

# Research Tuesdays

# Decolonising healthcare

**Professor Janet Kelly** 

Dr Kim O'Donnell



We acknowledge and pay our respects to the Kaurna people, the traditional custodians whose ancestral lands we gather on.

We acknowledge the deep feelings of attachment and relationship of the Kaurna people to country and we respect and value their past, present and ongoing connection to the land and cultural beliefs.

# Acknowledgment

Two Matriarchs who have led the work we have been doing collaboratively in decolonising kidney health care.



Inawinytji Williamson & Nari Sinclair



## We will share

- what we do
- how we do it, and
- what we have learned
  - about decolonising kidney health

We recognise that many people and services are striving to provide quality, responsive care.

There is also a lot more work for us all to do.

#### We are part of much larger collaborations











#### **Decolonisation**

The process of acknowledging and addressing the ongoing trauma and impact of colonisation by European powers on the First Nations People of Australia and working together to rectify the wrongs.

# **Productivity commission comments on Close The Gap**

Governments across Australia have largely not fulfilled their commitments under the agreement. They have not grasped the nature or the magnitude or the changes they promised to make.

They are unwilling to relinquish control, are lacking accountability, and have only tokenistic engagement with Indigenous organisations. Their actions don't align with what the community say will work.

Programs are not measured in terms of what the communities value as markers of change.

They continue to allocate public money ineffectively.

Natalie Siegel Brown, Commissioner, Productivity Commission THE UNIVERSITY OF ADELAID

# Colonisation of health care and research

**Australian First Nations People** have been developing health, wellbeing and environmental research for at least 65,000 years.



"Colonial scientific" approaches to health care and research were imported and developed in Australia over 236 years, alongside colonisation and racist policies and actions.

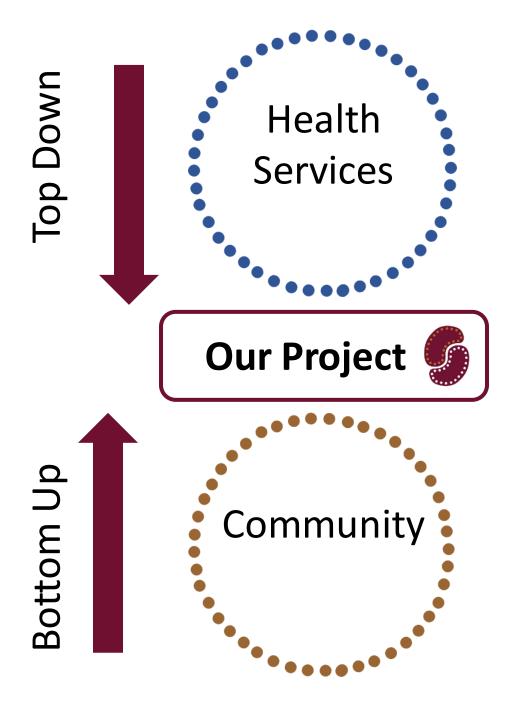
They have largely ignored First Nation Peoples' ways of knowing, being and doing [epistemology, ontology, axiology, methodology]



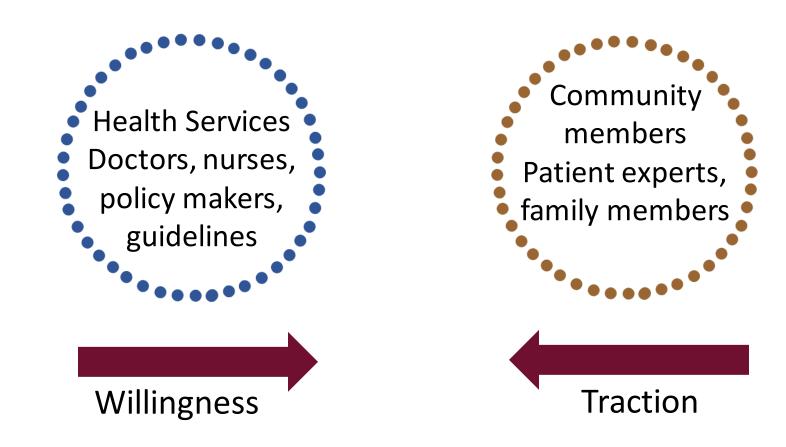
Many First Nations People have learned from experience to distrust Eurocentric health care and research, over many generations.

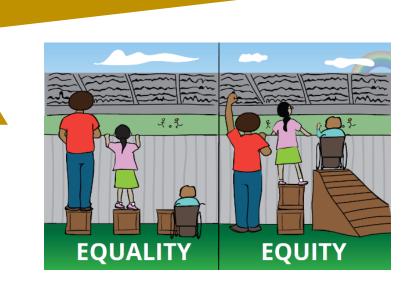


### **Colonised Systems**



#### **De-colonising Processes**





## Decolonisation

working in the Brave Space



Collective decision making



**Inclusion** 

#### Connection to:

- Spirit, spirituality, ancestors
- Family, community & kinship
- Country and culture
- Body, mind & emotions
- Life, death, life cycles

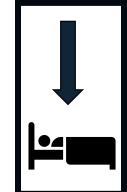
Culturally safe
health care as
defined by First
Nations recipients
of care

#### Requires:

- Taking time to build trusting relationships
- Two-way respectful communication
- Shared decision making
- Critical self-reflection
- Adequate, long-term funding & strategies

First Nations people's experiences of colonised health care

Autocratic, top-down decision making



#### **Exclusion**

Disconnection due to:

- Reliance of biomedical & physical evidence
- Separation of body parts, mind and spirit
- Focus on individuals
- · City centric, specialisation
- Short term funding





Akction
Aboriginal Kidney Care
Together – Improving
Outcomes Now

Aboriginal health practitioners, nurses, doctors & educators working alongside community members to improve care experiences and outcomes

Aboriginal patient experts are positioned as Chief Investigators, Project Leads and Reference Team Members



# First Nations People's experiences of kidney disease

First Nations peoples experience disproportionate levels of kidney disease in urban, regional and rural locations.

5 x more likely to develop kidney disease

4 x more likely to die from kidney disease, often at younger ages

In remote and very remote areas the rates of kidney disease are up to 20 times higher

(Kidney Health Australia. 2024)

#### Raises questions about:

- ongoing impacts of colonisation, policies and decision making
- transport and distance to services

#### Access to:

- health and wellbeing
- available infrastructure secure water, food, housing
- primary health care information, prevention, early detection and treatment of infections and other chronic health conditions
  - kidney health care

# Community consultations

Location: Port Augusta
Pika Wiya Aboriginal Health
Service, Feb 2019

Chris Forbes, CEO Kidney Health Australia Sue Crail, Nephrologist

Aboriginal Community members

Tahlee Stevenson, Registered Nurse



Roxanne Sambo, Aboriginal Health Practitioner



# **AKction 1 extended into AKction 2**

#### AKction

HTSA/ MRFF funding

2019-2022

- Community Consultations
- Patient journey mapping
- Stakeholder workshops
- Networking local, NT, international
- New national clinical guidelines



#### **Building relationships & trust**

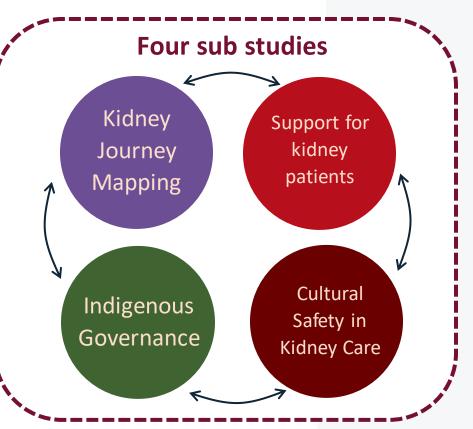
- Aboriginal patients & families Kidney health professionals
- Researchers Health services, systems, managers, & decision makers



#### **Methods**

Decolonising research, working together in a Brave Space

 Yarning • Dadirri (deep listening) • Ganma (knowledge sharing) • participatory action research • Restructuring hierarchies • Aboriginal patients experts positioned as chief investigators





#### **End goals**

Patients & families

Better kidney care, dialysis, transplantation, access, education, prevention

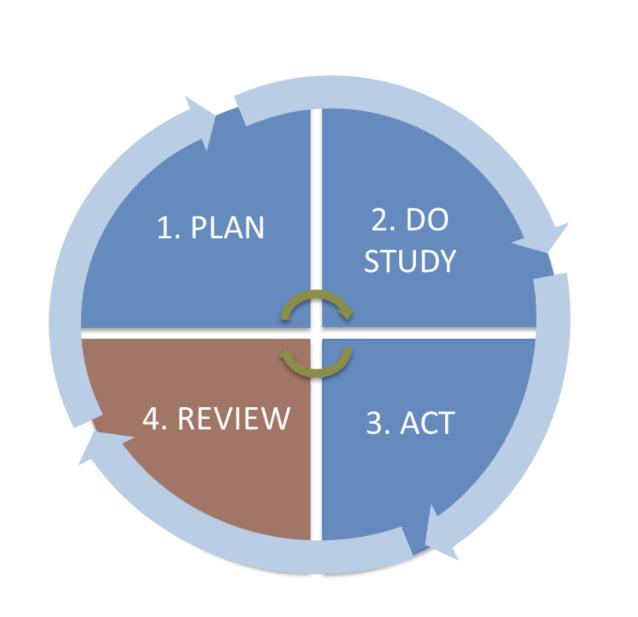
Health professionals

Cultural safety, training, effective partnership, Indigenous workforce

Health services & systems

Improved coordination
Guidelines & standards informed
by community Reducing racism

# Action research approaches





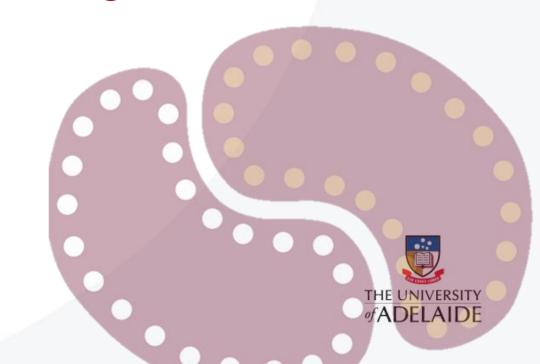


#### **AKction2: Four areas of research focus**



- 1. Indigenous governance "We are more than our disease!"
- 2. Support for Aboriginal kidney patients "We know what it is like"
- 3. Kidney journey mapping "No one else should have to experience this"
- 4. Cultural Safety in Kidney Care "Sometimes they just don't get it"

Overall aim: to improve the experiences and outcomes of kidney care for and with Aboriginal patients, families and community members and kidney health services in South Australia



# Indigenous governance - "We are more than our disease!"



#### **NIKTT Kidney Gathering**







# Peer support

#### "We know what it is like"

- Peer navigators
- Regional visits
- Working in collaboration with the National Kidney Transplantation Taskforce and the Compass project











# Kidney journey mapping "No one else should have to experience this"



# Sharing journey stories with community members





Rhanee Lester's journey

# **Kidney Journeys**

## Mapping against standards and guidelines



**NSQHS** Guide for **Aboriginal and Torres** Strait Islander Health







**NSQHS** Quality Improvement, Health Care and Accreditation Standards



#### **INDIGENOUS GUIDELINES**

MANAGEMENT OF CHRONIC KIDNEY DISEASE AMONG ABORIGINAL AND/OR **TORRES STRAIT ISLANDER PEOPLES** 



INSTITUTIONAL RACISM **CULTURAL SAFETY** 



**COMMUNITY AND FAMILY INVOLVEMENT** 



**TRANSPORTATION** 





ABORIGINAL AND/OR TORRES STRAIT ISLANDER **HEALTH WORK FORCE** 



**RISK FACTORS** SCREENING



REFERRAL



PUBLIC AWARENESS

EDUCATION

**SELF MANAGEMENT** 



KIDNEY-FAILURE



GUIDELINES www.cariguidelines.org

# **Cultural Safety**

- Cultural Bias Literature Review, Report & Policy Brief
- Embedding cultural safety into the inaugural national clinical guidelines
- The emergence of cultural safety in kidney care PhD study
- National Indigenous Kidney Transplantation Taskforce Gathering
  - Co-facilitation, Aboriginal space Tandanya, South Australia
- Co-designing Decolonising Clinical Care course at CALHN









POLICY BRIEF • DECEMBER 2020

CULTURAL BIAS INITIATIVES TO IMPROVE
KIDNEY TRANSPLANTATION FOR ABORIGINA
AND TORRES STRAIT ISLANDER PEOPLE

#### THE ISSUE

Kidney disease is a serious and increasing health probiamong Aboriginal and Tomes Stratt Islander people: Aboriginal and Tomes Stratt Islander people are more likely to experience kidney failure compared to other Australians, be disgnosed at an entire age, and have a higher prevalence of other health conditions. Despite t Aboriginal and Torres Stratt Islander people are four tife less likely to receiva a kidney transplant whem they no

Various forms of racism and cultural blass have been dentified as barriers to Aboriginal and Torres Strait Isla scople receiving equitable access to kidney transplantat he National Indigenous Kidney Transplantation Taskid NIKTT) was established in 2019 to improve access to, a ost-transplant outcomes from, kidney transplantation sock-transplant outcomes from, kidney transplantation boriginal and Torres Strait Islander people.

#### THIS PROJECT

This project is the first step under the NIKTT to review existing health service cultural bias initiatives. It makes recommendations to inform future activities that can address cultural bias in service delivery for kidney transplantation for Abortiginal and Torres Strait Islander Australians.

The project examined givey and peer reviewed literature from Australian cultural bas intilatives across kidney healthcare and other testinal yealthcare settings. It also included Aboriginal and Torres Staffs listander patients, families and community members and health professiona perspectives from community constitutions across Australia. Patients are recognised as expects of their own level experience of kidney disease and of how care is provided. They are in a unique position to identify barriers and gaps as well as propose possible solutions. Their voic must be privileged in this and wider discussions to achieve real change moving forward.

solutions that will work in the long term are those that are Aboriginal-led culturally responsive, located in Aboriginal organisations and evaluated

But Turner CEO MACCHO, National Indigenous Disable and Transplantation Conference, Actober



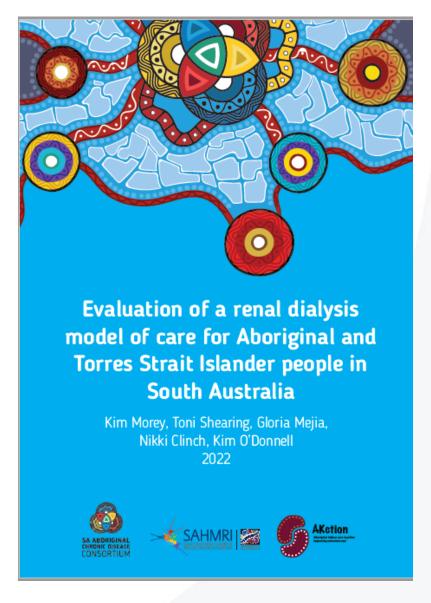
# New models of care

## Kanggawodli dialysis chairs – Australian First



Providing dialysis in a culturally safe environment as identified by the consumer group has improved attendance to regular dialysis

Being sensitive to consumer needs and not applying a one size fits all model





# Incorporating oral health care with kidney care

Kanggawodli dialysis – oral hygienist student clinical placement











# Organ Smoking Ceremony as part of healing for kidney transplant patients

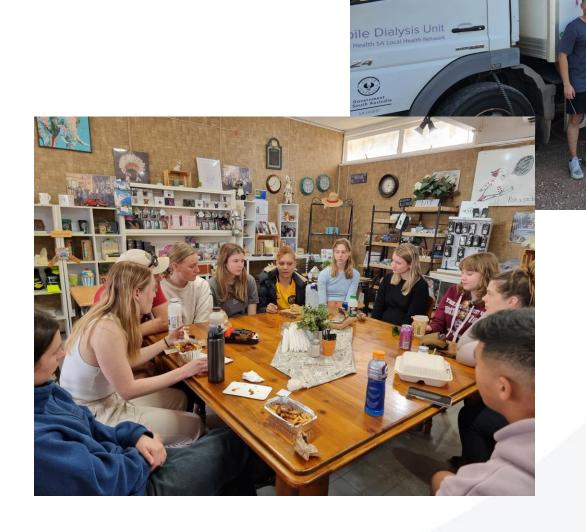




# Ceduna Kidney Yarning & Yalata Kidney Festival









# Culturally safe kidney care for Australian First Nations Peoples









<mark>Vimeo - video</mark>

https://vimeo.com/757374130



#### What we have learned and are still learning

- Researching while grieving losing friends, family and colleagues
- (losing 6 people in five years of AKction)
- Knowing when to step up, step back and walk alongside each other
- Collaboration rather than duplication shared resources and enhanced capacity; competition can divide people and resources
- Time + Respect = Trust
- Working in the Brave space we don't always get it right, but we keep trying
- The Brave Space Poem by Micky Scott Bey Jones



# AKction Team Members (current & past)

**AKction Reference Team/s:** Alice Abdulla, Aunty Christine Franks, Denise Champion, Donna Abdulla, Inawinytji Williamson, Jared Kartinyeri, Kelli Owen, Lili Simo, Aunty Lillian Neville, Matthew Hobbs, Nari Sinclair, Ramon Gadd, Rhanee Lester, Richard Brooks, Shellander Champion, Sherrie Jones & Waluwe Dono.

Chief and Associate investigators: Kim O'Donnell, Janet Kelly, Kelli Owen, Nari Sinclair, Rhanee Lester, Sam Bateman Josee Lavoie, Odette Pearson, Tamara Mackean, Melissa Arnold-Ujvari, Shilpa Jesudason, Stephen McDonald, Richard Le Leu, Kylie Herman, Lisa Jamieson, Su Crail, Tiffany Whittington.

**Project teams:** Alyssa Cormick, Amy Graham, Brandon O'Connor, Cassandra Glenn, Isaac Brown, Kate Schwartzkopff, Kimberly Taylor, Kynesha Temple Varcoe, Liz Rix, Penny Clough, Penny Smith & Tahlee Stevenson.

Collaboration teams: Alana Gunter, Amelia Ware, Amanda Biddle, Andrew Lane, Chris Russell, Dora Oliva, Erandi Hewawasam, Kate Tyrell, Kelly Clemente, Kurt Towers, Laura Lunardi, Margie Steffens, Michelle Sweet, Mitra Javanmard, Rebecca Munt, Roxanne Sambo, Sarah Furnell, Serena Fransca, Stephen Cornish, Sylvia Reynolds, Wade Allan, ANZDATA, AURHA - Adelaide University Rural Health Alliance, Ceduna Hosptial, Central and Northern Adelaide Renal Transplantation Services, Moorundi, Pika Wiya, Tullawon and Yadu Aboriginal Community Controlled Health Services, Indigenous Oral Health Unit, Kanggawodli Hostel, Kidney Health Australia, Menzies School of Health Research, National Indigenous Kidney Transplantation Taskforce, Panaku, Port Augusta Hospital & Purple House, SA Dialysis Truck.

PhD & Master's students: Kelli Owen, Melissa Arnold Ujvari, Nishanta Tangiralia & Samantha Bateman,

Honours students: Alyssa Cormick, Ayleen Castro, Basil Abou-Assali, Harmandeep Kaur, Millie Baker & Veda Mitra

3<sup>rd</sup> year health and medical sciences students: Claire Dekuyer, Ejaz Nijadi, Kai Loon Lau, Louise Channing



#### References

#### Ganma:

O'Donnell, K & Kelly, J 2011, 'Using Ganma knowledge sharing as a decolonising approach to conference planning and facilitation', *ALAR action learning and action research journal*, vol. 17, no. 2, pp. 137-156.

#### Dadirri:

West, R, Stewart, L, Foster, K & Usher, K 2012, 'Through a Critical Lens: Indigenist Research and the Dadirri Method', *Qualitative health research*, vol. 22, no. 11, pp. 1582-1590.

#### Yarning:

Bessarab, D & Ng'andu, B 2010, 'Yarning About Yarning as a Legitimate Method in Indigenous Research', *International Journal of Critical Indigenous Studies*, vol. 3, no. 1, pp. 37-50.

#### **Decolonisation:**

Sherwood, J., & Edwards, T. (2006). Decolonisation: a critical step for improving Aboriginal health. *Contemporary nurse*, vol. 22, no. 2, pp. 178–190.

For further information on our collaborations, please go to the following websites

AKction website < AKction- Aboriginal Kidney Care Together Improving Outcomes Now | University of Adelaide >

NIKTT website < Home | National Indigenous Kidney Transplantation Taskforce (niktt.com.au) >



make history.

