

Research forum and Workshops on chronic kidney disease

1. Research Forum: Monday 23rd, Tuesday 24th, [register here](#)
2. Workshops: Wednesday 25th July 2018, [register here](#)

Translational Research Institute (TRI), 37 Kent Street,
Woollongabba, Brisbane, Queensland 4102

Introduction and Contents

Time and Date: Research Forum on Monday 23rd and Tuesday 24th July, with workshops on 25th July 2018
Concurrent research skills workshops on 25th July will cover four streams – Clinical trials, Qualitative research, Registries, and Health economics

Venue: Translational Research Institute (TRI), 37 Kent Street, Woolloongabba, Brisbane, Queensland 4102

Outline

This nationwide [research forum and workshops](#) is for patients, clinicians, and researchers with an interest in conducting and implementing research to improve outcomes for people with chronic kidney disease. The forum provides a unique opportunity to hear and discuss innovative methods, high-priority research projects, and to meet potential collaborators. This will focus on research into chronic kidney disease, facilitated by infrastructure to support these activities in Australia and New Zealand including the:

- 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?

This forum is open to all health professionals working in the area of kidney disease – including nephrologists, nurses, dieticians, social workers, psychologists, physiotherapists and other disciplines - with a research interest in patients with kidney disease. This meeting is also open to consumers with CKD (patients or caregivers), policy makers and industry.

The research skills workshops are aimed at all clinical staff interested in research, and are applicable to most research areas.

Meeting Objectives

The goals of the forum are:

- To build capacity in clinical and population health research applied to CKD
- To facilitate enhanced multidisciplinary collaboration
- To promote the understanding and uptake of new methods
- To develop a shared research agenda among all relevant stakeholders, especially among patients and their caregivers

The goal of the workshops is to provide professional development in research skills.



Program

DAY ONE: MONDAY 23 RD JULY 2018, TRI AUDITORIUM, LEVEL 2	
Time	Session
9:00 am	Registration and coffee
9:30 am	Welcome: BEAT-CKD Research Forum Professor Carmel Hawley
9:45 am	SESSION 1: A BRAVE NEW WORLD (IN CLINICAL TRIAL RESEARCH) Chair: Professor Carmel Hawley
9:55 am	Adaptive trials: Use of Bayesian methods for trials of complex interventions in chronic diseases - Dr Tom Snelling
10:30 am	Discussion
10:40 am	Morning tea
11:00 am	SESSION 2: AKTN - ANZDATA Registry-based Clinical Trials Chair: Dr Magid Fahim
11.05 am	BEST-Fluids Study – Dr Michael Collins
11.20 am	RESOLVE Study – Associate Professor Meg Jardine
11.35 am	Panel discussion
11:50 am	Quick break
11:55 am	SESSION 3: AKTN – Clinical Trials Chair: Professor David Johnson
12:00 pm	REMOVAL-HD Study – Dr Rathika Krishnasamy
12:15 pm	FAVOURED Study – Dr Andrea Viecelli
12:30 pm	Panel discussion
12:45 pm	Lunch
1:30 pm	SESSION 4: ANZDATA Registry Update Chair: Professor Stephen McDonald
2:00 pm	Reproductive and Perinatal Epidemiology, and Public Health in Australia - Distinguished Professor Elizabeth Sullivan
2:45pm	Pregnancy and CKD: lessons learned from data – Dr Shilpa Jesudason
3:15 pm	Afternoon tea
3:40 pm	SESSION 5: ANZDATA Registry Chair: Professor Stephen McDonald
3:45 pm	Lessons learnt: Impact of Registry based trials on ANZDATA - Ms Kathryn Dansie
4:10 pm	PROMS and Registries? Where are we going? – Associate Professor Rachael Morton
5.00 pm	Forum Close
	Free time
6.00 pm	Conference dinner – Chu the Phat Restaurant, 109 Melbourne St, South Bank for informal drinks, followed by set dinner; Deposit required
7.00 pm	Presentation – PEXIVAS Study - Associate Professor Chen Au Peh
8.30 pm	Dinner ends

DAY 2: TUESDAY 24TH JULY 2018, TRI AUDITORIUM, LEVEL 2

Time	Session
9:00 am	Registration and coffee
9:30 am	SESSION 6: CARI-KHA/COCHRANE KIDNEY AND TRANSPLANT <i>Chair: Dr Martin Howell</i>
9:35 am	Consumer involvement in research – Mr Martin Chambers
10:05 am	New directions in consumer engagement: Cochrane and beyond – Ms Anneliese Synnot
10:45 am	Morning tea
11:15 am	SESSION 7: RESEARCH TRANSFER: AN OVERVIEW AND CONSUMERS AS EFFECTIVE AGENTS <i>Chair: Professor Jonathan Craig</i> Can we make evidence-informed practice change the norm? – Associate Professor Ian Scott “When it works, it is probably because they understand what we want of them”. Consumer involvement in research; so how active do you want it – Ms Jo Watson Taking small steps or a big leap on consumer engagement? Reflections on what can change with the big leap – Dr Sophie Hill
1:00 pm	Lunch Post-graduate/ECR session @ Room 2004 <i>Chairs: Yeoungjee Cho, Phil Clayton, Allison Tong</i>
2:00 pm	SESSION 8: PhD PRESENTATIONS + DISCUSSIONS <i>Chair: Associate Professor Allison Tong</i> Dietary protein and eGFR – Dr Amelie Bernier-Jean Consumer involvement in research (report of BEAT-CKD workshops) – Ms Talia Gutman SONG-PD – Ms Karine Manera Establishing a core patient-reported outcome for life participation in kidney transplant recipients – Ms Angela Ju
3:30 pm	Afternoon tea
3:45 pm	SESSION 9: PATIENT SESSION <i>Chair: Dr Martin Howell</i> Panel discussion: ways forward to improve consumer involvement in research
4:15 pm	Panellists: Dr Sophie Hill, Ms Jo Watson
4:30 pm	Forum Close

DAY THREE: WEDNESDAY 25TH JULY 2018 – WORKSHOP ONE, TRI Room 3000, Level 3

Time	Workshop One: Qualitative health research Facilitators: Allison Tong, Talia Gutman
9.30 – 10.00 am	Registration and coffee
10.00 – 10.20 am	SESSION 1: Introduction
	SESSION 2: Qualitative research design
10.20 – 10.40 am	Exercise 2a) Study design
10.40 – 11.00 am	SESSION 3: Data Collection
11.00 – 11.10 am	<ul style="list-style-type: none">• Observation• Document Analysis
11.10 - 11.30 am	Morning tea
11.30 – 11.50 am	SESSION 3: Data Collection (continued)
	<ul style="list-style-type: none">• Interviews
11.50 – 12.40 am	Exercise 3a) Interviews
12.40 – 1.00 pm	SESSION 3: Data Collection (continued)
	<ul style="list-style-type: none">• Focus groups
1.00 – 1.30 pm	Lunch
1.30 – 2.00 pm	Exercise 3b) Focus groups
2.00 – 2.30 pm	SESSION 4: Data Analysis
2.30 – 3.15 pm	Exercise 4a) Initial coding
3:15 - 3.30 pm	Afternoon Tea
3.30 – 4.20 pm	SESSION 5: Appraisal and reporting
4.20 – 4.45 pm	SESSION 6: Publishing qualitative studies
4.45 – 5.00 pm	Questions, evaluation and close
5.00 pm	Workshop close

DAY THREE: WEDNESDAY 25TH JULY 2018 – WORKSHOP TWO, TRI Room 6000, Level 6

Time	Workshop Two: Health Economics Facilitator: Martin Howell
8:30 – 9:00 am	Registration and coffee
9:00 - 10:30 am	SESSION 1: Introduction to economic evaluations – Part 1 What are economic evaluations? What costs? – it all depends on the perspective Discounting – why and how much? Questions/Discussion
10:30 – 10:45 am	Morning tea
10:45 – 12:30 pm	SESSION 2: Introduction to economic evaluations – Part 2 Types of benefits Estimating utility and QALYS – approaches and limitations Group Exercise – Calculating QALYs, and ICERs and how to interpret
12:30 – 1:15 pm	Lunch
1:15 – 3:00 pm	SESSION 3: Practical Applications – Informing Practice and Policy Clinical trials Economic models Pharmaceutical Benefits Advisory Committee
3:00 – 3:15 pm	Afternoon Tea
3:15 – 4:15 pm	SESSION 4: The Role of Preferences and Values What are preferences and how can they be measured? Whose preferences? Group discussion using a case study – e.g. deceased donor organs
4:15 pm	Workshop close

DAY THREE: WEDNESDAY 25TH JULY 2018 – WORKSHOP THREE, TRI SPARQ-Ed, Level 2

Time	Workshop Three: ANZDATA Registry Facilitator: Stephen McDonald
8:30 - 9:00 am	Registration and coffee
9:00 - 10:20 am	SESSION 1: Introduction: Basic structure of ANZDATA. Identity and comorbidity tables Core: Dialysis tables, peritonitis, transplant The rest of ANZDATA ANZOD
10:20 - 10:45 pm	Morning tea
10:45 - 12:45 pm	SESSION 2: Using ANZDATA – tricks to setting up the dataset. Merging. Common outcomes Basics of Multivariate model: selection, construction, assumptions Checking assumptions and dealing with violations and missingness Survival analyses 1. Basics of K-M, Cox model
12:45 - 1:30 pm	Lunch
1:30 - 2:30 pm	SESSION 3: Practical Issues Practical issues 1: Log files, projects, do and ado files Practical issues 2: Macros, loops and how to use them Practical issues 3: Graphs
2:30 - 3:00 pm	Afternoon Tea
3:00 - 3:30 pm	SESSION 4: Survival analyses 2: Extending the Cox model
3:30 - 4:15 pm	Putting it into practice – bring a question
4:15 pm	Workshop close

DAY THREE: WEDNESDAY 25TH JULY 2018 – WORKSHOP FOUR, TRI Room 2007, Level 2

Time	Workshop Four: Clinical Trials
8:00 – 8:30 am	Registration and coffee
8:30 – 9:15 am	SESSION 1: Introduction to clinical trials <i>Facilitator: Professor Carmel Hawley</i> Developing a question Why trials are essential Feasibility and pilot studies
9:15 - 10.15 am	SESSION 2: Trial Designs <i>Facilitator: Ms Elaine Pascoe</i> Parallel group, cross-over, and multi-arm factorial designs Cluster designs; superiority and non-inferiority objectives
10:15 - 10:30 am	Morning tea
10:30 - 11:30 am	SESSION 3: Trial Outcomes <i>Facilitator: Dr Magid Fahim</i> Developing an outcome Surrogate and composite outcomes Types of outcome measures and statistical structures
11:30 – 12:30 pm	SESSION 4: Randomization <i>Facilitator: Associate Professor Mark Chatfield</i> The need for random assignment Methods of randomisation, minimisation, blinding and allocation concealment
12:30 – 1:00 pm	Lunch
1:00 – 2:00 pm	SESSION 5: Sample size determination <i>Facilitator: Ms Elaine Pascoe</i> Calculating study size for common outcomes and designs Assumptions, adjustments for loss to follow-up and non-compliance
2:00 – 3:00 pm	SESSION 6: Adaptive designs <i>Facilitator: Associate Professor Stephane Heritier</i> Inefficiencies in traditional designs, types of adaptations, multi-arm Bayesian adaptive designs
3:00 – 3:15 pm	Afternoon Tea
3:15 – 4:00 pm	SESSION 7: Data monitoring <i>Facilitator: Professor Carmel Hawley</i> Interim monitoring of safety and efficacy data Data and safety monitoring boards
4:00 – 4:30 pm	SESSION 8: Running a clinical trial <i>Facilitator: Dr Magid Fahim</i> Real life considerations in starting and running a clinical trial
4:30 pm	Workshop close

BEAT CKD

BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE

2018 Research forum and workshops

Speaker and Chair Biographies



Dr Tom Snelling (BMBS DTMH GDipClinEpid PhD FRACP) is a paediatric infectious diseases physician at Princess Margaret Hospital, Western Australia, NHMRC Career Development Fellow and the Director of the Telethon Kids Institute's Wesfarmers Centre of Vaccines & Infectious Diseases.

His research addresses the implementation of health policy and clinical practice, in particular the evaluation of vaccination and other public health strategies to minimise the burden of childhood infectious diseases. This work integrates clinical trials with case-control and cohort studies and disease modelling. Tom is currently investigating how best to prevent and treat gastroenteritis, pneumonia, pertussis and other lower respiratory infections, and congenital rubella. His work has a strong focus on Aboriginal and international child health. Meanwhile, he is also investigating the safety of vaccination in early childhood.



Professor Carmel Hawley (MBBS, M.Med Sci, FRACP) is a full-time nephrologist at Princess Alexandra Hospital (PAH), Queensland. Her other current roles include Assistant Director, Haemodialysis Service at PAH, Professor, School of Medicine, University of Queensland, inaugural and current chair of Operations Secretariat of the Australasian Kidney Trials Network (AKTN). Under Professor Hawley's stewardship, the AKTN's research output is internationally recognised for its quality and impact, has driven major advances in the evidence, and directly informs the care and outcomes for people living with chronic kidney disease.

Carmel holds a Master's degree in Biostatistics, and has expertise in trial methodology, design and conduct. She is currently involved in numerous industry-led and/or investigator initiated international and national clinical trials as either a Principal or Associate Investigator, providing leadership and direction to emerging early and mid-career researchers. She is also heavily involved in the conduct of complex statistical analyses of observational data for the current Peritoneal Dialysis Working Party of the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry. This has led to the publication of numerous highly cited manuscripts of original research, many of which have informed current practice guidelines from the International Society of Peritoneal Dialysis (ISPD).



Professor David Johnson PSM MBBS (Hons, Univ Medal) (Qld), PhD (Syd), DMed(Res), FASN, FRACP is currently Director of the Metro South and Ipswich Nephrology and Transplant Service (MINTS) and Medical Director of the Queensland Renal Transplant Service at Princess Alexandra Hospital (PAH), Queensland, Professor of Medicine and Professor of Population Health at University of Queensland, and Director of the Centre for Kidney Disease Research, Brisbane, Australia. He holds international leadership responsibilities as President of the International Society for Peritoneal Dialysis (ISPD), Councillor of the International Society of

Nephrology (ISN), Co-Chair of the ISN Global Kidney Health Atlas, and Co-Chair of the Global PDOPPS Steering Committee.

He is the principal investigator on a number of large, multi-centre randomised controlled trials, including the balANZ, HERO, IDEAL, IMPENDIA, HONEYPOT and CKD-FIX trials, and is chair of the Data Safety and Monitoring Board for the FINESSE trial. He has won numerous research awards for his clinical and basic science studies in the areas of peritoneal dialysis outcomes, cardiovascular risk factor modification in uraemia, renal

transplantation, dialysis unit infection control, treatment of acute kidney injury and mechanisms of progressive chronic kidney disease. Internationally, David's contributions to nephrology have also been highly recognised.



Dr Magid Fahim (MBChB (Distinction), PhD, FRACP) is a full-time Senior Staff Specialist Nephrologist at the Princess Alexandra Hospital, a Senior Lecturer with the Faculty of Medicine, University of Queensland, and a Clinical Trialist with the Australasian Kidney Trials Network (AKTN). He undertook his medical training in both New Zealand and Australia, and currently cares for patients across the entire spectrum of chronic kidney disease. His primary research interests are in developing efficient clinical trial constructs that integrate research into clinical practice, and evaluating diagnostic and monitoring tools to improve clinical decision-making.

He chairs the AKTN working group on Trial Methodology and has been involved in the design and conduct of numerous randomised controlled trials and large, observational cohort studies. He is a member of the Cochrane Kidney Group Advisory Board, and the Early Career Researcher Committee (University of Queensland). He is currently supervising two doctoral students and has received numerous competitive research grants and awards.



Dr Michael Collins (MBChB FRACP PhD) is a Nephrologist at Auckland City Hospital, New Zealand, and has clinical and research interests in Transplantation. His research focuses on clinical trials and the epidemiology of kidney transplantation with the aim of improving care and outcomes for kidney transplant recipients. He is a 2017 and 2018 RACP Jacquot Research Establishment Fellow and has received funding from the BEAT-CKD program and the MRFF in Australia, and the HRC in New Zealand. He is the principal investigator of the BEST Fluids trial, which is a pragmatic registry based trial being conducted utilising the ANZDATA registry.



Associate Professor Meg Jardine (MBBS, FRACP, PhD) is a clinical researcher at The George Institute for Global Health, a Conjoint Associate Professor of Medicine at The University of UNSW and a practising nephrologist at Concord Repatriation General Hospital and the Sydney Adventist Hospital. Her research interests centre on the use of innovative and cost-effective methodologies to investigate the impact of pharmaceutical, device and health service interventions on outcomes for people with chronic disease. She is the Deputy Chair of the Scientific Committee of the Australasian Kidney Trials Network (AKTN) and the immediate past

Chair of the Haemodialysis Working Group, AKTN. In addition, she is a member of the ISN Advancing Clinical Trials Committee and a member of the national nephrology association (ANZSN) Research Advisory Committee as well as a Can-SOLVE CKD International Research Advisory Committee member. She has contributed to Working Groups and Conferences of the International Society of Nephrology and to national and international guideline groups.



Dr Rathika Krishnasamy (MBBS, FRACP, PhD) is an Academic Clinical Nephrologist, based at the Sunshine Coast University Hospital and Senior Lecturer for the Faculty of Medicine at the University of Queensland. She is an emerging clinical trialist and early career researcher in cardiovascular disease and chronic kidney disease-mineral and bone disorders (CKD-MBD) with a proven outstanding track-record in trial design and conduct in less than 2 years following completion of her PhD. She played an integral role in leading the REMOVAL-HD

trial in all aspects of development and conduct in Australia and New Zealand resulting in successful completion of recruitment in the allocated time-frame. Dr Krishnasamy is the Australian Fellow for the RESOLVE study; a global, pragmatic, NHMRC funded, and comparative effective trial of dialysate sodium concentrations in haemodialysis. She holds numerous national appointments including Clinical Trialist and Executive Operations Secretariat at the Australasian Kidney Trials Network (AKTN), Haemodialysis Working Group member for the AKTN and Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, steering committee for the Australian Calciphylaxis Registry and ANZ/Canada Exercise Collaboration Group.



Dr Andrea Viecelli is a Nephrologist in Brisbane and enrolled in a PhD examining strategies for improving vascular access outcomes in patients on haemodialysis. She is a lead investigator in the FAVOURED study, an international, multicentre randomised controlled trial of fish oil and aspirin for preventing arteriovenous fistula failure. She is also a member of the Coordinating Committee for the global Standardised Outcomes in Nephrology Group (SONG) initiative, which aims to improve the relevance, reliability and comparability of evidence informing clinical decision-making by developing core outcomes across the spectrum

of kidney disease based on the shared priorities of patients, clinicians, researchers and policy makers. As the project coordinator for the SONG-Haemodialysis Vascular Access working group, she is conducting clinical and qualitative research to establish a standardised core outcome measure for haemodialysis vascular access.



Professor Stephen McDonald is based at the Royal Adelaide Hospital as Director of Dialysis and a Senior Staff Nephrologist at The Central Northern Renal and Transplantation Service (based at the Royal Adelaide Hospital), and Clinical Director of Renal Services for the Country Health region of SA Health. He is Executive Officer of the Australia and New Zealand Dialysis and Transplant Registry, and holds academic status as Clinical Professor in the Department of Medicine of the University of Adelaide, and Principal Research Fellow in the SA Health and Medical Research Institute. Following clinical training in nephrology at various hospitals in Adelaide, he moved to the world of epidemiological research at Menzies School of Health Research in Darwin in 1998. There he examined relationships between early kidney and cardiovascular disease and markers of inflammation and nutrition among remote Aboriginal communities. He also spent time as a general physician to a number of remote Aboriginal communities. Later he returned to Adelaide to a post-doctoral position in the ANZDATA Registry, and ultimately staff nephrologist post with the Dept. of Nephrology & Transplantation Service at The Queen Elizabeth Hospital and more recently in the amalgamated Central Northern Adelaide Renal and Transplantation Service at the Royal Adelaide Hospital. He retains a substantial interest in non-metropolitan renal services in his role as Clinical Director for Renal Services for County Health SA; he also provides the renal transplant assessment service in Alice Springs and Darwin. As a clinician, his practice includes care for in- and out-patients with all types of kidney disease including acute and chronic kidney disease, people receiving all forms of dialysis and those with kidney transplants.



Distinguished Professor Elizabeth Sullivan (MD, MPH, MMed (Sexual Health), MBBS, Cert SRH., Cert Executive and Management Development, FAFPHM (Fellow Australasian Faculty of Public Health Medicine)) is a public health physician and medical epidemiologist. She is Assistant Deputy Vice Chancellor Research, Director Australian Centre for Public and Population Health Research, and Head of Discipline of Public Health at UTS. She is academic lead of Athena SWAN at UTS and committed to gender equity in research. She established AMOSS, a national maternity research system for rare severe conditions in pregnancy in 2009. Formerly Director of the National Perinatal Epidemiology and Statistics Unit in the School of Women's and Children's Health from 2002-May 2014. She has specialised in reproductive and perinatal epidemiology.



Dr Shilpa Jesudason (MBBS, PhD, FRACP) is a Staff Specialist Nephrologist and Chair of the Clinical Research Group at the Royal Adelaide Hospital's Central Northern Adelaide Renal and Transplantation Service (CNARTS). Her clinical and research interests include Parenthood in Patients with Kidney Disease. She runs a Renal Pregnancy Clinic for preconception counselling, antenatal and postnatal care, and her research program employs a broad array of methodologies (population data linkage, registry, cohort studies, qualitative, basic science) to investigate parenthood outcomes for women and men with renal disease. As Chair of the CNARTS Clinical Research Group she leads a number of patient-centred studies to improve clinical care and practice in CNARTS and beyond. She is also the National Clinical Director of Kidney Health Australia, the peak consumer education, support and advocacy organisation.



Kathryn Dansie works as a Research Officer at the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA). She has studied Biomedical Science, majoring in Anatomy and Physiology, with Honours in Neuroscience. She worked previously in Paramedic Science as a Research Officer, where she was involved in a range of projects in the field of Emergency Medicine. She is also currently studying her Masters in Biostatistics. In her position at ANZDATA she is responsible for integration of registry-based trials into the ANZDATA registry and is involved in data linkage projects, consumer engagement and registry based Patient Reported Outcome Measures (PROMs).



Associate Professor Rachael Morton (MSc (Clin Epi) (hons), PhD) is Associate Professor and Director of health economics at the NHMRC Clinical Trials Centre, Sydney Medical School, University of Sydney. She holds an NHMRC Translating Research Into Practice (TRIP) Fellowship. She specialises in trial-based and modelled economic evaluation, and elicitation of patient preferences using discrete choice experiments. Her research incorporates patient-centred and economic outcomes into clinical trials of diagnostic tests, new treatments and models of care to facilitate policy decision-making on the basis of cost-effectiveness. Rachael's research interests include health economics applied to melanoma and chronic kidney disease, with a particular focus on patient reported outcome measures in clinical quality registries. She also has an interest in health

equity in disadvantaged populations both in Australia and overseas. Her methodological interests include systematic reviews of economic evidence, assessment of test evaluation and monitoring, measurement of quality of life and wellbeing, and end-of-life care.



Dr Martin Howell is a Research Fellow in Health Economics in the Sydney School of Public Health at the University of Sydney and the Centre for Kidney Research at The Children's Hospital Westmead. His research focuses on applied health economics research predominantly in the areas of assessment of preferences using discrete choice (DCE) methods to address complex health research questions, and conduct of trial based economic evaluations in the area of nephrology. His PhD project involved the application of a type of DCE known as a Best Worst Scaling survey (BWS) to elicit kidney transplant patient preferences for outcomes after transplantation. Other areas of expertise, include the development of clinical practice guidelines, having worked with the KHA-CARI clinical practice guidelines group since 2008. Prior to 2008, Dr Howell had a long career as a soil and environmental scientist.



Professor Jonathan Craig (MBChB, DipCH, FRACP, M Med (Clin Epi), PhD) is an internationally recognised clinician and scientist, and holds the position of Vice President and Executive Dean of the College of Medicine & Public Health at Flinders University. Jonathan has made a significant contribution to the clinical research landscape in the prevention, identification, management and treatment of chronic kidney disease, particularly in relation to children and in Indigenous communities. He has led the formation of state, national and international networks to conduct high-quality, relevant trials in children and has been instrumental to the development and implementation of best-practice methods and guidelines relating to chronic kidney disease in Australia and globally. Professor Craig holds a large number of board and advisory panel positions, including as a member of the National Health and Medical Research Council (NHMRC) Advisory Group on the Synthesis and Translation of Research Evidence, a member of the Pharmaceutical Benefits Advisory Committee, a member of the Medicare Services Advisory Committee, a member of the International Advisory Panel for Singapore's Agency for Care Effectiveness, and President of the Australia-NZ Society of Nephrology. He is a past member of the WHO expert review panel for global strategy and plan of action on public health, innovation and intellectual property, a past chairman of the Steering Group of the Cochrane Collaboration, and a past member of the Expert Advisory Group for the Structural Review of NHMRC's Grant Program.



Mr Martin Chambers is a health advocate with several medical organisations, and sits on the BEAT-CKD Consumer Advisory Board as a member. In the past twelve years, he has applied his business skills to health advocacy with a focus on the requirements of kidney patients and consumers using the public hospital systems. Mr Chambers brings extensive and varied experience of over 40 years gained from major energy organisations, having started his working life in Tasmania and spending the last 25 years in Brisbane. His key strengths are in engineering and finance combined with substantial senior project development and management work.



Anneliese Synnot is a Research Fellow with Cochrane Consumers and Communication Review Group (CCCRG) at La Trobe University, and Cochrane Australia, Monash University. She has worked on a number of research projects in partnership with consumers and other stakeholders, including policy makers, health professionals and the not-for-profit sector. Annie leads the CCCRG's review prioritisation activities, and is supporting their priority author teams to meaningfully involve consumers and other stakeholders in their systematic reviews. As part of her PhD, she is evaluating the stakeholder engagement approach being used by one of the priority Cochrane review teams. Annie's research interests include innovations in evidence synthesis, including living systematic reviews, and new ways to involve and work with stakeholders in systematic review prioritisation and production.



Associate **Professor Allison Tong** is a Principal Research Fellow at the Sydney School of Public Health, The University of Sydney. She holds an Australian National Health and Medical Research Council (NHMRC) Career Development Fellowship. She is a social scientist and has experience in using applied qualitative research methods to the area of chronic disease; to inform practice and policy for improved patient-centred outcomes. Allison has a particular interest and experience in stakeholder engagement (including patients and consumers) in the context of research priority setting and the development of core outcomes for research. She co-founded and is on the Executive Committee of the global Standardised Outcomes in Nephrology (SONG) Initiative, which aims to establish consensus-based core outcomes across the spectrum of chronic kidney disease (www.songinitiative.org). Allison developed the consolidated criteria for reporting qualitative health research (COREQ), and the enhancing transparency in reporting the synthesis of qualitative health research [ENTREQ];

which are both endorsed as key reporting guidelines by leading journals and by the international EQUATOR Network for promoting the transparency of health research. She has taught qualitative health research methods internationally for government and university institutions including Stanford University, Mayo Clinic, and The University of Calgary.



Associate Professor Ian Scott (MBBS, MHA, MEd, FRACP) is consultant general physician and Director of Internal Medicine and Clinical Epidemiology at Princess Alexandra Hospital in Brisbane. He is Associate Professor of Medicine at University of Queensland, currently co-chairs the Queensland Statewide General Medicine Clinical Network, is the inaugural chair of the Australian Deprescribing Network, and a member of Queensland Policy and Advisory Committee on new Technology (QPACT). He sits on committees of the Royal Australasian College of Physicians, Queensland Health, and Australian Commission on Quality and Safety

in Health Care. His research interests include clinical decision-making and means for minimising low value care.



Jo Watson has been involved in the Australian HIV response since the early nineties, including as the HIV treatments officer for the state group PLWHA (NSW)(1995 – 1998); before joining the National Association of People living with HIV Australia (NAPWHA) as Executive Director (1998 – 2014). She contributed to national HIV treatments advocacy and research programs over that time, and represented NAPWHA in Australian and International HIV research initiatives and clinical trials. She is the current Deputy Chair of the Consumers Health Forum, Chair of the national HTA Consumer Consultative Committee, and a NAPWHA Special Representative. She has been a member of the Pharmaceutical Benefits Advisory Committee (PBAC) since 2012, and in August 2017 was appointed as the inaugural Deputy Chair. Jo is currently involved in several projects to develop more pathways for patient engagement in health technology assessment, and capacity building for patient representatives.



Sophie Hill is the Head, Centre for Health Communication and Participation at La Trobe University. The Centre collaborates with a range of consumer organisations, health professionals, health care services, governments and universities in Australia and internationally to conduct leading research into priority health communication and participation topics.

The Centre is also home to Cochrane Consumers and Communication, which is part of the international organisation, Cochrane. It provides the editorial base for high-quality systematic reviews of the evidence around interventions or approaches which affect the way consumers interact with each other, with health care professionals, health services, or health researchers.

Dr Hill participates actively in consumer participation policy circles. She is a member of the Patient and Family Council for Safer Care Victoria. From 2006 to 2016, she retained membership of Victoria's Consumer Participation Reference Committee for the implementation of the policy 'Doing it with us not for us', for the Victorian Department of Health & Human Service. She served as chair for its Subcommittee on Health Information and Health Literacy from 2011-2014.



Amélie Bernier-Jean is a PhD student at the Centre for Kidney Research affiliated with the University of Sydney. She completed her nephrology training in 2016 in Montreal, Canada. She is interested in the impact of lifestyle on chronic kidney disease (CKD). Her work examines the dietary patterns associated with CKD progression as well as the benefits of exercise training in people with CKD. Her thesis is currently supported by an NHMRC Post-Graduate scholarship.



Karine E Manera is a Research Officer and PhD candidate with the Sydney School of Public Health, The University of Sydney. She uses qualitative and quantitative research methods to generate evidence for improving shared decision-making in the area of chronic kidney disease, and has applied this approach in global and multi-language studies.



Talia Gutman is a Research Officer and PhD candidate at the Sydney School of Public Health, The University of Sydney, Australia. Her primary research interest is in the area of patient and caregiver involvement in research in chronic kidney disease. She has conducted international qualitative studies on patient involvement in research in chronic kidney disease and has experience in interviews, focus groups, nominal group technique, and survey research to elicit stakeholder perspectives with the goal of informing patient-centred programs and interventions.



Elaine Pascoe is a Research Academic in the Faculty of Medicine at the University of Queensland and Head of Biostatistics and Data Management for the Australasian Kidney Trials Network (AKTN), providing leadership in data management and statistical analysis for clinical trials coordinated by the AKTN and offering a statistical consulting service to researchers in kidney disease at Princess Alexandra Hospital. She is a member of the AKTN Scientific Committee, which is responsible for evaluating new trial proposals and overseeing the development and conduct of large trials in kidney disease in Australia and New Zealand. She is also a member and previous chair of the Scientific Committee Methodology Working Group, which offers methodological support to members of clinical working groups. Before joining AKTN in 2011, she worked as a biostatistician for 10 years at Princess Margaret Hospital (PMH) for Children in Perth, Western Australia, and for 6 years as a research consultant at Edith Cowan University. While at PMH, she served as statistician on the Scientific Advisory Sub-committee to the hospital's Human Research Ethics Committee.



Associate Professor Stephane Heritier obtained his PhD in Statistics from Geneva University, Switzerland, in 1993, with his thesis involving methodological issues in robust inference. He started his biostatistician career at the Clinical Epidemiology Unit of Geneva University Hospital, followed by an experience in the pharmaceutical industry with Merck-Serono. He moved to Australia in 2002 to be appointed Senior Research Fellow at the NHMRC Clinical Trials Centre, Sydney University, gaining experience in biostatistical methodology, design and analyses of clinical trials and collaboration with clinicians. He was also involved in teaching for postgraduate students in biostatistics. He joined the George Institute in 2006 to work mainly on large-scale studies in cardiovascular and renal diseases, neurological and mental health, critical care and injury prevention. As Head of Statistical Research he led an innovative statistical research program in clinical trial methodology and survival analysis. Stephane moved to Melbourne in September 2014 to become Associate Professor of Biostatistics at DEPM. His research interests include adaptive designs, cluster randomised trials, robust methods in biostatistics, multistage disease modelling and penalised likelihood for survival data. He is a chief investigator on several NHMRC grants and is involved in statistical consulting within the Faculty of Medicine and for other institutions including the pharmaceutical industry.



Associate Professor Mark Chatfield (MA (Oxon) MSc) Mark is a diligent, experienced, applied biostatistician in the Faculty of Medicine at the University of Queensland. He has had substantial involvement with randomised controlled trials and is an expert user of Stata statistical software. In collaboration with other researchers, he has published over 70 manuscripts in peer-reviewed international journals and has achieved over \$20M in NHMRC project grant funding. He is currently co-supervising three PhD students. He is an Honorary Fellow (Associate Professor) with Menzies School of Health Research, where he worked 2012-2017. He has also worked at QIMR Berghofer Medical Research Institute (2017-8), NHMRC Clinical Trials Centre, University of Sydney (2009-2012), UK MRC Human Nutrition Research (2006-9), Department of Public Health and Primary Care, University of Cambridge (2002-6).

Information

Time and Date: Research Forum on Monday 23rd and Tuesday 24th July, with workshops on 25th July 2018
 Concurrent workshops on 25th July will cover four streams – Clinical trials, Qualitative and Consumer Engagement, Registries, and Health economics

Venue: Translational Research Institute (TRI), 37 Kent Street, Woolloongabba, Brisbane, Queensland 4102

Outline

This nationwide [research forum and workshops](#) is for patients, clinicians, and researchers with an interest in conducting and implementing research to improve outcomes for people with chronic kidney disease. The forum provides a unique opportunity to hear and discuss innovative methods, high-priority research projects, and to meet potential collaborators. This will focus on research into chronic kidney disease, facilitated by infrastructure to support these activities in Australia and New Zealand including the:

- 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

For more information, see <http://beatckd.org/2018-forum/>