

Research forum on chronic kidney disease

Wednesday 23rd August and Thursday 24th August 2017

South Australian Health and Medical Research Institute (SAHMRI)
Adelaide, South Australia

Introduction and Contents

Time and Date: Wednesday 23rd August and Thursday 24th August 2017

Venue: South Australian Health and Medical Research Institute (SAHMRI), Adelaide, South Australia

Cost: Free registration (inclusive of catering).

Outline

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

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

Who can attend?

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

Meeting objectives

The goals of the forum are:

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



Outline of Program*

The program is subject to change and will be updated as speaker/topics are confirmed.

| DAY 1: WEDNESDAY 23 RD AUGUST 2017 | |
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| Time | Session |
| 9:00 am | Registration and coffee |
| 9:30 am | Welcome: BEAT-CKD Research Forum <i>Prof Stephen McDonald</i> |
| 9:35 am | SESSION 1: INNOVATION IN EVIDENCE AND DATA Chair: A/Prof Allison Tong Living evidence <i>A/Prof Julian Elliott</i> Machine learning <i>Prof Jean Yang</i> Panel discussion |
| 10:20 am | Morning tea |
| 10:40 am | SESSION 2: MEASUREMENT IN CKD Chair: Armando Teixeira-Pinto Nominal group technique to identify and explain patient priorities <i>Camilla Hanson</i> How to generate and evaluate clinical core outcome measures <i>Dr Andrea Viecelli</i> Patient-reported outcome measures <i>Angela Ju</i> Measuring cognitive function in patients with CKD: why it matters and what to consider <i>Anita Van Zwieten</i> Measuring early kidney disease in children <i>Dr Nick Larkins</i> |
| 11:20 am | SESSION 3: EXPOSURES AND COMPLICATIONS IN CKD Chair: Dr Shilpa Jesudason Food and nutrients <i>Valeria Saglimbene</i> KidneyTEXT – e-health to improve diet in CKD <i>Jess Stevenson</i> Cancer screening <i>Laura James</i> Cancer <i>Dr Anna Francis</i> |
| 11:50 am | SESSION 4: ENGAGING THE INDIGENOUS COMMUNITY IN CKD RESEARCH Chair: Shilpa Jesudason Antecedents of renal disease in Aboriginal and non-Aboriginal children (ARDAC) <i>Lindsay Hardy</i> KHA-CARI: engaging community in developing guidelines <i>Donisha Duff</i> |
| 12:40 pm | Lunch |
| 12:45 pm | BEAT-CKD Post-graduate/Early Career Research Network Launch (by invitation) |
| 1:30 pm | SESSION 5: THE BIG (DATA) PICTURE Chair: Prof Stephen McDonald What is possible with observational research? <i>Dr Lyle Palmer</i> |
| 2:15 pm | Registry based trials update <i>Prof Stephen McDonald & A/Prof Carmel Hawley</i> |
| 2:35 pm | Afternoon tea |
| 2:50 pm | SESSION 6: KIDNEY TRANSPLANTATION – ARE WE GETTING IT RIGHT? Chair: Prof Stephen McDonald & Dr Philip Clayton Part 1: Developing an Evidence Base for Organ Allocation Policy |

Current state *Dr Philip Clayton*

EPLET matching to reduce de novo DSAs *Dr Ankit Sharma*

Donor-recipient matching algorithms *Vaishnavi Calisi*

Simulating current and future allocations *Aarti Gulyani*

4:00 pm

Part 2: Getting the Framework Right

Current waitlisting practices *Dr Matthew Sypek*

Waitlisting in indigenous patients *Prof Stephen McDonald*

Beyond the experts – what do the community think about allocations? *Dr Martin Howell*

Ethical dimensions of current and future practice *Drew Carter*

5.00 pm

Forum Close

DAY 2: THURSDAY 24TH AUGUST 2017

Time

Session

8:15 am

BEAT-CKD Business Meeting

9:15 am

Registration and coffee

9:30 am

SESSION 7: ATKN SESSION

Chair: Prof David Johnson

Platform Trials: A model for integrated research and healthcare improvement *Steve Webb*

10:15 am

SWAT (studies within a trial) - embedded research *Elaine Pascoe*

11:00 am

Morning tea

11.30 am

SESSION 8: TRIAL PROPOSALS

Chair: A/Prof Carmel Hawley

Trial Proposal 1

IMPEDE-PKD Trial *Dr Andrew Mallett*

12:00 pm

Trial Proposal 2

A linkage study to define the perioperative outcomes of patients on renal replacement therapy *Dr Menaan Palumuthusingam*

12.30 pm

Trial Proposal 3

A symptom management trial: post-dialysis fatigue *Dr Matthew Roberts*

1:00 pm

Lunch

2:00 pm

SESSION 9: CONSUMER ENGAGEMENT

Chair: Prof Stephen McDonald

Framework for consumer engagement *Kathy Mott*

2:30 pm

Beat CKD workshop report *Prof Stephen McDonald & Dr Martin Howell*

3:00 pm

KHA and consumer representation *Dr Shilpa Jesudason*

3:30 pm

Panel discussion: ways forward to improve consumer engagement

4:00 pm

Forum Close

Attendee List

| First name | Surname | Affiliation |
|------------|--------------|---|
| Michael | Bartlett | |
| Amelie | Bernier-Jean | University of Sydney / Centre for Kidney Research |
| Vaishnavi | Calisa | University of Sydney |
| Katrina | Campbell | Princess Alexandra Hospital / Bond University |
| Drew | Carter | The University of Adelaide |
| Swasti | Chaturvedi | Royal Darwin Hospital |
| Yeoungjee | Cho | Princess Alexandra Hospital / AKTN |
| Phil | Clayton | ANZDATA Registry |
| Margie | Conley | Princess Alexandra Hospital |
| Ian | Cornell | PKD Foundation of Australia |
| Judy | Cornell | PKD Foundation of Australia |
| Kathryn | Dansie | SAHMRI |
| Jacqueline | Dennis | Kidney Health Australia / SA Kidney Club |
| Donisha | Duff | Kidney Health Australia |
| Paula | Dunn | The George Institute for Global Health |
| Julian | Elliott | Cochrane Australia |
| Magid | Fahim | AKTN/University of Queensland |
| Anna | Francis | Children's Health Queensland |
| Jonathan | Gleadle | Flinders University |
| Basu | Gopal | CNARTS, Royal Adelaide Hospital |
| Nicholas | Gray | Sunshine Coast University Hospital |
| Carmel | Gregan-Ford | KHNZ |
| Aarti | Gulyani | ANZDATA Registry |
| Talia | Gutman | University of Sydney |
| Derick | Halaliku | Monash University |
| Camilla | Hanson | Centre for Kidney Research |
| Lindsay | Hardy | Centre for Kidney Research |
| Carmel | Hawley | Princess Alexandra Hospital / AKTN |
| Martin | Howell | The University of Sydney |
| Kylie | Hurst | ANZDATA Registry |
| Shariful | Islam | The George Institute for Global Health / The University of Sydney |
| Laura | James | University of Sydney |
| Meg | Jardine | Concord Repatriation General Hospital /The George Institute |
| Shilpa | Jesudason | Royal Adelaide Hospital |
| David | Johnson | Metro South and Ipswich Nephrology & Transplant Service / Princess Alexandra Hospital |
| Angela | Ju | The University of Sydney |
| Marianne | Kerr | The Centre for Kidney Research / Children's Hospital at Westmead |
| Maleeka | Ladhani | The University of Sydney / Lyell McEwin Hospital |
| Kelly | Lambert | University of Wollongong |
| Nicholas | Larkins | Centre for Kidney Research / Princess Margaret Hospital |
| Paul | Lawton | Menzies School of Health Research |
| Richard | Le Leu | CNARTS, RAH |
| Jonathan | Ling | Monash Medical Centre |
| Pamela | Lopez-Vargas | Centre for Kidney Research |

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| Marie | Ludlow | Kidney Health Australia |
| Andrew | Mallett | Royal Brisbane & Women's Hospital |
| Stephen | McDonald | ANZDATA Registry |
| Charlotte | McKercher | Menzies Institute for Medical Research / University of Tasmania |
| Anthony | Meade | CNARTS |
| Robyn | Montgomery | Royal Hobart Hospital |
| Harry | Moody | SCGH |
| Kathy | Mott | SAHMRI |
| Shyamsundar | Muthuramalingam | Flinders University |
| Jade | Newman | The George Institute for Global Health |
| Dharmenaan | Palamuthsingam | Princess Alexandra Hospital / University of Queensland |
| Lyle | Palmer | The University of Adelaide |
| Elaine | Pascoe | AKTN |
| Roberto | Pecoits-Filho | PUCPR, Brazil |
| Kevan | Polkinghorne | Monash Medical Centre/Monash University |
| Nitesh | Rao | Lyell McEwin Hospital |
| Donna | Reidlinger | AKTN |
| Matthew | Roberts | Eastern Health/Monash University |
| Hannah | Robert-Tissot | University of Tasmania |
| Valeria | Saglimbene | The University of Sydney |
| Ankit | Sharma | Centre for Kidney Research |
| Brendan | Smyth | The George Institute for Global Health |
| Jessica | Stevenson | Centre for Kidney Research/The University of Sydney/St George Hospital |
| Matthew | Sypek | ANZDATA Registry |
| Armando | Teixeira-Pinto | The University of Sydney |
| Allison | Tong | The University of Sydney |
| Hanh | Tran | Royal Adelaide Hospital |
| Shahid | Ullah | ANZDATA |
| Anita | van Zwieten | The University of Sydney / Centre for Kidney Research |
| Andrea | Viecelli | University of Queensland |
| Steve | Webb | The George Institute for Global Health |
| Angela | Webster | The University of Sydney |
| Roger | Wyndham | Concord Hospital |
| Jean | Yang | The University of Sydney |
| Gigi | Yeung | St George Hospital |