



THE UNIVERSITY  
*of* ADELAIDE

## 2021 AIATSIS Summit, Adelaide SA

Kelli Owen & Dr Kim O'Donnell  
(On behalf of the AKction Team)

AKction1 was funded by Health Translation SA  
(2019-2021-extended due to Covid)  
AKction2 is funded from a NHMRC Ideas Grant (2021-2026)

**ABORIGINAL  
KIDNEY  
CARE  
TOGETHER  
IMPROVING  
OUTCOMES  
NOW**



# Welcome to country

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Kaurna Elder Doris May Graham  
(nee Edwards 1912- 2004)

On the headstone memorial  
Grandma Doris's words of wisdom:  
**'Trust was the start of it, Joy was  
part of it, Love is the heart of it.'**



# Background



- Australian Nursing Society and Central and Northern Adelaide Renal and Transplant Service committed to:
  - Improving the health of Aboriginal people with renal disease
  - Developing a culturally-responsive health system
  - Promoting Aboriginal community health and wellbeing
- **However, no Aboriginal community consultation had occurred prior to this.**



Who am I and what authority do I have to speak here today?



# AKction 1 Aim



- To provide opportunities for Aboriginal kidney patients and family members, health professionals, health services, academics and researchers to work together to improve kidney care in South Australia.

- Identify
- Respond
- Inform
- Improve

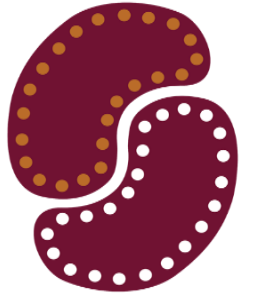




## AKtion 1 – activities

- AKtion Reference Group
- Community consultations – Kanggawodli, Pt Augusta, Ceduna
- Patient journey mapping – workshop and case studies
- Kidney yarning Get Together – collective peer support – Kanggawodli
- Workshop focused on accommodation and transport issues
- Helped inform the new model of dialysis care at Kanggawodli
- COVID – closed face book page, Art project
- Mental health training for ARG members

# Research Team



- Dr Janet Kelly, University of Adelaide
  - Ms Nari Sinclair, AKction Reference Group co-lead, Aboriginal health consumer
  - Melissa Arnold-Chamney, University of Adelaide
  - Dr Odette Pearson, Wardliparingga Aboriginal Research Unit, SAHMRI
  - Ms Tiffany Whittington, Central Adelaide Local Health Network
  - Associate Professor Shilpa Jesudason, Central Northern Renal & Transplantation Service
  - Professor Stephen McDonald, Central Northern Renal & Transplantation Service
  - Ms Tahlee Stevenson, Marie Stopes Clinic, Melbourne
  - Ms Inawintji Williamson, AKction Reference Group co-lead, Aboriginal health consumer
  - Dr Kim O'Donnell, University of Adelaide
- **This research was a collaboration between**
  - Aboriginal community members
  - Adelaide Nursing School, University of Adelaide
  - Central Northern Adelaide Renal & Transplantation Service / SA Health
  - Aboriginal Research, SAHMRI
  - The Aboriginal Chronic Disease Consortium
  - Aboriginal Community Controlled Health Services
  - Kidney Health Australia
  - Purple House, Alice Springs
  - The Transplantation Society of Australia and New Zealand & NIKTT - National Indigenous Kidney Transplantation taskforce

# Methods



- Aboriginal community consultations
- Focus groups
- Patient journey mapping
- Identification of barriers and enablers, and effective strategies for improvement
- Priority setting and knowledge translation workshops
- Education package development for staff and students



# Community Engagement

- Aboriginal Reference Groups:
  - Pre-consultation for planning
  - Post-consultation for validation
  - Ongoing communication
- Format:
  - Art session
  - Framework of questions – free discussion
  - Sub-group yarning (key themes)
  - Group sharing



# A partnership approach



An approach that often occurs in health care & research	<i>The preferred approach: working in collaboration and partnership</i>
<p><b>Top Down approach</b> Health care staff and services direct care</p> <p><b>Disconnect</b></p> <p><b>Bottom UP approach</b> Aboriginal patients, family, community feel positioned below</p> <p>A top down, bottom up, approach where cultural safety is not guaranteed and providing feedback can feel or be unsafe.</p> <p>17/09/2024</p>	<p>Patients, family &amp; community members</p> <p>Health care staff and services</p> <p>2 way conversations</p> <p>Sharing important information and personal preferences</p> <p>Willingness to listen, engage &amp; respond</p> <p><b>Equity &amp; safety</b></p> <p>Equitable and safe ways for recipients of care people and all staff to be actively involved in identifying priorities, strengths, gaps, responsibilities and responsiveness of care.</p>



# aKtion

Aboriginal kidney care together - improving outcomes now



## Community Leaders

- Local
- National

## Local Leaders

- Involved in all aspects

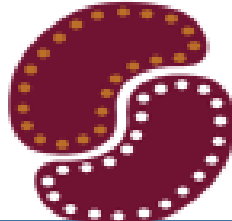




# aKction

Aboriginal kidney care together - improving outcomes now

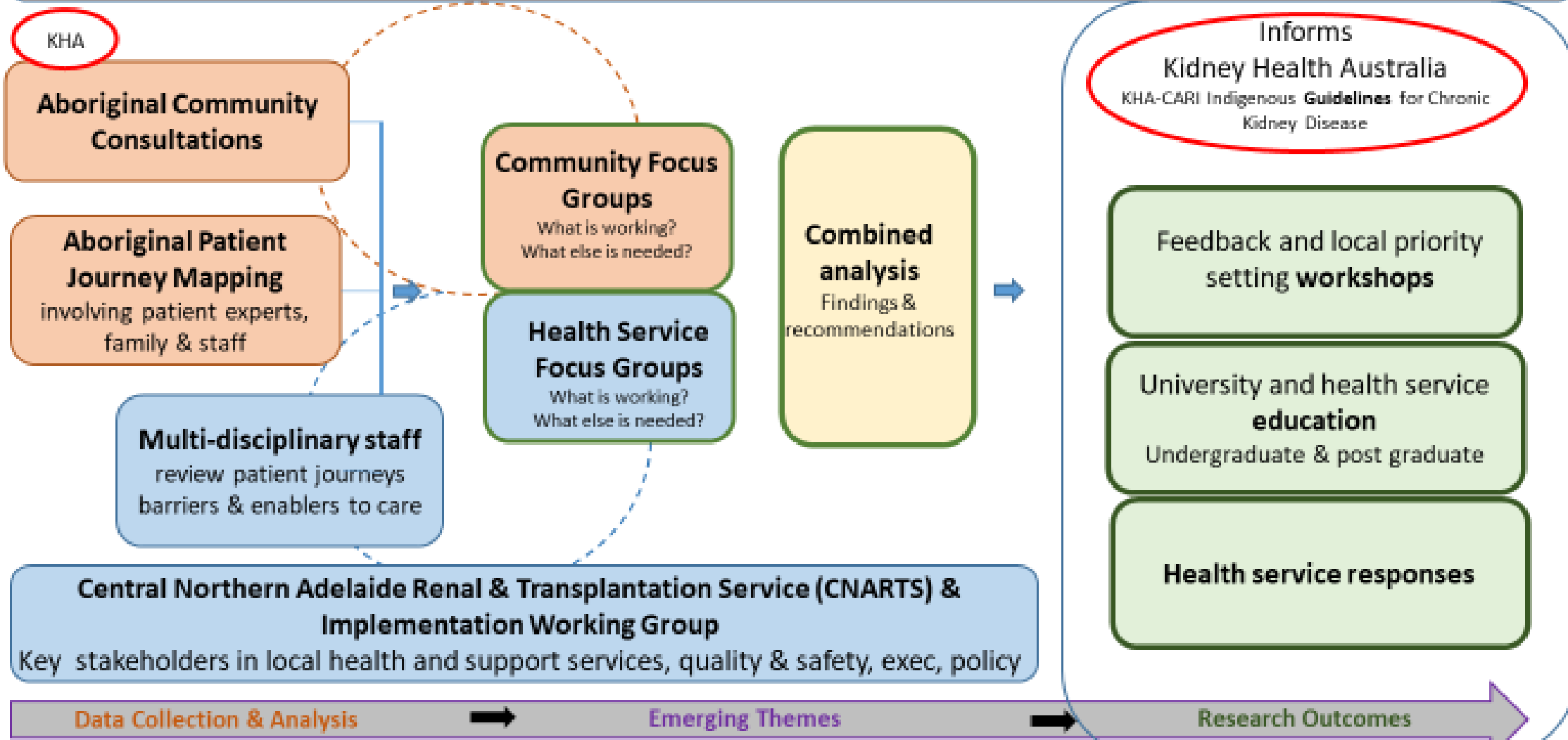
- Initially gathered for consultations for Guidelines and research
- Has grown into a “movement” of community expertise
- Shaping kidney health in SA
- Embedding this expertise in SA Renal Services
  - Dialysis management
  - New dialysis Services – Kangawoddli Hostel
  - Transplant Management
  - Patient Navigators
  - National Profile



National Indigenous Kidney Transplant Taskforce

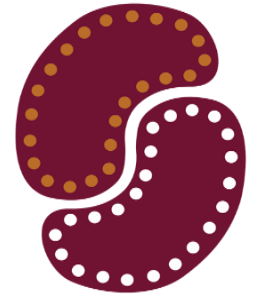
**Aboriginal Community Reference Group**  
consumers & carers

- Community
- University of Adelaide
- Renal & support services
- SAHMRI
- Aboriginal Chronic Disease Consortium
- Aboriginal Health Services
- Kidney Health Australia
- Purple House

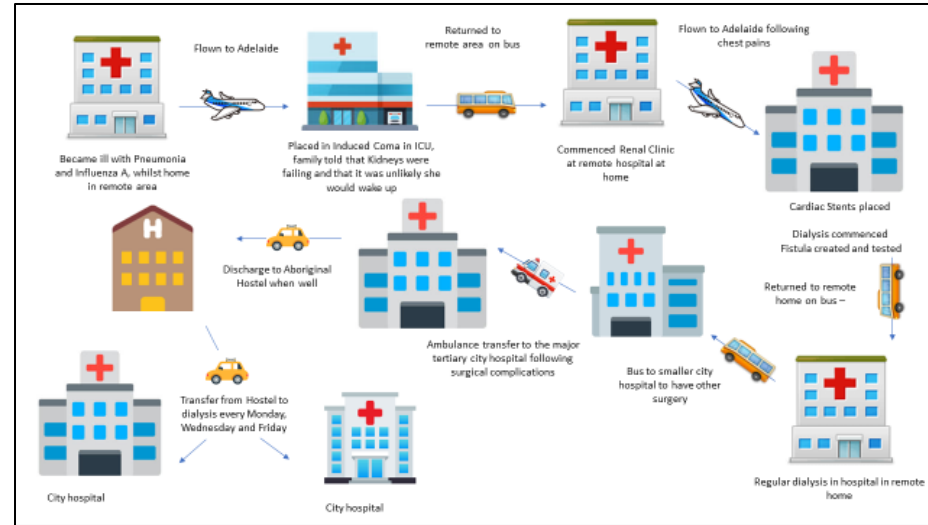


Data Collection & Analysis → Emerging Themes → Research Outcomes

# Aktion1 knowledge translation activities involving research team and ARG members



- Radio
- Artwork
- Reports
- Newspapers
- Workshops
- Conference presentations
- Aboriginal health fair stall
- Peer review papers in progress
- Interstate and international visitors
- Guest speakers for nursing students
- Resource development – Health Journey Mapping
- Community meetings at Kanggawodli – peer support
- Social media platforms – Face Book page & Instagram
- Family sharing, keeping community members updated – relational networking



# So where to now?

## AKction2

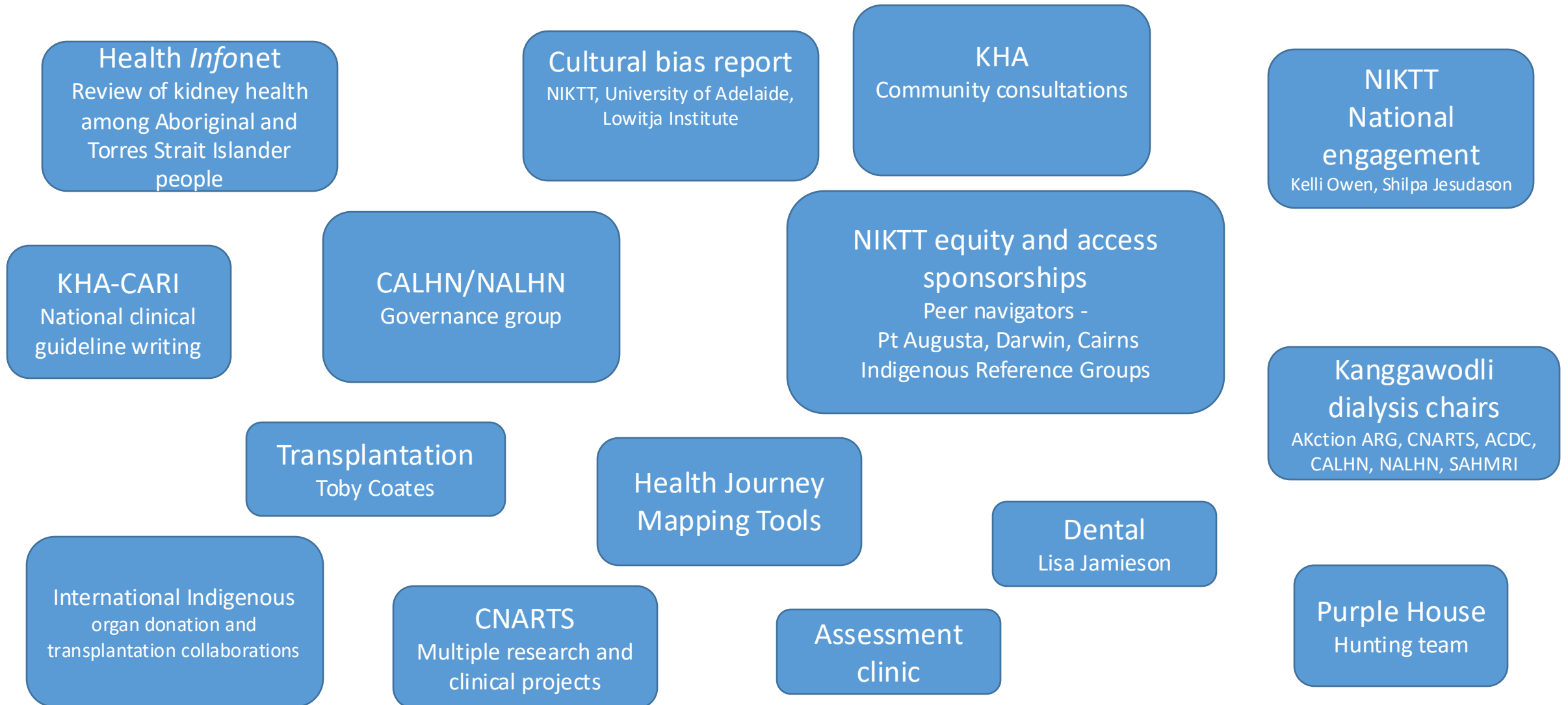
- Received a National Health Medical Research Council Ideas Grant (5 years funding 2021-2026)
  - Community members as Chief Investigators for AKction 2
- 4 years of building
  - Trust and Relationships
  - Sharing Knowledge(s)
  - Re-empowerment of community voices
  - Translation into action



**aKction**

Aboriginal kidney care together - improving outcomes now

# What else is happening in the Aboriginal kidney space in SA, nationally and internationally?







## **AKtion2: using Decolonising Methodologies to co-design improvements in Aboriginal Kidney Care**

### ***Indigenous methods***

Yarning – relaxed conversations  
Dadirri – deep listening  
Ganma - knowledge sharing

### **Combined Indigenous/Western methods**

*Working at the interface in Brave Spaces*

Co-creation, collective decision making

Participatory Action Research

*Look & Listen, Think & Discuss,*

*Take Action Together*

### ***Western methods***

Interviews, focus groups

Surveys, evaluation

Critical reflection

### ***AKtion1 processes & findings - 2019-20***

Aboriginal kidney patients,  
families and communities

Real world kidney health  
experiences & priorities.

*AKtion1* Reference Group

Community consultations

Journey Mapping Tools

### ***Four interwoven sub studies***

1 Indigenous governance

2 Kidney journey mapping

3 Patient support needs

4 Cultural safety in health care

### ***Health carers, standards & guidelines***

Renal health professionals

Health Action Framework

Cultural safety

Reducing racism

National Indigenous

renal clinical guidelines

### **Outcomes**

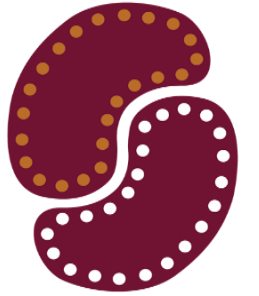
**Patients:** improved kidney health journeys, outcomes and quality of life, reduced readmissions

**Health professionals & services:** Aboriginal informed patient centred care & best practice evidence based framework, cultural safety training tools, partnerships with community, Indigenous workforce

**Systems:** improved coordination of care within and across health services, future research leaders

## AKction2

is based on the 4 main priorities determined by Aboriginal community members and the ARG



1. **Indigenous governance** *“We are more than our disease!”*
2. **Kidney journey mapping** *“No one else should have to experience this”*
3. **Support for Aboriginal kidney patients** *“We know what it is like”*
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

# Workforce



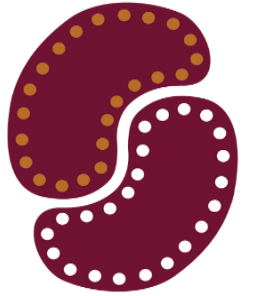
## **Sub Study 1: Indigenous governance “*We are more than our disease!*”**

### **Aim**

To identify processes and resources required to enable the establishment and sustainability of effective Indigenous governance and shared decision making in kidney health care.

### **Research activities**

Reference group, yarning, Ganma, Dadirri, interviews and focus groups, scoping review, critical reflection



# Models of care

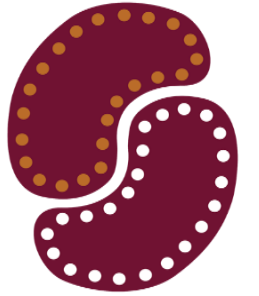
**Sub study 2: Kidney journey mapping “*No one else should have to experience this*”**

## **Aim**

To derive improvements in models of kidney care by assessing kidney patient journeys and care experiences

## **Research activities**

Mapping, photo voice, artwork, quality improvement tools, workshops, implementation



# Peer support

**Sub study 3: Support for Aboriginal kidney patients – “*We know what it is like*”**

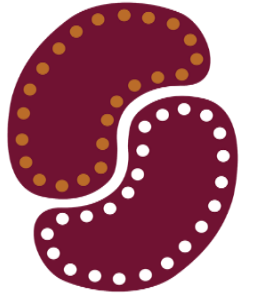
## **Aim**

To identify, pilot and evaluate a response to the support needs of Aboriginal kidney care patients and family members as they begin kidney care journeys.

## **Research activities**

Peer navigator pilot project

# Cultural safety



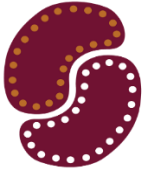
## Study 4: Cultural Safety in Kidney Care- *“Sometimes they just don’t get it”*

### **Aim**

To identify the cultural safety training needs of South Australian kidney health staff, pilot and evaluate the effectiveness of new training tools utilising Aboriginal kidney journey case studies.

### **Research activities**

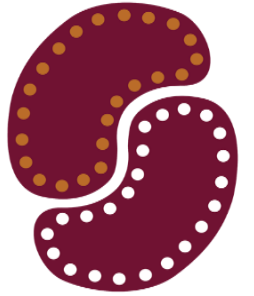
Feedback from patients and families, staff survey, co-create a cultural safety education package



# AKction2 Investigators

Chief Investigators	Associate Investigators
Kim O' Donnell Janet Kelly, Kelli Owen Rhanee Lester, Nari Sinclair Samantha Bateman Josee Lavoie	Odette Pearson Tamara Mackean Shilpa Jesudason, Stephen McDonald Su Crail Eleanor Garrard Melissa Arnold Chamney Richard Le Leu Lisa Jamieson

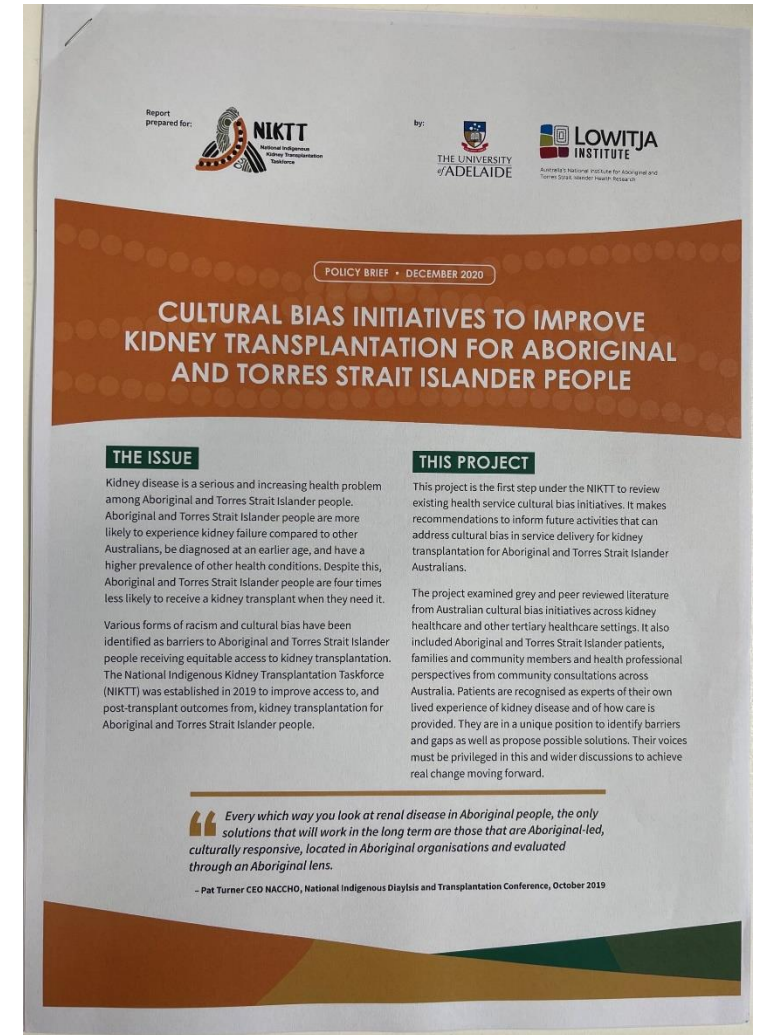
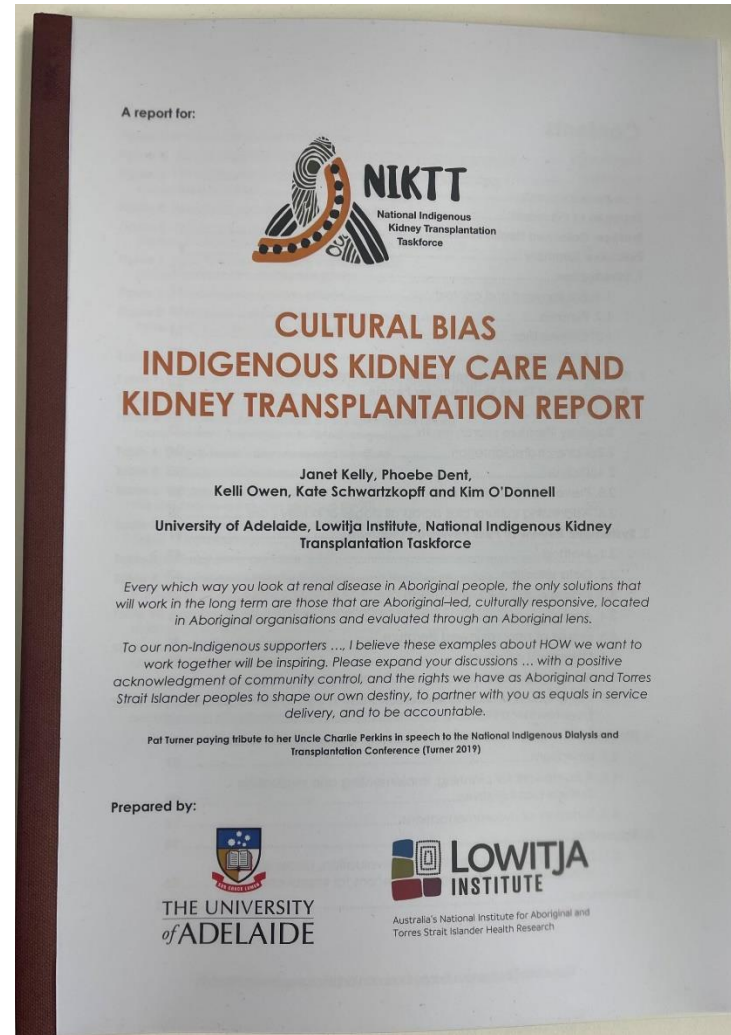
# AKction2 - 7 Teams



- **ART AKction Reference Team** (formerly AKction1 Reference Group)
  - Community members; patient experts with lived experience of kidney care and family members
- **ARC AKction Researchers/Clinicians**
  - People who are part of AKction 1 but are not listed CIs or AIs
- **ASK AKction Stakeholders**
  - Key stakeholders for kidney care and support
- **ACT AKction Connecting Team**
  - The team working to facilitate the project - CIs & AIs
- **APT Akction Project Team**
  - Project team employed at University of Adelaide to work on AKction2
- **AKction Elders**
  - An Aboriginal Elder woman and man to
- **AKction Students**
  - Post graduate and undergraduate students



Cultural Bias  
Indigenous Kidney  
Care and Kidney  
Transplantation  
Report & policy  
brief



# Questions?

