



# BEAT-CKD Annual Research Forum and Workshops

12-13 August 2019

Holme Building, Science Road  
The University of Sydney NSW 2006

# Introduction

**Time and Date:** Monday 12<sup>th</sup> August 2019 to Tuesday 13<sup>th</sup> August 2019

**Venue:** Holme Building, Science Road, The University of Sydney, NSW 2006

**Cost:**

- The Main Forum is free to attend.
- The standard registration for workshops is \$50 (including GST); or free for consumers (patients, family members, consumer representatives)

**Registration:** <http://beatckd.org/forum2019/>

**Outline**

The BEAT-CKD annual research forum/workshops are for patients, family members, caregivers, clinicians, and researchers with an interest in conducting and implementing research to improve outcomes for people with chronic kidney disease. This open forum provides a unique opportunity to hear and discuss innovative methods, high-priority research projects, and to meet potential collaborators.

This forum will be facilitated by the BEAT-CKD “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?**

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 patients with chronic kidney disease, family members, consumer representatives, caregivers, policy makers and industry.

The workshops are open to anyone 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 chronic kidney disease
- To foster 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 May be subject to change

DAY ONE: MONDAY 12 <sup>TH</sup> AUGUST	
Time	Session
8:30 am	<a href="#">Registration and coffee</a>
9:30 am	<p><b>Welcome</b> Jonathan Craig</p> <p><b>Acknowledgement of Country</b> Victoria Sinka</p>
9:45 am	<p><b>SESSION 1: CONSUMER ENGAGEMENT</b> Chairs: Nicki Scholes-Robertson, Allison Tong</p> <p><b>Listening to community voices</b> – Luke Macauley, Shilpa Jesudason</p> <p><b>Engaging First Nation People in clinical research and developing leadership in research</b> – Sandra Eades</p> <p><b>Involving patients in research: a two-way street</b> Michelle Banfield</p> <p><b>Panel discussion</b> Nicki Scholes-Robertson, Shilpa Jesudason, Luke Macauley, Sandra Eades, Michelle Banfield</p>
11:00 am	<a href="#">Morning tea</a>
11:15 am	<p><b>SESSION 2: LEARNINGS FROM AUSTRALIA AND NEW ZEALAND DIALYSIS AND TRANSPLANT (ANZDATA) REGISTRY</b> Chair: Stephen McDonald</p> <p><b>Association between publication of the Initiating Dialysis Early and Late (IDEAL) study and change in dialysis initiation practice</b> – Chris Davies</p> <p><b>BEST Fluids: comparison of enrolled and non-enrolled patients</b> – Kathryn Dansie</p> <p><b>Burden of travel to dialysis</b> – Emily Duncanson and Shahid Ullah</p> <p><b>Organ utilisation and allocation</b> – Phil Clayton and Matthew Sypek</p> <p><b>Panel discussion</b> Phil Clayton, Kathryn Dansie, Chris Davies, Emily Duncanson, Matthew Sypek, Shahid Ullah</p>
12:30 pm	<a href="#">Lunch ECR Speed Network Lunch Session – all welcome @ Holme</a>
2:00 pm – 5:30 pm *Afternoon tea at 3:30 pm @ Holme Building	<p><b>CONCURRENT WORKSHOP 1: Involving consumers in research in CKD</b> Talia Gutman, Nicole Scholes-Robertson, Chandana Guha, Emily Duncanson, Allison Tong, Shilpa Jesudason, Martin Howell</p> <p>Patient involvement across the research-translation cycle can help to align research with the goals, priorities and values of patients. Increasingly, funders, journals, policy makers are “mandating” patient involvement. This practical workshop will cover: the need for patient involvement in research; what is patient involvement; how to involve patients across the research-translation cycle (setting priorities and research questions, designing studies (interventions, recruitment), selection of outcomes, dissemination and implementation, and how to report patient involvement (in publications, grant applications).</p>
2:00 pm – 5:30 pm *Afternoon tea at 3:30 pm @ Holme Building	<p><b>CONCURRENT WORKSHOP 2: Statistical analysis with R</b> <b>Location: Edward Ford Building Computer Laboratory</b> Armando Teixeira-Pinto, Jean Yang, Phil Clayton, Shahid Ullah</p> <p>In this workshop, participants will be given a brief introduction to the statistical software R (with RStudio). Participants will: learn the basic principles of the R language, how to import data and perform basic data management, be provided with examples of graphs, and learn how to do common analysis, such as fitting logistic regression. Participants with prior experience in R or other statistical programs will develop understanding of the potential of R in more sophisticated analyses, such as machine learning methods and complex statistical models. This will be a “hands on” workshop. Computers will be available for the participants. Participants who bring their own laptop should install R and RStudio.</p>
6:30 pm	<a href="#">Dinner at Thai Pothong 294 King St (please register)</a>

DAY 2: TUESDAY 13 <sup>TH</sup> AUGUST 2019	
Time	Session
7:30 am	BEAT-CKD Management Meeting (closed)
9:00 am	Registration and coffee
9:30 am	<p><b>SESSION 3: Novel trials and complex interventions</b> Chairs: Carmel Hawley</p> <p><b>Incremental HD trial</b> – Martin Wolley <b>Idiopathic Membranous Nephropathy</b> – Bhadran Bose <b>Panel discussion</b> Martin Wolley, Bhadran Bose</p>
10:30 am	<p><b>SESSION 4: RESEARCH TRANSFER</b> Chairs: Germaine Wong, Martin Howell</p> <p><b>Embracing the new paradigm in guidelines: Patient values, collaboration, living evidence, access and equity</b> – Martin Howell</p>
11:00 am	Morning tea
11:15 am	<p><b>SESSION 4: RESEARCH TRANSFER cont.</b></p> <p><b>Making an impact in practice and policy</b> – Andrew Wilson <b>Using data linkage to inform policy and practice</b> – Samantha Lain <b>The voice for change – the role of the patient community in advocacy</b> – Chandana Guha <b>Panel discussion</b> Andrew Wilson, Chandana Guha, Nicole Scholes-Robertson, Luke Macauley, Martin Howell, Samatha Lain</p>
12:30 pm	Lunch
1:30 pm – 4:00 pm	<p><b>WORKSHOP 3: The ins and outs of research grant writing</b> Germaine Wong, Jonathan Craig, Stephen McDonald, Carmel Hawley Steve Alexander, Pearly Harumal</p> <p>In this workshop, participants will learn the basics of developing a research proposal for a peer-reviewed granting body. Each section of a grant proposal (aims, background/significance, methods, statistical plan and analysis) will be discussed by the Chief Investigators of the BEAT-Program, and other facilitators including Steve Alexander and Pearly Harumal from The University of Sydney. Topics will include funding application, ethical approval, publication strategies and grant administration. Participants are also welcomed to bring a draft of their research synopsis, if available, for discussion.</p>
*Afternoon tea at 3:30 pm @ Holme Building	
4:00 pm	Forum Close

# Chair and Speaker Biographies



**Professor Stephen Alexander** is a paediatric nephrologist at Children's Hospital at Westmead with a longstanding interest regulatory T cells and transplant tolerance in including human studies and mouse models of transplant rejection/tolerance and glomerulonephritis. He also has an interest in genetic kidney disease and genomics in transplantation. He has led the laboratory of the Centre for Kidney Research for over 15 years. His group has studied a range of transplant tolerance and inflammatory phenomena in patients and in animal models of islet, kidney, heart, skin and liver transplantation and glomerulonephritis. They have also been involved in studying genetic kidney disease and in establishing testing for this and research on undefined mutations. He has a medical degree from Melbourne and has worked in Melbourne, Perth, Boston and Sydney. He has an MPH from Harvard SPH and an MD from University of Sydney. He has served on ANZSN council and is currently the President of the TSANZ and on council for IPTA. He is an associate editor for Transplantation. His funding is from the NHMRC, JDRF, ARC and NIH. His publications are in NEJM, Lancet, Blood, JEx Med, Nat comm. He is part of the Centre for Personalised Immunology based at ANU and works with the CMG at the Broad Institute.



**Michelle Banfield** Michelle's early research experience was in biological anthropology, focusing on the behaviour and social systems of primates. When she returned to research in 2004 following a period of ill health, she worked in the areas of consumer-focused research and the use of technology for the self-management of mental health problems. Her PhD explored mental health consumers' priorities for research on depression and bipolar disorder in Australia. Michelle's research interests include effective services and policy for mental illness. She heads the Lived Experience Research Unit at the Centre for Mental Health Research, incorporating ACACIA: The ACT Consumer & Carer Mental Health Research Unit. ACACIA aims to increase the involvement of ACT mental health consumers and carers in the research process and conduct research relevant to their needs. From 2015-17, Michelle completed an ARC Discovery Early Career Researcher Award (DECRA) fellowship looking at service access and navigation for people with serious mental illness. In mid-2018 she commenced an MRFF/NHMRC Translating Research into Practice Fellowship to explore the implementation of mental health peer work. As part of her commitment to active consumer involvement, Michelle has strong connections with consumer organisations and representation. In 2012 she was appointed to the National Mental Health Consumer Reference Group and became a member of the Health Care Consumers' Association of the ACT (HCCA) Executive Committee. Through these roles, Michelle hopes to foster strong ties between the consumer and research communities.



**Professor Jeremy Chapman** Professor Jeremy Chapman is a British–Australian nephrologist, renal physician and transplant surgeon. He has been the director of the Division of Medicine and Cancer at Westmead Hospital in Sydney since 2007. Professor Chapman was born in London, studied medicine at the University of Cambridge, gaining a Bachelor of Medicine, Bachelor of Surgery (MB BChir), Master of Arts (MA) and Doctor of Medicine (MD). From 1984 to 1987, he was a lecturer and research fellow at the University of Oxford. Professor Chapman migrated to Australia in 1987 and commenced lecturing at the University of Sydney and practicing medicine at the newly opened Westmead Hospital. Professor Chapman is a Board member of the Western Sydney Local Health District, Westmead Medical Research Foundation and is Chairman, Australian Bone Marrow Donor Registry, since 1991 and Manager of the Australian National Kidney Matching Service, since 1988. He served as President of The Transplantation Society between 2008 and 2010. In 2014, Expertscape named Professor Chapman the world's leading expert in kidney transplantation. He was awarded the Medal of the Order of Australia in 2003 for establishment of the Australian Bone Marrow Donor Registry. In 2015, he was appointed as a Companion of the Order of Australia for eminent service to medicine, particularly in the areas of clinical and biomedical research, to the development of ethical policy and practices for organ donation, acquisition and transplantation, and to renal medicine organisations and publications. In July 2019, Jeremy retired from clinical practice, however, he is continues to be active contributor to renal and transplant research.



**Professor Jonathan C. Craig** (MBChB, DCH, MMed (Clin Epi), FRACP, PhD) is Vice-President and Executive Dean of the College of Medicine and Public Health at Flinders University. He is a paediatric nephrologist/clinical epidemiologist, with research focussed on improving the health of people with chronic kidney disease, children, and the health and well-being of Indigenous people. His awards include International Distinguished Medal of the National (US) Kidney Foundation (2010), and TJ Neale Award for Outstanding Contribution to Nephrological Science. He is the Coordinating Editor of the Cochrane Kidney and Transplant Group and President of the Australia-New Zealand Society of Nephrology. He is a member of the NHMRC Advisory Group on the Synthesis and Translation of Research Evidence, NHMRC Health Translation Advisory Committee, a member of the Pharmaceutical Benefits Advisory Committee, the Medicare Services Advisory Committee, and the Life Savings Drug Program Expert Panel. He is a past Chair of the Steering Group of Cochrane, is a past member of the Expert Advisory Group for the Structural Review of NHMRC's Grant Program, past non-executive board member of Kidney Health Australia and past member of the WHO expert review panel for global strategy and plan of action on public health, innovation and intellectual property.



**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).



**Christopher Davies** is a biostatistician at the Australia and New Zealand Dialysis and Transplant registry (ANZDATA) within the South Australian Health and Medical Research Institute. At ANZDATA, Chris provides statistical support for the generation of regular reports and the extraction of data for custom external requests. Chris also conducts analyses for ANZDATA research projects and in collaboration with those in the nephrology community. Chris completed a PhD in Statistics at the University of Adelaide, focussing on group-based trajectory modelling. His research interests include methods for comparing centres, and for longitudinal data.



**Emily Duncanson** works as a Research Officer at the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and is a registered psychologist. Her primary research interests are exploring quality of life issues and psychological wellbeing of people undergoing renal replacement therapies and that of their caregivers and families, using qualitative methods. She is involved in a number of projects at ANZDATA, including exploring the burden of travel to dialysis, needle distress among people receiving HD, the Symptom Monitoring With Feedback (SWIFT) Trial, and increasing consumer involvement in the ANZDATA's work. She has been involved in various BEAT-CKD consumer engagement initiatives, in particular, increasing consumer involvement at scientific meetings including ANZSN Annual Scientific Meeting 2018 and at ISN World Congress of Nephrology 2019.



**Chandana Guha** is a consumer representative and research assistant with the Centre for Kidney Research, Sydney School of Public Health. As a trained statistician she began her career at the UNSW teaching undergraduates and postgraduates in the department of economics. When her daughter was diagnosed with kidney disease and received a transplant at the age of 11 years, Chandana changed focus and joined Transplant Australia to develop an online patient support resource for transplant recipients on post-transplant care. This comprehensive resource called "Living with your Transplant" is aimed at patients, carers and anyone interested in navigating life after a solid organ transplant. Keenly interested in patient-centric kidney research 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-GN) initiative, which aims to develop core outcomes for people living with glomerular disease. Chandana is passionate about raising awareness around organ donation and educating patients on post-transplant care.



**Talia Gutman** is a PhD Candidate at The University of Sydney School of Public Health, with a NHMRC scholarship. The aim of her PhD is to establish an evidence-based framework for patient involvement in research in kidney disease. Talia has published 13 peer reviewed articles and has presented at international conferences. In 2018 she was Plenary Speaker at the Scientific Meeting of the ANZ Society of Nephrology, speaking on principles and strategies for patient involvement in research in kidney disease. She is leading the development of consumer involvement strategies and methods for the KHA-CARI Guidelines and the Standardised Outcomes in Nephrology (SONG) Initiative. She is a member of the International Society of Nephrology Working Group for patient involvement in clinical research, and the Patient-Centred Research Network (PACER). She has been involved in establishing and coordinating a national consumer advisory board for the Better Evidence and Translation in Chronic Kidney Disease (BEAT-CKD) collaboration and has led consumer workshops for the CARI Guidelines and multinational patient-centred projects.



**Dr Pearly Harumal** is Director of Research Grants and Contracts within the Research Portfolio. Her team is responsible for the submission and post-award management of all research grants administered by the University of Sydney, including Internal DVC-Research Schemes. This includes the review of applications prior to submission, managing research agreements for successful grants, and all grant variations and reporting requirements. Pearly completed a PhD in Molecular Parasitology at the Menzies School of Health Research (Darwin), following which, she accepted a postdoctoral position in Sydney to work on a commercial project involving monoclonal antibodies in cancer therapy. Pearly made a transition to communications and research management in 2005 and has worked in various Research and Grants Management roles in Medical Research Institutes prior to joining the University of Sydney in 2015.



**Prof Carmel Hawley** (M.Med Sci (Med Stat), FRACP, MB BS (Hons)) is a physician researcher and Clinical Trialist. Her current Clinical roles include Staff Nephrologist, Department of Nephrology; Director of Nephrology; and Clinical Director of Haemodialysis Services at the Princess Alexandra Hospital, Brisbane. Professor Hawley is the current Chair of the Executive Operations Secretariat for the Australasian Kidney Trials Network (AKTN). She has been a lead investigator in numerous investigator-initiated and industry trials and is a key member of several national and international collaborations including Co-Chair, ANZSN Research Advisory Committee; Scientific Advisory Board, Polycystic Kidney Disease Foundation; and Committee member of PAH Research Committee. Her past roles include Member of Nephrology, Dialysis, Transplantation of the Australian & New Zealand Society of Nephrology (ANZSN); Member, Advisory Board, Canadian Trials Network; Member and Inaugural Chair of the Home Dialysis Advisory Committee; Member, Scientific Committee, International Quotidian Registry; and Regional Examiner for the Royal Australasian College of Physicians (RACP). She is currently an editorial reviewer for *Nephrology*, and a reviewer for *ANZ Journal of Medicine*, *Nephrology Dialysis Transplantation*, *Medical Journal of Australia*, and *Haemodialysis International*. Professor Hawley has had a 20 year involvement in clinical trials and has a substantial track record in supervising and mentoring the next generation of clinical researchers in addition to teaching epidemiology, biostatistics and clinical trial design at both state and national levels. She has published over 400 peer-reviewed journal articles, as well as numerous review articles, book chapters, letters and case reports. She has been an invited presenter and lecturer at more than 160 state, national and international events in the scientific community, and has been the recipient of upwards of \$47,800,000 in research grant funding, including \$42,000,000 from the National Health and Medical Research Council's grant program. In recognition of her significant contribution to the field of research, in 2018 Professor Hawley was awarded Kidney Health Australia's highest accolade, the Kincaid-Smith medal.



**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.



**Dr Samantha Lain** is a perinatal epidemiologist and Research Fellow with qualifications in Health Sciences, Epidemiology and Economics. She currently works in Child Population and Translational Health Research at the Children's Hospital at Westmead Clinical School. Her research interests include; examining infant health service utilisation, childhood education and developmental outcomes using large linked population-based datasets. Her current postdoctoral fellowship is assessing the impact of newborn screening results on childhood neurodevelopment.



**Luke Macauley** is a Consumer Partner and Research Assistant working on the Kidney Health Australia Youth Program, which aims to address the exceptionally high graft loss rates, significant burden of disease, and low wellbeing of adolescents and young adults with kidney disease. In 2017, at 23 years old, Luke was diagnosed with End Stage Kidney Disease, and after peritoneal dialysis and a transplant from his father, was able to return to university and complete his Bachelor of Psychological Sciences with Honours at the University of Adelaide. Having seen firsthand how undiagnosed kidney disease can impact on young adults' mental health and participation in life, Luke is now driven to improve the experiences of newly diagnosed young adults living with kidney disease by combining his education in psychology with his experience as a young adult with ESKD. He also contributes as a patient partner to the Central Northern Adelaide Renal & Transplantation Service (CNARTS) Clinical Research Group and the NAV-KIDS steering committee, and is currently completing a research internship with the Centre for Kidney Research focused on General Practitioner perspectives of screening for and managing Chronic Kidney Disease.



**Professor Stephen McDonald** Based at the Royal Adelaide Hospital, Stephen McDonald is 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.



**Nicole Scholes-Robertson** is a patient partner, physiotherapist, and a PhD candidate at the Sydney School of Public Health, The University of Sydney. In 2014, Nicki commenced dialysis and was fortunate to receive a living donor kidney transplant from her brother. Her research focus is on access to dialysis and transplantation services for rural and remote patients in Australia. Nicki has given several invited presentations, including at the Global Health Policy Forum at The World Congress of Nephrology on "Quality, Sustainability and Equity of Care: a patient's perspective." Nicki is also a co-chair of the BEAT-CKD Consumer Advisory Board and is a Steering Group member of the Standardised Outcomes in Nephrology (SONG-GN) initiative, which aims to develop core outcomes for people living with glomerular disease. Most recently Nicki has been chosen as a finalist for the Volunteer of the Year - Individual Award in the 2019 HNE Health Excellence Awards. Nicki lives in Armidale NSW where she has founded a kidney support group that is ongoing and loves to grow roses in her spare time.



**Victoria Sinka** is a Proud Pitjantjatara Woman, with Aboriginal, Australian South Sea Islander and Maltese Heritage. Victoria has always lived in Western Sydney and her dedication to addressing and improving the social and health inequities in Indigenous communities see's her embracing wholeheartedly the Aboriginal Concept of Health. Victoria's background includes serving in the public and private sectors. Victoria also has an Academic background in Public Health; she holds a degree in the Graduate Diploma in Indigenous Health Promotion and is currently studying the Master of Public Health. Joining in May 2018, "The ARDAC Kidney Health Study significantly unites two worlds knowledge in ending chronic disease for our children and our children's children and in Nganana (all of us)"



**Mathew Sypek** graduated from the University of Adelaide and undertook advanced training in adult nephrology (FRACP) in Melbourne at The Alfred Hospital and Monash Medical Centre, and in the UK at Oxford University NHS Trust. He completed additional post-fellowship training in paediatric nephrology at the Royal Children's Hospital Melbourne and continues to practice in both adult and paediatric settings. Matthew commenced a PhD through the University of Melbourne in 2016 examining immunological factors in kidney transplant allocation. Since 2017 he has also held the position of Epidemiology Fellow at the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). His areas of interest include renal transplantation, organ allocation, epidemiology, transitional care and environmental sustainability.



**Dr. Armando Teixeira-Pinto** is an Associate Professor of Biostatistics at the University of Sydney. He received his PhD in Biostatistics in 2007 from Harvard University. His research interests are in statistical methodology applicable to clinical, epidemiological and health services research, in particular in the areas of nephrology, cardiovascular diseases and mental health.



**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 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 involving patients in research, particularly in 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](http://www.songinitiative.org)). She also founded the Patient-centred Research (PACER) Network ([www.pacernetwork.org](http://www.pacernetwork.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.



**Dr. Shahid Ullah** is a Senior Biostatistician at South Australian Health and Medical Research Institute (SAHMRI). He is responsible for statistical support to the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry at SAHMRI. His current role is to interact with a range of external stakeholders including contributors to the ANZDATA registry from around Australia and New Zealand, together with a wide range of collaborating groups to support safety and quality activities and the planning of appropriate health services. Dr Ullah contributes to the strong research group in clinical settings within the ANZDATA, and across the nephrology communities in Australia and New Zealand through leading and developing new biostatistical projects of his own, as well as collaborating with clinicians and researchers by providing specific biostatistical expertise. In addition to supporting statistical methodology and modelling, he is also actively involved with writing statistical analysis sections for peer review articles and methodological papers for statistics, medicine and health-related journals. He has skills to supervise honours, masters and PhD students. He is also an Editor-in-Chief, Editorial Member and Statistical Adviser for journals. He publishes in top ranking journals and his research activities have been disseminated in 172 authored publications through a variety of forums including peer-reviewed journals, reports, conference abstracts and other papers. He has been awarded over \$1.2 million in

collaborative research grants as the named Associate and Chief Investigators. He is also a President of the Statistical Society of Australia South Australia Branch.



**Professor Andrew Wilson** (BMed Sci, MBBS(Hons), PhD, FRACP, FAFPHM) is Co-Director of the Menzies Centre for Health Policy, and Professor of Public Health in the Sydney School of Public Health, University of Sydney and Director of the NHMRC Australian Prevention Partnership Centre (Sax Institute). He is the Chair of the Pharmaceutical Benefits Advisory Committee for the Australian Government. He has specialist qualifications in public health and clinical medicine, and a PhD in epidemiology. His research interests concern the application of epidemiology to informing decision making in clinical medicine, public health, and health service policy and planning. His papers and reports include aspects of prevention and management of chronic disease, evaluation of the effectiveness and responsiveness of health care and the impact of social and physical environment on health.



**Dr Martin Wholley** is a nephrologist based at the Royal Brisbane and Women's Hospital. He is an early career researcher having completed a PhD in 2017 under Professor Michael Stowasser investigating secondary forms of hypertension, and he has ongoing research interests in this field currently participating in a 5 year Foundation Leducq Transatlantic Network of Excellence Grant investigating the role of potassium in hypertension. He also has research interests in physiological and practical aspects of dialysis provision.



**Associate Professor Germaine Wong** is a transplant nephrologist at Westmead Hospital, Sydney with special interests in transplantation and clinical epidemiology. She is also NHMRC Career Development Research Fellow and Principal Research Fellow at the School of Public Health, University of Sydney. Her main area of research interests include: transplant epidemiology, cancer and chronic kidney disease, life-course epidemiology, social ethics in organ donation and allocation, decision analytical modelling, health economics, population health research, and quality of life studies in patients kidney transplants.



**Professor Jean Yang** is an applied statistician with expertise in statistical bioinformatics. She was awarded the 2015 Moran Medal in statistics from the Australian Academy of Science in recognition of her work on developing methods for molecular data arising in cutting edge biomedical research. Her research stands at the interface between medicine and methodology development and has centered on the development of methods and the application of statistics to problems in -omics and biomedical research. She has made contributions to the development of novel statistical methodology and software for the design and analysis of high-throughput biotechnological data including that from microarrays, mass spectrometry and next generation sequencing. Recently, much of her focus is on integration of multiple biotechnologies with clinical data to answer a variety of scientific questions. This includes developing various approaches and methodologies in statistical machine learning and network analysis. As a statistician who works in the bioinformatics area, she enjoys research in a collaborative environment, working closely with scientific investigators from diverse backgrounds.