

# **Improving Aboriginal and Torres Strait Islander Kidney Care in Australia**

Sharing projects, guidelines and strategies



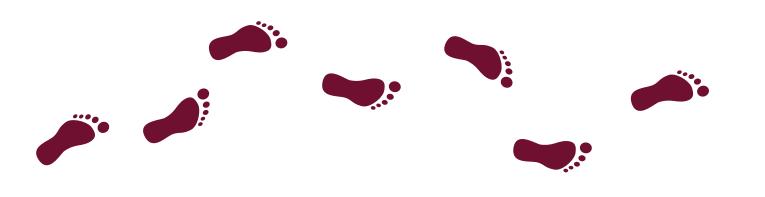
#### **AKction**

Aboriginal Kidney Care Together
– Improving Outcomes Now

# **Acknowledgment of Country**

We would like to acknowledge the traditional owners and pay respect to their spiritual and physical connections to land, seas, and waterways where cultural practices are strong and thriving today as always.

This presentation includes photos of people who have passed. They and their families have given us permission to share their images to continue their work as kidney warriors.







# Usual health care & research processes

#### **AKction**

Top Down

Health care & research

Disconnect

**Bottom Up** 

Patients, family & community

Patient experts, family & community members Co-design

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

Resources & support

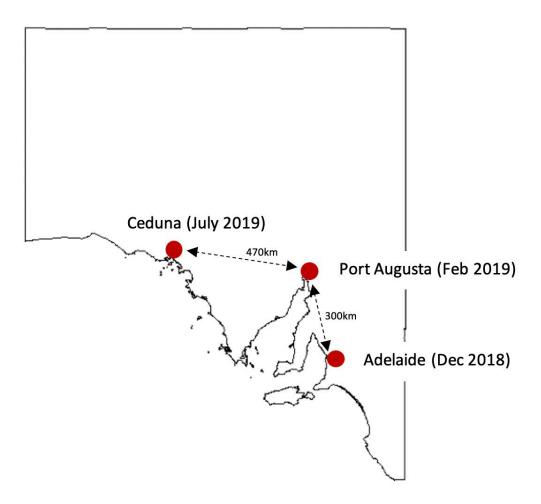
Willingness to listen, engage & respond

**Equity** 

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



# **Community Consultations**





#### TRANSCONTINENTAL PORT ALIGISTA

Home / News / Local News FEBRUARY 7 2019 - 3:52PM

#### Kidney health consultation in Port Augusta

Marco Balsamo

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

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



JUNE 14 2019 - 12:00PM

#### Ceduna hosts kidney health consultation

Luca Cetta Local News

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



# Yarning

Chris Forbes, CEO Kidney Health Australia Sue Crail, Nephrologist Location: Pika Wiya Aboriginal Health Service teaching space

Tahlee Stevenson, Registered Nurse



Roxanne Sambo, Aboriginal Health Practitioner

# Community consultations and community priorities informed:

#### Methods

- focus groups & interviews
- kidney journey mapping

Local kidney care

Regional & state-wide (provincial) kidney care

New National Clinical and Cultural Safety guidelines

# **Community consultations**



Indigenous Health | ⊕ Open Access | ⊕ ⊕ ⊜

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 ... See all authors 

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First published: 07 July 2022 | https://doi.org/10.1111/1753-6405.13280

# The importance of family and community

Being well involves more than just health care- the role of Country, family & community

Community based strength and resilience

## Prevention and early detection

Preventing disease and providing health information in ways that work for community

Earlier detection to prevent the shock of diagnosis

## Better access to quality care

- Better transfer of knowledge to help people understand and navigate care and treatment options
- Social determinants of health impede access to care
- Juggling multiple chronic health priorities
- A difficult path to transplantation

Using polices, funding and guidelines to improve care

#### Workforce

- Care delivered by our own people
- Peer support and peer navigators
- Increasing cultural training and responsiveness of kidney health professionals





Indigenous Health | ⊕ Open Access | ⊚ • ⊕ •

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

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

First published: 07 July 2022 | https://doi.org/10.1111/1753-6405.13279



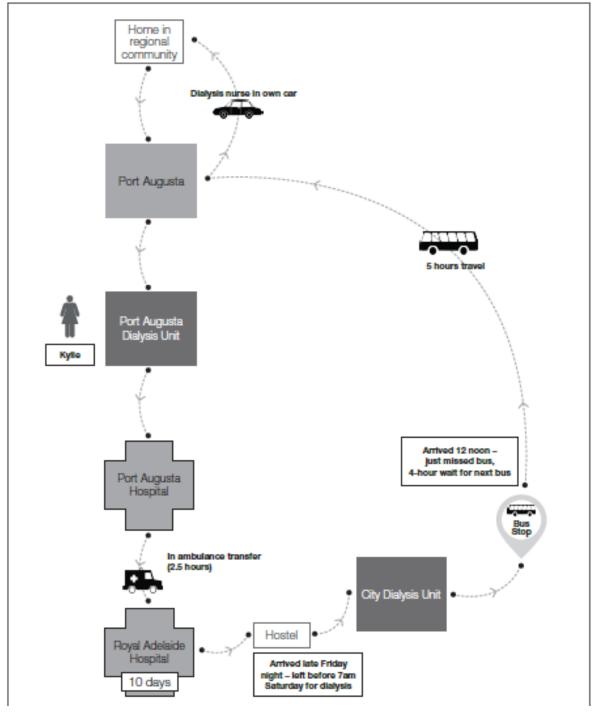


https://www.lowitja.org.au/page/research/research-categories/health-services-and-workforce/service-solutions/completed-projects/managing-two-worlds-together-state-3-aboriginal-patient-journey-mapping-tools-project



https://www.lowitja.org.au/page/services/tools/health-journey-mapping





# Recommendations for culturally safety kidney care for First nations Australians



https://kidney.org.au/get-involved/advocacy/yarning-kidneyconsultations/cari-guidelines-recommendations-for-culturally-safekidney-care-for-first-nations-australians

#### **INDIGENOUS GUIDELINES**

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





- 1
- · INSTITUTIONAL RACISM
- · CULTURAL SAFETY
- 2
- · COMMUNITY AND FAMILY INVOLVEMENT
- 3
- TRANSPORTATIONACCOMMODATION NEEDS
- ABORIGINAL AND/OR
   TORRES STRAIT ISLANDER
   HEALTH WORK FORCE
- 5
- RISK FACTORS
- SCREENING
  - REFERRAL
- 6
- PUBLIC AWARENESS
- EDUCATION
- SELF MANAGEMENT
- 7
- MODELS OF CARE
  PRE-DIALYSIS
- PRE-DIALYSIS
- KIDNEY-FAILURE,
  - TRANSPLANTATION



www.cariguidelines.org @cariguidelines

#### **Recommendations & Implementation plan**

Some are inspirational or being addressed locally

- Travel and accommodations for all patients and family members 'for all healthcare interactions'
- Community-controlled' dialysis services delivered by Indigenous clinical team members in Indigenous communities.
  - Actively looking at options in Far North and West of South Australia
  - 2 new remote dialysis services by Purple House Aboriginal community controlled health service
  - Aboriginal Health Practitioner providing dialysis and support in remote Ceduna

hospital



- 1 Reviewing where dialysis chairs are located, working toward increasing staffing in rural and remote areas Stephen McDonald
- 1 Decolonising training for CNARTS (renal) staff
- 2 Indigenous Reference Group Royal Adelaide Hospital & National Indigenous Kidney Transplantation Taskforce –NIKTT
- 2 Aboriginal people with lived experience as chief investigators, reference group members, co presenters, co authors
- 3 Kanggawodli dialysis chairs in an Aboriginal hostel
- 3 Regional review of accommodation, currently work arounds
- 4 Piloting and then embedding new workforce Aboriginal Health Practitioners, Peer Navigators, supporting Aboriginal nurses and students
- 5 Identifying opportunities to improve screening, referral, community awareness/education remote Yalata visit
- 6 New resources with Aboriginal people Kidney Health Australia
- 6 Working across teams, including pharmacists etc
- 6 Working with existing Apps to make them kidney specific
- 7 Models of care continually reviewing options
- 7 Research to improve PHC Kidney health relationships Shilpa
- 7 Earlier detection working with communities and Aboriginal health services
- 7 Transplantation work up, dental care renal collaborations





#### **Equity**

Strengths based

**Safety**Communication

Partnership
Co-design

# One example Mapping kidney journeys - dialysis

Aboriginal people from city, rural and remote locations

- Separated from family, community, culture and supports
- Experience significant accommodation and transport challenges, particularly when transferred to the city for dialysis
- Sometimes miss dialysis and appointments
- Become increasingly unsupported, lonely and unwell

# Dialysis Project – health service perspective

**CNARTS - Central and Northern Renal and Transplantation Service, Brian Farmer** 

# Key Issue

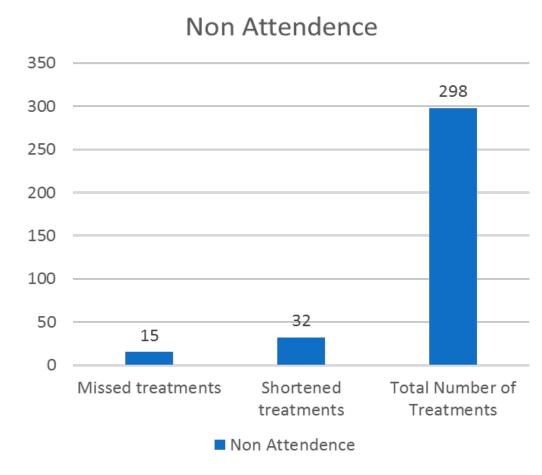
- A cohort of consumers regularly missed dialysis
- Over a 6 month period a total of 5% of available sessions were lost.
- 8% of available sessions were shortened. I.e. Full dialysis time not completed.
- Lost time equated to 1 weeks worth of dialysis per patient
- Reasons for missed or shortened dialysis were mainly cultural in nature
- https://www.abc.net.au/news/2020-11-26/sa-dialysis-trial-has-promising-results-foraboriginal-patients/12914018

## Goals

- Improved Consumer Engagement
- Provide Dialysis in a culturally safe appropriate environment
- Improve attendance to dialysis.
- Reduction in out of hours presentations due to missed dialysis

## Nonattendance to dialysis

- Non Attendance to dialysis and subsequent associated complications.
- Within the focus group (4Pts) over a six month period a total of 15 dialysis sessions were lost and 32 sessions were shortened.
- Regular nonattendance led to out of hours admissions due to complications of missed dialysis.



## Nonattendance to Dialysis and associated costs

- 14 hospital presentations in 6 months costing approximately \$23K to SAAS and RFDS
- 35 occupied bed days in same period? Cost \$105K
- 10 occupied bed days in 6 month period of trial program. ?cost \$30k
- SAAS costs \$5K
- Cost Saving of approximately \$93K

## Key Changes Implemented

- Commenced Dialysis in a culturally safe place
- 2 Chairs treating 4 patients on M/W/F
- Operating 2 dialysis shifts between 0700hrs to 1900hrs
- Located in the main dining room
- Mixed staffing model with RN's and Aboriginal Health Practitioners (AHP's)



# Key Changes Implemented

- Consumers given full access to stable accommodation including
  - Access to GPs
  - Access to AHP's
  - Diabetes Nurse Educators
  - Dieticians
  - Social Worker



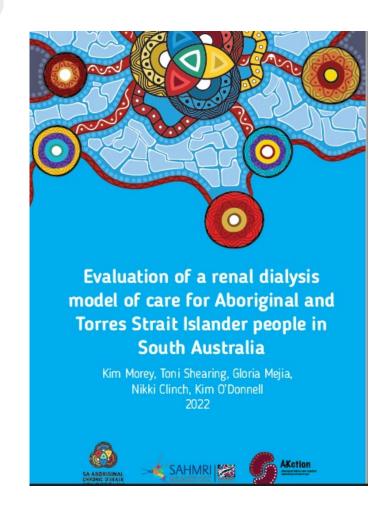
# Key Changes Implemented

- Renal Physician Clinics
- Podiatry services
- Assistance to get to and from Outpatient appointments
- Entry onto Integrated Pathways Program while resident at Kanggawodli.

Now a 3 chair unit!

## Lessons Learnt

- Consumer engagement is the Key
- 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 has shown to have a positive effect
- Finding the right partners to work with is paramount



#### Dialysis trial focusing on culture boosts health options for Indigenous patients

By Patrick Martin



## Results

# Improved patient experiences and patient-centred culturally responsive care

#### Improved:

- Safety of physical environment (distance, stairs, temperature)
- Positive social interaction with other people
- Cultural appropriateness of service
- Access to the service
- Connection with family

### Service provider experiences

#### Improved:

- Nutritional options for patients
- Access to clinical services, specialists and medications
- Access to other services
- Social and emotional wellbeing of patients
- Flexibility of dialysis treatment
- Empowerment and quality of life
- Rapport and communication between health providers and patients





Some dialysis patients have become well enough to travel home for cultural / respite dialysis.

More people have completed kidney transplantation workup, so that they can return home, permanently







https://health.adelaide.edu.au/nursing/aboriginal-kidney-care/