

Artwork "My Kidney Journey" by Inawinytji Williamson; used with permission



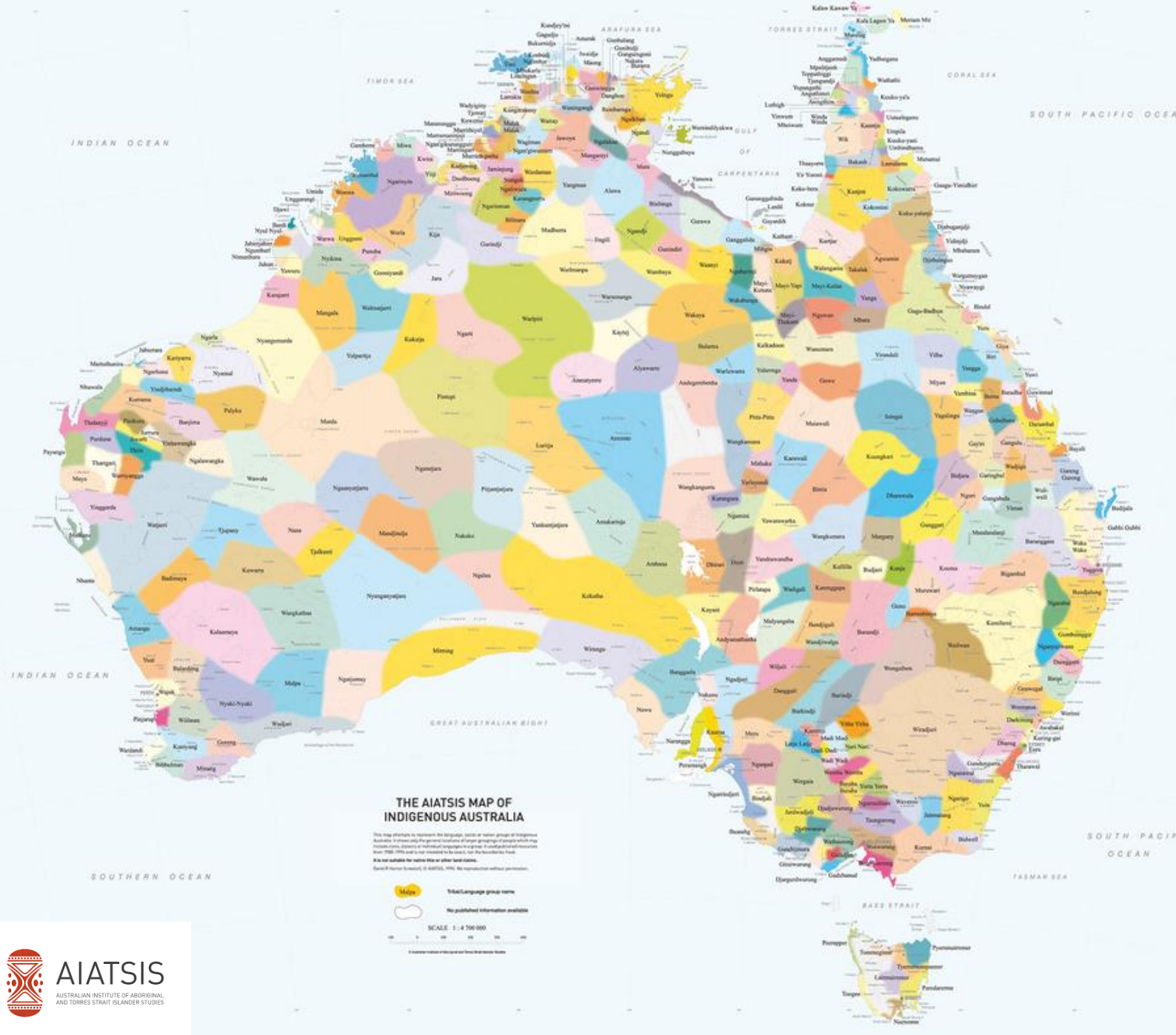
Co-creating community-led Aboriginal Health research



The Royal Australasian  
College of Physicians



*Warning to Aboriginal and Torres Strait Islander people, this presentation contains images of people who have died.  
All images used with permission of individuals and/or families.*



**THE AIATSIS MAP OF INDIGENOUS AUSTRALIA**

This map attempts to represent the language, social or nation groups of Indigenous Australia, in line with the general locations of larger groupings of people which may include cities, towns or individual languages or groups of individuals that have been 1980-1990 and is not intended to be used for the boundaries of land. It is not suitable for nation or other land purposes. Source: Bureau of Statistics, © 2010, 1990. All reproduction without permission.

**Main**      Tribal/Language group name  
 No published information available

SCALE: 1:4 700 000

# First Nations people experience a higher burden of kidney disease

Overrepresented in all stages of chronic kidney disease

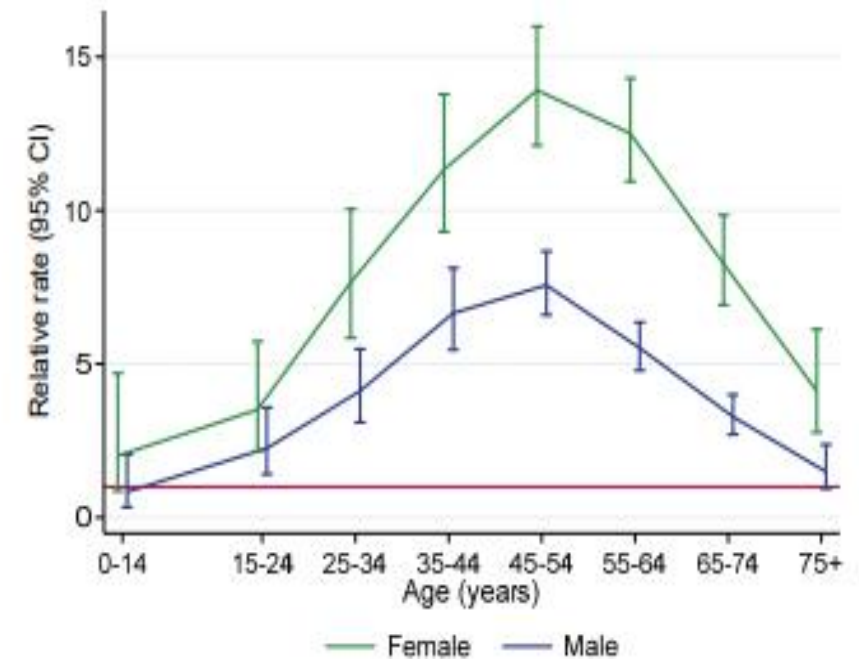
- Increased incidence & prevalence
- Increased progression of disease

Increased kidney failure rates 2-13x higher

Poorer access to dialysis and transplantation

Perceived poor outcomes

Relative rate of treated kidney failure; First Nations and non-Indigenous Australians 2016 -2020



“Disparities between Indigenous and non-Indigenous patients with end-stage kidney disease in access to kidney transplantation are not explained by patient or disease related factors. Changes in policy and practice are needed to reduce these differences.”

Khanal et al. 2018

**AKTION**

ABORIGINAL KIDNEY CARE TOGETHER IMPROVING OUTCOMES NOW!



Inawinytji Williamson,  
Nari Sinclair

# Usual health care & research processes

**Top Down**  
Health care & research



Disconnect

**Bottom Up**  
Patients, family & community



**AKTION**

ABORIGINAL KIDNEY CARE TOGETHER IMPROVING OUTCOMES NOW!

Patient experts,  
family &  
community  
members

Co-design



Health services &  
health professionals  
practice, policy,  
clinical guidelines &  
data interpretation

Resources & support

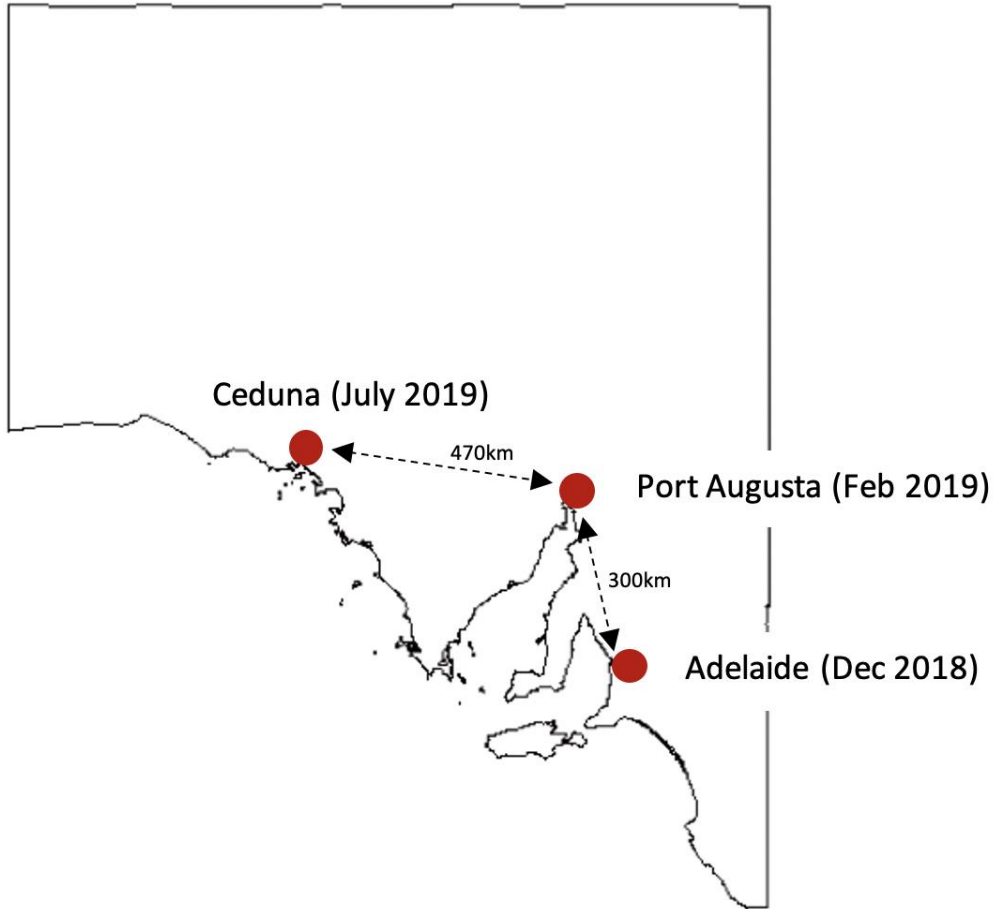
Willingness to listen,  
engage & respond

**Equity**

Providing community members with additional resources  
and support to enable equitable involvement & outcomes



# Community Consultations



## West Coast Sentinel

JUNE 14 2019 - 12:00PM

### Ceduna hosts kidney health consultation

Luca Cetta

Local News



Ceduna hosted three days of Indigenous Voices Yarning 'Kidney Health' consultation sessions this week aimed at improving kidney care in Aboriginal communities.

## RANSCONTINENTAL PORT AUGUSTA

/ News / Local News

ARY 7 2019 - 3:52PM

### dney health consultation in Port Augusta

Balsamo

Local News

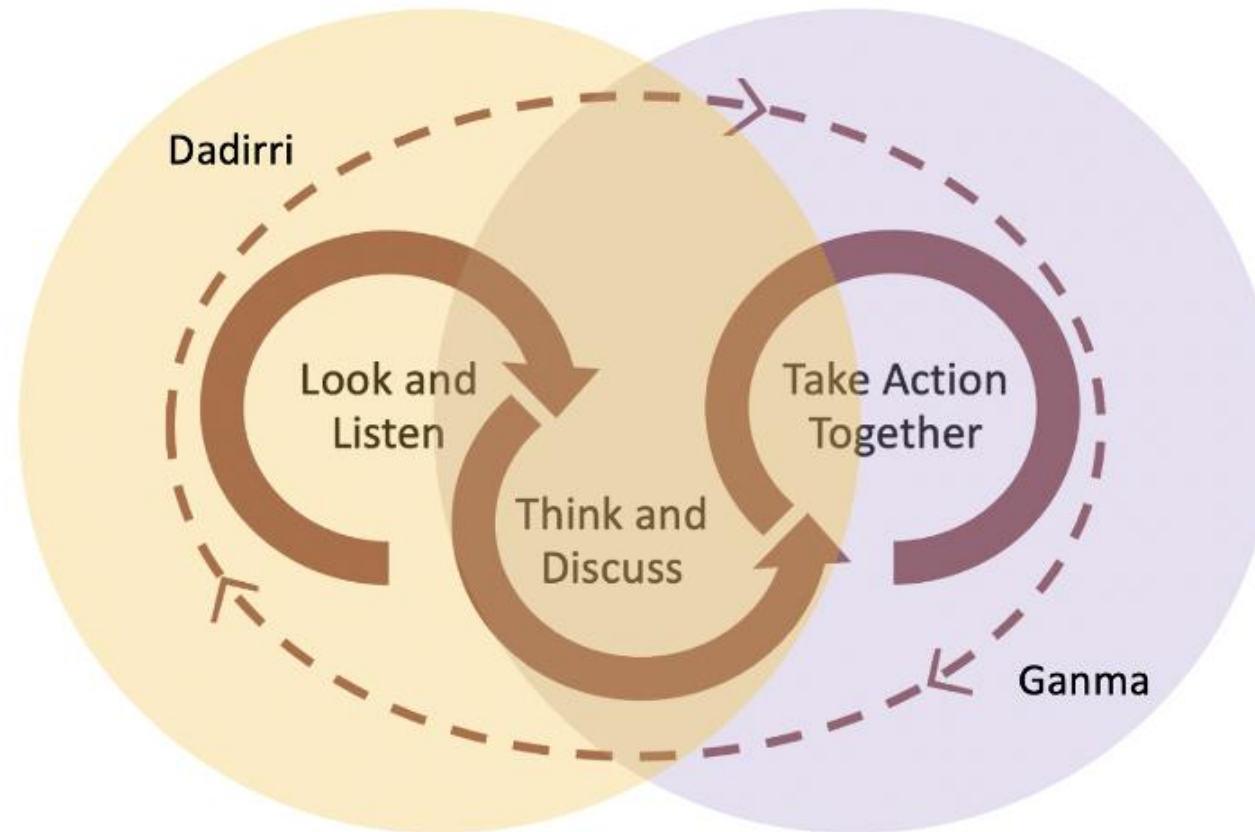


ALTH: Inawintji Williamson paints the story of her life on an old renal dialysis machine, with help from her nieces, Kani George and Rhoda Tjitayi.

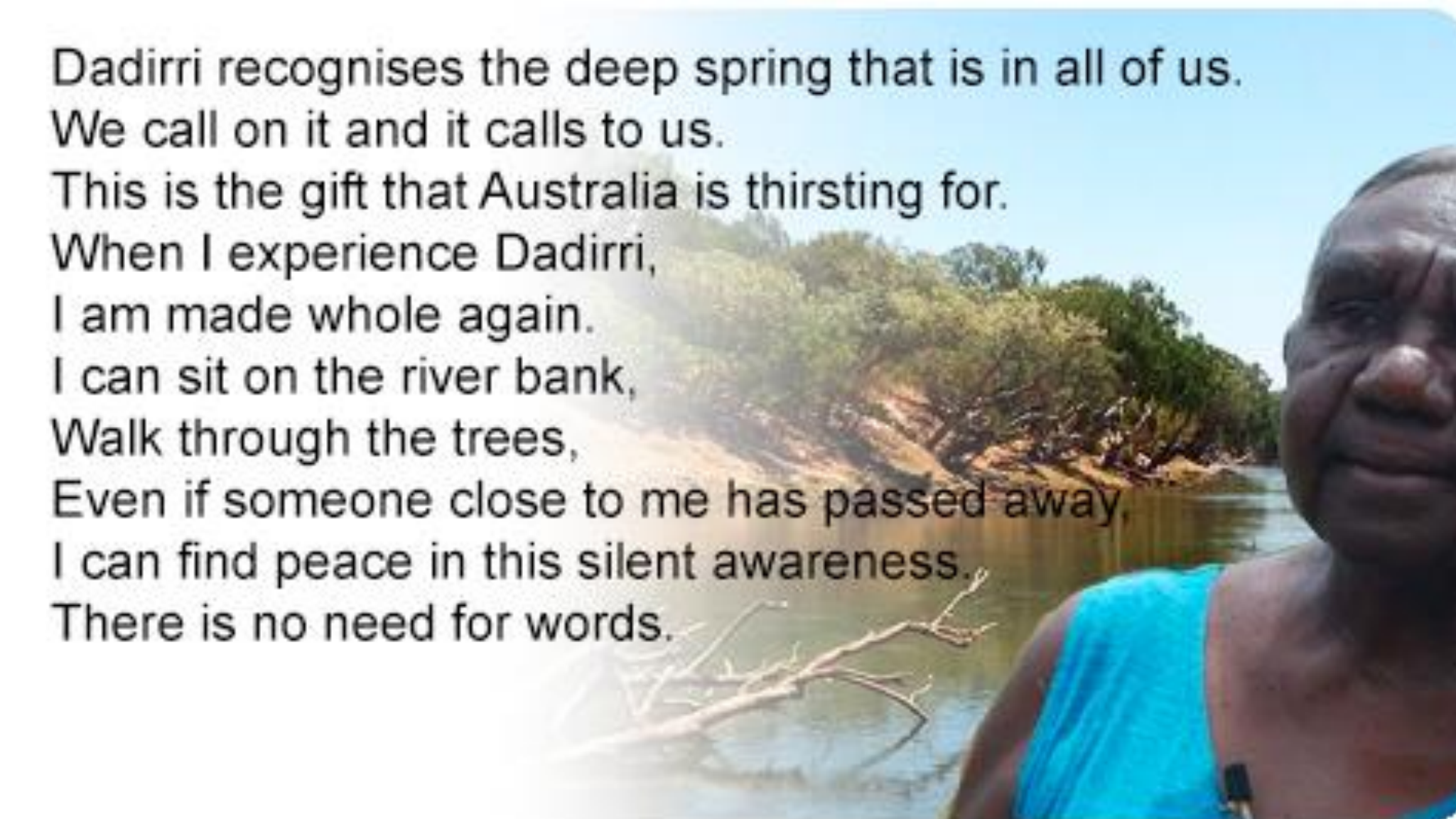
Two-day Indigenous Voices Yarning 'Kidney Health' consultation brought researchers and nurses together with Aboriginal people with kidney issues to discuss the best ways to improve kidney care.

## Real Ways of Working Together: co-creating meaningful Aboriginal community consultations to advance kidney care

Samantha Bateman✉, Melissa Arnold-Chamney, Shilpanjali Jesudason, Rhanee Lester, Stephen McDonald, Kim O'Donnell, Kelli Owen, Odette Pearson, Nari Sinclair, Tahlee Stevenson, Inawinytji Williamson, Janet Kelly



Community-based Participatory Action Research (PAR)

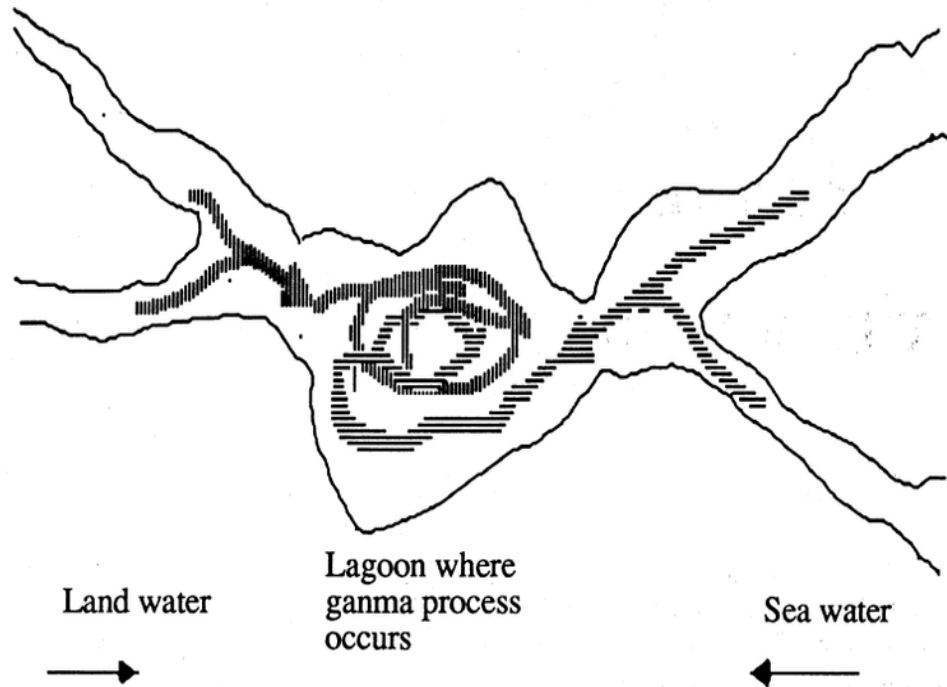


Dadirri recognises the deep spring that is in all of us.  
We call on it and it calls to us.  
This is the gift that Australia is thirsting for.  
When I experience Dadirri,  
I am made whole again.  
I can sit on the river bank,  
Walk through the trees,  
Even if someone close to me has passed away,  
I can find peace in this silent awareness.  
There is no need for words.

Dr Miriam-Rose Ungunmerr, AM



# Ganma



*"fresh-water springs to make waterholes, and salt water from the sea are interacting with each other, with the energy of the tide and the energy of the bubbling spring.*

*When the tide is high the water rises to its full. When the tide goes out the water reduces its capacity....*

*In this way, the Dhuwa and Yirritja sides of Yolngu life work together.*

*And in this way, balanda (non-Yolngu) and Yolngu traditions can work together.*

*There must be balance; if not, either one will be stronger and will harm the other"*

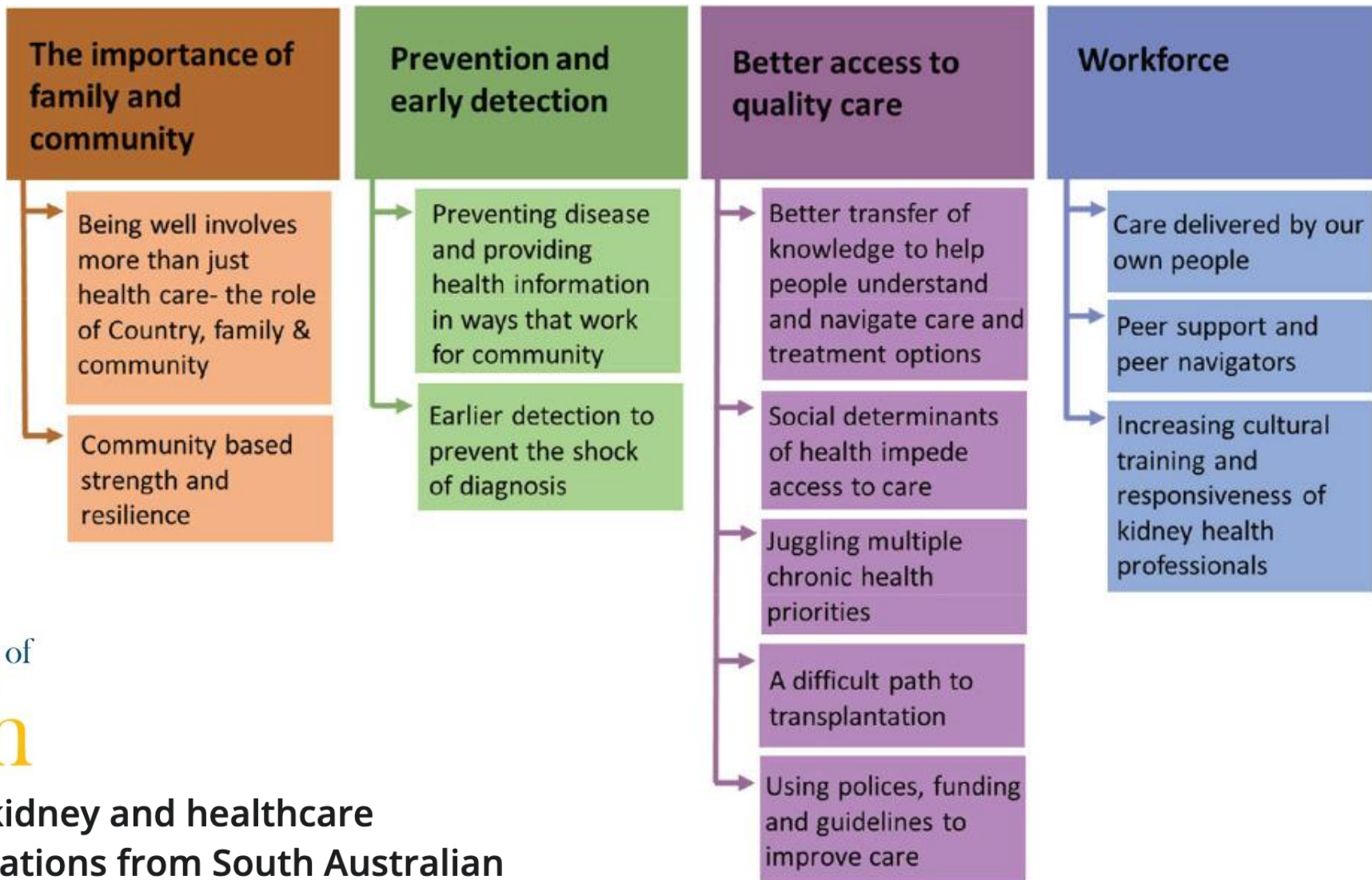
*Raymattja Marika-Munungguritj*



# REFERENCE TEAM!



Back: Ramon Gadd, Jared Katinyeri, Kelli Owen, Rhanee Lester.  
Front: Inawinytji Williamson, Nari Sinclair, Matthew Hobbs, Lily Neville

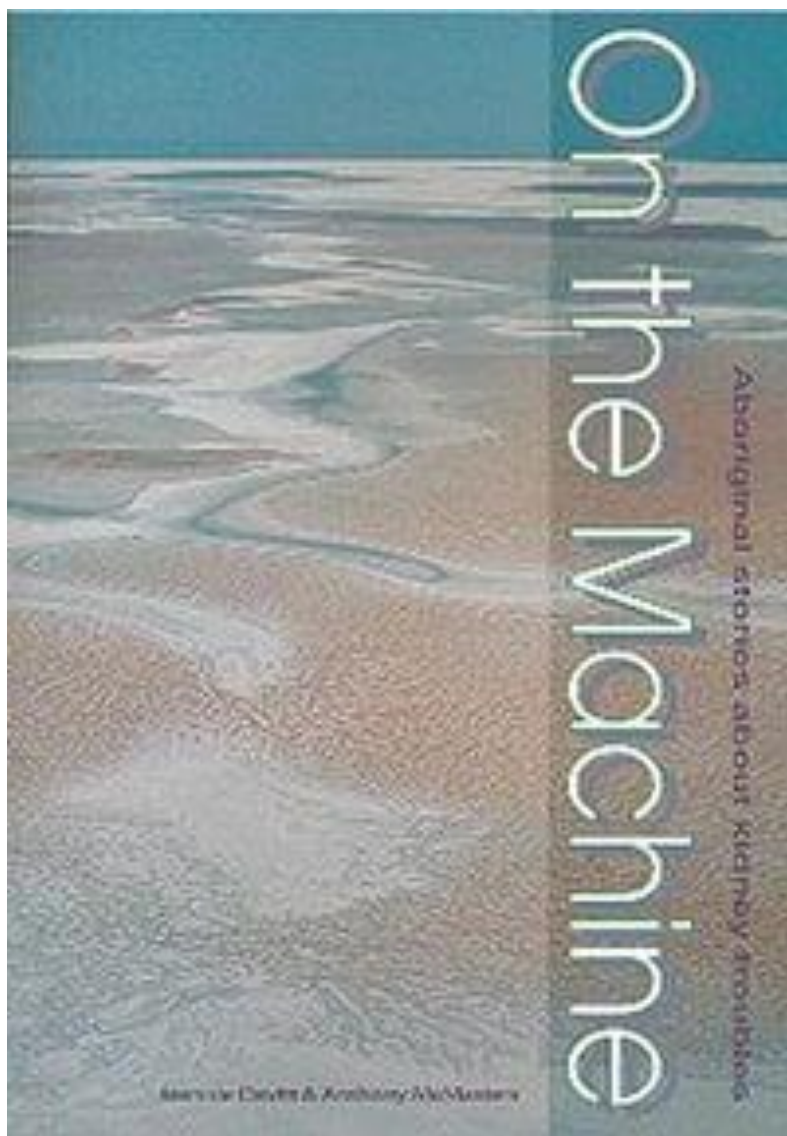


Australian and New Zealand Journal of

# Public Health

## Aboriginal patients driving kidney and healthcare improvements: recommendations from South Australian community consultations

Janet Kelly ✉, Tahlee Stevenson, Melissa Arnold-Chamney, Samantha Bateman, Shilpanjali Jesudason, Stephen McDonald, Kim O'Donnell, Odette Pearson, Nari Sinclair, Inawinytji Williamson



*Nephrology* 1998; 4, Suppl., S111–S117

Can We Afford Not To Treat End-Stage Renal Disease?

**‘They don’t last long’: Aboriginal patient experience of end-stage renal disease in Central Australia**

JEANNIE DEVITT AND ANTHONY McMASTERS

*Central Australian Aboriginal Congress, Alice Springs, Northern Territory, Australia*

# The Guardian

## 'Institutionalised racism' reason for fewer Indigenous kidney transplants

**Kidney specialist Paul Lawton says Indigenous 'compliance' challenges misunderstood so patients thought high-risk and less likely to go on waiting list**

ABC NEWS

### Racism likely at play in low Indigenous kidney transplants, AMA says

By Indigenous affairs reporters [Bridget Brennan](#) and [Isabella Higgins](#)  
Posted Thu 14 Dec 2017 at 6:40am, updated Thu 14 Dec 2017 at 8:07am



### Unacceptable kidney transplant rate for Indigenous Australians

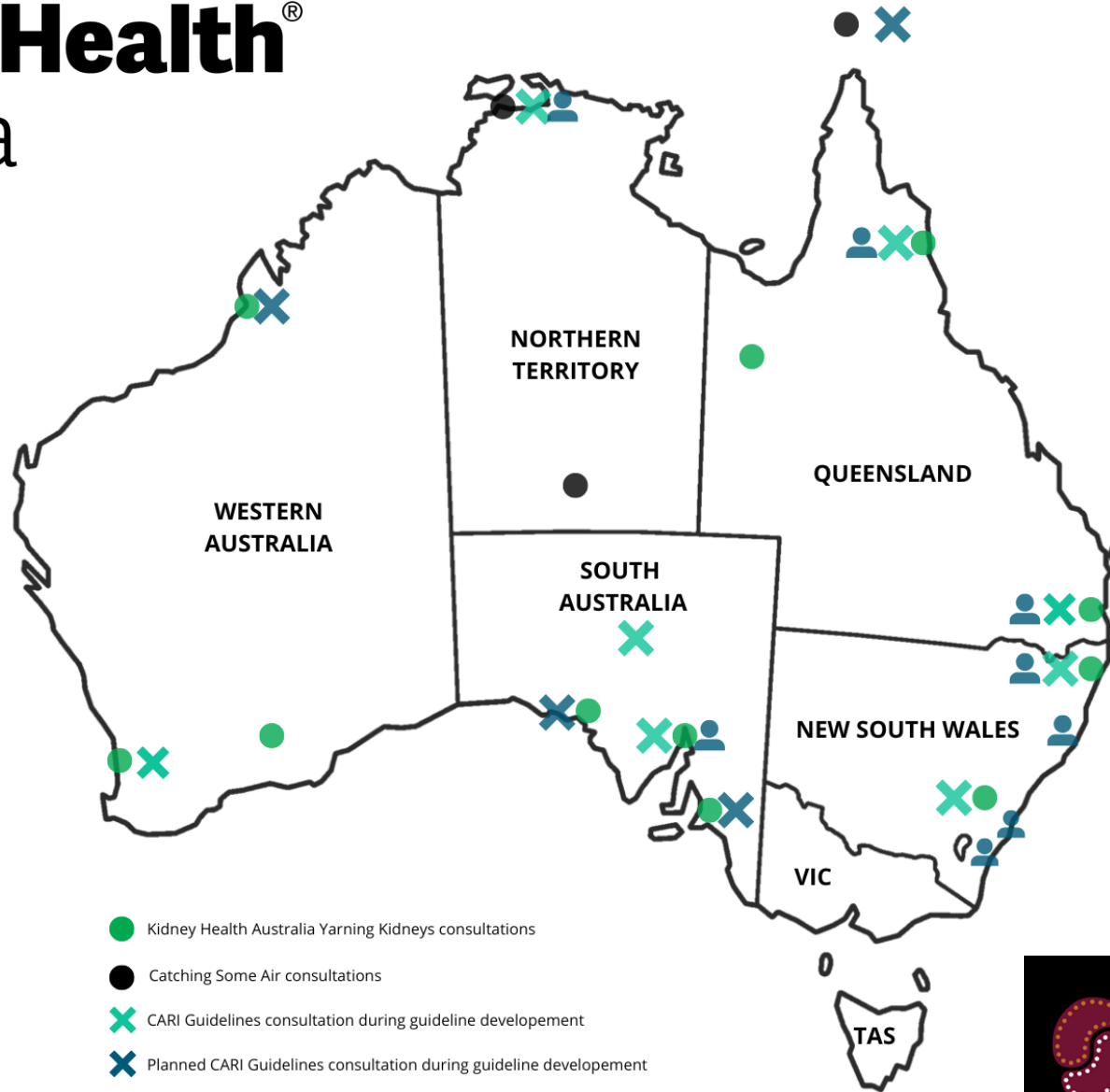
Published 15 December 2017



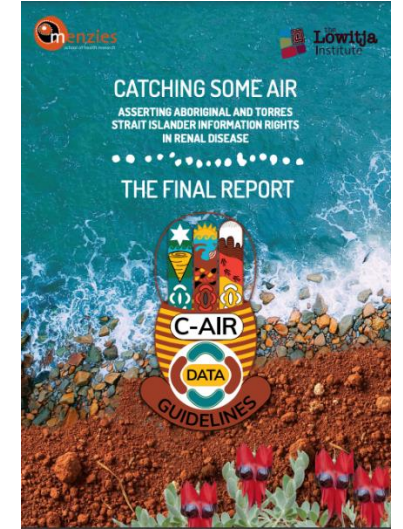
<p>AMA President Dr Michael Gannon has called for urgent attention in addressing the gap between Indigenous and non-Indigenous Australians accessing kidney transplants.</p>



# Kidney Health<sup>®</sup> Australia



- Kidney Health Australia Yarning Kidneys consultations
- Catching Some Air consultations
- ✕ CARI Guidelines consultation during guideline development
- ✕ Planned CARI Guidelines consultation during guideline development
- CARI Guidelines First Nations Guideline Work Group member





# Recommendations for culturally safe and clinical kidney care for First Nations Australians



[cariguideines.org](http://cariguideines.org)  
[@cariguideines](https://twitter.com/cariguideines)

Developed in partnership with:



# Community messages

Racism is evident and common

Increasing access to care on Country

Current transport and accommodation inadequate

Increasing family and community involvement

Increased First Nations Health Workforce required

Education, detection, and care needs to be led by community for community





Early detection and management of disease

Issues beyond  
a clinical focus

Guidelines  
must address  
**these issues**



# Adapted Evidence to Decision framework

	Domain	Description
	Community voice	<ul style="list-style-type: none"><li>• Needs identified in community consultations</li><li>• Any other feedback from community</li></ul>
	Cultural safety considerations	<ul style="list-style-type: none"><li>• Other cultural safety issues not raised in the consultations</li><li>• Cultural, historical and social context</li></ul>
	Clinical evidence	<ul style="list-style-type: none"><li>• Balance of benefits and harms</li><li>• Certainty of the evidence</li></ul>
	Costs, capacity, equity and other resources	<ul style="list-style-type: none"><li>• Cost-effectiveness data if available</li><li>• Costs implications to individual, health systems and organisations – including increasing capacity</li><li>• Equity issues – rural and remote, socioeconomic status.</li></ul>

# Guidelines advocate for improved health service delivery

## Culturally safe and responsive care

- Addressing institutional racism
- Removing race as a risk factor
- Improved First Nations governance
- Improved cultural safety training
- Increased involvement of family and community
- Increased recognition of social determinants of health

## Increased early detection of chronic kidney disease

- Earlier screening
- Earlier referral to nephrologists
- Increased community involvement in public awareness and education

## Increased First Nations health work force

- Increased professional support for First Nations health workforce
- Increased training in CKD treatment and management
- Increased strategic commitment and retention of First Nations health workforce

## Increasing care on Country

- Increased accommodation and transport services
- Increased community control of health services
- Improved dialysis services in rural and remote locations

# All health services evaluate and address institutional racism in their services

## Transforming institutional racism at an Australian hospital

Christopher John Bourke<sup>A D</sup>, Henrietta Marrie<sup>B</sup> and Adrian Marrie<sup>C</sup>

Key Indicators and Criteria	Scoring	Score
<b>1. Participation in organisation leadership/governance</b>		
• Legal visibility in relevant health service legislation	20	?
• Aboriginal and Torres Strait Islander representation at health service board level	10	?
• Representation at Executive Management level	10	?
<b>Total</b>	<b>40</b>	<b>?</b>
<b>2. Policy implementation</b>		
• Closing the Gap in Aboriginal and Torres Strait Islander health outcomes	10	?
• Community engagement	10	?
• Public Reporting and Accountability in annual reports	10	?
<b>Total</b>	<b>30</b>	<b>?</b>

<b>3. Service delivery</b>		
• Aboriginal and Torres Strait Islander Health Service Plan	10	?
• Cultural competence	10	?
• Selected Health Service Performance Indicators	10	?
<b>Total</b>	<b>30</b>	<b>?</b>
<b>4. Recruitment and employment</b>		
• Aboriginal and Torres Strait Islander health workforce development	10	?
• Aboriginal and Torres Strait Islander participation in health workforce	10	?
<b>Total</b>	<b>20</b>	<b>?</b>
<b>5. Financial Accountability and Reporting: Closing the Gap Funding</b>		
• Common wealth contribution	10	?
• State/Territory contribution	10	?
<b>Total</b>	<b>20</b>	<b>?</b>
<b>Score</b>	<b>140</b>	<b>?</b>

**Institutional Rating scored against criteria**

Score:	>110	80–109	60–79	40–59	20–39	<20
<b>Evidence of Inst. Racism:</b>	Very low	Low	Moderate	High	Very high	Extreme

© Henrietta Marrie and Adrian Marrie 2014



# Removing race as a risk factor for chronic kidney disease



Family history of chronic kidney disease



Diabetes



High blood pressure



Obesity



Smoking



Heart disease



Acute kidney injury



Low birthweight (<2.5 kgs)



Previous kidney infection damage



Social disadvantage



- Remoteness
- Lower socioeconomic status



- Lower education



- Insecure housing
- Other impacts of colonisation

Factors associated with CKD among First Nations Australians

# Earlier screening for CKD

## All individuals identifying as First Nations Australians

Kidney health check should be included in Aboriginal and Torres Strait Islander Peoples Health Assessments



### Under 18 Years of Age

Screen for red flags of CKD

- Family history of CKD
- Clinical history of diabetes, hypertension, obesity, cigarette smoking, established CKD & acute kidney injury
- Clinical history of low birthweight
- Clinical history recurrent childhood infections

Considerations of:

- Socioeconomic status, regional/rural and remote location, housing status, education level

**Undertake a kidney health check if concerned**

### 18 Years or over

Undertake a kidney health check, including the following tests;

- Blood tests
- eGFR
- Urine albumin: Creatinine ratio (ACR)

# Earlier referral to specialist services

**≈50% of kidney function**  
(eGFR  $\leq$  45 mL/min/1.73m<sup>2</sup>)

**Persistent protein in the urine**  
(significant albuminuria  
>30 mg/mmol)

**Referral to  
Kidney Doctor**

**Sustained rapid decrease  
in kidney function**  
(10% decrease in kidney function  
eGFR >10 mL/min/1.73m<sup>2</sup>/ year)

**High blood pressure  
that is difficult to treat**



NIKTT aims to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander peoples by:

1. Creating networks and empowering communities
2. Collecting data to examine waitlisting barriers
3. Piloting new models of care
4. Investigating how to address cultural bias





## Equity and Access Projects

1. "On Track to Transplant" Peer Navigator Project
2. Pika Wiya Health Service Renal Aboriginal Health Practitioner Project
3. Kimberley kidney transplant assessment outreach service
4. Pilbara and Goldfields kidney transplant assessment outreach service
5. Top End Health Service Aboriginal health professional project
6. Purple House Hunting Peer Navigator Project
7. Cairns Health Service Patient Mentor Project
8. Princess Alexandra Hospital Transplant Education Program

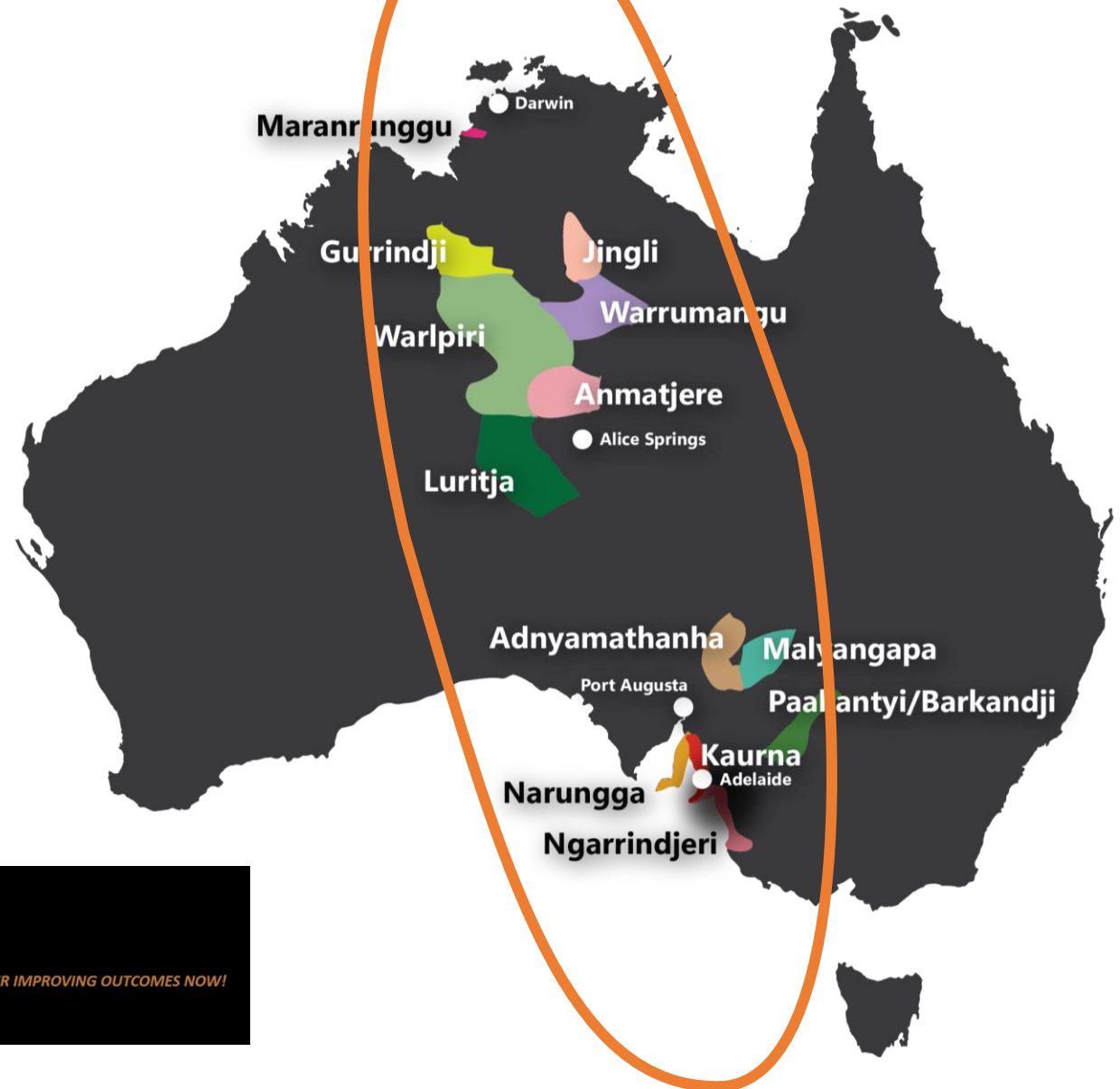




# Compass Project

A co-designed, coordinated, sustainable, and supportive Patient Navigator program

Aim to reduce the impact of Chronic Kidney Disease on Aboriginal and Torres Strait Islander people

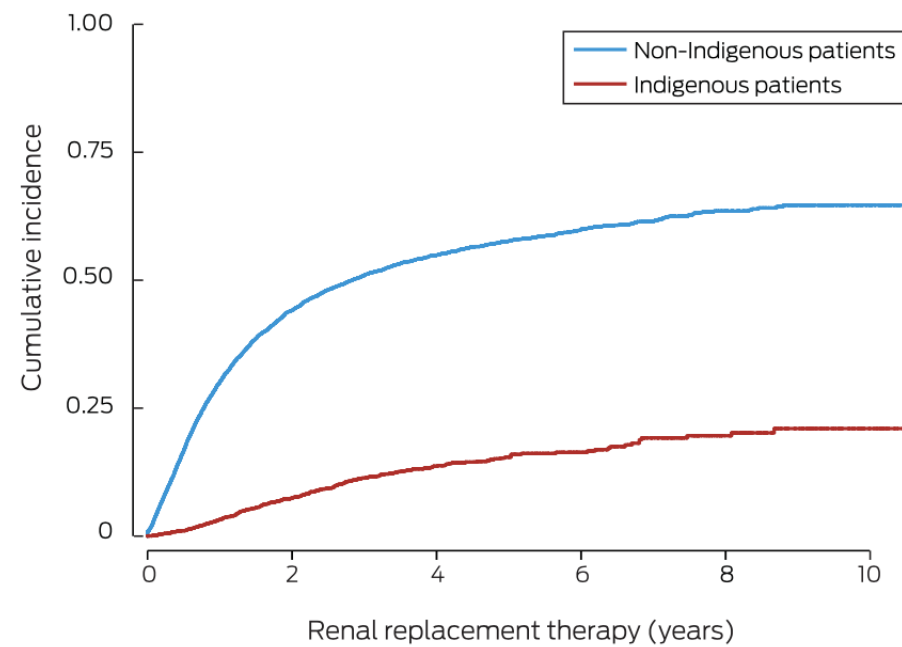




## Disparity of access to kidney transplantation by Indigenous and non-Indigenous Australians

Namrata Khanal<sup>1,2</sup>, Paul D Lawton<sup>3</sup>, Alan Cass<sup>3</sup>, Stephen P McDonald<sup>1,2,4</sup>

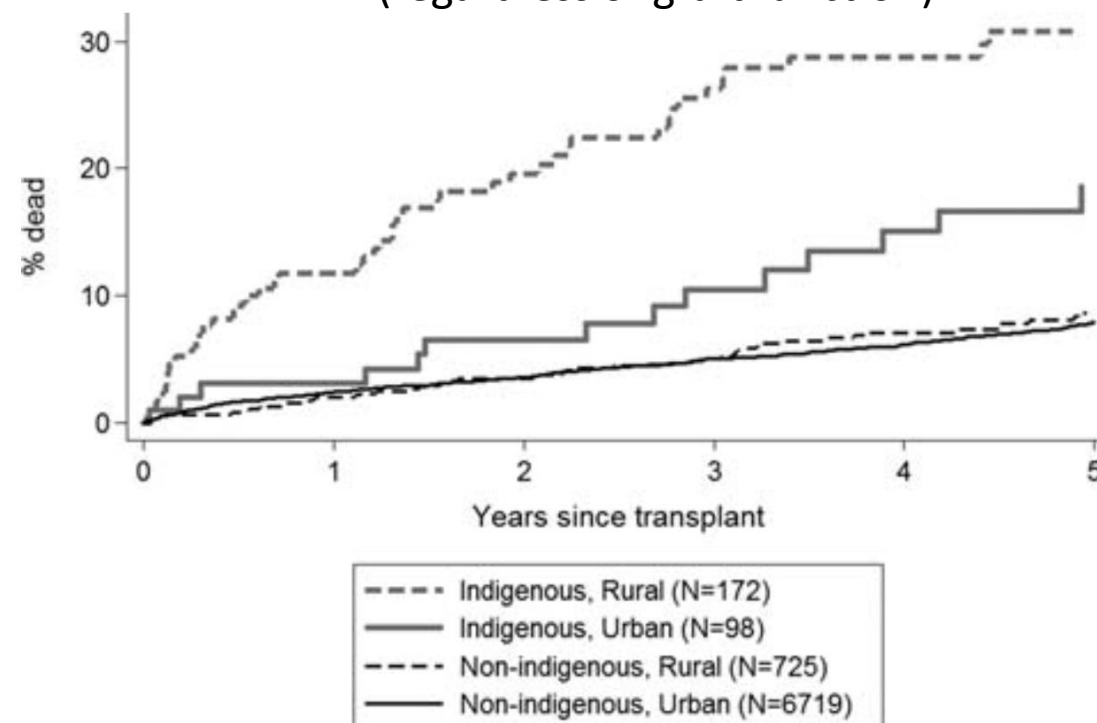
### 2 Unadjusted Kaplan–Meier curve for cumulative incidence of wait-listing after initiation of renal replacement therapy, by Indigenous status



## Residential Location and Kidney Transplant Outcomes in Indigenous Compared With Nonindigenous Australians

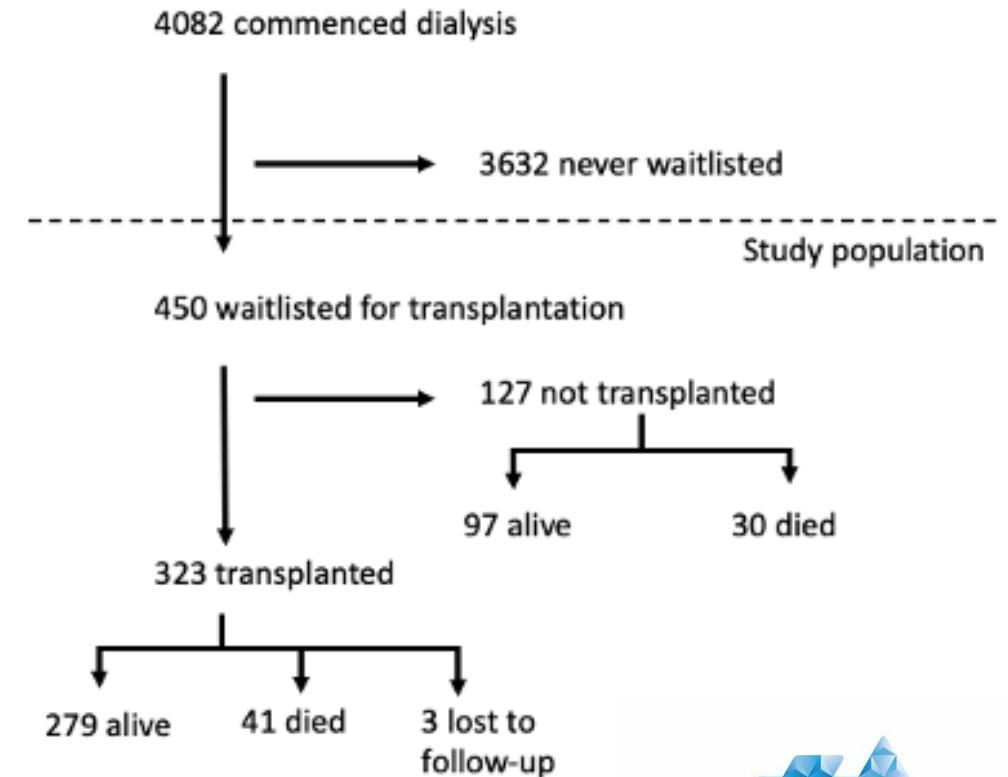
Katherine A. Barraclough, MBBS(Hons), FRACP, PhD,<sup>1</sup>  
Blair S. Grace, Postgrad Dip, PhD, Postgrad Cert Biostatistic,<sup>2,3</sup>  
Paul Lawton, MBBS, FRACP,<sup>4</sup> and Stephen P. McDonald, MBBS, FRACP, PhD<sup>2-3</sup>

### Unadjusted patient mortality (regardless of graft function)

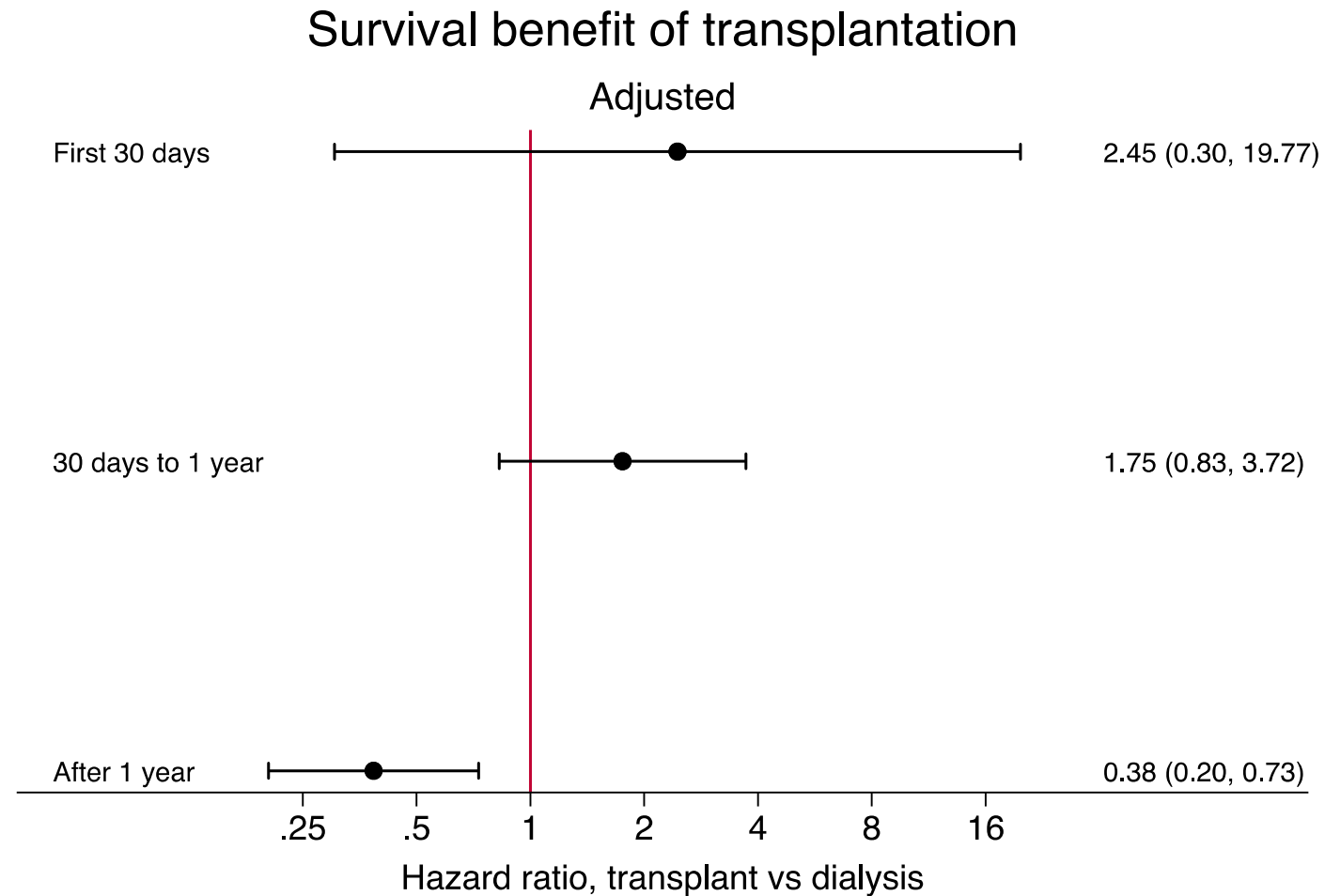


# Good data is key!

- **Aim** Establish the survival benefit of kidney transplantation over remaining on dialysis for Aboriginal and Torres Strait Islander Australians eligible for transplantation.
- **Population:** Aboriginal and Torres Strait Islander Australians commenced dialysis 1/07/06 - 31/12/20 included on the deceased donor waitlist
- **Intervention:** Kidney transplantation
- **Comparator:** Remaining on dialysis
- **Outcome:** Patient survival



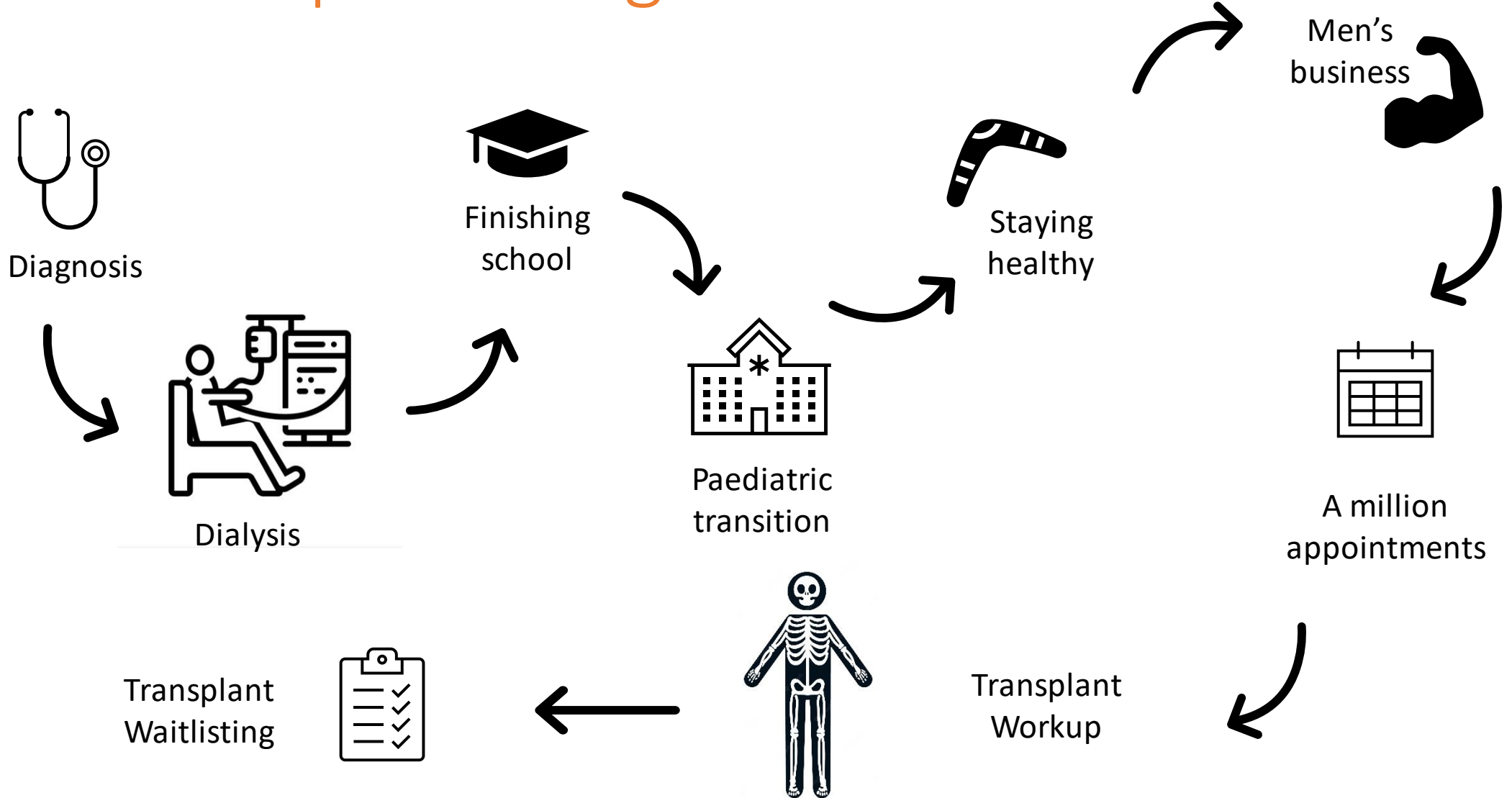
# Survival benefit of deceased donor transplantation







# Mum as a peer navigator







You gotta see it, to be it.



**6 days post  
transplant!!**

# Acknowledgements

SB is funded by NHMRC, RACP and BEAT-CKD

KO is funded by NIKTT & NHMRC

We give thanks to all those who have given the gift of life through organ donation.

CARI team for their hard work and awesome slides

