

Aboriginal Kidney Care Together Improving Outcomes Now July 2023



ACKNOWLEDGEMENT OF COUNTRY

We would like to acknowledge the traditional custodians and their Elders whose lands we live and work upon, the Kaurna people as the traditional owners and pay respect to their spiritual and physical connections to land, seas, skies and waterways where cultural practices are strong and thriving today as always. Their Sovereignty has never been ceded.

We also give our love and respect to other Aboriginal and Torres Strait Islander people from their respective nations from the Lands and Seas of Australia.

We acknowledge all other Aboriginal and Torres Strait Islander people who live and work on Kaurna Yarta and other Aboriginal lands within South Australia, and wish to acknowledge the allies who invest in walking beside us, in front of us and behind us.

Newsletter editors







INSIDE THIS ISSUE

Message from the AKction team2
A2RT meeting2
Knowledge Translation3
Yarning up with Penny4
Meningococcal Story4
NAIDOC
Student and Research update .6

SPECIAL POINTS OF INTEREST

- Penny joins the newsletter editorial team
- New newsletter format do you like it?

CURRENT AKCTION2 REFERENCE TEAM MEMBERS:

Denise Champion
Shellander Champion
Ramon Gadd
Jared Kartinyeri
Rhanee Lester
Kelli Owen
Lili Simo
Nari Sinclair
Marissa Wilson

MESSAGE FROM THE AKCTION2 TEAM

Welcome to the July edition of our AKction2 monthly newsletter. First things first:

Spirit Check!

- Take a moment to ground yourself and acknowledge and invite Miwi (Ngarrindjeri for Spirit) into your space.
- ∞ Take moment of silence and remembrance for our Kidney Warriors who are no longer with us. May their legacy live on through our works.

As we continue through Winter, the health and wellbeing of people is important. There are more colds and flu's. One big threat that we are facing is Meningococcal disease. Please ensure that you rug up and stay warm and take care of each other.

The photos of NAIDOC celebrations on socials look amazing.

We got to yarn with Penny once she got back to us from Pipalyatjara.

There are updates from the A2RT and we are looking forward to yarning about music, medications and peer support at the August

AKCTION 2 REFERENCE TEAM (A2RT)

August agenda.

- ∞ Patsy Tan, music therapist at RAH and the Centre for Aboriginal Studies in Music (CASM) is interested in building a collaboration with AKction.
- ∞ 'Medication brainstorming'—bring your medications and your stories about your medications and how you incorporate medications into your daily routine.

STAND UP STRONG, YARN UP LOUD GATHERING

On Friday 28th July Janet, Melissa, Penny and Liz from AKction and some of the University of Adelaide Aboriginal nursing students and staff attended the follow up gathering for SA Aboriginal and Torres Strait Islander Nurses, Midwives and Students and Non Indigenous Allies.

This event brings together the three universities, TAFE SA, health services and CATSINaM—the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives to discuss how we can better support Aboriginal and Torres Strait Islander student and staff recruitment and retention.

The event was held at TAFE SA this year, and will be hosted by Flinders University next year. AKction helped support the inaugural Gathering at the University of Adelaide in November 2022, as part of our wider cultural safety activities.

ANZSN

2-6 September ŌTUATAHI / CHRISTCHURCH

Our CI Kelli Owen will be presenting on the COMPASS project . GUIDING KIDNEY CARE THROUGH ABORIGINAL PATIENT NAVIGATORS

COMPASS is funded through a MRFF (Medical Research Future Fund). and is a 2 year research project across four sites; Darwin, Alice Springs, Port Augusta and Adelaide.

The aim is to strengthen the backbone of Australia by establishing a coordinated approach through Patient Navigators assisting patients to navigate a complex health care system in a culturally safe way. This project touches all stages of Chronic Kidney Disease from diagnosis to post transplant.



KNOWLEDGE TRANSLATION

HEALING OUR SPIRITS WORLDWIDE

Rhanee Lester, Nari Sinclair and Kynesha Temple-Varcoe have worked with Kelli Owen on presentations for the Healing our Spirits Worldwide—the 9th gathering in Vancouver Canada.

Kelli will travel to Vancouver to present in person while the team will copresent either as a pre recording or live online (details yet to be finalised).

Thank you to all who supported financially through the go-fund-me page. The money raised will support Kelli's travel and the team to copresent from Adelaide.





Penny at Lightning Dreaming rocks near

Yuendumu



Penny and her mum at Uluru



Penny's Family

YARNING UP WITH PENNY CLOUGH

My mob are English/Anglo Australian

I was born on and grew up on Peramangk Country and given the name Penelope so if you are looking for me on email I am Penelope.clough@adelaide.edu.au Penelope is a mouthful so we shorten it to Penny

I now live in Mount Barker which is also Peramangk country and there is a growing number of artworks and information plaques across the region acknowledging the Perenangk people as the Frist Nation in the region.

As far as bush tucker goes I have tried bush currents (awalyuru) and maku (witchetty grubs), these are the only delicacies I have tried yet, and enjoyed both. My favourite drink is tea, any type of tea!! My favourite holiday destination—anywhere BUSH I love camping. My favourite song at the moment is King Stingray - Camp Dog - because it reminds me of communities I have lived and worked in. My favourite TV show at the moment is True Colours (SBS/Netflix) because I helped create the dialysis scene in episode 6 and because it is wonderful to hear language spoken.

I am grateful beyond words for the opportunity to work with AKction. Becoming an ally is an ongoing process and I am always learning. AKction helps me learn and be better, helps me do better.

MENINGOCOCCAL STORY

There has been a recent spike in cases of Meningococcal disease and some of our team have lost friends to this illness. The illness is caused by bacteria that infects the lining of the brain. It is contagious and considered a medical emergency. Vulnerable people are infants and small children and people who are immunosuppressed. There are vaccinations available for certain strains of the bacteria meningococcal B, meningococcal ACW&Y and meningococcal C. Not all strains of the meningococcal bacteria have a vaccine. It is best to talk to your health care team about the vaccinations that would be best for you.

Keep an eye out for the following symptoms and if you are at all worried see a doctor or present to an Emergency Department Immediately.

- ∞ Fever
- ∞ Headache
- ∞ Neck Stiffness
- ∞ Light sensitivity
- ∞ Nausea &/or vomiting
- ∞ Diarrhoea
- $\infty \quad \text{Drowsiness and confusion}$
- ∞ Difficulty walking &/or talking

And watch for these signs in your little ones

- ∞ Refusing to eat
- ∞ Fretful and irritable
- ∞ Very tired and floppy
- ∞ Twitchy or fitting
- ∞ A high moaning cry

Treatment is with Antibiotics through a drip in Hospital, and possibly in the Intensive Care Unit.





Kelli, Rhanee, Kim and Ashum March

Rhanee and Noeleen Lester

NAIDOC 2023

Nangka Nina! Warndu? Ngai mityi Rhanee-nha, Ngatyu Adnyamathnha Yurartu. Ngai yura mityi Unakanaha, Ngatyu Adnyamathana moiety Ararru

Hello! Are you well?

 $My \ name \ is \ Rhanee \ Lester, \ and \ I \ am \ an \ Adnyamathanha \ woman \ from \ the \ Northern \ Flinders \ Ranges \ in \ South \ Australia.$

I am also known as Unakanha (meaning 3rd born child who is female) and my moiety is Ararru which represents the North Wind People.

I feel honoured to be able to stand here today and speak a tribute for our Elders, so when I am asked to deliver a speech or talk of some kind for any given reason, I think about how best I can connect to my audience and how I establish that connection through my delivery style.

So, seeing as this is 'For Our Elders' and in particular for my Elders I am going to go old school and read for you a "Letter to my Apa and Marmar", my First Elders Lynch and Rhoda Ryan of the Adnyamathanha people.

Dear Apa and Marmar, I've been asked to give a speech for NAIDOC – a tribute 'For Our Elders' and it made me wish so bad that you were still here with us. It's been a very long time since I've seen you both and although I miss you very dearly, I carry you with me wherever I go.

Apa I was very young when you passed away, but I remember loving you very much. I was the little cabbage patch bibi of the family - curly hair, colored eyes and dimples. I remember visiting you on Clontarf Street in Port Augusta, right next to the pink salt lake with the view of the Flinders Ranges calling to us in the distance. I remember your walking stick, your emu egg carvings, campfires in the backyard with family around. A very clear memory was our family gatherings in the creek beds on country, your cousins would bring along their families and all of us knew who was who. You taught us how to find water in the creek bed by digging a deep soak, you taught us how to keep the water clean so it could be used for drinking and cooking. You taught me life skills – You taught me as a child at 5 years old and I still carry this knowledge with me today. I remember the day we laid you to rest in Quorn, everybody was very sad. I was in the car piled up with all the other cousins and I was crying. My Ngarlami Aunty Denise, your eldest daughter came up to me and asked me "Why are you crying darling" and I remember saying to her my Grandpa died. I missed you then and I still miss you now and I am so grateful that there are photos and quotes of your wisdom and knowledge that I can still access today. I acknowledge you for being an educator, an advocate, a knowledge keeper, a talented artist a devout husband, a caring father, loving grandfather and a strong Adnyamathanha Yura.

Marmar my cute little nana shuffler. Where do I even start with you my dear. I miss you, I love you and I thank you from the bottom of my heart. You taught me so much about humbleness, about commitment and dedication, about love for family and love for country and how to keep strong in faith and belief. I remember drinking cups of tea with you at the kitchen table on Clontarf Street, with the window wide open letting in the cool summer breeze on a warm day. How you gathered the crumbs on the table from the toast and biscuits into a neat pile to be scooped off the table and dusted off over the kitchen sink. I remember you catching me and Candy as kids at the bottom of the pantry eating raw flour, so that was the day you taught us how to cook a damper and feed ourselves and the family there is so much to be grateful for because of you. I was 17 years old when you passed away and we were all very sad to lose the Matriarch of our family. At the time of your passing, I didn't know it but I was chronically ill, in the lead up to my diagnosis of Chronic Kidney Disease it was you who I spoke to in my prayers every day and every night. I know you heard and answered me often as I felt warmly comforted throughout my toughest of times. I held onto the thought that you Marmar are still with me – Protecting Me, Guiding Me, Loving Me!

ELDERS TEACHING with RHANEE LESTER

As my Elders have taught me, I now pass on to you:

- E Education is the Key.
- L Leadership requires you to not only lead, but to be able follow.
- D Discipline to keep you on track and focused.
- E Energy to keep going and Never Give Up.
- R Respect is as much earned as it is given.
- S Sovereignty has never been ceded!



Jared and Kim

ABORIGINAL KIDNEY CARE TOGETHER IMPROVING OUTCOMES NOW

The AKction Project Team consists of the following deadly members

Project Leads

Dr Kim O'Donnell

Assoc. Prof Janet Kelly

Project Co-ordinator/ support

Penny Clough RN

Chief Investigators

Kelli Owen

Nari Sinclair

Rhanee Lester

Samantha Bateman

Joseé Lavoie

Aboriginal Kidney Care Together Improving Outcomes Now C/- Adelaide Nursing School University of Adelaide Level 4, Adelaide Health & Medical Sciences Building Cnr North Terrace & George Street ADELAIDE South Australia 5005



STUDENT UPDATE

Mellissa Arnold Ujvari has successfully completed her PhD major review, and her first PhD article focusing on the CARI Guidelines, cultural safety and clinical care has been accepted for publication in the upcoming Renal Society of Australasia Journal. Melissa has just submitted her second article about the emergence of Cultural Safety in Kidney Care in Australia.

Kelli Owen is working toward an all-Indigenous supervision team to support her study focused on Indigenous Governance, and Kim O'Donnell and Odette Pearson are in the process of completing the University PhD supervision course. This is another fabulous step forward for the team.

Sam Bateman continues to publish papers as part of her PhD. The latest is Models of Care to address disparities in kidney health outcomes for First Nations people, published in Kidney International, which is a major achievement.

Three of the nursing Honours students are in their data collection analysis stages. Veda Mitra has completed three interviews with Aboriginal people about their lived experience of kidney disease and COVID 19. Ayleen Castro is interviewing Aboriginal people about their experiences of kidney transplantation from first phone call to when they leave hospital, and Millie Baker is interviewing Aboriginal people about their experiences of kidney transplantation after they leave hospital. They will use both kidney journey mapping and thematic analysis (drawing out themes from what people tell them). Ayleen and Millie are both keen to talk to more people over the next few weeks.

Harmandeep Kaur is another nursing Honours student who has joined AKction and met with the AKction Reference Team to discuss her topic. She will be focusing on mental health/social and emotional well-being support for Aboriginal people with kidney disease. Harmandeep will hold a focus group to discuss Aboriginal people's experiences of accessing support and services, mapping what mental health/social and emotional well-being services are currently available for Aboriginal people with kidney disease in South Australia, and identifying key points in people's kidney journeys where they might need to access these services.

AKction team writing activities

Kynesha Temple Varcoe met with Liz Rix and Nari Sinclair, Kelli Owen and Rhanee Lester last week to on a paper for Croakey focused on Bringing Spirituality into the Academic space. This paper links with the presentation that Kelli Owen, Rhanee Lester and Kynesha will deliver for the Canadian Healing our Spirits conference.

Latest publications:

Arnold-Ujvari, M., Rix, E., Yip, A., Tunnicliffe, D. & Kelly, J. (2023) CARI Guidelines, Culturally safe and clinical kidney care for First Nations Australians: A Summary. Renal Society of Australasia Journal. (in press)

Bateman, S, Riceman, M, Owen, K, Pearson, O, Lester, R, Sinclair, N, ... Jesudason, S 2023, 'Models of care to address disparities in kidney health outcomes for First Nations people', Kidney International. https://www.kidney-international.org/article/Soo85-2538(23)00484-2/fulltext