2023 Annual Research Report

Central Northern Adelaide Renal and Transplantation Service (CNARTS)

Shaping the future of health with world-class care and world-class research

Government of South Australia
Health
Central Adelaide Local Health Network

Contents

This report is produced by Dr Richard Le Leu and Prof Shilpa Jesudason on behalf of CNARTS. Any queries about the content please contact Dr Richard Le Leu (richard.leleu@sa.gov.au)

Welcome message

This is now the 7th Annual Research Report from the Central Northern Adelaide Renal and Transplantation Service (CNARTS), Central Adelaide Local Health Network.

The CNARTS team of researchers and clinical staff, across many disciplines, continue to embed a culture of research into our day-to-day practice and care of patients.

In this report, we highlight the significant achievements of our team, through our laboratory studies, clinical trials, cohort studies and quality improvement initiatives. Each year as we create this report, we have opportunity to reflect on the scope and scale of research in CNARTS and the passion and dedication with which our talented team conducts research.

This report encapsulates our commitment to advancing knowledge and improving patient outcomes through innovation in the field of nephrology. We are enormously proud of our collaborative spirit and the partnerships we have forged with patients, other research groups and research institutions. We are also immensely grateful for the steadfast dedication of every one of our sponsors and supporters.

We hope this report will educate, inspire and motivate the next generation of researchers, and give patients hope that we are striving to create an environment where innovation can thrive and compassionate care can flourish.

We hope you enjoy this year's Annual Report.

Prof Shilpa Jesudason

Chair of CNARTS
Clinical Research Group

Prof Randall Faull

Head of Unit CNARTS

CNARTS – About us

The Central Northern Adelaide Renal and Transplantation Service (CNARTS) is the largest renal unit in South Australia and the third largest renal unit in Australia, caring for over 1700 patients with kidney failure, and many thousands more at all stages of chronic kidney disease. CNARTS currently provides dialysis services to approximately 900 dialysis patients, including supporting 170 home dialysis patients. CNARTS also provides supportive care to 170 patients and supports around 1000 existing transplant recipients. In 2023, CNARTS performed 105 transplants which included 3 kidney-pancreas and islet cell transplants.

Central and Northern Adelaide Renal and Transplantation Services (CNARTS)

Mission statement

CNARTS has a strong history of research, delivering pioneering therapies and advancing care in general nephrology but also many specialised areas where we have been national and world leaders.

We aim to:

- *Improve the understanding of the science underpinning kidney diseases, dialysis and kidney transplantation, type 1 diabetes and hereditary pancreatitis*
- *Conduct translational research that is patient-centred and leads to improvements in treatments, outcomes and the patient experience*
- *Advance the use of new technologies, methodologies and treatments*
- *Support and mentor staff and students to build a highly skilled future research workforce*

Research sponsors

We are very grateful for the generous donors and fundraisers who support our research efforts. Without this support we would not be able to progress projects to improve the lives of people living with kidney disease.

The Hospital Research Foundation Group

hospitalresearch.org.au

Kidney, Transplant & Diabetes Research Australia

kidneydiabetesresearch.org.au

The Hospital Research Foundation (THRF) Group funds life-changing medical research, improved treatments and healthcare services in the community.

Kidney, Transplant and Diabetes Research Australia (KTDRA) is a charity of THRF Group. Together, KTDRA and THRF commit funds to advance kidney research through a number of CNARTS projects, including:

- Supporting the state-of-the-art Biospherix Chamber in Adelaide to enable faster and safer Total Pancreatectomy with Islet Auto Transplantation (TP-IAT) procedures to cure people of debilitating pancreatitis – **$1,400,000**
- Supporting women with kidney disease to overcome their challenges to become mothers – **$150,000**
- Implementing the INJECT program (improving needle fear management in haemodialysis patients) into clinical practice – **$54,000**
- Investigating the role of machine perfusion at room temperature to improve the quality of deceased donor organs, increasing the number of organs available for transplant – **$64,643**
- Funding for the CNARTS Clinical database that will help us understand how we care for patients, the quality of care they get and their outcomes to ensure our care is world class – **$200,000**
- Investigating Tacrolimus exposure in pregnancy through advancing therapeutic drug monitoring and exploring impact on outcomes – **$50,000**
- Exploring the effect of an exercise program on peritoneal dialysis outcomes – **$22,800**
- Funding research investigating various diet recommendations to improve the overall gut health in kidney transplant recipients and prevent diarrhoea immediately after transplant – **$70,418**
- Funding organ preservation to improve the quality of deceased donor organs – **$58,142**
- Supporting research into the epidemiology of hereditary pancreatitis in South Australia – **$45,300**

KTDRA and THRF Group provided a $1.4 million grant to purchase a Biospherix Chamber that will be a game-changer for patients who require Total Pancreatectomy with Islet Transplantation procedures to alleviate excruciating pain.

$50,000 raised at Gala Ball!

Passionate fundraiser Helena Kollias (pictured top left) held a special 'Gala Ball for Research' at the InterContinental Adelaide in September 2023 and raised an incredible **$50,000!**

The night featured live music, a live auction, a three-course meal and drinks, and a research update from Professor Toby Coates AO.

CNARTS staff with the Health Minister, Chris Picton

Lions Clubs raise $28,000 for Biospherix Chamber

kidneydiabetesresearch.org.au/news-stories/latest-news/research-capability-expands-thanks-to-generous-lions-clubs/

Adelaide's state-of-the-art Biospherix Chamber has added another key component, thanks to the generosity of South Australian service clubs.

Seventeen Lions clubs spanning from Mount Gambier to Edwardstown, as well as donations from the public, raised an incredible **$28,000** for the Biospherix Chamber in 2023!

The selfless donation, administered through KTDRA, has allowed the team at the Centre for Clinical and Experimental Transplantation (CCET) to purchase a Cell Purification Islet Isolator to build on their research into hereditary pancreatitis and Type 1 diabetes.

10 years of supporting young kidney patients

KTDRA was proud to fund a morning tea celebrating the 10-year anniversary of the Royal Adelaide Hospital's renal Young Adult Clinic.

kidneydiabetesresearch.org.au/news-stories/latest-news/a-decade-of-supporting-young-kidney-patients/

The clinic, which runs every two months, assists 40 young people with chronic kidney disease to transition from paediatric support to adult healthcare services.

Thank you to other generous fundraisers

Community fundraiser Angus Heida raised **$1,600** by asking for donations at a farewell party at the Piccadilly movie Theatre before moving overseas.

The Aberfoyle & District Lions Club raised **$1,000** for KTDRA.

Members of the renal Young Adult Clinic team (L–R) Dan, Hilary, Danielle, Robert, Sadia and Ky-Lee.

Royal Adelaide Hospital Research Fund

Since 1981, the Royal Adelaide Hospital (RAH) Research Fund has been raising funds for life-saving medical research at the RAH.

Current research projects supported by the RAH Research Fund include:

- Improving the self-management for people with chronic kidney disease through a patient activation approach - **$35,000** (2022-23)
- The role of allergen-specific IgG4 antibodies in clinical desensitisation after allergen immunotherapy - **$49,404**

Royal Adelaide Hospital Research Fund

rahresearchfund.com.au

Awards and Fellowships

Dr Griffith Perkins received an Award for *Outstanding Contribution* from the Australian & New Zealand Society for Immunology (ASI) – Advanced Immunology School.

Dr Griffith Perkins also awarded *Mary Overton Early Career Research Fellowship* from the RAH Research Committee (RRC) and Health Services Charitable Gifts Board (HSCGB).

Dr Griffith Perkins was awarded Kidney International-International Society of Nephrology Editorial Fellowship.

The ISN-KI Early-Career Researcher (ECR) Award recognises outstanding research in basic and clinical science published in Kidney International (KI) in 2022.

A/Prof Chris Drogemuller received the CALHN *Allied Health & Scientific Professions Excellence Award* for excellence in patient centred care and innovation.

Dr Karthik Venkataraman was awarded the *Inaugural Higher Degree by Research (HDR) Scholarship* from Kidney, Transplant and Diabetes Research Australia (KTDRA) to investigate how to best manage a patient 24 hours after a kidney transplant.

kidneydiabetesresearch.org.au/news-stories/latest-news/world-first-research-exploring-post-operative-care-after-kidney-transplant/

The **AKction** team was awarded *The Health Equity Award* from the Renal Society of Australasia (RSA). This award is for a nephrology team who has demonstrated a deep understanding of the diversity and differences in our communities to address health inequalities for Aboriginal, Torres Strait Island, Maori and Pacifica patients.

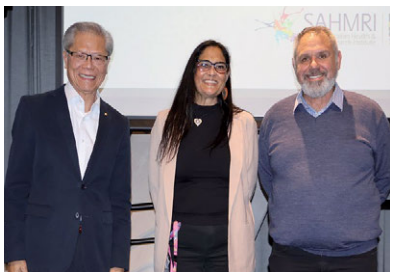
Each year within the University of Adelaide, the Faculty of Health and Medical Sciences holds an Executive Deans Award ceremony to acknowledge and recognise outstanding contributions of staff across the faculty. **Prof Toby Coates AO** was the recipient of the *Executive Deans Senior Research award* for 2023.

Dr Michael Collins was the winner of the *Kidney Health Australia Award* for Best Clinical Research Presentation at the Australian and New Zealand Society of Nephrology (ANZSN) Annual Scientific meeting *"BEST-FLUIDS: Balanced crystalloid solution vs. saline to prevent delayed graft function in deceased donor kidney transplantation".*

Dr Georgie Irish won the *Early Career Research Award (Clinical Science)* at the Transplant Society of Australia and New Zealand Annual Scientific Meeting *"Transplant professionals' perspectives on reporting of travel for organ transplantation: An international cross-sectional study".*

Dr Karthik Venkataraman won the *Early Career Research Award (Clinical Science)* at the Transplant Society of Australia and New Zealand Annual Scientific Meeting *"Association between slow graft function and long term graft outcomes".*

Dr Erandi Hewawasam (ANZDATA Registry) was awarded an *Early and Mid-Career Research Award* bestowed upon her by the South Australian Women's Health Research Translation & Impact Network supported by Health Translation SA



Kelli Owen (ANZDATA Registry) was the recipient of the *Neville Fazulla Scholarship, SAHMRI.*

The Neville Fazulla Aboriginal Health Scholarship has been established in recognition of the contribution Neville Fazulla made to Aboriginal health both within South Australia and nationally.

L–R Hieu Van Le AC, Kelli Owen

Research funding

Clinical Research Group

$200,000

2021–2023 Kidney, Transplant & Diabetes Research Australia (KTDRA) Project Grant

S Jesudason, P Clayton, R Le Leu

Central and Northern Adelaide Renal and Transplantation Service (CNARTS) Clinical Data Base Project

This database will help us understand how we care for patients, the quality of care they get and their outcomes – we can then be sure that our care is world class.

$54,000

2023 Kidney, Transplant & Diabetes Research Australia (KTDRA)

G Radisic, R Le Leu, K Collins, A Burke, F Donnelly, K Hill, A Chur-Hansen, S McDonald, S Muthuramalingam, B Tan, S Jesudason

Implementation of the INJECT program (Improving needle fear management in haemodialysis patients) into clinical practice at Central Northern Adelaide Renal and Transplantation Services

$1,950,172

2021–25 NHMRC Ideas Grant

K O'Donnell, J Kelly, K Owen, R Tsetsakos, N Sinclair, S Bateman, J Lavoie

AIs: S Jesudason, R Le Leu, O Pearson, T Mackean, S McDonald, S Crail, E Garrard, M Arnold-Chamney, L Jamieson

AKction2: Aboriginal Kidney Care Together - Improving Outcomes Now

This project brings together Aboriginal kidney patients and families, health professionals, health services, academics and researchers improve the experiences and outcomes of kidney care for and with Aboriginal* patients, families and community members and kidney health services in South Australia.

$69,463

2023 Diabetes Australia

J Manning, S Jesudason, Pollock C

Uncovering NEDD4L as a new regulator and potential biomarker in diabetic nephropathy

$70,000

2023–24 Kidney, Transplant & Diabetes Research Australia (KTDRA) – Higher Degree by Research (HDR) Scholarship

K Venkataraman

Post-operative haemodynamic management after kidney transplant to improve early graft function

Centre for Clinical and Experimental Transplantation

$500,276

2020–2023 Commercial in Confidence (International)

T Coates and C Drogemuller

Intracutaneous Ectopic Pancreas (IEP) creation by seeding Human Stem Cell-derived Islets (HSCI) into integrated BTM.

$380,000

2021–2023 The Juvenile Diabetes Research Foundation (International)

T Coates and C Drogemuller

Proof of concept trial of intracutaneous islet transplant. 2-SRA-2022-1086-M-B.

$370,000

2021–2023 The Juvenile Diabetes Research Foundation (Australia)

T Coates and C Drogemuller.

Proof of concept trial of intracutaneous islet transplant 2-SRA-2022-1096-M-B.

$20,000

2022–2023 Research Collaboration Grant University of Wollongong (Australia)

T Coates and C Drogemuller

Pre-vascularised 3D printed constructs for pancreatic islet transfer and transplantation.

$750,000

2022–2025 Targeted Translation Research Accelerator (TTRA) Program (Australia)

S Grey, C Drogemuller and T Coates

Restoring glucose control in T1D patients with genetically engineered GARV-AAV2-A20-islet cells – a first in Human safety and efficacy trial. TTRARP2097

$118,495

2023–2026 The Hospital Research Foundation

C Drogemuller and T Coates

Establishing islet isolation in Adelaide - Total pancreatectomy and Islet-Auto Transplantation (TPIAT).

$10,000

2023–2023 The Hospital Research Foundation

T Coates, C Drogemuller and J Scaffidi

Investigating Chimeric Antigen Receptor (CAR) Regulatory T cells as a Novel Therapy for Type 1 Diabetes.

Centre for Clinical and Experimental Transplantation continued...

$2,014,561

2022–2027 The Medical Research Future Fund (MRFF)

T Coates, C Drogemuller, H Pleass, R Couper, J Chen, S De Sousa, S Khurana, L Palmer, Professor A Brown, N Rogers, D Torpy

HEPATA: Hereditary Pancreatitis and AutoIslet Transplant Trials in Australia

The aim of this project is to collect the evidence required for TP-IAT to become a reimbursed medical procedure for the treatment of hereditary pancreatitis (HP) (grant term 2022-2027). To achieve this, 24 HP patients will undergo TP-IAT and the impact on disease progression, quality of life, reduction in pain medication, hospitalisations, health costs and economic impacts will be determined. This will allow a formal application to the government for assessment of TP-IAT to become a reimbursed medical procedure.

ANZDATA, ANZOD and BEAT-CKD

$150,000

2022–2024 The Hospital Research Foundation

S Jesudason, E Hewawasam, C Green, S McDonald

The Kidney Mums Project: Advancing pregnancy planning and care for women with kidney disease

The Kidney Mums Project aims to transform the experiences and outcomes of women living with kidney disease who wish to achieve motherhood. The Kidney Mums toolkit will be developed to support women and their clinicians to navigate decisions about pregnancy and deliver best-practice care for positive maternal and foetal outcomes.

$2,500,000

2021–25 National Health and Medical Research Council – Centre of Research Excellence

A Tong, J Craig, C Hawley, G Wong, D Johnson, N Scholes-Robertson, S McDonald, K Howard, S Jesudason, A Teixera-Pinto

Partnering with patients with chronic kidney disease to transform care and outcomes (CRE-PACT)

The mission of this project is to transform the care and health of people with CKD by answering patient/caregiver-prioritised research questions and addressing outcomes that are critically important to patients.

$975,000

2020–24 NHMRC Investigator Grant – Leadership 1

S McDonald

Building on Registry data to improve dialysis and kidney transplantation

Clinical Trials

$2,904,210

2022–2027 The Medical Research Future Fund (MRFF)

C Au Peh, B Bose, D Johnson, V Jha, D Jayne, E Milanzi, M Griffith, J Wetzels, A Kronbichler, A Liew

REMIT: An international, multi-centre, randomised clinical trial to compare Obinutuzumab + Calcineurin Inhibitor to Corticosteroid + Cyclophosphamide treatment regimens in Primary Membranous Nephropathy

Professor Chen Au Peh and a team of 20 nephrologists from 12 countries, will receive $2,904,210 (grant term 2022–2027) to fund an international clinical trial to compare treatment regimens in Primary Membranous Nephropathy, a rare kidney disease that causes leakage of protein in the urine and severe swelling of the body.

The REMIT trial will compare Obinutuzumab + Calcineurin Inhibitor to Corticosteroid + Cyclophosphamide treatment regimen in Primary Membranous Nephropathy Primary Membranous Nephropathy. Currently, treatment involves giving corticosteroid and cyclophosphamide. Unfortunately, this treatment has many undesirable side effects. Hence, we need to find better treatment with less side effects. This trial will compare new treatment comprising of Obinutuzumab and calcineurin inhibitor to the old treatment.

$593,970

2021–24 Canadian Institutes of Health Research

C Bohm, P Bennett, G Castillo, B Corradetti, M Di Nella, S Jesudason, J MacRae, C McIntyre, J Penny, J Presseau, K Tennankore, S Thompson, N Verdi, K Wilund, B Waldvogel

Trial of Intradialytic Cycling Kidney Exercise Rehabilitation for Cardiac Stunning in Hemodialysis (TICKERS_HD)

Clinical Research Group

- The Clinical Research Group (CRG) coordinates, fosters and provides oversight for all clinical research projects (not including clinical trials) within CNARTS.
- The CRG operates under the direction of the Executive Committee is committed to enhancing research collaborations between various disciplines (medical, nursing and allied health) and facilitating sharing of knowledge and expertise, mentorship and guidance for researchers at all stages of their career.
- The CRG is currently pursuing mixed methodology research across a range of patient-centred themes, with the goal of evidence-based change to clinical practice and improvement of clinical care. A key focus is cross-discipline collaborative efforts.
- The CRG has pioneered the development of a new clinical database for CNARTS clinicians to capture the specialised data required for researching, measuring and auditing service delivery, patient care and health outcomes across the patient journey, including end stage kidney disease, patients on dialysis and transplant patients.
- The CRG Executive provides governance for CNARTS on all research projects using CNARTS patients and/or data.
- Monthly meetings via Zoom alternating Monday and Wednesday (chaired by Dr Richard Le Leu) to discuss and share current clinical research within CNARTS.

Vision Statement

To embed a culture of research into daily clinical practice within CNARTS.

Executive Committee

Dr Richard Le Leu, CRG Research Co-ordinator

Prof Shilpa Jesudason, Chair of CRG

Prof Randall Faull

Tiffany Whittington

A/Prof Phil Clayton

Anthony Meade

Dr Michael Collins

Project Staff in 2023

- Dr Richard Le Leu (Clinical Research Coordinator)
- Ms Gorjana Radisic (Research Officer)
- Ms Samantha Welke (Project Officer)

CRG projects for 2023

Improving Management of Needle Distress during the Journey to Dialysis through Psychological EduCation and Training (The INJECT Program)

Lead: Prof Shilpa Jesudason

Team: G Radisic, R Le Leu, F Donnelly, K Hill, A Burke, K Collins, A Chur-Hansen, B Tan, S Muthuramalingam, L Macauley, S McDonald

(Collaboration with the School of Psychology, University of Adelaide and Clinical Psychology, CALHN)

Following the completion of the feasibility pilot study, the INJECT program has now progressed into the implementation stage. The key developments are outlined below:

1. The development and validation of the innovative Measuring Needle Fear (MNF) tool, designed to identify dialysis patients experiencing needle fear, have been successfully completed. This tool will be integrated into clinical practice at CNARTS to screen all new patients awaiting dialysis treatment for needle fear.
2. Novel Cognitive Behaviour Therapy (CBT) modules aimed at assisting patients in managing their needle fear will soon be accessible on a platform managed by SA Health. Patients identified as having needle fear through the MNF tool assessment will have the opportunity to participate in our patient education program. This program will be seamlessly integrated into the SA Health platform, ensuring accessibility for all interested patients.
3. A Dialysis Nurse education program, focusing on best practices for trauma-free cannulation and supporting patients with needle fear, has been implemented into clinical practice at CNARTS. This program is available to all nurses performing arteriovenous fistula (AVF) cannulation.

The patient self-management program will be supported by nursing education, enhancing nurses' understanding of needle fear and improving support for patients implementing self-management strategies. Our current objective is to complete the translation of the research findings from the INJECT program into clinical practice within CNARTS and assess the program's utilisation and effectiveness.

Funded by:

- The Health Services Charitable Gifts Board (HSCGB) ($52,000)
- RAH Research Committee Clinical Project Grant ($50,000)
- RAH Research Fund – The INJECT campaign ($52,000)
- Kidney, Transplant and Diabetes Research Australia (KTDRA) ($54,000)

Exploring potential clinical implications of the gut microbiota in kidney transplant recipients

Lead: Anthony Meade

Team: J Choo (SAHMRI), G Rogers (SAHMRI), S Sims (SAHMRI), R Le Leu, T Coates, S Jesudason

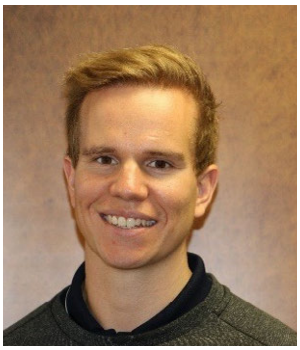
(Collaboration with the Microbiome and Host Health Programme, SAHMRI)

This project investigated dietary intake and the frequency of GI symptoms and changes in the gut microbiome pre and post kidney transplant. The results showed that diet did not alter between pre- and post-transplant. Overall, the diet quality was poor, with low fruit, vegetables, legumes and wholegrains intake at both pre- and post-transplant. Significant gut dysbiosis (a microbial imbalance or dysfunction) was observed following kidney transplant and this imbalance was associated with gastrointestinal symptoms. Using a pre-clinical model, our investigation of a dietary fibre type as a prebiotic strategy suggests that the fibre alone does not confer effective improvements to the intestinal microbial community when supplemented at pre- or post-transplant.

Funded by:

- Allied Health, Pharmacy and Nursing RAH Research Committee ($30,000)
- Kidney, Transplant and Diabetes Research Australia (KTDRA) ($50,000)

Fit, strong or active: What should we focus on to improve the lives of peritoneal dialysis (PD) patients?



Lead: Brett Tarca (PhD candidate)

Team: T Wycherley, P Bennett, A Meade, R Le Leu, S Jesudason, K Ferrar

(Collaboration with Allied Health and Human Performance, University of South Australia)

This research study is exploring the modifiable physical factors that predict physical functioning for patients receiving peritoneal dialysis (PD). This 12-month longitudinal cohort study will assess physical activity levels / sedentary behaviour, muscle strength and cardiorespiratory fitness as predictors of physical function at three time points (baseline, 6 months and 12 months) in PD patients. Data collection concluded in November 2022 with the final number of completed assessments at each timepoint as follows; Baseline (n=83), 6-month follow up (n=39), 12-month follow-up (n=28). The main results showing; 1) all factors were moderate-strongly associated with physical function at baseline, 2) cardiorespiratory fitness was the strongest influence on physical function and, 3) temporal declines in cardiorespiratory fitness, quadricep strength, physical activity and an increase in sedentary behaviour were observe, highlighting the need for intervention.

Ecological Momentary Assessment to Explore Fatigue, Mood and Physical Activity Levels in People Receiving Peritoneal Dialysis

Lead: Brett Tarca (PhD candidate)

Team: T Wycherley, S Jesudason, T Boyle, P Bennett, A Meade, R Le Leu, M Borlace, M Ovenden, K Ferrar

(Collaboration with Allied Health and Human Performance, University of South Australia)

This research study is exploring the fluctuations and relationships between fatigue, mood and physical activity for people receiving peritoneal dialysis (PD). This 7-day intensive longitudinal will explore the within day and day to day experience that people experience through the use of mobile technology (ecological momentary assessment). Ecological momentary assessments allow for capturing of data in real-time and real environments with survey questions triggered at 5 times throughout each day. A study protocol has been published in Peritoneal Dialysis International (dx.doi.org/10.1177/0896860821992243) Data collection concluded at end of 2022 with 48 participants completing the protocol. The results showed; 1) within-day fluctuations in fatigue that appear to be at their least severe in the mid-morning to early afternoon before progressively rising, peaking at bed time, 2) higher fatigue level was associated with decreased energy and poorer mood, 3) higher amount of physical activity completed was associated with lower fatigue levels and improved mood and 4) high feasibility with the majority of participants finding the App and mobile phones easy to use with potential that this type of technology could help manage their condition. A manuscript has been accepted for publication in Kidney International Reports (Dec 2023) (doi.org/10.1016/j.ekir.2023.12.024).

Funded by:

- Allied Health Professional Collaborative Grants SA Health, The Hospital Research Foundation-UniSA ($21,000)

Aboriginal Kidney Care Together- Improving Outcomes Now – AKction2

Co Leads: Dr Kim O'Donnell, Prof Janet Kelly

Team: K Owen, R Lester, N Sinclair, S Bateman, J Lavoie, I Williamson, J Kartinyeri, R Gadd, L Simo, C Franks, T Reid, M Wilson, D Champion, S Champion, O Pearson, T Mackean, S Jesudason, S McDonald, M Arnold- Ujvari, R Le Leu, L Jamieson, K Herman, P Clough, A Cormick, T Stevenson, L Rix, B O'Connor.

(Collaborations are being established with Community members, University of Adelaide, CNARTS services and sites, SAHMRI, ANZDATA, The National Indigenous Kidney Transplantation Taskforce, Kidney Health Australia, Menzies School of Health Research NT, Beyond Content SA)

2024 brings AKction2 into their 4th year of the five-year NHMRC funded project. 2023 was a busy year, filled with traveling, sharing, learning and lots of love. Unfortunately, 2023 also saw the passing of Inawinytji Williamson and Nari Sinclair, the Matriarchs and founding members of the AKction Reference Team.

Aboriginal Kidney Care Together- Improving Outcomes Now – AKction2 continued...

These incredible kidney warriors were fierce, yet gentle and cheeky advocates for equitable and culturally safe care for people with kidney disease. It was their commitment and activism that helped to bring the AKction project and team together in the first place. We thank them for their guidance and the knowledge and wisdom they shared with so many since this project began. With permission and encouragement from their families we will continue to tell their stories as we walk together on this journey.

Networking, sharing findings and building relationships with Communities and health providers around the state was a big focus for the year, beginning with Close the Gap Day in March. In May, members of the team travelled to Ceduna where they held a Community Stakeholder meeting to bring together local kidney warriors and health service providers. In August Team members partnered with the Adelaide University Rural Health Alliance to attend the annual Yalata Kidney Festival. Supported by the SA Health Kidney Bus and Dr Sam Bateman, this was an incredible opportunity that brought together the Yalata community, healthcare students and health care providers for a week of activities and education specific to kidney health. In November Janet and Rhanee also travelled to Pt Augusta to present at the community Kidney Yarning Circle, hosted by the Indigenous Program of Experience in the Palliative Approach program. Throughout the year, 3 of the teams' honours students also completed their projects. Focusing on improving transplant journeys (both within hospital and post-discharge) and understanding the experiences of COVID-19 for First Nations renal patients, the students mapped patient journeys and worked with the Reference Team over the last 2 years. All 3 students, Ayleen Castro, Millicent Baker, and Veda Mitra attained a 1st class honours grade and their data and findings will inform sub-study 2 (Support for Kidney Patients).

AKction members also attended several national and international conferences throughout 2024. Presenting in Cairns at the Lowitja Institute International Indigenous Health & Wellbeing conference, in New Zealand at the Australian and New Zealand Society of Nephrology Meeting and in Canada at the Healing our Spirit Worldwide Conference. Additionally, team members also presented at the Renal Society of Australia conference in Sydney, where AKction2 was also awarded the team prize for health equity in recognition of their contribution to supporting best practice models and outcomes for and with First Nations communities.

Funded by:

- AKction 2 is funded by: NHMRC Ideas Grant ($1,950,172)

Patient activation in advanced chronic kidney disease: a cross-sectional study

Lead: Laura Lunardi (PhD candidate)

Team: R Le Leu, S Jesudason, A Xu, L Matricciani, P Bennett

This study measured the patients' level of knowledge, skill, and confidence in patients with chronic kidney disease (CKD) stage 5 not receiving dialysis. This cross-sectional study recruited 204 people with CKD stage 5 not receiving dialysis within CNARTS. Patient activation was measured using the 13-item Patient Activation Measure (PAM-13). Sociodemographic and clinical outcome data (emergency department visits, admissions) were collected from medical records. Morisky Medication Adherence Scale was used to determine self-report medication adherence. Most people with stage 5 CKD not on dialysis had low levels of patient activation. Thus, they lack the skills, knowledge, and motivation to take an active role in CKD self-management. Patient age and education were strongly associated with levels of patient activation, as were the number of hospital emergency department visits, and medication adherence. These findings provide an insight into this vulnerable patient cohort imminently approaching kidney failure which often requires complex and demanding kidney treatment options.

This study is the platform for further investigating components that increase engagement in positive health-related behaviours for a more active role in self-management.

Funded by:

- 2022 Allied Health, Pharmacy and Nursing RAH Research Committee ($35,000)

Clinical database that will help us understand how we care for patients, the quality of care they get and their outcomes

Lead: Prof Shilpa Jesudason

Team: S Welke, R Le Leu, P Clayton

This project has developed a secure clinical database for capturing the specialised data required for researching, measuring and auditing service delivery, patient care and health outcomes across the patient journey, including end stage kidney disease, patients on dialysis and transplant patients. The clinical database was co-designed with clinicians to facilitate auditing and reporting to enable new insights and innovation in service delivery evidence-based care, and world-class benchmarks for improving patient care. The database will also collect critical service feedback directly from consumers, with the ability to send and collate surveys and has flexibility to expand with service developments and evolving treatments.

This database has greatly improved data knowledge, understanding and application capabilities for CNARTS busy clinicians, particularly through further developments in easily accessed and informative data dashboards.

The available data is now informing the development of new and enhanced services and care pathways to improve patient care, treatment choices and to reduce unnecessary hospitalisations.

Funded by:

- Kidney, Transplant and Diabetes Research Australia (KTDRA) ($200,000)

Benefits and Burdens of Kidney Transplantation for First Nations Australians

Lead: Dr Sam Bateman (PhD Candidate)

Team: S Jesudason (Principal Supervisor), O Pearson, P Clayton, S McDonald

Sam is progressing well through her PhD investigating models of care for Aboriginal and Torres Strait Islander people living with kidney disease. In 2023 her systematic review "Models of care to address disparities in kidney health outcomes for First Nations people" was published in Kidney International and informed the "Recommendations for culturally safe kidney care for First Nations Australians: a guideline summary", published in the Medical Journal of Australia. She is working with the COMPASS team to drive the peer navigator project and co-presented this with Kelli Owen at the ANZSN ASM in Christchurch in September. She is currently working on her final PhD project, understanding the relationship between ethnicity, remoteness and late referral on the KPI of preformed dialysis access. She continues to work collaboratively with the AKction group as a chief investigator and values the relationships and contributions the project and reference teams make to both her research and clinical work.

Funded by:

- NHMRC post-graduate scholarship
- RACP Jacquot Award for Excellence Research Entry
- BEAT-CKD post-graduate scholarship

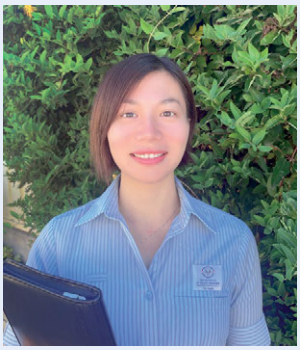
Pilot Randomised Controlled Trial of Advanced Recovery Room Care Post Living Donor Kidney Transplantation

Lead: Dr Karthik Venkataraman

Team: M Collins, G Ludbrook, T Coates

The optimum method to manage patients post renal transplantation is unknown. Significant heterogeneity exists in practice, with transplanting centres managing patients post operatively in intensive care units, high dependency units and renal wards. No comparative data exists to inform practices. The advanced recovery room is a model of post operative recovery, designed to provide high dependency unit level of care to patients. We have designed a pilot open-label randomised controlled trial (RCT), randomising recipients of living donor transplantation in a 1:1 ratio to either post operative care in the Advanced Recovery Room Care (ARRC) at the Royal Adelaide Hospital or the current standard of care, which is management on the renal ward. The intervention will include the ARRC bundle of care, involving closer haemodynamic monitoring, more frequent medical officer review and the ability to assess and address post operative hypotension with fluids and vasopressors. The primary outcomes are 1) safety, defined by adverse events assessed by the Severity Assessment Code (SAC), 2) feasibility, assessed by recruitment percentage and adherence to protocol. The primary efficacy endpoint is the mean difference in 24 hour blood pressure between groups. This is the first RCT investigating the level of post operative care in renal transplantation. Results from this RCT will lay the foundation for future trials, designed to assess the optimum post operative care of patients undergoing renal transplantation.

The futility of post-haemodialysis blood glucose levels: a retrospective cohort study



Lead: Jing Zhang

Team: R Le Leu, A Xu, P Bennett

The objectives of this study were to determine the rate of out-of-range post-haemodialysis (HD) blood glucose levels (BGLs), the rate of out-of-range post-HD BGLs that are clinically acted upon, the type of intervention and outcome of each intervention, and the associations between post-HD BGLS and relevant clinical predictors. Data was collected from 1703 HD sessions from 22 participants aged 67 + 12years, with a median time receiving dialysis 3.1 years. The proportion of out-of-range post-HD BGLs was estimated to be 87.3%. No out-of-range post HD-BGLs were clinically acted upon, there were no intervention episodes or outcomes of these interventions in the study sample. Factors such as pre-HD BGL readings, amount of intradialytic fluid removal, dialysate dextrose concentration, sex, dialysis time, whether receiving subcutaneous or oral anti-hyperglycaemic agents were found to have some association with post-HD our-of-range BGL. It was concluded that routine post-HD BGL testing has limited clinical utility in the routine care for people with diabetes receiving HD.

doi.org/10.1111/jorc.12492

Funded by:

- The Health Services Charitable Gifts Board (HSCGB) ($16,400)

Providing Medication Education to Renal Transplant Recipients: Are We Getting It Right?

Lead: Dr Sadia Jahan

Team: T Doody, J Goh, H Tran

Successful medication-taking behaviour by kidney transplant recipients is associated with long-term survival and is dependent on knowledge of medication regimens with medication counselling playing a major role in this. The optimal way of medication education delivery is not known, and our project is to evaluate current forms and to obtain feedback on alternative strategies. We utilised the validated Kidney Transplant Understanding Tool (K-TUT) to determine our patients' level of knowledge regarding their transplant medications. We also developed a patient survey assisting in classifying level of health literacy related to transplant medication knowledge.

As part of feasibility, results have been obtained from eight patients with 2/8 from Indigenous background and 2/8 patients' primary language being non-English.

In terms of the questions asked about preparedness for medicines post-transplant, direct quotes include "I was a bit nervous because I didn't realise there were so many tablets to start off with so that was a bit of a shock" and "No, I wasn't confident at first, I was a bit scared of how much tablet I had to take". One emerging theme is that the information booklet is not being read (7/8) with comments such as "I just didn't have time" and "I had so much going on". Another theme pertains to different delivery of education in the form of "mobile app would be good, (explaining) the tablets" and "A mobile app would probably be handy because the doctor and pharmacist can update it quickly". Data from our patients have clear emerging themes, and it will be prudent to continue recruitment into the study, to clearly identify areas for improvement with knowledge about possible implementation of alternative education strategies.

Exploring the experience of breathlessness for people living with kidney failure

Lead: Maria Chilvers (PhD candidate)

Team: M Williams (Principal Supervisor), K Johnson, K Ferrar, S Jesudason, P Bennett

(Collaboration with Allied Health and Human Performance, University of South Australia)

This research study explores how the sensation of dyspnoea is assessed in kidney failure by health professionals and is part of the larger PhD research program which seeks to understand the sensation of dyspnoea in people living with kidney failure. The descriptive, cross-sectional survey explores clinicians' attitudes, beliefs and self-reported practices in dyspnoea assessment and management. Data collection concluded February 2023 with 125 participants completing the survey. Manuscript is currently being prepared with the results showing; 1) clinicians value routine assessment of dyspnoea severity and 2) knowing about patient's dyspnoea can guide clinical decision making and patient care. Preliminary results were presented at the Renal Society of Australasia Annual Conference (May 2023). Further studies are proposed to explore the day-to day fluctuations and the impact of dyspnoea from the perspective of the people living with kidney failure.

Centre for Clinical and Experimental Transplantation (CCET)

The CNARTS laboratory is based at the new biomedical precinct within the University of Adelaide Health and Medical Sciences building. The laboratory has continued its excellence in training the next generation of scientists and clinicians further enhancing its reputation for producing outstanding independent researchers, with a research focus on kidney disease, diabetes and other diseases of the pancreas.

The laboratory is led by Prof Toby Coates AO and includes clinician scientists: A/Prof Chen Au Peh and A/Prof Shantanu Bhattacharjya. Chief Scientist A/Prof Chris Drogemuller is Head of the laboratory that includes a team of senior scientists, grant funded scientists, technical officers, PhD and Honours students. Many previous laboratory students have gone onto leadership roles in nephrology and transplantation from the CNARTS laboratory and become independent researchers in leading institutions all around the world. To date, the lab has had 3 prestigious CJ Martin fellowships awarded and a Rhodes Scholar.

Visions Statement

To train the next generation of medical doctors and scientists in basic laboratory science for application to the causes and treatment of renal diseases and organ transplantation.

Laboratory Staff

- A/Prof Chris Drogemuller (Chief Scientist)
- Dr Griffith Perkins (Post-Doctoral Fellow)
- Svjetlana Kireta (Senior Medical Scientist)
- Dr Plinio Hurtado (Senior Grant Funded Scientist)
- Julie Johnston (Technical Officer)
- Jodie Nitschke (Senior Grant Funded Scientist)
- Daniella Penko (Senior Grant funded Scientist)

Students

- Denghao Wu (PhD candidate)
- Brigette Clarke (PhD candidate)
- Jacqueline Scaffidi (PhD candidate)
- Nick Chai (PhD candidate)
- Dylan Barnett (PhD Candidate)
- Jessica Lee (PhD Candidate)
- James Besanko (Masters Candidate)
- James Zuiani (PhD Candidate)

Laboratory Research Projects

SIR ZOSTER: Safety and Immunogenicity of Recombinant ZOSTER vaccine in kidney transplant recipients

Researchers: G Perkins, M Tunbridge, C Chai, D Penko, J Nitschke, S Kireta, J Johnston, CJ Drogemuller, J Scaffidi, J Zuiani, G Irish, PR Hurtado, PTH Coates

Associate Researchers: P Hissaria, B Grubor-Bauk, S Chadban, J Singer, L Rowntree, C Furst, N Spurrier

Immunosuppressed kidney transplant recipients are disproportionately impacted by infections. While vaccines are available to prevent many infections, their effectiveness is often reduced in transplant recipients due to the effect of immunosuppressive medications. Additionally, some vaccines, like the live attenuated shingles vaccine (ZOSTAVAX), cannot be used by immunosuppressed patients. A newer vaccine against shingles (SHINGRIX) was recently approved for use by immunosuppressed patients in Australia.

In this recently initiated study, we are investigating how well kidney transplant recipients respond to the SHINGRIX vaccine, and the effect that mTOR inhibitors might have to boost this response.

This study will enrol 100 participants (kidney transplant recipients and their cohabitants) across the Royal Adelaide Hospital and the Royal Prince Alfred Hospital in Sydney. Participants will receive two doses of the SHINGRIX vaccine, and key aspects of their immune response will be assessed by investigators within CNARTS, the University of Adelaide, and the Peter Doherty Institute in Melbourne.

This will be the first study to compare the response of kidney transplant recipients and non-immunosuppressed individuals, for whom the vaccine is highly effective at preventing shingles. The study is a continuation of our work to develop mTOR inhibitors as an adjuvant to boost vaccine responses in transplant recipients, and will include a 1 year blood sample to decipher how mTOR inhibitors influence a key stem cell-like immune cell population that provides long-term protection against shingles.

First in Human INCEPTR trial (INtraCutaneous, Ectopic Pancreas TRial)

Researchers: T Coates, C Drogemuller, D Penko, J Johnston, J Nitschke, S Kireta, C Etherton, A Rickard and CNARTS Clinical Trials unit

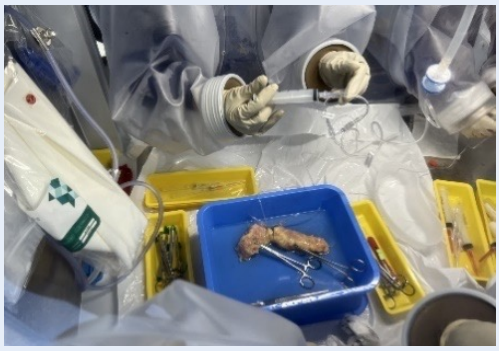
Associated researchers: J Greenwood, M Wagstaff, D Torpy, B Clarke, T Kay, T Loudovaris, L Mariana

This project is supported by the Juvenile Diabetes Research Foundation International (New York) and Australia, to develop an alternative extra hepatic site for islet transplantation. Following on from registration and initiation of the INCEPTR trial in 2022, 3 patients were activated and received a Novosorb ® scaffold implant followed by an intracutaneous islet transplant. All 3 patients tolerated the procedure well with all displaying early signs of graft function. The 3 month and 12 month trial data will be reported in 2024.

Intracutaneous Ectopic Pancreas (IEP) creation by seeding Human Stem Cell-derived Islets (HSCI) into integrated BTM

Researchers: T Coates, C Drogemuller, J Nitschke, S Kireta, D Penko, J Johnston

Associated researchers: J Greenwood



This project is a long-standing collaboration between one of the largest international diabetes companies, Novo Nordisk, our islet transplant research team and Beta Cell Technologies. This project will determine the effectiveness of intracutaneous islet transplantation of stem cell derived islets. If successful this would negate the need for islets purified from deceased organ donors, leading to a more consistent supply and quality of islets for transplantation. In addition, by removing the need for donor islets the transplantation procedure can be planned for in advance, with the islets provided at the optimal time for transplantation. Leading to better outcomes for transplant recipients.

The Development of Chimeric Antigen Receptor (CAR) Regulatory T Cells as a Novel Therapy for Type 1 Diabetes

Researchers: J Scaffidi, T Sadlon, V Bandara, S Barry and T Coates

This project is investigating the ability to render regulatory T cells (Tregs) specific for a known autoantigen of type 1 diabetes (T1D) via chimeric antigen receptor (CAR) expression. We propose that these cells will be better able to suppress the autoimmune response that occurs in T1D.

During 2023 manufactured CAR T regs from T1D patient T regs as a proof of concept. This year, we aim to complete our final experiments testing these patient-derived CAR Tregs which includes looking further into their gene expression following antigen stimulation.

In 2023, this project was awarded a $60,000 grant from Diabetes Australia to further progress this project in animal studies.

Development of new approaches to measure proteolysis and glycosylation profiling of high and low affinity corticosteroid-binding globulin (CBG) in septic shock using mass spectrometry

Researchers: J Lee, T Coates, E Meyer, D Torpy

Associated Researchers: M Anderson, P Hoffman, Z Bayraktar, P Mittal, C Young, P Hurtado, W Rankin

This project aims to measure different affinity forms and glycoforms of corticosteroid-binding globulin (CBG) in the setting of sepsis. CBG binds cortisol at a high affinity, and the CBG:cortisol binding affinity is reduced reversibly by pyrexia and acidosis, and reduced irreversibly by neutrophil elastase cleavage at the reactive centre loop (RCL) of CBG, converting high affinity CBG to a low affinity form. These characteristics allow for optimisation of spatiotemporal distribution of free cortisol in the setting of sepsis. Previous research by E Meyer, D Torpy et al, has shown that reduced CBG is an independent predictor of ICU mortality in septic shock patients, highlighting the importance of CBG in septic shock survival.

We aim to further investigate the impact of relative abundance of different CBG affinity forms and glycoforms on septic shock outcome, and to measure these using mass spectrometry. We are collaborating with the proteomics team at UniSA and Macquarie University on this project. In 2023, through collaborative efforts, we have succeeded in purification of CBG for downstream mass spectrometric analysis and have successfully achieved glycosylation profiling and direct detection of low affinity CBG using mass spectrometry. Data analysis is in progress.

This project is supported by HSCGB grants from the Royal Adelaide Hospital Endocrine Unit, and Margorie Hooper travel grant (RACP foundation) was awarded to J Lee to facilitate collaboration with Sydney.

Adrenal cell transplantation for Addison's disease using biodegradable temporising matrix technology

Researchers: B Clarke (PhD candidate), S Kireta, P Hurtardo, T Coates, D Torpy

Associated Researchers: C Christou, J Greenwood, J Kollias, J Johnston, D Penko, J Nitschke, C Drogemuller, E Concannon

The aim of the project is to explore the use of adrenocortical cell transplantation as a novel approach to the treatment of primary adrenal insufficiency. There is a need to improve the outcomes for individuals with Addison's disease, as morbidity and mortality remain significantly increased compared to the general population, even with current gold standard medical therapy.

During 2023, my research studies focused on characterising the cell surface markers of adrenocortical cells. Subsequently we evaluated candidate markers for the identification of adrenocortical cells using flow cytometry, with the ultimate goal of better characterising the composition of cell preparations for use in future transplantation studies.

The data from our pilot study of autologous adrenocortical cell transplantation into a cutaneous site using integrated biodegradable temporising matrix in a large animal model was presented at the Endocrine Society of Australia Annual Scientific Meeting in Brisbane, as a finalist in the ESA Gail Risbridger Junior Scientist Award.

This project has been undertaken in collaboration with Beta-Cell Technology and is supported by a Royal Adelaide Hospital Clinical Project Grant and HSCGB grants from the Royal Adelaide Hospital Endocrine Unit. Surgical equipment used in the large animal model was donated by Medtronic.

Total Pancreatectomy and Islet Auto Transplantation (TPIAT)

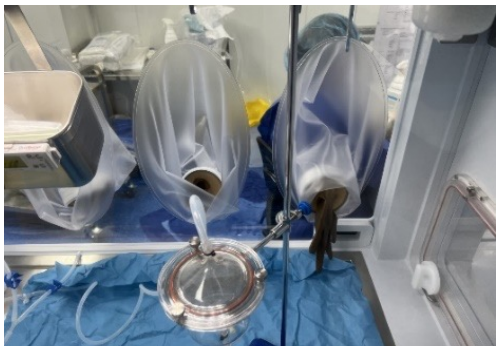
Researchers: T Coates, C Drogemuller, S Kireta, D Penko, J Johnston, J Nitschke, C Etherton, A Rickard, G Radisic, D Wu, G Perkins, C Russell

Associated researchers: D Torpy, S Khurana, J Chen, J Couper, R Couper, E L Neo

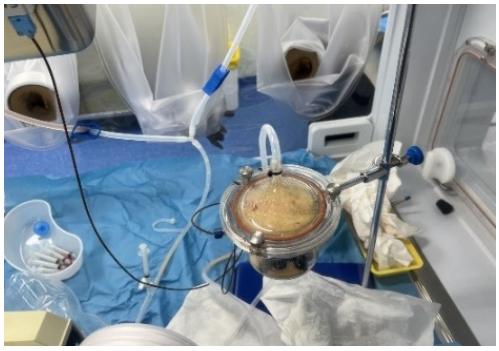
With the generous support of the hospital research foundation, the LIONS Club and the state government we have established a new clinical program for the treatment of hereditary pancreatitis. The program involves removing a patient's own pancreas, thus removing the source of chronic pain and also removing the likelihood they will go on to develop pancreatic cancer in their 40-50's. Once the pancreas has been surgically removed it is processed to isolate the islets within, the cells responsible for secreting insulin and controlling our blood sugar levels. The islets are then transplanted back into the patient's liver where they will remain and secrete insulin in response to changing blood glucose levels. This transplant procedure will prevent the patient from becoming overtly diabetic and in some cases not requiring any exogenous insulin at all to control their blood sugar levels.

Excitingly, in the last quarter of 2023 we processed 5 donor pancreas within the newly established Biospherix facility. This provided a great opportunity for ongoing training of staff in the islet isolation process, operation of the Biospherix system, development of SOPs and collection of safety and quality data required to initiate clinical activity. All of which is essential for isolation of islets within the new system for transplant into hereditary pancreatitis patients undergoing the TPIAT procedure.

In 2023, significant progress was made towards the establishment of the first national hereditary pancreatitis REDCap database, led by project manager Gorjana Radisic. The database is a crucial element of the MRFF HEPATA grant, required to comprehensively and accurately understand the prevalence and impact of HP on individuals and families, and to evaluate the outcomes of TP-IAT as a curative solution, in the context of the Australian population. To date, 6 HP patients have undergone the TPIAT procedure, funded through the HEPATA grant, and their outcomes will be captured in the newly established HP database. With the aim being to utilise the captured data to support the TPIAT procedure becoming a government funded medical procedure available to all Australians living with this disease.



Chamber before pancreas is loaded



Pancreas loaded into chamber midpoint of tissue digestion

Empty chamber at completion of digestion

Mapping of Cell-Free DNA in SLE Patients: Identifying Markers of Disease Activity

Researchers: P Hurtado, E Hurtado and C Peh

This research proposal targets the urgent need for novel diagnostic markers and early indicators of disease activity in systemic lupus erythematosus (SLE). It aims to investigate the association between unique cell-free DNA (cfDNA) sequences or patterns and disease activity in SLE patients. Through the identification of specific markers, the project seeks to improve the accuracy of assessing disease activity, optimise drug intervention decisions, and prevent organ damage, in particular, kidney damage. Using machine learning, this study intends to develop predictive algorithms that can identify cfDNA patterns or sequences indicative of diagnostic or disease activity significance in SLE. By analysing known cfDNA sequences from SLE patients in various disease stages and healthy controls, the research aims to discover patterns or sequences that could lead to the development of new diagnostic tools, such as PCR tests. The availability of such tests would not only facilitate early and precise diagnosis but also offer new critical markers for monitoring disease activity, enabling timely interventions and improving patient care.

The Genetic Epidemiology of Hereditary Pancreatitis in South Australia

Researchers: D Wu, CJ Drogemuller, G Radisic, C Etherton, A Rickard, GB Perkins, J Zuiani, S De Sousa, PT Coates

Associated Researchers: D Adelson, G Irish, S Jahan

Hereditary Pancreatitis (HP) is a debilitating condition caused by inheritance of a variety of genetic mutations. HP results in inflammation of the pancreas from a young age, chronic abdominal pain, and dependency upon pain management opioids. Severe cases of HP are candidates for total pancreatectomy and islet auto transplant (TP-IAT) surgical treatment. This project is the first to identify Australian families suffering from HP and assess correlation between phenotypic disease outcome and genotypic variant. Patients with HP were identified from existing hospital records at the Royal Adelaide Hospital, Women's and Children's Hospital, St. Vincent's Hospital in Melbourne, and Westmead Hospital in Sydney. Medical Interviews were conducted for enrolled patients. Salivary biosamples were obtained from patients and family members to be whole-exome-sequenced (WES) and analysed in silico using bioinformatics toolkits (GATK) and the Integrative Genomics Viewer (IGV) developed by the Broad Institute.

A total of 21 pedigrees comprising 155 individuals were recruited for the project. Overall, 76% of HP presented with clinical onset before the age of 10. Ongoing opioid usage for pain management in the HP cohort was 55% and 64% of patients reported ongoing moderate to severe pain. Strikingly, HP was 67 times more prevalent in Indigenous populations than non-Indigenous. Our estimated prevalence of HP is higher than previously described and disproportionately affect Indigenous populations. The percentage of HP patients requiring lifelong analgesics is alarming and genetic factors are an important cause of pancreatitis in Australian children. Bioinformatics analyses of WES genotypic data yielded a list of 33potentially pathogenic variants identified outside of known HP-associated gene including *ECE1, GJA5,* and *SPTBN5*. The study described the prevalence of HP in an Australian population for the first time, highlighted the importance of utilising genetic testing protocols to guide medical decision-making in HP, generated candidates of ptoential pathogenic genetic varaints associated with HP disease risk, and successfully established a patient registry for candidates of TP-IAT treatment.

Re-purposing rapamycin as a vaccine adjuvant to enhance pathogen-specific T cell response and longevity of immune memory in immunocompromised transplant patients

Researchers: N Chai, G Perkins,C Drogemuller,B grubor-bauk, T Coates

T cells are highly dynamic immune cell population. During viral infection or following vaccination, naïve T cells undergo rapid expansion and differentiation into both effector and memory progeny, mediating immediate and long-term protection.

Cellular metabolism also plays a critical role in shaping T cell response. The mammalian target of rapamycin (mTOR), a central metabolic regulator that perceives and integrates micro environmental signals to coordinate cell growth, proliferation, function, and survival during the early stages of T cell activation and fate determination. Previous studies have demonstrated that suppressing mTOR activity by its inhibitor, rapamycin, significantly enhances the formation of antigen-specific memory T cells in the context of vaccination or viral infection in mouse models. However, whether rapamycin exerts a similar effect in humans still remains controversial.

During 2022, we have conducted an animal study to further investigate and optimise the effect of rapamycin on primary and booster vaccine responses. Peri-vaccination of rapamycin has shown an increase in the average magnitude and quality of vaccine-specific T cells in mice. A greater stimulatory effect was observed in mice commencing rapamycin prior to primary vaccination rather than during the booster phase. Interestingly, rapamycin was also associated with the induction of an antigen-responsive naïve cell population highly expressing the SCA-1 marker, indicative of the stem-like memory T cell (Tscm) phenotype. This suggests that inhibition of mTOR by rapamycin during vaccination induces antigen-reactive Tscm formation.

Tscm is a rare memory T cell subpopulation with characteristics of self-renewing and robust proliferative capacity which have been found to confer durable protection in smallpox and yellow fever vaccination. This project will further explore the underlying mechanisms by which (1) mTOR inhibition regulates immune cell metabolism to induce long-lived Tscm and (2) the impact of immunosuppressive medications on Tscm generation in transplant patients.

Portal Venous Pressures and Liver Function Tests Following Islet Cell Transplantation: A Single-Centre Experience

Lead: Vincent Trinh

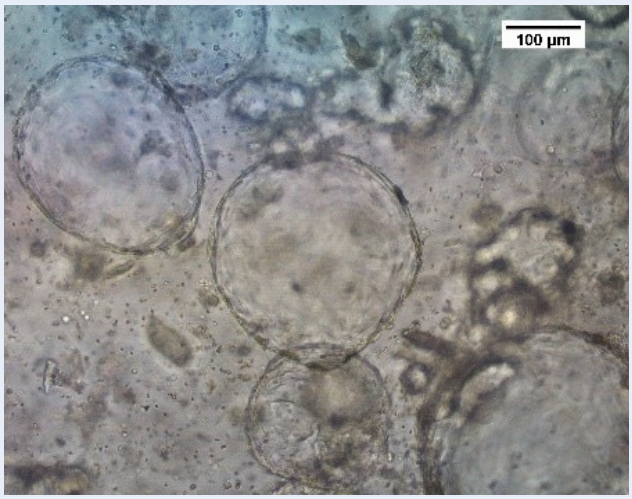
Team: A Orsillo, C Etherton, A Rickard, T Coates

The retrospective audit aimed to examine the factors associated with portal pressure increase and their association with liver functions tests (LFT) derangement. This audit included all allogeneic and autologous islet cell transplantation (ICT) performed at a single tertiary centre was conducted to identify recipient and islet preparation characteristics. Thirteen autologous and 27 allogeneic ICT were audited. Autologous recipients received higher packed cell volumes (PCV, 7 vs 1.7mL, $p < 0.01$). No baseline differences were observed in portal pressures or LFTs between groups. Observed differences in peak, close and portal pressure change did not reach statistical significance. The autograft group experienced an earlier transaminase peak day 1 post-operatively ($p < 0.01$) with up trending cholestatic enzymes day 14 post-procedure. PCV had no strong association with portal pressures and mixed correlations with LFTs. Moderate and strong correlations were found between portal pressures and baseline ALT, AST, and ALP values in the autologous recipients. It was concluded that although common trends were observed in LFTs following ICT, the varied strength of their correlation with portal venous pressures may make them an unreliable predictive factor.

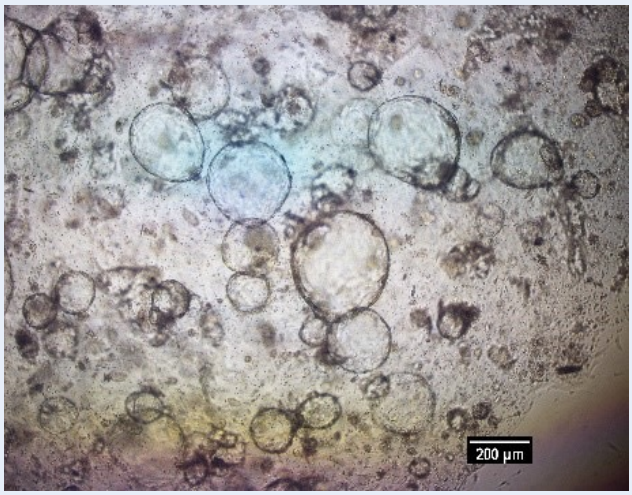
Characterisation of Pancreatic Organoids in hereditary pancreatitis and normal individuals

Researchers: J Zuiani (PhD candidate, University of Adelaide), G Perkins, S Grey, C Drogemuller, T Coates

Hereditary pancreatitis (HP) is a chronic disease caused by a series of HP associated genetic mutations. This condition manifests in adolescence, leading to inflammation, severe abdominal pain, and the eventual development of pancreatic fibrosis, endocrine and exocrine insufficiency and a substantially increased risk of pancreatic cancer. There is currently a lack of models to effectively study the disease, as the gene mutations involved lack sufficiently homologous animal counterparts. As such, this project aims to develop an organoid model to study hereditary pancreatitis.



We have generated pancreatic organoids both from healthy individuals and patients with hereditary pancreatitis, utilising samples taken from total pancreatectomy with islet autotransplantation (TPIAT) procedures. These organoids have been characterised through qPCR and immunohistochemistry staining for amylase and krt19 determining that the cells maintain acinar characteristics in 3D culture conditions.



This model will allow for investigation into the phenotypic differences and mechanisms of patient specific gene mutations through the use of both healthy control and patient derived organoids. This model will also aim to provide a platform for the development and testing of new potential HP treatments.

Organ preservation and resuscitation by isothermic oxygenated machine perfusion in an ex-vivo porcine model

Researchers: D Barnett, J, Bastian, A, Kanhere, D Daniel, R Bhattacharjya, S Bhattacharjya, T Coates

There is a constant supply and demand mismatch in organ transplantation which prevents the ever-increasing number of Australians who would benefit from this life-saving treatment from receiving it in a timely fashion. As a result, clinicians are relying on more and more marginal organs that previously would have been discarded without having objective biomarkers to assess organ quality or predict likelihood of function following transplant.

Machine perfusion technologies offer the potential to both evaluate the quality of organs ex-vivo and potentially even resuscitate damaged organs prior to transplantation. Because of this there has been a significant interest in the investigation of normothermic machine preservation. This technology however remains expensive and complicated resulting in limited uptake in clinical practice compared to the current gold standard of static cold storage. In an effort to simply the process of machine perfusion we are investigating whether it is possible to remove temperature manipulation completely from the machine perfusion.

In the last 12 months our group has successfully extracted and measured ATP from snap frozen tissue samples to measure the ability of isothermic perfusion to maintain cellular energy stores during 5 hours of preservation. This showed ATP levels were maintained and trended upwards during preservation, confirming maintained energy homeostasis. We have also developed a novel scoring system with an expert histopathologist to standardise reporting and comparison of the extent of microscopic structural damage to organs during preservation. We have also been able to demonstrate the ability of isothermic perfusion to maintain viable Islets of Langerhans in the porcine pancreas responsible for insulin production and visualise them in samples taken from pigs much smaller than previously reported.

In the subsequent 12 months we will be completing the current round of experimental work looking to validate the histological scoring system and undertake further experiments investigating the ability of isothermic perfusion to mitigate ischaemia-reperfusion injury by analysing the molecular pathways upregulated and downregulated during preservation comparted to static cold storage.

This project is gratefully supported financially by Kidney, Transplant & Diabetes Research Australia and could not be completed without the assistance from the staff at SAHMRI PIRL.

Evaluation of heart transplant transportation device in a pig model

Researchers: J Besanko (Masters candidate, University of Adelaide

Supervisors: J Beltrame, J Edwards, T Coates

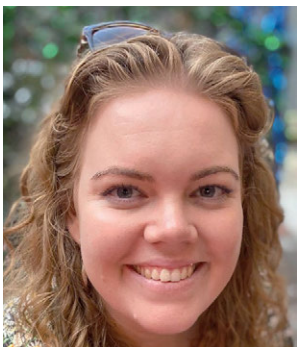
Evidence from randomised human and experimental trials indicate that the results of heart transplantation improve with the use of perfusion of donor hearts. In these studies, we evaluated the efficacy of a novel mechanical perfusion device in preserving procaine hearts for six hours ex vivo. The device utilises hypothermic perfusion with celsior solution at a low flow rate of 40ml/min. This device is small, portable, weight 16kgs, operates on batteries, fits in a standard economy domestic airline seat and facilitates the flow of oxygenated hypothermic fluid.

This research is divided up into three study segments; recirculation studies, reanimation studies and transplantation studies. To date the recirculation studies are completed and the reanimation studies are nearing completion. Details of reanimation are as follows; 12 Porcine hearts were explanted using standard techniques and randomised to either be preserved via cold storage (n=6) or mechanical perfusion (n=6). Following preservation, the hearts were reanimated on a bench bypass circuit and assessed for two hours. Cardiac performance was assessed in the working model after a stabilization period in non-working status (langendorff model).

Preliminary data demonstrates the mechanical perfusion device was superior preservation compared to cold storage in terms of cardiac performance (Cardiac output) on the bench bypass circuit electron microscopy, and biochemical normality.

These findings suggest that the mechanical perfusion device provides an alternative to cold storage preservations and has the potential to improve the preservation of hearts for transplantation.

A Financial Audit of Total Pancreatectomy and Islet-Auto Transplantation with Remote Isolation compared with Traditional Medical Management and the expected complications of Hereditary Pancreatitis: A South Australian Perspective



Lead: Prof Toby Coates

Team: A Rickard, C Etherton, T Doody, A Yu, S Jahan, A Silverwood, C Drogemuller, D Wu, M Boiarski, D Torpy, R Couper, S Khurana, J Chen, T Kay, T Loudovaris

This audit set out to clarify the full expense for state & federal government to provide total pancreatectomy and islet-auto transplantation (TPIAT), compared to traditional medical management and complications of hereditary pancreatitis (HP). This was a single centre retrospective cohort analysis of 15 patients who underwent TPIAT in South Australia from 2017 to May 2023. We conducted a review of electronic medical records for patient outcomes data, categorised an optimal, mean-average, and least-optimal patient experience, identified elements of care involved in TPIAT, traditional medical management, and complications of HP, and utilised patient costing data from the Central Adelaide local Health Network activity dashboard and General Ledger, Oracle Corporate systems and specialist staff. Cost of these care elements were calculated and compared in optimal, mean-average, and least-optimal contexts. This audit illustrated economic value of TPIAT surgery in the treatment of HP and prevention of disease progression. TPIAT expense ranged from $175,000 to $500,000 per patient, whilst traditional medical management ranged from $70,000 to $2.5 million. The annual expense post-TPIAT of $3000 per patient provides an estimate of potential savings for commonwealth and state governments. Currently this procedure is only accessible through medical research grants, hence it is the hope this information should prove useful for review and indexation of Australia's Medicare system.

ANZDATA CNARTS Report 2023

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects and reports the incidence, prevalence, and outcome of dialysis treatment and kidney transplantation for patients with end-stage kidney failure across Australia and New Zealand.

The mission of the registry is to improve the quality of care and outcomes for people with end-stage kidney disease in Australia and New Zealand by:

- Collecting and analysing accurate and comprehensive data from all patients receiving long-term dialysis or kidney transplantation in Australia and New Zealand,
- Producing and disseminating reports,
- Informing the development of practice, policy, and health services,
- Working with stakeholders to improve the understanding of kidney disease and outcomes of treatment.

The ANZDATA Registry encourages and enables the highest quality of care for people in Australia and New Zealand with end-stage kidney disease by providing information that is complete, accurate, clear, relevant, readily available, and timely.

The following information pertains to current research, publications, projects, events, conferences, and talks presented by ANZDATA staff and its affiliates.

ANZDATA Research staff

Current employees

- **Prof Stephen McDonald** (Director of Strategy and Policy): stephen@anzdata.org.au
- **Dr Phil Clayton** (Technical Director): phil@anzdata.org.au
- **Dr Georgina Irish** (Director of Analytics and Reporting): georgina@anzdata.org.au
- **Ms Kylie Hurst** (Registry Manager): kylie@anzdata.org.au
- **Ms Kelly Marshall** (Registry Associate General Manager): kelly@anzdata.org.au
- **Prof Shilpa Jesudason** (Investigator): shilpa.jesudason@sa.gov.au
- **Dr Chris Davies** (Lead Biostatistician): chris2@anzdata.org.au
- **Ms Feruza Kholmurodova** (Biostatistician): feruza@anzdata.org.au
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- **Dr Dominic Keuskamp** (Post-Doctoral Research Fellow): dominic@anzdata.org.au
- **Ms Jasmin Mazis** (Patient Engagement Project Officer): jasmin@anzdata.org.au
- **Ms Lavern Greenham** (Clinical Research Coordinator): lavern@anzdata.org.au
- **Ms Emily Duncanson** (Research Officer & Registered Psychologist): emily@anzdata.org.au
- **Ms Katie Cundale** (Program Manager NIKTT): katie@anzdata.org.au
- **Ms Kelli Owen** (NIKTT – Consumer Engagement Coordinator): kelli@anzdata.org.au
- **Dr Samantha Bateman** (PhD candidate): samantha.bateman@sa.gov.au
- **Dr Alison Weightman** (PhD candidate): alison@anzdata.org.au
- **Ms Annie Conway (**Data Scientist / Biostatistician): annie@anzdata.org.au
- **Dr Eric Au** (Epidemiology Fellow): eric@anzdata.org
- **Ms Isabelle Haklar** (Research Officer): isabelle@anzdata.org.au

Former staff members

- **Dr Shyam Muthuramalingam** (Consumer Engagement Coordinator): shyam@anzdata.org.au
- **Ms Kathryn Dansie** (Biostatistician): kathryn@anzdata.org.au
- **Mr Isaac Brown** (NIKTT – Junior Research Officer): isaac@anzdata.org.au

Projects

Pregnancy and Kidney Research Australia (PKRA)

Lead: Prof Shilpa Jesudason

Researchers: E Hewawasam, N Tangirala, C Davies, S McDonald.

Consumer engagement support: J Mazis

Parenthood advisory group members: J Boag, C Green, L Heffernan, B Huuskes, C Maistry, K Owen, S Muthuramalingam, A Tolic, A Williamson, A Sluiter, E Newman.

In 2022/23, the ANZDATA Parenthood group rebranded as PKRA, bringing together consumers and researchers across Australia to address patient-prioritised research into pregnancy planning and care for people living with kidney disease. PKRA undertakes mixed-methods projects with a strong focus on consumer codesign and partnership throughout.

pkra.com.au/research-activity

anzdata.org.au/anzdata/research/registry-projects/#uagb-tabs__tab8

Consumer activities: Throughout the year, our consumers have actively participated in the following initiatives:

- Setting research priorities and co-designed methodology
- Speaking at engagement events, talks, and public forums
- Annual review of parenthood data capture within ANZDATA
- Co-authorship on publications
- Co-investigators on grant applications
- Developing consumer resources and checklists
- Facebook page development in partnership with Kidney Health Australia aimed at fostering peer support

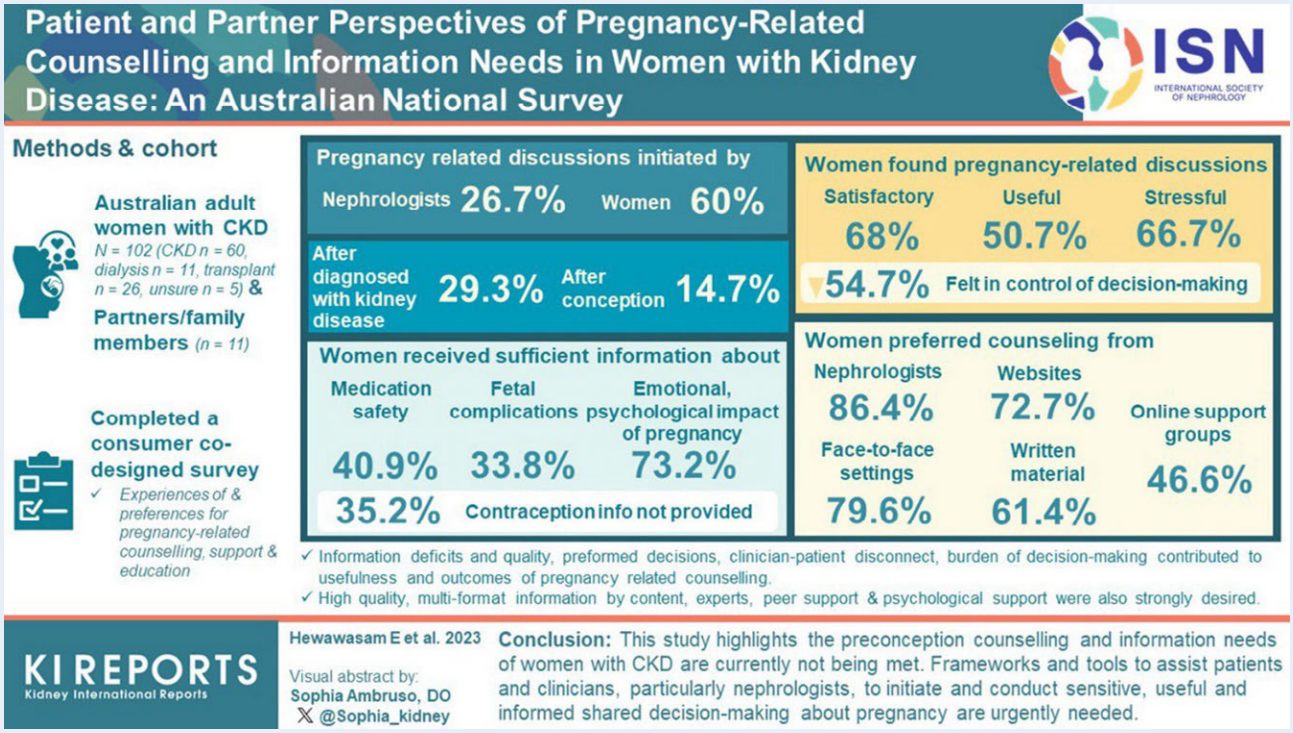
After going through kidney disease for nearly 20 years, I'm proud to be a Consumer Partner and see the differences PKRA are making for the pregnancy journey of people with kidney disease.

Adela Tolic

The **ANZDATA Parenthood Working Group,** established in 2023, reviews registry data capture for parenthood, promotes utilisation and community awareness, assists in report development, and presents research findings at meetings. Click for more details: anzdata.org.au/anzdata/about/working-groups/parenthood-working-group/

Current projects

1. **Perinatal, ANZDATA, hospital data linkage study**
   - Labour and delivery outcomes - N Tangirala, E Hewawasam, S Jesudason
   - Pregnancies women had before they subsequently started KRT – S Jahan, E Hewawasam, S Jesudason
   - Follow-up of children born to transplanted mothers – E Hewawasam, C Davies, S McDonald, Z Li, E Sullivan, S Jesudason.
2. **The "Kidney Mums Toolkit"**
   S Jesudason, E Hewawasam, C Green, S McDonald
   Implementation and evaluation of an online toolkit of resources for patients and clinicians to navigate safer parenthood decisions and care for better pregnancy outcomes in women with kidney disease.
3. **Pregnancy outcomes in women with earlier stages of CKD using CKD and cardiac disease in pregnancy registry in SA**
   J Hopkins, P Andraweera, A Orsillo, M Arstall, E Aldridge, R Le Leu, M Ladhani, N Tangirala, E Hewawasam, S Jesudason
4. **Kidney doctors' perspectives on the management of pregnancy in women with CKD: an interview study**
   M Wyld and A Jaure, E Hewawasam, S Jesudason
5. **Understanding drivers of decision-making about pregnancy with CKD in both clinicians and patients**
   N Tangirala, E Hewawasam, M Howell, S Jesudason
6. **Tasmanian CKD linkage dataset study with access to information about kidney disease, perinatal outcomes, hospital admissions and pathology data**
   Prof Matthew Jose, L Cuthbertson, A Kitsos, T Saunder, E Hewawasam, S Jesudason
7. **Perspectives of reproductive health in First Nation's women with CKD**
   Collaboration Aboriginal Kidney Care Together, Improving Outcomes Now" (AKCTION) Reference Team in SA, N Tangirala, K Owen, K O'Donnell, J Kelly, A Graham, E Hewawasam, S Jesudason



Exploring patient travel

Lead: Prof Stephen McDonald

Researchers: C Davies, K Dansie, E Duncanson, P Clayton, S Jesudason, S Ullah, A Gulyani, D Keuskamp.

Using ANZDATA data and sophisticated geospatial models, we have performed analyses of travel time and distance between patients' residential postcodes and dialysis units, to characterise the burden of travel for patients and identify where patients are treated geographically in Australia. Geospatial analysis is also being used to describe variation in kidney replacement therapy patient incidence across Australia and over the last two decades, to determine the emergence of hotspots of incidence.

Survival after COVID Infection – impact of treatment modality

Lead: A/Prof Solomon Menahem

Researchers: P Kolovos, G Irish, F Kholmurodova, C Davies, H Kulkarni

This project explores the characteristics of kidney replacement therapy patients with a COVID-19 infection and examines whether their survival was impacted by treatment modality.

Understanding changes to practice patterns in dialysis care during the COVID-19 pandemic

Lead: Dr Daniela Potter

Researchers: A Conway, C Davies, S Kotwal, G Irish, A Pilmore, P Clayton, K Polkinghorne.

This project aims to describe the changes to practice patterns that occurred during the initial phase of the pandemic among dialysis patients in Australia and New Zealand.

Data linkage projects

Lead: Prof Stephen McDonald

Researchers: C Davies, K Dansie, D Keuskamp, P Clayton, A Conway.

- National Joint Replacement Registry – Analysis has started on a large national linked data set between the Australian Orthopaedic Association National Joint Replacement Registry (AOA NJRR) and ANZDATA, examining joint replacements in the treated kidney failure cohort for the period 2003-2016. Early analyses have determined that Australian Kidney replacement therapy (KRT) patients experience higher rates of hip replacement than the non-KRT population, particularly for the diagnosis of osteonecrosis. There is however no difference in the rate of revision surgery between dialysis, transplant, and the non-KRT population.
- Cardiac Surgery Registry – In 2022, a national linked dataset was created between ANZDATA and the Australian and New Zealand Society of Cardiac & Thoracic Surgeons Database (ANZSCTS), which collects data on most cardiac surgical procedures. Key research aims include quantifying (1) the risk of developing end-stage kidney disease (treated with KRT) after cardiac surgery, and (2) the risks of cardiac surgery for KRT patients. Early analyses have determined that Australian KRT patients experienced higher rates of cardiac surgery and worse post-surgical outcomes than the non-KRT population, consistent across most surgical indications. Further analyses will look at the risk of developing treated kidney failure after cardiac surgery.

Data linkage projects continued...

- **Intensive Care Registry –** In 2022 a national linked dataset was created between ANZDATA and the Australian & New Zealand Intensive Care Society Adult Patient Database, which collects data from over 90% of Intensive Care Units (ICUs). Key research aims include quantifying the incidence, cause, and duration of ICU admission for KRT patients. Early analyses have determined that Australian KRT patients experienced higher rates of ICU admission than the non-KRT population, particularly for non-surgical diagnoses. Further analyses will look at quantifying the duration and outcome of ICU admission for KRT patients.
- **Intensive Care Units –** In 2023 a linked dataset was created between ANZDATA, South Australian and Northern Territory Intensive Care Units, inpatient hospitalisation, and deaths data. This dataset will look at longer-term outcomes of ICU admission and enable quantification of the risk for any critical care patient of developing kidney failure (treated with KRT).
- **Sharesource (Baxter) APD** The Baxter "Claria" APD device (introduced into practice in late 2018 and used by most people in Australia receiving peritoneal dialysis) collects individual treatment characteristics for each peritoneal dialysis session into a database – "Sharesource". This project links the Sharesource database with the ANZDATA registry. In 2023 we have made progress towards refining the data transfer process, ensuring an accurate match with the registry, and assessing overall data quality. We are currently studying trends and changes in the demographic composition of patients receiving peritoneal dialysis and assessing these alongside trends in patient outcomes. Data from the Sharesource database can help us get a clearer picture of the nightly experiences of patients, and how they relate to various outcomes; for example, the role of alarm patterns and how they might affect how long a patient remains on the treatment.

SWIFT – Symptom Monitoring WIth Feedback Trial (SWIFT) -Patient reported outcome measures (PROMS) in Australia & New Zealand kidney dialysis units and the ANZDATA Registry

Lead: Prof Rachael Morton (Chief Investigator, University of Sydney)

Researchers: P Bennett, S Jesudason, S McDonald (clinical lead), P Kumar.

The Symptom monitoring WIth Feedback Trial (SWIFT) is a novel two-arm cluster randomised trial testing the hypothesis that symptom monitoring using the IPOS-Renal questionnaire with feedback to clinicians and patients, improves quality of life and overall survival for patients receiving haemodialysis. This trial is conducted in collaboration with the ANZDATA registry in Adelaide and the NHMRC Clinical Trials Centre, University of Sydney.

SWIFT has recruited over 1680 participants in 53 units across New South Wales (NSW), Queensland (QLD), Victoria (VIC), and South Australia (SA). 28 units have now completed the trial.

Our new units include – NSW Tweed, QLD Toowoomba, SA Gawler, VIC Northern Health Service Melbourne

We will continue to work through the start-up of the remaining units in NSW, QLD, VIC, and SA and have been negotiating contracts with Fresenius units for their participation in the trial.

We have submitted an Ethics application for Northern Territory (NT) units with the Menzies. We anticipate commencing the trial in the NT units around May 2024. We are also in the process of getting the surveys translated into commonly used native languages for participants' easy use.

For Western Australian (WA) Units Contracts and research governance offers submissions are underway. We are aiming to start the trial as soon as possible in WA units.

The clinician-focused sub-study has commenced with Dr Matthew Anderson and Mr Sam Herzog (SWIFT research assistant) having conducted qualitative interviews with clinicians at several participating SWIFT units. This qualitative interview study aims to understand the usual practices for symptom monitoring and management for adults managed on haemodialysis and will be conducted in parallel with the randomised trial. The SWIFT Team would like to acknowledge and thank all those involved in the trial thus far including participants, clinical staff, and research support.

Better Evidence and Translation – Chronic Kidney Disease

Researchers: S Jesudason, S McDonald, S Bateman, G Irish

Engagement support: J Mazis

Better Evidence and Translation – Chronic Kidney Disease (BEAT-CKD) is a collaborative research network dedicated to enhancing the quality of life for individuals affected by chronic kidney disease. Our primary objective is to generate robust and reliable research evidence that empowers patients, healthcare professionals, and policymakers to make well-informed decisions regarding healthcare.

BEAT-CKD was initially founded with generous funding from the NHMRC Program Grant (APP1092957) and currently provides support to four research and translation organisations throughout Australia including Australia and New Zealand Dialysis and Transplant Registry.

The objectives of BEAT-CKD are to:

- Identify promising interventions that address health outcomes of high priority to patients, caregivers, health professionals, and policymakers.
- Provide robust evidence about these interventions.
- Identify and evaluate strategies to deliver these interventions in diverse clinical settings.

In 2023, BEAT-CKD began collaborating with consumers to develop and create a series of online modules addressing consumer engagement strategies within research. They also rebranded and opened up their online seminar series to both clinicians and consumers.

In November of 2023 BEAT-CKD held an end-of-year forum at the South Australian Health and Medical Research Institute (SAHMRI) the theme of the workshop was "Partnering with patients and caregivers to disseminate and implement research". The workshop welcomed health professionals specialising in kidney disease, as well as patients with chronic kidney disease, consumer representatives, caregivers, and industry professionals. The event was an opportunity for networking and establishing meaningful relationships among patients, caregivers, researchers, and healthcare professionals.

Picture 1: Clinicians and Consumers at the BEAT-CKD end-of-year forum held at SAHMRI

Picture 2: BEAT-CKD presentation at the Australian and New Zealand Society of Nephrology (ANZSN) Aukland, New Zealand

Picture 3: Pamphlets and information at the ANZDATA stall at ANZSN New Zealand

National Indigenous Kidney Transplantation Taskforce

Secretariat team: S McDonald, J Hughes, K Owen, K Cundale

The National Indigenous Kidney Transplantation Taskforce (NIKTT) was a Commonwealth-funded grant project that ran from 2019-2023. Led by a Secretariat based in Adelaide and Darwin, the NIKTT aimed to improve access to kidney transplantation for Aboriginal and Torres Strait Islander people. 2023 saw the Taskforce finish its series of activities, which culminated in a Final Report and published Supplement in the Medical Journal of Australia. The Taskforce's main activities included: (1) analysing data collected through ANZDATA on reasons why patients were not placed on the transplant waitlist; (2) assessing the impact of pilot projects across the country to increase access to the transplant waitlist and transplantation itself; (3) examining the role of cultural bias in kidney care settings; and (4) establishing a strong consumer role in transplantation pathways through the creation of a national consumer panel and Indigenous Reference Groups.

In March 2023, the Secretariat team travelled to Canberra to present the Assistant Minister for Health and the Assistant Minister for Indigenous Australians with a three-year proposal for continued work on transplantation equity. In early 2024, the Secretariat was funded by the Department of Health and Aged Care to continue its work. The Secretariat will be housed within ANZDATA and will focus, in the short-term, on: (1) creating a data dashboard through ANZDATA to track equity metrics nationally; (2) hosting a second Gathering conference that will bring together consumers, carers, clinicians, and advocates to foster further collaboration to improve kidney transplantation access and outcomes for Aboriginal and Torres Strait Islander people; (3) supporting existing and establishing new Indigenous Reference Groups at transplantation units, and (4) developing a long-term plan for a consumer-led organisation that represents the health and wellbeing of Aboriginal and Torres Strait Islander people living with kidney disease and transplantation.

The NIKTT Secretariat in Canberra: (L-R) Kelli Owen, Assistant Minister for Indigenous Health Malarndirri McCarthy, Assistant Minister for Health Ged Kearney, Stephen McDonald, Jaquelyne Hughes, Katie Cundale

Attendees at the first transplantation equity Gathering in Adelaide, Dec 2022

The COMPASS project: Guiding kidney care through Aboriginal patient navigators

Lead: Ms Kelli Owen

Researchers: S Bateman, M D'Antoine, I Brown, K Cundale, I Haklar

Kidney disease disproportionately impacts Aboriginal and Torres Strait Islander people in Australia. Because the pathway to transplantation is often complex, confusing, and culturally unsafe, Aboriginal-led solutions are needed to ensure safe and equitable care. However, there is currently a disconnect between Aboriginal kidney Patient Navigator programs in South Australia and the Northern Territory: two jurisdictions that share one transplantation unit. The COMPASS project – Connecting Our Mob: Patient navigators As Sustainable Supports – aims to integrate Patient Navigators into the transplantation pathway in Darwin, Alice Springs, Port Augusta, and Adelaide. The project will examine how best these roles work within the existing systems and identify barriers and enablers to sustainable implementation. For more information, see nikkt.com.au/compass.

Clinician Survey of ANZDATA Quality Indicator Presentations

Lead: Prof Stephen McDonald

Researchers: C Davies, E Duncanson, N Gray

In 2023, data collection was completed for an online clinician survey that was undertaken to assess the comprehensibility of various display options for quality indicator data in kidney care that is collected and reported by ANZDATA. The survey aimed to assess comprehension of the data, decision-making, and preferences for the presentation formats. Analysis of the survey data is underway, and the results will be used to improve the ANZDATA hospital-specific performance reports.

Consumer-prioritised Quality Indicator Outcomes in Kidney Failure Care Survey

Lead: Prof Stephen McDonald

Researchers: E Duncanson, N Gray, C Davies, S Muthuramalingam, E Johns, Z Tasevski, K McColm, J Mazis

In 2023, researchers at ANZDATA conducted an online consumer survey to understand the views of people with lived experience of kidney disease, regarding the importance of various quality indicators in kidney failure care. Analysis of survey results will commence in early 2024.

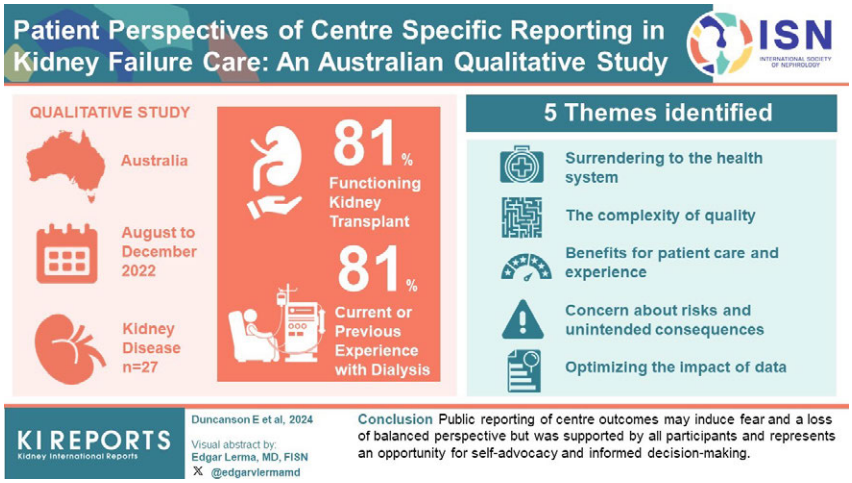
The investigator team on this study includes consumers, kidney doctors, and researchers – consumer partners have so far reviewed the study protocol and survey questions and will review the study findings and help to inform the next steps for this work.

Consumer views of quality indicator reporting in kidney care – Qualitative Study

Lead: Prof Stephen McDonald

Researchers: E Duncanson, N Gray, C Davies, S Muthuramalingam, E Johns, Z Tasevski, K McColm, M Hempstalk

In 2023, researchers at ANZDATA completed a qualitative study exploring the views and opinions of people with kidney disease, about quality indicator data of dialysis and transplant centres and ANZDATA's reporting of this information.




Keli Owen (COMPASS)

Collage of presenters: Top left, Keli Owen (COMPASS); Top right, Consumer and clinician engagement event (SAHMRI) hosted by ANZDATA; Bottom left, Jasmin Mazis speaking at Health Translation South Australia panel; Bottom right, Dominic Keuskamp speaking at SAHMRI (Adelaide)

ANZDATA Consumer Advisory Panel

In 2023, Consumer Representatives were invited to apply for the newly established ANZDATA Consumer Advisory Panel (CAP). Eleven consumers were carefully selected to bring their lived experiences and perspectives of chronic kidney disease, whether as patients or caregivers, from across Australia and New Zealand.

The ANZDATA CAP has been tasked with several key responsibilities, including:

- Providing valuable feedback to the ANZDATA Executive team on consumer priorities for registry outcomes, data collection, and areas of research focus from a consumer viewpoint.
- Collaborating closely with ANZDATA staff to develop consumer-specific plain language summaries, infographics, and other consumer-facing materials.
- Offering insights to the ANZDATA Executive team on emerging issues in consumer engagement at local, national, and international levels, from a registry perspective.
- Guiding effective consumer and community engagement strategies within the activities of the ANZDATA Registry.

The ANZDATA CAP will play a crucial role in ensuring that the voices and perspectives of consumers are not only heard but also actively considered in the ongoing operations of the ANZDATA Registry.

Consumer Engagement Events

World Kidney Day 2023

On March 9, 2023, World Kidney Day was observed globally, advocating for Kidney Health for All: Preparing for the Unexpected, Supporting the Vulnerable.

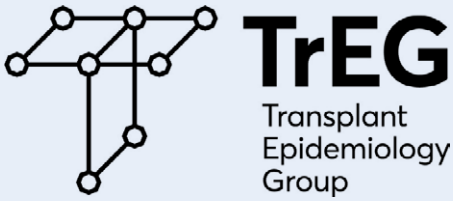
To emphasize the significance of World Kidney Day, ANZDATA hosted a clinical and consumer engagement event, aiming to raise awareness about kidney health as well as an online social media campaign called #showusyourkidneys.

Shilpa Jesudason presenting at the World Kidney Day Event SAHMRI

ANZDATA Staff Twitter (X) campaign for World Kidney Day #showusyourkidneys.

TrEG

The Transplant Epidemiology Group was inaugurated in 2023. Based with the Australian and New Zealand Dialysis and Transplant Registry, our interdisciplinary team of researchers, epidemiologists, clinicians, and statisticians collaborates to explore epidemiological trends associated with transplantation.



Director: A/Prof Philip A Clayton

Executive Directors: Georgina L. Irish and Lachlan McMichael

Current Projects

1. **Post-Transplant Outcomes**
   The Association between Early Graft Function, Donor Type and Long-term Kidney Transplant Outcomes. **Venkataraman K, Irish G, Collins M, Clayton P**
2. **Donor Factors**
   - The Impact of Donor and Recipient Diabetes on Patient and Graft Survival in Renal Transplant Recipients. **Orsillo A, Kholmurodova F, Clayton P, Chadban S, Weightman A, Irish G**
   - Dual kidney donor profile index: A Registry analysis of Dual Kidney Transplants from the ANZDATA Registry. **Irish G,** Beecher M, Sanun R, Rowan R, Shah R, K Heggerty, R Francis, **Coates PT, Clayton P**
   - Outcomes for live kidney donors following nephrectomy in Aotearoa New Zealand: the live donate NZ study" Chan L, **Irish G,** Goh T, Alnasrallah B, **Davies C,** Sypek M, **Clayton P, Collins M**
   - Deceased Donor System Performance in a Jurisdiction with Early Communication Between Transplant and OPO professionals. **McMichael L,** Chang D, Malley I, Butler H, Keenan S, Gill J, Gill J
3. **Prediction scores and decision making**
   - Should I have a transplant? Using flexible parametric models to predict survival after kidney transplant waitlisting. **Irish G,** Mulley W, **Clayton P**
   - Take it or wait. Should I Accept this kidney. **Irish G, Clayton P**
   - Values, preferences, and risk tolerance of people waitlisted for a kidney transplant: a systematic review. Cutting R, Muscat D, Patel P, De La Mata N, **Irish G,** Wyld M, White A, Webster A
4. **Global Epidemiology**
   - A blind spot in transplantation– exploring the potential of an international travel for organ transplantation registry **Irish G,** Fadhil R, Rondeau E, Nagral S, Ahmadipour M, **Coates PT%,** Martin DE
   - Capacity for the management of kidney failure in the Oceania and South East Asia (OSEA) region: Report from the 2023 ISN Global Kidney Health Atlas. Francis A, Wainstein M, **Irish G** et. al.
   - Data monitoring systems and capacity for early risk identification for kidney disease in world regions and countries. **Irish G,** Caskey F, Razeen Davids M, Tonelli M, Yang C, Bello A and Johnson D
   - How Big Is Our Blind Spot? Estimating The Burden Of Organ Failure Unmet By Transplantation. **McMichael L,** Sridhar V, Lopez R, Levine D, Teuteberg J, Verna EC, Schold J, Gill JS.
   - Who is currently waitlisted for kidney transplantation and how do practices differ across the US, Australia & the UK? **McMichael L,** Gill JS, Nitsch D, Kadatz M, **Clayton P**
5. **Health economics**
   What is the cost of evaluating patients for kidney transplantation? **McMichael L,** Gill J, Klarenbach S, Kadatz M, **Clayton P**

Consumer engagement activities

We are very grateful for the contributions of members of the ANZDATA Consumer Advisory Panel for the contribution to Transplantation epidemiology research.

We are grateful to the various kidney units, patients and staff for their cooperation and contributions of data to ANZDATA and other registries that have been used as part of our work.

tregaustralia.org.au

X: @TrEG_Australia

CNARTS Clinical Trials Unit

The Central Northern Adelaide Renal and Transplantation Service (CNARTS) Clinical Trials Unit recruits for and coordinates clinical trials in patients with Chronic Kidney Disease (CKD), Kidney Failure (KF) and renal transplants across metropolitan and country areas of South Australia, Northern Territory and New South Wales. Medications that are standard of care for kidney patients were trialled for the first time in the CNARTS Clinical Trials Unit, thereby bringing new treatments directly to our patients. These medications include Tacrolimus, Everolimus and Myfortic for kidney transplant patients; Aranesp, Ferinject and Difelikefalin for patients with CKD /KF and Tolvaptan for patients with Polycystic Kidney Disease.

We conduct clinical trials in collaboration with Vascular Surgery, Immunology Clinical Trials, the Islet Transplant team, the CNARTS Clinical Research Group, the School of Pharmacy and Medical Sciences, University of South Australia, Australasian Kidney Trials Network (AKTN) and The George Institute.

During the COVID-19 pandemic, the CNARTS Clinical Trials team continued to develop new strategies to meet study requirements for patient visits, study specific laboratory tests and delivery of study medication. Patient visits which were routinely been conducted at the RAH were conducted either off site at The Queen Elizabeth Hospital, Hampstead Dialysis Centre or by phone. These important strategies continue post the COVID 19 pandemic to maintain patient safety and continuity of the studies post COVID-19.

During 2023, CNARTS researchers and patients have been involved in over 30 clinical trials. With encouraging results, patients enrolled in several of our studies were offered the opportunity to receive open label medication in open label extension studies. In 2024 we will be commencing new trials in IgA Nephropathy, Membranous Nephropathy, CKD, Calciphylaxis and treatments for prevention of renal transplant rejection in Kidney Transplant Recipients.

CNARTS Clinical Trial staff

- Karen Fischer
  (Clinical Trials Assistant)
- Krystal Skinner
  (Clinical Trial Coordinator)
- Meg Hockley
  (Assoc. Nursing Unit Manager)
- Bronwyn Hockley
  (Nursing Unit Manager)

2023 Clinical trials

Transplant trials:

1. **TMCT-04:** A Randomized Controlled Trial of Urine CXCL10 Chemokine Monitoring Post- Renal Transplant
   Investigator Led & PI: A/Prof Robert Carroll
2. **CARSK study:** Canadian-Australian Randomised Trial of Screening Kidney Transplant Candidates for Coronary Artery Disease
   carsk.org
   Sponsor: The University of Sydney PI: Dr Philip Clayton
3. **IM103-392:** A phase II, single arm multicentre trial of thymoglobulin, belatacept and sirolimus in pancreatic islet transplant recipients.
   Sponsor: The University of Sydney **PI:** Prof Toby Coates
4. **INCEPTR BTM:** Intra-cutaneous ectopic pancreas' - A prospective evaluation of a novel treatment for Type I Diabetes Mellitus employing deceased donor islets implanted into modified, preintegrated Biodegradable Temporising Matrix (BTM) dermal replacement.
   Sponsor: Beta Cell Technologies Pty. Ltd. **PI:** Prof Toby Coates
5. **219900 (RSV OA=ADJ-023):** A Phase 2b, randomized, controlled, open-label study to evaluate the immune response and safety of the RSVPreF3 OA investigational vaccine in adults (≥18 years of age) when administered to lung and renal transplant recipients comparing 1 versus 2 doses and compared to healthy controls (≥50 years of age) receiving 1 dose
   Sponsor: GlaxoSmithKline Biologicals S.A. **PI:** Prof Toby Coates
6. **AT-1501-K102:** A Phase 1b, Multicenter, Open-Label Study to Evaluate the Safety, Pharmacokinetics and Efficacy of AT-1501 in Patients Undergoing Kidney Transplant
   Sponsor: Eledon PI: Prof Toby Coates

CKD/Glomerulonephritis trials:

7. **CLNP023A2301:** A multi-center, randomised, double-blind, placebo controlled, parallel group, phase III study to evaluate the efficacy and safety of LNP023 in primary IgA nephropathy patients.
   Sponsor: Novartis **PI:** Dr Chii Yeap
8. **CLNP023A2002B:** A multicenter rollover extension program (REP) to evaluate the long-term safety and tolerability of open label iptacopan in adult participants with primary IgA nephropathy who have completed study CLNP023X2203 or CLNP023A2301
   Sponsor: Novartis **PI:** Dr Chii Yeap
9. **GOAL study:** Comprehensive Geriatric Assessment for Frail Older People with Chronic Kidney Disease to Increase Attainment of Patient-Identified Goals - A Cluster Randomised Controlled Trial
   Investigator Led: AKTN **PI:** A/Prof Shilpa Jesudason
10. **M11-001 aHUS Registry:** An Observational, Non-Interventional, Multi-Centre, Multi-National Study of Patients with Atypical Hemolytic-Uremic Syndrome.
    Sponsor: Alexion Pharmaceuticals **PI:** A/Prof Robert Carroll
11. **021FSGS16010:** A Randomized, Multicenter, Double-Blind, Parallel, Active Control Study of The Effects of Sparsentan, A Dual Endothelin Receptor and Angiotensin Receptor Blocker, On Renal Outcomes in Patients with Primary Focal Segmental Glomerulosclerosis (FSGS)
    Sponsor: Travere **PI:** A/Prof Chen Au Peh
12. **OMS721-IGA-001:** A Randomized, Double-blind, Placebo-controlled, Phase 3 Study of the Safety and Efficacy of OMS721 in Patients with Immunoglobulin A (IgA) Nephropathy (ARTEMIS-IGAN)
    Sponsor: Omeros Corp **PI:** A/Prof Chen Au Peh
13. **NEF-301:** A randomized, double-blind, placebo-controlled study to evaluate efficacy and safety of Nefecon in patients with primary IgA nephropathy at risk of progressing to end-stage renal disease (NefIgArd)
    Sponsor: Calliditas Therapeutics AB **PI:** A/Prof Chen Au Peh

14. **NEF-301OLE:** An open label extension (OLE) Study to the evaluate efficacy and safety of Nefecon treatment in patients with IgA nephropathy who have completed Study NEF-301
    Sponsor: Calliditas Therapeutics **PI:** A/Prof Chen Au Peh
15. **021IGAN17001:** A Randomized, Multicenter, Double-blind, Parallel-group, Active-control Study of the Efficacy and Safety of Sparsentan for the Treatment of Immunoglobulin A Nephropathy (PROTECT Study)
    Sponsor: Travere **PI:** A/Prof Chen Au Peh
16. **KBP5074-3-001:** A Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study to Assess the Efficacy and Safety of KBP-5074, a Mineralocorticoid Receptor Antagonist, in Subjects with Uncontrolled Hypertension Who Have Moderate or Severe (Stage 3b/4) Chronic Kidney Disease (CLARION CKD)
    Sponsor: KBP BioSciences PTE. Ltd. **PI:** Dr Chii Yeap
17. **CR845-310302:** A Multicenter, Randomised, Double-Blind, Placebo-Controlled 12-Week Study to Evaluate the Safety and Efficacy of Oral Difelikefalin in Advanced Chronic Kidney Disease Subjects with Moderate-to-Severe Pruritus with an up to 52-Week Long-Term Extension
    Sponsor: CARA Therapeutics **PI:** Dr Chii Yeap
18. **402-C-1808:** A Phase 3 Trial of the Efficacy and Safety of Bardoxolone Methyl in Patients with Autosomal Dominant Polycystic Kidney Disease (FALCON Study)
    Sponsor: REATA Pharmaceuticals **PI:** Prof Randall Faull
19. **417-201-00007:** A Phase 3, Multicenter, Randomized, Double-blind, Placebo-controlled Trial to Evaluate the Efficacy and Safety of Sibeprenlimab Administered Subcutaneously in Subjects with Immunoglobulin A Nephropathy (Visionary)
    Sponsor: Otsuka Pharmaceuticals **PI:** Dr Chii Yeap
20. **TESTING ON:** Therapeutic Evaluation of Steroids in IgA Nephropathy Global- Post-Trial ObservatioNal Cohort Study
    Sponsor: The George Institute for Global Health George **PI:** A/Prof Chen Au Peh
21. **The Renal Life Cycle Study** a Randomized Controlled Clinical Trial to Assess the Effect of Dapagliflozin on Renal and Cardiovascular Outcomes in Patients with Severe Chronic Kidney Disease
    renal-lifecycle.com/en/home-en/
    Sponsor: The George Institute for Global Health **PI:** A/Prof Shilpa Jesudason
22. **IMPEDE-PKD Trial:** Implementation of Metformin therapy to Ease Decline of kidney function in Polycystic Kidney Disease (IMPEDE-PKD) Randomised Placebo-Controlled Trial
    aktn.org.au/impede-pkd/
    Sponsor: AKTN PI: Prof Randall Faull

Renal Failure/Dialysis trials

23. **RESOLVE:** Randomised Evaluation of SOdium dialysate Levels on Vascular Events, Protocol Number: GI-RM-7338
    aktn.org.au/resolve/
    Investigator Led: AKTN **PI:** A/Prof Philip Clayton
24. **TEACH-PD:** A pragmatic, registry-based, international, cluster-randomised controlled trial examining the use of TEACH-PD training modules for incident PD patients versus existing practices on the rate of PD-related infections
    aktn.org.au/teach-pd/
    Sponsor: AKTN PI: Prof Stephen McDonald
25. **PHOSPHATE study:** Pragmatic randomised trial of High or Standard PHosphAte Targets in End-stage kidney disease
    aktn.org.au/phosphate-trial/
    Sponsor: AKTN **PI:** A/Prof Philip Clayton.

26. **TRACK study:** Treatment of CVD with low dose Rivaroxaban in Advanced CKD.
    tracktrial.org
    Sponsor: George Institute **PI:** Prof Shilpa Jesudason
27. **Patient Activation:** Improving self-management for people with chronic kidney disease through a patient activation approach.
    Investigator Led & PI: Laura Lunardi RN, NP
28. **Improving the therapeutic use of vancomycin** in patients undergoing dialysis treatment
    Investigator Led & PI: Dr Lachlan McMichael
29. **ACTIVATE AVF:** A study of the safety and feasibility of the Vessel Restoration System for AVF to promote the physiologic and functional maturation of upper-extremity autologous End-to-Side Arteriovenous Fistulas (AVF) in Patients with Chronic Kidney Disease:
    Sponsor: Alucent **PI:** Dr Ewan Macaulay
30. **Symptom monitoring WIth Feedback Trial (SWIFT):** A Registry-Based Cluster Randomised Controlled Trial to determine the clinical effectiveness and cost-effectiveness of symptom monitoring with feedback to clinicians and patients compared with standard care in improving quality of life outcomes at 12 months for adults on haemodialysis.
    anzdata.org.au/anzdata/research/registry-trials/swift/
    Sponsor: NHMRC Clinical Trials Centre The University of Sydney **PI:** Prof Stephen McDonald
31. **BEAT CALCI:** Better Evidence And Translation for Calciphylaxis
    beat-calci.sydney.edu.au
    Sponsor: NHMRC Clinical Trials Centre The University of Sydney **PI:** Dr Michael Collins
    Sponsor: AKTN **PI:** Prof Randall Faull

Student supervision in 2023

Mirabel Alonge (PhD candidate, University of Adelaide) "Using pharmacokinetic principles to improve the safety of tacrolimus in kidney transplant recipients"

Supervisors: B Sallustio, S Jesudason, A Somogyi

Dr Dylan Barnett (PhD candidate, University of Adelaide) "Organ preservation and resuscitation by isothermic oxygenated machine perfusion in an ex-vivo porcine model"

Supervisors: PT Coates, S Bhattacharjya

Dr James Besanko (Masters candidate, University of Adelaide) "Evaluation of heart transplant transportation device in a pig model"

Supervisors: PT Coates, J Beltrame, J Edwards

Dr Samantha Bateman (PhD candidate, University of Adelaide) "Benefits and Burdens of Kidney Transplantation for First Nations Australians"

Supervisors: S Jesudason, O Pearson, P Clayton, S McDonald

Nick Chai (PhD candidate, University of Adelaide) "Exploring the adjuvant effect of mTOR inhibitor on boosting vaccine-induced T cell responses in immunocompromised transplant patients"

Supervisors: PT Coates, G Perkins, C Drogemuller

Maria Chilvers (PhD candidate, University of South Australia) "Exploring the experience of breathlessness for people living with kidney failure"

Supervisors: M Williams, K Johnson, K Ferrar, S Jesudason, P Bennett

Dr Jessica Lee (PhD candidate, University of Adelaide) "Development of new approaches to measure proteolysis and glycosylation profiling of high and low affinity corticosteroid-binding globulin (CBG) in septic shock using mass spectrometry"

Supervisors: PT Coates, D Torpy

Dr Brigette Clarke (PhD candidate, University of Adelaide) "Adrenal cell transplantation for Addison's disease using Biodegradable Temporising Matrix technology"

Supervisors: PT Coates, P Hurtado, D Torpy

Dr Georgie Irish (PhD candidate, University of Adelaide) "Decision making in kidney transplantation"

Supervisors: P Clayton, PT Coates

Dr Alice Krige (PhD candidate, University of South Australia) "Normothermic extra-corporeal perfusion in an ovine model of kidney transplantation"

Supervisors: PT Coates, L Palmer

Laura Lunardi (PhD candidate, University of Adelaide) "Patient activation in Chronic Kidney Disease"

Supervisors: P Bennett, L Matricciani, R Le Leu

Dr Lachlan McMichael (PhD candidate, University of Adelaide) "Understanding the path to kidney transplantation"

Supervisors: P Clayton, J Gill, M Kadatz, S Klarenbach

Jacqueline Scaffidi (PhD candidate, University of Adelaide) "Chimeric Antigen Receptor T regulatory cells (CAR-Tregs) as a therapy for autoimmune-driven Type 1 Diabetes"

Supervisors: PT Coates, S Barry

Brett Tarca (PhD candidate, University of South Australia) "Exploring Relationships Between Fatigue, Mood, Physical Function and Physical Activity in People Receiving Peritoneal Dialysis" - PhD conferred October 2023

Supervisors: K Ferrar, T Wycherley, S Jesudason, P Bennett

Dr Nishanta Tangirala (Masters candidate, University of Adelaide) "Can I have a baby?"

Complexities in decision making around pregnancy in Australian women with kidney disease"

Supervisors: S Jesudason, E Hewawasam

Dr Karthik Venkataraman (PhD candidate, University of Adelaide) "Post-operative haemodynamic management after kidney transplant to improve early graft function"

Supervisors: M Collins, PT Coates

Dr Alison Weightman (PhD candidate, University of Adelaide) "Decision Making in Deceased Donor Kidney Transplant Offers"

Supervisors: P Clayton, S Coghlan

Denghao Wu (PhD candidate, University of Adelaide) "The genetic epidemiology of hereditary pancreatitis in South Australia"

Supervisors: PT Coates, L Palmer, K Kassahn, C Drogemuller

James Zuiani (PhD candidate, University of Adelaide) "Characterisation of Pancreatic Organoids in hereditary pancreatitis and normal individuals"

Supervisors: S Grey, C Drogemuller, PT Coates

Conference abstracts 2023

2023 Transplantation Society of Australia and New Zealand Annual Scientific Meeting, Brisbane

"BEST-FLUIDS: Balanced crystalloid solution vs. saline to prevent delayed graft function in deceased donor kidney transplantation"

Collins M, Fahim M, Pascoe E, Hawley C, Johnson D, Varghese J, Hickey L, Clayton P, Dansie K, McConnochie R, Vergara L, Kiriwandeniya C , Reidlinger D, Mount P, Weinberg L, McArthur C, Coates T, Endre Z, Goodman D, Howard K, Howell M, Jamboti J, Kanellis J, Laurence J, Wai L, McTaggart S, O'Connell P, Pilmore H, Wong G, Chadban S

"Associations between slow graft function and long-term kidney transplant outcomes"

Venkataraman K, Irish G, Collins M, Clayton P

"Rapamycin as a vaccine adjuvant to improve cellular meditated-t cell response following covid-19 vaccination"

Chai C, Perkins G, Yeow A, Mekonnen Z, Grubor-Bauk B, Coates PT

"A phase 3 study comparing CMV prophylaxis with Letermovir versus Valganciclovir in kidney transplant recipients"

Carroll R, Limaye A, Budde K, Humar A, Garcia-Diaz J, Murata Y, Teal V, Gilbert C, Haber B

"The adsorption crossmatch cells and elution (AXE) technique to identify true hla specific antibodies"

Leahy R, Carroll R, Sullican L, Emery T, Tsiopelas E, McDonald K, Sullivan H, Munasinghe W, Fleet A, Deayton S, Lake M, Bilogrevic F

"Transplant professionals' perspectives on reporting of travel for organ transplantation: An international cross-sectional study"

Irish GI, Fadhil R, Rondeau E, Nagral S, Coates PT, Ahmadipour M, Martin D.

"The epidemiology of hereditary pancreatitis in Australia and its effect on patient of total pancreatectomy with islet auto-transplantation (TP-IAT)"

Wu D, De Sousa S, Adelson D, Drogemuller C, Coates PT

"Increased early mortality risk following kidney transplant failure in Australia and New Zealand (1980–2019)"

Lee D, Nguyen M, Clayton PT, Mulley W

"Portal venous pressures and liver function tests following islet cell transplantation: a single-centre experience"

Trinh V, Orsillo A, Etherton C, Rickard A, Coates PT

"Converting the 'Un-transplantable' kidney to transplants: An analysis of outcomes to develop a dual-kidney donor profile index"

Beecher M, Sanun R, Shah R, Coates T, Francis R, Hegerty K, Clayton P, Irish G

"Bariatric surgery and transplantation in patients receiving chronic dialysis: 15-year experience in Australia and New Zealand"

Chandler S, Palamuthusingam D, Hopkins G, Boudville N, Pascoe E, Talaulikar G, Mc Donald S, Silvalingam P, Jose M, Hawley C, Johson D, Fahim M

"A case series of successful kidney transplantation from snake envenomation donor kidneys"

Jefferis J, Gill J, Coates PT, White J, Peh CA , Francis R, Cho Y, Johnson D, Viecelli A

"The changing incidence and risk of renal allograft thrombosis in Australia and New Zealand: A registry analysis"

Simm K, Irish A, Bhandari M, Davies C, McDonald S

"High prevalence of thrombotic events (TES) in autosomal dominant polycystic kidney disease (ADPKD) post-nephrectomy"

Chan J, Bhattacharjya, Olakkengil S

American Society of Nephrology (ASN), Philadelphia, USA

"Modifiable Physical Factors that Influence Physical Function for People Receiving Peritoneal Dialysis"

Tarca B, Jesudason S, Bennett P, Wycherley T, Ferrar K

"Rates and Outcomes of Cardiac Surgery for People Receiving Long-Term Dialysis or Kidney Transplantation in Australia"

McDonald S, Keuskamp D, Davies C, Smith J, Baker R, Williams-Spence J, Tran L, Polkinghorne K

"Mobile Technology to Explore Real-Time Symptom Data and Physical Activity in People Receiving Peritoneal Dialysis"

Tarca B, Jesudason S, Bennett P, Wycherley T, Ferrar K

"Hereditary Renal Amyloid and Kidney Transplantation"

Jahan S, Latte J

"Providing Medication Education to Renal Transplant Recipients: Are We Getting It Right?"

Jahan S, Doody T, Goh J, Tran H

Australian and New Zealand Society of Nephrology (ANZSN), Christchurch

"Patient activation in people with chronic kidney disease not receiving kidney replacement therapy: A cross-sectional survey"

Lunardi L, Le Leu R, Britton A, Xu Q, Matricciani L, Jesudason S, Bennett P

"Advanced recovery room care vs standard of care in living donor kidney transplantation: A pilot randomised controlled trial"

Venkataraman K, Collins M, Ludbrook G, Coates T

"Pre-operative kidney disease & post-operative mortality for coronary artery bypass grafting in Australia 2001-2019"

Keuskamp D, Davies C, Baker R, Polkinghorne K, Reid C, Smith J, Tran L, Williams-Spence J, Wolfe R, McDonald S

"Hospital mortality following intensive care admission of adults with kidney disease 2018-2020: An Australian data linkage study"

Keuskamp D, Davies C, Clayton P, Pilcher D, Chavan S, Secombe P, Jones S, Reddi B, McDonald S

"Improvements in access to kidney transplantation for Aboriginal and Torres Strait Islander people"

McDonald S, Cundale K, Owen K, Hughes J

"Not on the list: Clinician-reported reasons for non-listing for kidney transplantation"

McDonald S, Cundale K, Davies C, Owen K, Hughes J

"Balanced electrolyte solutions versus normal saline for kidney transplantation: An updated systematic review and meta-analysis of randomised controlled trials"

Wan S, Wyburn K, Chadban S, Collins M

"Impact of preconception chronic kidney disease on pregnancy outcomes and postpartum maternal kidney function – A novel analysis of linked perinatal and pathology datasets"

Cuthbertson L, Jesudason S, Hewawasam E, Saunder T, Kitsos A, Jose M

"Consumers find a nutrition education video on gut health in chronic kidney disease (CKD) to be effective, understandable, and actionable"

Trimingham C, Weber K, Pesek D, Meade A

Renal Society Australasia (RSA), Sydney

"Nurses' practices and beliefs regarding assessment and management of dyspnoea in people with kidney failure"

Chilvers M, Ferrar K, Johnson K, Jesudason S, Bennett P, Richards M

"Point of care ultrasound (POCUS) training for arteriovenous access assessment and cannula placement for dialysis"

Hill K, Jaensch A, Biddle A

"One unit's experience quality improvement projectfor haemodialysis access monitoring and surveillance"

Jingna J

ISN World Congress of Nephrology (WCN)

"Patient perspectives of pregnancy counselling and education in women with kidney disease: An Australian national survey"

Orsillo A, Hewawasam E, Stallard B, Jesudason S

"Commencement of kidney replacement therapy within 12 months after childbirth in Australia"

Hewawasam E, Jahan S, Jesudason S

"Rates of outcomes of cardiac surgery among dialysis & transplant patients 2010-2019: An Australian registry linkage study"

McDonald S, Keuskamp D, Polkinghorne K, Baker R, Tran L, Williams- Spence J, Wolfe R, Smith J, Reid C

"Development and validation of a screening tool for identification of needle fear in dialysis patients - Measuring needle fear tool"

Radisic G, Le Leu R, Esterman A, Donnelly F, Chur-Hansen A, Collins K, Burke A, McDonald S, Macauley L, Muthuramalingam S, Jesudason S

"How can nurses support haemodialysis patients who experience needle fear? An online educational intervention for nephrology nurses"

Radisic G, Le Leu R, Esterman A, Donnelly F, Duncanson E, Collins K, Burke A, Chur-Hansen A, McDonald S, Macauley L, Jesudason S

American Transplant Congress

"Deceased Donor System Performance in a Jurisdiction with Early Communication Between Transplant and OPO professionals"

McMichael LC, Chang D, Malley I, Butler H, Keenan S, Gill J, Gill JS.

Australian College of Nurse Practitioners (ACNP)

"Advance Care Planning: The Nurse Practitioner role"

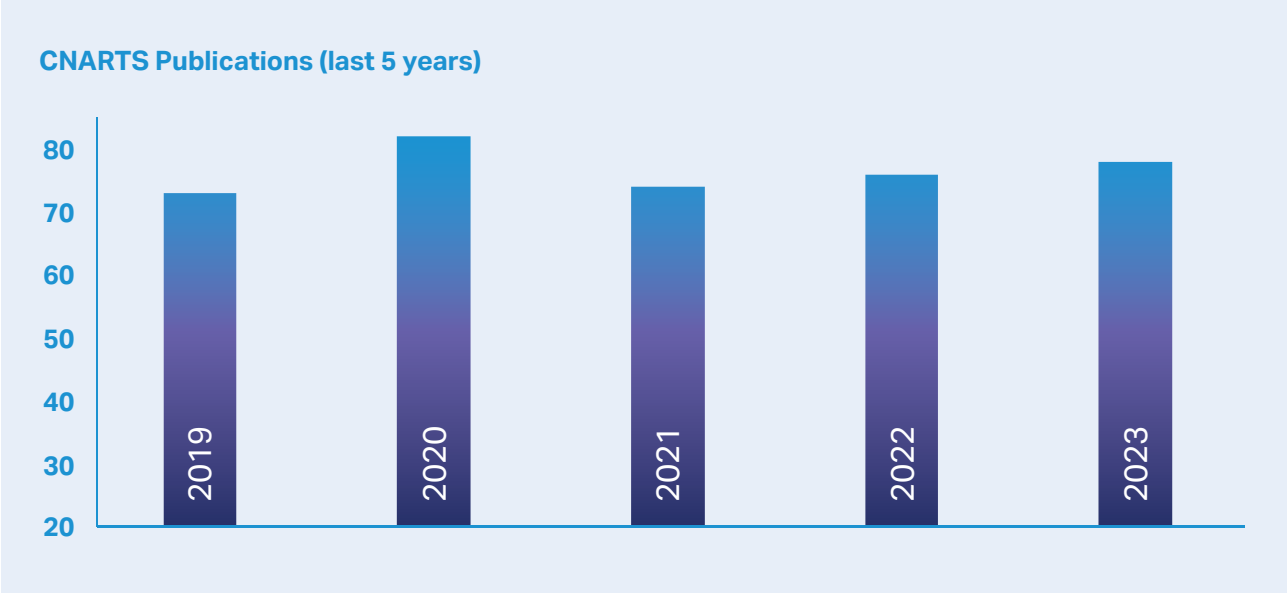
Lunardi L

World Organisation of Family Doctors (WONCA)

"Lessons learnt from understanding the consumer experience of the journey to dialysis across the primary/tertiary care interface"

Bollen C, Jesudason S, Welke S, Kellie A

Publication in 2023



Clinical Research Group and General CNARTS

Biruete A, Hill-Gallant K, Lloyd L, **Meade A,** Moe S, St-Jules D and Kistler B (2023). "Phos'tering a Clear Message: The Evolution of Dietary Phosphorus Management in Chronic Kidney Disease". *J Renal Nutr,* 2023; 33(6S): S13–S20.
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Duncanson E, Chur-Hansen A, **Le Leu R,** Macauley L, Burke A, **Donnelly F,** Collins K, **McDonald S** and **Jesudason S.** "Dialysis Needle-Related Distress: Patient Perspectives on Identification, Prevention, and Management." *Kidney Int Rep,* 2023; 8(12): 2625-2634.
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Guymer C, **Jahan S,** Bahrami B, Sia D, **Tan B, McDonald S,** and Simon S. "Calciphylaxis, Beware the Ophthalmic Mimic: A Case Series." *Clin Nephrol Case Stud,* 2023; 11(1):136-46.
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He I, Poirier B, Jensen E, Kaur S, Hedges J, **Jesudason S,** Jamieson L, and Sethi S. "Demystifying the Connection between Periodontal Disease and Chronic Kidney Disease - an Umbrella Review." *J Periodontal Res,* 2023; 58(2) 874-892.
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Jahan S, and Carroll R. "How Should Acute T Cell-Mediated Rejection of Kidney Transplants Be Treated: Importance of Follow-up Biopsy from Kidney Transplantation." *Transplant Direct,* 2023; 9(7): p e1498.
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Jahan S, Hale J, Malacova E, Hurst C, Kark A, and Mallett A. "Real World Evaluation of Kidney Failure Risk Equations in Predicting Progression from Chronic Kidney Disease to Kidney Failure in an Australian Cohort." *J Nephrol,* 2023.
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Kim C, **Tan R,** Tan J, Otto S, Nolan J, Brealey J, and **Rao N.** "Patterns of Podocyte Infolding Glomerulopathy and Collapsing Glomerulopathy Seen in a Patient with Systemic Lupus Erythematosus: A Case Study." *Pathology,* 2023;55(6): 886-890.
dx.doi.org/10.1016/j.pathol.2023.02.005

Kim S, van Zwieten A, Wyld M, **Ladhani M,** Guha C, Dominello A, Mallitt K, Francis A, Mannon R, and Wong G. "Sociodemographic Drivers of Donor and Recipient Gender Disparities in Living Kidney Donation in Australia." *Kidney Int Rep,* 2023; 8(8): 1553-61.
dx.doi.org/10.1016/j.ekir.2023.05.016

Le Leu R, Bennett P, Dansie K, Shanahan L, A. Chur-Hansen A, Collins K, Burke A, **Donnelly F,** Duncanson E, **Meade A, McDonald S,** and **Jesudason S.** "Changes in Symptom Burden in the First 6 months after Dialysis Commencement: A Prospective Longitudinal Observational Cohort Study." *J Nephrol,* 2023; 36: 1485-1488.
dx.doi.org/10.1007/s40620-023-01603-1

Lunardi L, Hill K, Xu Q, **Le Leu R,** and Bennett P. "The Effectiveness of Patient Activation Interventions in Adults with Chronic Kidney Disease: A Systematic Review and Meta-Analysis." *Worldviews Evid Based Nurs'* 2023; 20(3): 238-258.
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Radisic G, Le Leu R, Donnelly F, Duncanson E, Collins K, Burke A, Chur-Hansen A, **McDonald S,** Hill K, Macauley L, and **Jesudason S.** "How Can Nurses Support Patients on Hemodialysis Who Experience Needle Fear? An Online Educational Intervention for Nephrology Nurses." *Nephrol Nurs J,* 2023; 50 (5): 423-28.

Meade A, Dawson J, Mullan A. Revisiting Intradialytic Parenteral Nutrition: How Can We Apply the Evidence in Clinical Practice? *Adv Kidney Dis Health,* 2023 30(6):502-507.
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St-Jules D, Lloyd L, **Meade A,** Biruete A, Kistler B, and Carrero J. "Deconstructing Disease-Related Malnutrition: A New Assessment Framework for Clinical Practice." *J Ren Nutr,* 2023; 33(6): 707-16.
dx.doi.org/10.1053/j.jrn.2023.04.002

Symons T, Bowden J, McKenzie A, Fallon-Ferguson J, Weekes L, Ansell J, Murphy R, **Jesudason S,** Saxena M, Nichol A and Straiton N. "Development of the Consumer Involvement & Engagement Toolkit: A Digital Resource to Build Capacity for Undertaking Patient-Centred Clinical Trials in Australia." *Public Health Res Pract,* 2023; 33(1): e32122209.
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Tan R, **Rao N,** Horwood C, Passaris G, and Juneja R. "Recurrent Nephrolithiasis and Loss of Kidney Function: A Cohort Study." *Int Urol Nephrol,* 2023; 55: 1539-47.
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Tarca B, Jesudason S, Bennett P, Wycherley T and Ferrar K. "Characteristics and Frequency of Physical Activity and Exercise-Related Side Effects in People Receiving Peritoneal Dialysis." *J Ren Nutr,* 2023;
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Tarca B, Jesudason S, Wycherley T, **Le Leu R,** Ovenden M, Meade A, Bennett P, Boyle T, and Ferrar K. "Ecological Momentary Assessment to Explore Fatigue, Mood, and Physical Activity Levels in People Receiving Peritoneal Dialysis." *Kidney Int Rep'* 2023;
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Tunnicliffe D, **Bateman S,** Arnold-Chamney M, Dwyer K, Howell M, Gebadi A, **Jesudason S,** Kelly J, Lambert K, Majoni S, Oliva D, Owen K, Pearson O, Rix E, Roberts I, Taylor K, Wittert G, Widders K, Yip A, Craig J and Phoon R. "Recommendations for Culturally Safe Clinical Kidney Care for First Nations Australians: A Guideline Summary." *Med J Aust,* 2023; 219 (8): 374-385.
dx.doi.org/10.5694/mja2.52114

van Zwieten A and **Jesudason S.** "Work Participation in Chronic Kidney Disease: Action Is Needed to Avoid Accumulating Health and Social Disadvantage for Patients." *J Nephrol,* 2023; 36: 1235-1237.
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Weightman A, Coghlan S, and **Clayton P.** "Respecting Living Kidney Donor Autonomy: An Argument for Liberalising Living Kidney Donor Acceptance Criteria." *Monash Bioeth Rev,* 2023; 41: 156-173.
dx.doi.org/10.1007/s40592-022-00166-4

Welke S, Duncanson E, Bollen C, **Britton A, Donnelly F, Faull R,** Kellie A, **Le Leu R,** Manski-Nankervis J, **McDonald S,** Richards K, **Whittington T,** Yeoh J, and **Jesudason S.** "The Impact on Patients of the Tertiary-Primary Healthcare Interface in Kidney Failure: A Qualitative Study." *J Nephrol,* 2023; 36: 2023-35.
dx.doi.org/10.1007/s40620-023-01742-5

Centre for Clinical and Experimental Transplantation (CCET):

Alcheikh A, **Perkins G,** Pucar P, Cecchin A, Chai C, **Tunbridge M,** Akerman A, Aggarwal A, Milogiannaki V, Turville S, Allen S, P. Hissaria, T. Banovic, **Coates PT,** and Ross D. "Humoral and Cellular Immunity to Sars-Cov-2 Ancestral and Omicron Ba.5 Variants Following Vaccination in Myelofibrosis Patients." *Blood Cancer J,* 2023; 13(50).
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Asare P, **Hurtado PR,** Tran H, **Perkins G,** Roscioli E and Hodge S. "Reduction in Rubicon by cigarette smoke is associated with impaired phagocytosis and occurs through lysosomal degradation pathway." *Clin Exp Med',* 23: 4041–4055.
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Boudko S, Pedchenko V, Pokidysheva E, Budko A, Baugh R, **Coates PT,** et al. "Collagen IV of Basement Membranes: III. Chloride Pressure Is a Primordial Innovation That Drives and Maintains the Assembly of Scaffolds." *J Biol Chem,* 2023; 299(11) : 105318.
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Chadban S, Singer J and **Coates PT.** "That Sinking Gut Feeling: Is Transplant-Induced Dysbiosis Contributing to Allograft Outcomes?", *Kidney Int,* 2023; 103(3): 454-457.
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Coates PT and Wong G. "One If by Land, and Two If by Sea, but What Is the Signal for Rejection?", *Kidney Int,* 2023; 104(3): 439-440.
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Graves L, Torpy D, **Coates PT,** Alexander I, Bornstein S, and Clarke B. "Future Directions for Adrenal Insufficiency: Cellular Transplantation and Genetic Therapies." *J Clin Endocrinol Metab,* 2023; 108(6): 1273-1289.
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Montarello N, Wong H, Jeffries A, **Perkins G,** Hissaria P, Stokes M, Raith E, Teo K, Bradley J. Pfizer BNT 162b2 COVID-19 vaccine-induced fulminant myopericarditis: A case study. *Crit Care Resusc.* 2023; 25(3):155-157.
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Nangaku M, Kitching A, Boor P, Fornoni A, Floege J, **Coates PT,** Himmelfarb J, Lennon R, Anders H, Humphreys B, Caskey F, and Fogo A. "International Society of Nephrology First Consensus Guidance for Preclinical Animal Studies in Translational Nephrology." *Kidney Int,* 2023; 104(1): 36-45.
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Norton T, Lynn M, Rossouw C, Abayasingam A, **Perkins G,** Hissaria P, Bull R, and Lynn D. "B and T Cell Responses to the Bnt162b2 Covid-19 Mrna Vaccine Are Not Impaired in Germ-Free or Antibiotic-Treated Mice." *Gut,* 2023 (Jul 27 2023).
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Perkins G and Fairchild R. "Linking Donor-Specific Antibody Generation with Natural Killer Cells in Antibody-Mediated Kidney Graft Rejection." *Kidney Int,* 2023; 104(4): 644-646.
dx.doi.org/10.1016/j.kint.2023.07.014

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