will be followed by a forum and workshop which will both be open to the broader membership of the BEAT-CKD/CRE-PACT Network and other consumers, researchers, health professionals and students who would like to attend.

Workshop cost and reimbursement:

- The cost to attend will be free.
- External members of the PAG (i.e. who do not have a research/academic appointment) will be reimbursed \$50 per hour for the operations meeting.
- Consumers attending the workshop in person (external i.e. who do not have a research/academic appointment) will be provided with a \$50 reimbursement of travel expenses. This will be organised by the respective sites as processes at the various institutions differ.

Registration: https://uqmedicine.syd1.qualtrics.com/jfe/form/SV_3UeptUURKYUU1sW

Outline

The BEAT-CKD Centre for Research Excellence – Partnering with patients to transform care and outcomes (CRE-PACT) annual forum and workshop is for patients, family members, caregivers, clinicians, and researchers with an interest in involving patients in research across the spectrum of chronic kidney disease. The proposed theme of this year’s workshop is “*Partnering with patients and caregivers to disseminate and implement research*”.

This event will be facilitated by the BEAT-CKD CRE pillars:

- Australasian Kidney Trials Network (AKTN)
- Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)
- Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines
- Cochrane Kidney and Transplant

Who can attend the forum and workshop?

All researchers and health professionals working in the area of kidney disease – including nephrologists, nurses, dietitians, social workers, psychologists, physiotherapists and other disciplines – with an interest in involving consumers in research in kidney disease. This event is also open to patients with chronic kidney disease, family members, consumer advocates, caregivers, policy makers and industry representatives.

Preliminary Objectives

The goals of the event are to:

- Review and establish plans for the CRE-PACT (Management Committee only).
- Promote understanding and discuss ways to enhance, expand and extend patient/caregivers involvement in research in chronic kidney disease with a focus on dissemination and implementation.
- Provide opportunities for networking and to establish and build relationships among patients, caregivers, researchers and health professionals.
- To identify consensus-based strategies to effectively disseminate and implement research findings to patients and caregivers to in a meaningful way that is important to patients.

Preliminary Program

MONDAY 20TH NOVEMBER 2023

Time Session

BEAT-CKD Forum & Workshop

11:30am Registration opens, lunch and networking on arrival

12:00pm Welcome: TBC.
Acknowledgements of Country (AUS & NZ): TBC.

12:05pm Overview and update on BEAT-CKD – key highlights

- Training: imPACT Training Program (Anastasia Hughes, 5mins)
- Research: seminars, consumer involvement (TBC, 5mins)
- Partnership: engagement and dissemination (Shilpa Jesudason, 5mins)

12:20pm Panel Discussion: Learnings from consumer-initiated and consumer-led projects (30mins)
Chair: Nicki Scholes-Robertson

- Consumer Advisory Boards for trials (Chandana Guha, 5mins)
- TBC (5mins)
- TBC (5mins)

12:50pm Presentation: Making an Impact – Dissemination and Implementation of Research
Chair: Jonathan Craig
Presenter: Adeera Levin (15mins)

1:10pm **WORKSHOP: Dissemination, Implementation and Impact of Research**
Chair: Allison Jaure

Background: The generation of research evidence is intended to improve care and outcomes for patients. Despite this, research is disseminated predominantly through biomedical journals for health professionals. There is growing recognition that research should also be accessible for patients and caregivers. Some scientific journals, including in nephrology, have developed plain language summaries and consumer-facing materials. Also, the impact of research is traditionally measured based upon academic-based metrics (e.g. number of publications, citations, journal ranking). However, the impacts of research of importance to patients are not well-known. Additionally, consumers are not routinely involved in the implementation of research into practice and policy. Strategies are needed for disseminating research to consumers in a meaningful way and to facilitate the evaluation of research impacts of importance to consumers.

Aim: To describe the perspectives of consumers and researchers on the dissemination and implementation of research in chronic kidney disease.

Participants: patients, caregivers, clinicians, researchers, policy makers, representatives from stakeholder organisations (e.g. KHA, ANZSN, RSA).

In-person and online, via zoom

Program:

- a) Facilitated breakout group discussion
 - i. Dissemination – how can research be communicated to consumers? (25mins)
 - ii. Implementation – how can consumers be involved in implementing research in practice and in policy? (25mins)

2:00pm 10min break, refreshments

2:10pm iii. Impact – what impacts of research are meaningful to consumers? (25mins)

2:35pm b) Summary from each group (presented by Allison Jaure, 25mins)

3:00pm Event Close (including thank you and evaluation)

Presenter biographies

TBC