



# PACER Network Consumer Q&A Panel

1:00-3:00 pm, Tuesday 10 September 2019

Seminar Room  
Kids Research

# Introduction

**Time and Date:** 1:00 - 3:00 pm, Tuesday 10<sup>th</sup> September 2019

Lunch from 1:00 pm and panel discussion from 2:00 pm

**Venue:** Seminar Room, [Kids Research](#)

**RSVP:** by Sunday 8<sup>th</sup> September at <https://tinyurl.com/pacerinvolve>

We will be hosting a consumer Q&A panel on meaningful and sustainable consumer involvement in health research

For those who cannot attend in person, the session will also be broadcasted live on Zoom [here](#) and a recording will be uploaded onto the website afterwards.

It will be an opportunity for consumers with experience or an interest in research, researchers and clinicians to network and discuss purposeful and active consumer involvement in health research.

There will be time for online or in-person attendees to ask questions at the end.

If you have any questions about this event you can email Elyssa at [sph.pacer@sydney.edu.au](mailto:sph.pacer@sydney.edu.au)

## Program

Time	Session
1:00-2:00 pm	Networking lunch
2:00-2:15 pm	<b>Welcome</b> Allison Tong and Chandana Guha <b>Acknowledgement of Country</b> Victoria Sinka <b>Panelist Introductions</b>
2:15-2:45 pm	<b>Panel Discussion</b> Chairs: Allison Tong, Chandana Guha Consumer Representative Panelists: Amanda Sluiter, Anne McKenzie, Elaine Todd & Jan Mumford
2:45-3:00 pm	Q&A and panel close



# Chair and Panelist Biographies



**Professor Allison Tong**, *Sydney School of Public Health*

Allison is a Principal Research Fellow at the Sydney School of Public Health, The University of Sydney. She has experience in using applied qualitative research methods to the area of chronic disease; to inform practice and policy for improved patient-centred outcomes. She has a particular interest and experience involving patients in research, particularly in research priority setting and the development of core outcomes for research. She co-founded the global Standardised Outcomes in Nephrology ([SONG](#)) Initiative, which aims to establish consensus-based core outcomes across the spectrum of chronic kidney disease.



**Chandana Guha**, *Centre for Kidney Research*

Chandana is a consumer representative and research assistant with training in statistics. When her daughter was diagnosed with kidney disease and received a transplant at the age of 11 years, Chandana joined Transplant Australia to develop the online patient support resource "[Living with your Transplant](#)" for post-transplant care. She currently works on the NAVKIDS<sup>2</sup> program - a study on the effectiveness of a patient navigator in supporting children diagnosed with kidney disease and their families. She is also a steering group member of the Standardised Outcomes in Nephrology ([SONG-Kids](#)) initiative.



**Amanda Sluiter**, *Perinatal Society of Australia and New Zealand*

I am a kidney transplant recipient and the mother of two children born prematurely. I am an active member of PSANZ as the Co-Chair of the Consumer Advisory Panel and consumer representative for IMPACT Network which is dedicated to improvement of maternal and perinatal health by promoting well-designed randomised controlled trials (RCTs), and dissemination and application of their results. I have a particular interest in improving patient care and support within the hospital environment.



**Anne McKenzie**, *Telethon Kids Institute & Consumers Health Forum of Australia*

Anne is the Manager of Community Engagement at Telethon Kids. She was previously Head of the Consumer and Community Health Research Network where she established a Strategic Framework and Program of Work for consumer and community involvement across the WA Health Translation Network's partner organisations. She is a senior consumer representative for Consumers Health Forum of Australia, former Chair of Health Consumers Council WA, Honorary Life Member of the Health Consumers Council WA, Member of the Order of Australia and serves on key state and national health committees.



**Elaine Todd**, *Consumer Dementia Research Network & Alzheimer's Australia*

I became a carer in April 1996 and this started my future involvement in consumer advocacy and dementia research. I was an inaugural member of Alzheimer's Australia NSW Consumer Reference Group; the Alzheimer's Australia Consumer Dementia Research Network; Health Consumers NSW; and COTA NSW Consumer Reference Group - giving me the privilege to be included in some very interesting research projects over the years. I volunteer with The Royal Rehabilitation Centre at Ryde am a member of Combined Pensioners and Superannuants Association and a sub-Branch member of RSL NSW.



**Jan Mumford**, *Cancer Voices, Genetic Alliance Australia & Australasian Gastro Intestinal Trials Group*

Jan survived pancreatic cancer as a young mother of three children. As Chair of the AGITG Consumer Advisory Panel, she hopes to help make information about new cancer treatments available to future pancreatic cancer sufferers. Jan is also part of the Cancer Council NSW Consumer Review Panel and is the Executive Director of Genetic Alliance Australia, who support individuals and families affected by a rare genetic condition or rare disease, where she works with research groups to provide a community perspective.