



# The AKtion 2 & Health Journey mapping

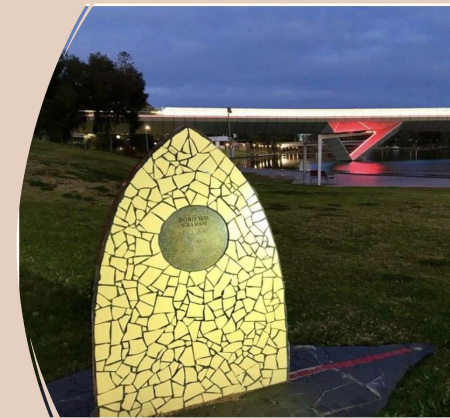
Aboriginal Kidney care together  
- improving outcomes now

Presentation: Rural Clinical School 15 July 2022  
Amy Graham & Janet Kelly



# Acknowledgment of Country

We would like to acknowledge Aboriginal and Torres Strait Islander Peoples as 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.



# About us

## Amy Graham

- Grew up in Adelaide, Kaurna, Narungga woman, Aboriginal Health Practitioner, AMIC Worker, Coordinate AKction Project.



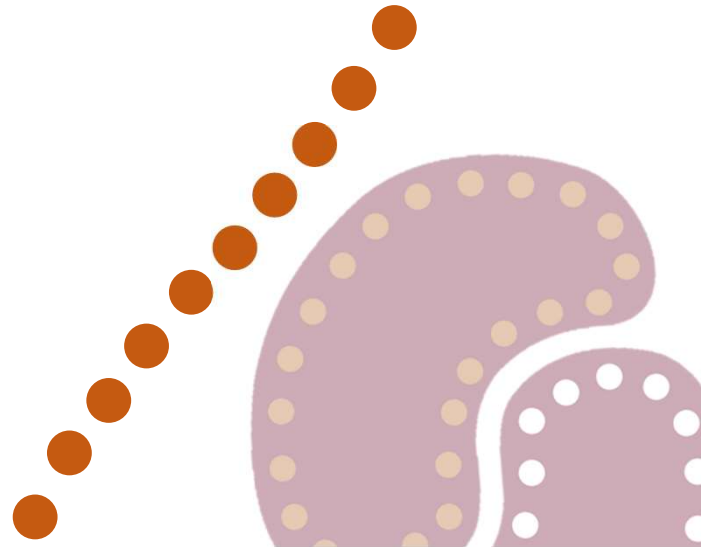
## Janet Kelly

- Grew up on Kangaroo Island, German/British ancestors, community health nurse, collaborative health research with Aboriginal people to improve health care, course coordinator.



# The AKtion2 Project

- Aboriginal Kidney Care Together-  
Improving outcomes now
- Aims to improve kidney care for and with  
First Nations Peoples in South Australia  
and beyond
- Based at the University of Adelaide  
Nursing School
- NHMRC Ideas Grant Funding



# ART- The AKction Reference Team

- Ten Aboriginal people with lived experience of CKD
- Personal, family & carer experiences
- Haemodialysis, peritoneal dialysis, transplantation
- Metropolitan, rural, regional, remote
- Guide the research project



ARG: Shared with permission of individuals and their families



# AKAction 1 extended into AKAction 2

## AKAction 1

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

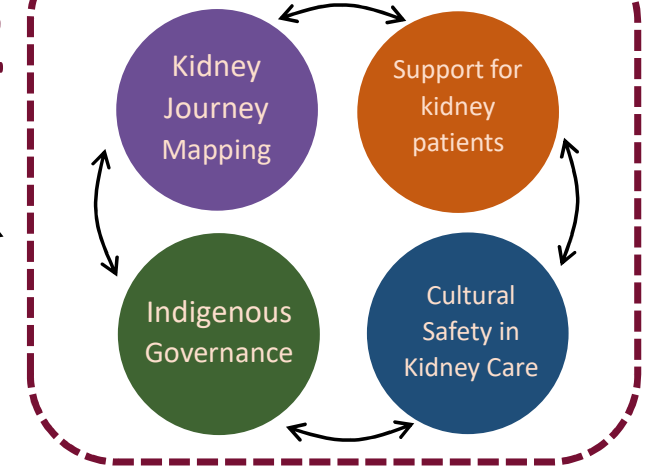


### Methods

*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

### Four sub studies



## AKAction 2 5 Year NHMRC Ideas Grant Funding

### End goals



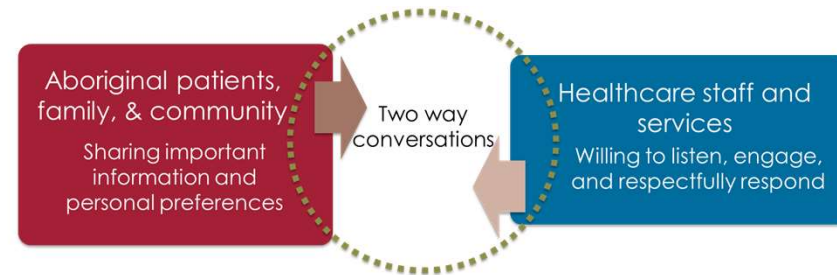
# Methodology: Decolonised PAR



- AKtion applies decolonised methods and a participatory action research (PAR) approach
- Look & listen, think & discuss, take action together
- Prioritises First Peoples knowledge, ways of being, knowing and doing
- Acknowledges people as experts of their own lives and experiences
- Flips typical colonial hierarchies on their heads e.g. community members as chief investigators

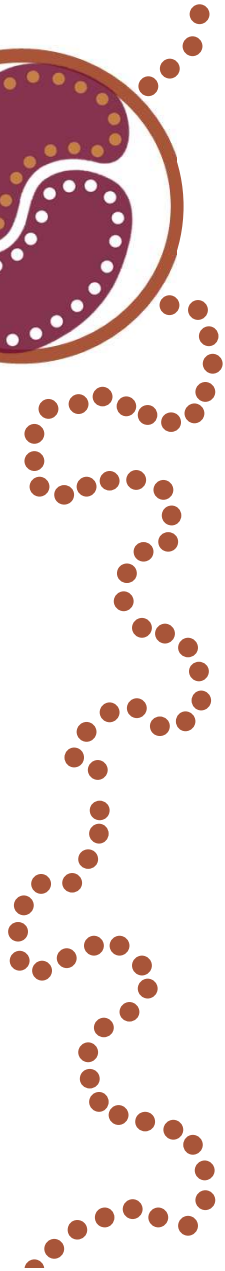
## Co creation & codesign

What should happen in healthcare & research



## Top down

What often happens in healthcare & research



# Croakey Health Media

- 3 Sponsored articles on AKtion research project
- 1 opinion piece on developing Health Journey Mapping (HJM) Resource
- Hosted Twitter account @WePublicHealth



More than a patient: cultural and clinical knowledge on a healing journey



Dreaming big: building a movement in Aboriginal kidney healthcare



Holding that space: game-changing kidney project has 'research activism at its core'

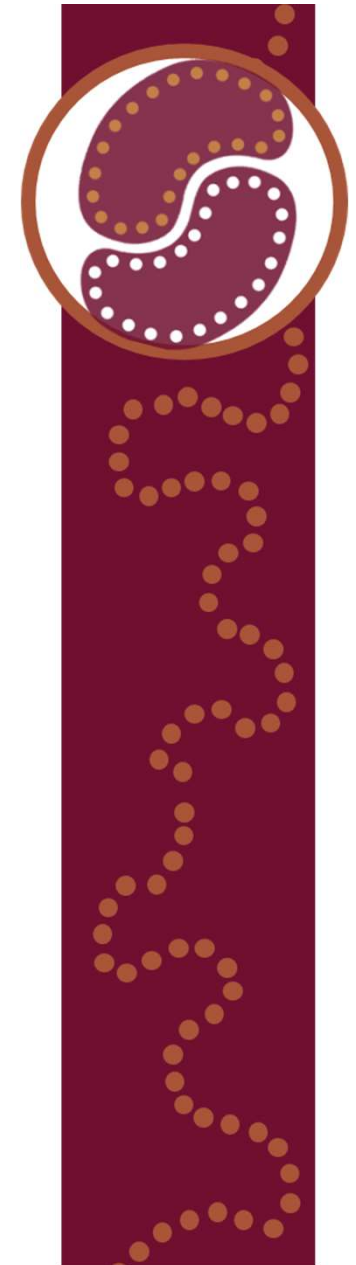


Sharing vibrant, productive and creative journeys to improve kidney care for First Peoples



Health Journey Mapping: having a yarn about health

<https://www.croakey.org/category/croakey-professional-services/kidneycaretogether/>





# Health Journey Mapping -HJM

- Funded by the Lowitja Institute
- 3 tools with different purposes, to be used in healthcare settings
- To map health journeys, identify strengths and gaps in care, plan, strategise, continuous quality and improvement (CQI), support cultural safety
- Resources follow principles safety, equity and partnership
- These are achieved through co-design, two way communication, and applying a strength based approach to mapping

## Clinical

For busy clinicians in every day clinical practice, using plan, do, study, act and review. Used to identify priorities and needs of individuals; assists in planning and enacting strategies to improve care.

## Detailed

A comprehensive care planning and evaluation tool, using look & listen, think & discuss, take action together, and review. Identifies areas to focus on; and strategies to best improve experiences and outcomes of care.

## Strategic

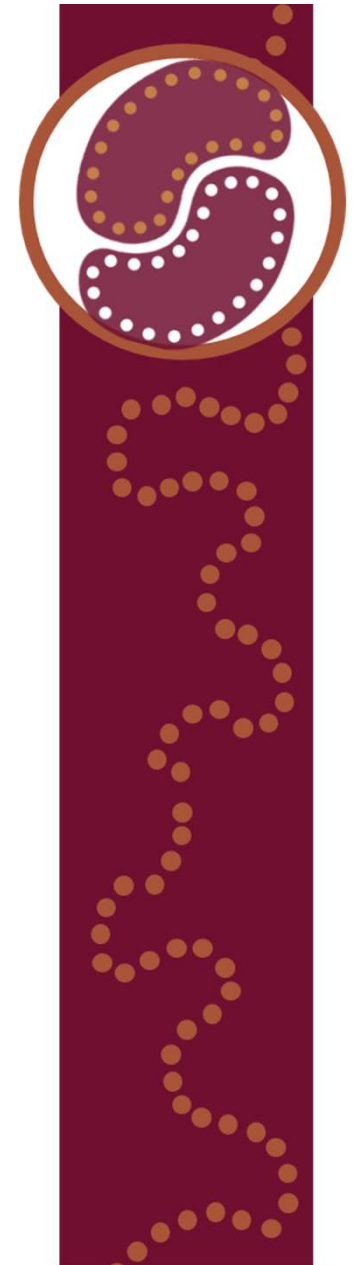
A higher level tool that brings together multiple perspectives of patient, family, and health services across different stages of a journey. It assists in the development and review of strategies that recognise both strengths and gaps in care. Findings and strategies can be considered together to address issues across journeys and to review actions made.

### HJM Tools



### HJM Principles

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



# Health Journey Mapping -HJM

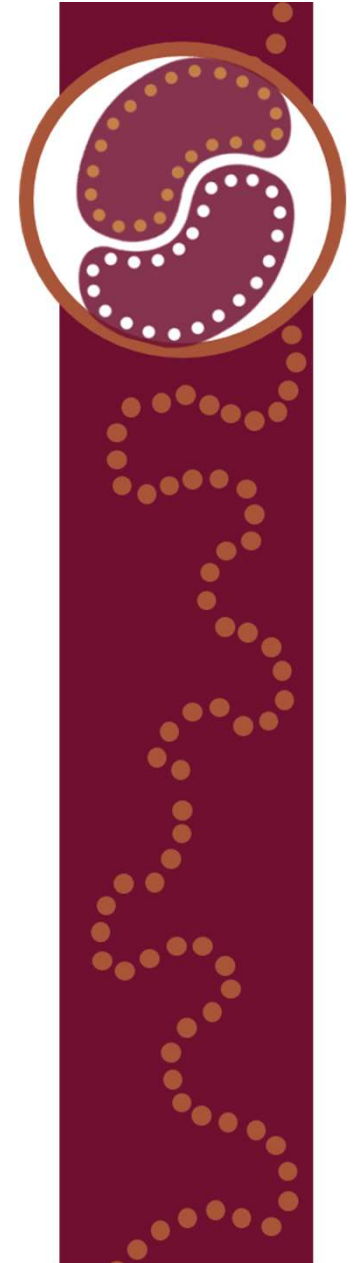
Work out which slides to use  
? Embed video

**Book side room for presentation**

**HJM Tools**

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

**HJM Principles**



# Clinical tool

Plan			
Details		How will you approach the mapping and ensure safety?	Trigger/ Reason for mapping:
Whose Journey?	Mrs Brown **	Peer navigator will spend time with Mrs Brown. Karen to follow up with NUM at RAH	Mrs Brown has an appointment and possible admission to city hospital
Who is doing the mapping/role?	Karen (NUM) and Rose (peer navigator)		
Date:	16/06/2021		
Location:	Regional Dialysis		
Do	Study	Act	Review
<b>Collect Information</b> What are the priorities and needs for this person? From whose perspective?	<b>Interpret Information</b> How can these needs be supported, and who can support them?	<b>Stop, Think, Act</b> What actions will/have been taken to support these needs, and who is making them?	<b>Evaluate, Think, Learn</b> How affective have these actions been?
Mrs Brown prefers same gendered care. Mrs Brown is a respected Elder and prefers people to call her "Mrs Brown". English is Mrs Brown's third language. Interpreters needed for consent. Mrs Brown has not been to the city hospital before and is concerned about communication and support during appointments, investigations, hospital care, when discussing treatment options and providing informed consent. If personal/cultural needs are not met, Mrs Brown may disengage or leave the hospital.	Peer navigators could meet Mrs Brown prior (face to face or via Tablet), accompany her at the city hospital, and advocate for interpreter use when required. Mrs Brown's niece lives in a suburb nearby and could accompany her to appointments, and assist with personal care. Ensure city staff are aware of her name preferences.	<p><b>Action plan: What strategies will be put in place and who will implement them?</b> Organise peer navigators to work with Mrs Brown. Book a female interpreter. Contact family when admission date is known.</p> <p><b>Actions taken: What strategies have been achieved, and by whom?</b> Female interpreter booked, and attended treatment option meeting. Niece involved in care during admission.</p>	<p><b>Did it work, and from whose perspective?</b> Putting "Mrs Brown" above the bed prompted most but not all staff to use her preferred name. Mrs Brown liked having her niece support her in the hospital. The peer navigator &amp; interpreter helped with informed consent.</p> <p><b>What else needs changing?</b> Better visual resources to help with explaining complex procedures (from Mrs Brown &amp; peer navigators)</p> <p><b>What have you learned for next time?</b> Linking patients with peer navigator via video conferencing, prior to going to the city, works well.</p>

# Detailed Mapping Tool



## Stage 1: Look & Listen

Whose Journey: Mrs Brown \*\*

Who is doing mapping: Rose, Mrs Brown, Bonnie (Mrs Brown's daughter)

Date:

What is the reason/trigger for mapping?	What is your planned approach?	How you will ensure the process is respectful, safe, collaborative & fair?	What are your focuses? (Type your answers below)
Mrs Brown has recently moved to regional dialysis, after being in the city. She is originally from a remote community. She has been missing dialysis, and has an upcoming admission to a city hospital. Mrs Brown was referred to the peer navigator to discuss her comprehensive health and wellbeing needs.	To have a yarn with Mrs Brown and her daughter over a cuppa before dialysis. [date] First language: [ ] Second language: [ ] Third language: English	Mapping with Mrs Brown and her daughter Bonnie in her first language to ensure she is active in the conversation. Meet in meeting room near dialysis, but not during dialysis (privacy) Focus on how situation can be improved to best support Mrs Brown. Consider and discuss who this information will be shared with (Karen) and how.	<ol style="list-style-type: none"> <li>1 Cultural safety</li> <li>2 Access</li> <li>3 Food security</li> <li>4 Comprehensive health &amp; wellbeing needs</li> <li>5 Financial</li> <li>6 Physical and biological</li> <li>7</li> <li>8</li> <li>9</li> </ol>

## Stage 2: Think & Discuss

## Stage 3: Take Action Together

## Stage 4: Review Effectiveness

Focus (Select a focus from the drop down menu)	Stage 2: Think & Discuss			Stage 3: Take Action Together		Stage 4: Review Effectiveness		
	Collect What is happening? Gather data from patients, staff, case notes, other sources	Interpret What does it mean? Compare to relevant standards, policies, priorities, KPIs. Data analysis and interpretation.	Summarise What are the key point or, results?	Prepare What is your action plan to inform, change and or improve the situation, while keeping people safe?	Act What action was taken individually and collectively?	Evaluate Has the situation improved and for whom?	Review What else needs to be done?	Learning What could be changed or improved next time?
Cultural safety	Respected Elder, prefers being called Mrs Brown Prefers same gender care	If Mrs Brown does not receive culturally safe care she may disengage or leave Standard 2: partnering with consumers: - creating a person-centred health system - including patients in shared decision making - ensuring patients are partners in their own care	Respectfully call her Mrs Brown Same gendered care	Write note in case notes, and include clinical map with immediate care needs to notify staff at city hospital. Have notifications of Mrs Brown's preferences	Notification has been put in Mrs Brown's notes regarding her preferences and her preferred name was written above her bed while she was in the city hospital	Most staff members at the hospital referred to her as "Mrs Brown" as prompted by the name written above her bed When available Mrs Brown had same gendered care, but this was not always an option with specialists	Staff (niece) need to be reminded of Mrs Brown's preferences and respect her wishes. Family to be notified of specific appointments so that they can also attend	Feedback on whether staff are following notifications or not
Access	Currently relying on family to drive her to appointments, Uses a wheelie walker	Mrs Brown has been missing dialysis appointments when family are unable to drive her, limited regional transport, limited mobility Communicating for safety: - systems and strategies	Limited access to transport, and decreased mobility	Plan Mrs Brown's appointments when family are available to drive her Organise dialysis bus pick up and drop off Taxi vouchers for late dialysis finish	Mrs Brown's family have organised to arrange family members to help assist driving her to appointments	Mrs Brown is now attending all dialysis sessions Check which family member to contact when appointment times change	Add family member contact details when booking appointments Monitor situation to ensure family can maintain driving Mrs Brown to appointments	Check with all patients who are missing dialysis & appointments whether they are having transport and/or communication issues

# Strategic Mapping Tool



## Look & Listen: Planning & Details

Where Journey: Mrs Brown

What is your planned approach?	How you will ensure the process is respectful, safe, well-known for the patient?	What are the stages of your journey? (Type your answers below)	What is the date?	Who is doing the mapping?	What is the location?
To have a quiz with Mrs Brown and her daughter Danni over a quiz. Working will be in Mrs Brown's first language.	Mapping with Mrs Brown and her daughter Danni using oral, written and visual mapping to reduce language communication and address Mrs Brown's strengths and what she has achieved in prior care.	1. Living in remote community 2. Initial treatment or diagnosis 3. Fistula and start dialysis in city hospital 4. Move to regional town and dialysis unit 5. Transfer to city hospital for heart check up 6. Heart tests at city hospital 7. Return to regional town and dialysis unit 8. Follow up	Jan-21 Sep-20 Nov-20 Feb-21 Jan-21 Jan-21 Jul-21	remote community remote community, RCCHS City Hospital Regional dialysis unit Regional dialysis unit/city hospital City hospital Regional dialysis unit Regional dialysis unit	

What are the stages of your journey? (Type your answers below)	What is the date?	Who is doing the mapping?	What is the location?
1. Living in remote community	Jun-20		remote community
2. Initial treatment or diagnosis	Sep-20		remote community
3. Fistula and start dialysis in city hospital	Nov-20		City Hospital
4. Move to regional town and dialysis unit	Feb-21		Regional dialysis unit
5. Transfer to city hospital for heart check up	Jun-21		Regional dialysis unit/city hospital
6. Heart tests at city hospital	Jun-21		City hospital
7. Return to regional town and dialysis unit	Jun-21		Regional dialysis unit
8. Follow up	Jul-21		Regional dialysis unit

Think and Discuss: What is happening?		Think & Discuss: What can be improved?				Act: What will we do next?		Review: What have we learned?							
Health care journey What happened for the patient/family at this stage of the journey?	Family & carer's journey What happened for family members at this stage of the journey?	Life experiences What was happening outside of health care interactions? (e.g. access, family, community, culture, ability, employment, financial, wellbeing)	Patient/family/carer's experiences		Health care provider's experiences	Together	System plan	System issues	Enablers How the situation improved for whom?	Impeders What else needs to be done?					
What is working?	What is not working?	What can be improved and how?	What is working?	What is not working?	What can be improved and how?	What is the gap?	What are we going to do to fill the gap?	Who will do it and how?	What has been done, and by whom?	What are the next steps?					
Living in remote community in her home town. Developed fistula, decreased mobility, started using a walker in town.	Living together in a remote community. Caring for community and Country together.	Rheumatoid Arthritis living in remote community.	Working together with Mrs Brown's health and wellbeing needs are being met by local RCCHS.	Could walk on her hand to walk in wet hills.	Family helped with transport.	Client was pick up by Aboriginal Health Professionals/ RN looking after diabetes.	Change over of RN, many agency nurses.	Longer ambulance.	Longer term health professionals.	RHP take greater role in diabetes education and management.	Client's appointment to diabetes manager.	Client's appointment to diabetes manager.	RHP's role to more involved in care planning and providing medication and supplies.	Clearer care plan.	Each patient has a plan, as well as their own medicines and supplies.
Mrs Brown became more unwell. Went to local RCCHS, was visiting kidney doctor (nephrologist) and was diagnosed with kidney disease. Referred to city for more tests. Kidney biopsy confirmed kidney failure.	Family very concerned. Her daughter Danni travelled to the city with her, with 2 of her children. Danni is an Aboriginal Education Officer at the remote community school.	Danni searching for somewhere to stay in the city. Mrs Brown, Danni, and children stayed with another family member for a while.	Health care in city - was not kidney doctor. Danni was with Mrs Brown at all appointments.	Home medication support. Could not be helped with children. Confused about kidney care and options. Not enough time to make a decision with family.	Many accommodation options. Include other family members in discussions - wider link. Many discussions to explain what is happening.	Rapid assessment and diagnosis of kidney disease. Booking interpreter for appointments.	City members, patient transport. Her phone or video link for interpreters. Include peer navigators in care early.	Transfer appointment to enable access to health care. Clear communication and understanding about new diagnosis of kidney disease. Opportunity to discuss in first language.	Consider options available. Book appointments as soon as in general multiple trips to hospital's. Include peer navigators earlier, particularly for people from remote areas.	Dialysis assessment clinic. Peer navigators. Rural specialist who is working alongside peer navigators.	Individualised care plan included transport considerations. Peer navigators included earlier. Improved linking with peer navigators and interpreters (where available). Mrs Brown was able to talk through her options.	Increased transport assistance. Increased appointment times. Improved linking with peer navigators and interpreters (where available). Mrs Brown was able to talk through her options.	Greater uptake of services by staff at all RCCHS facilities.	Greater uptake of services by staff at all RCCHS facilities.	
Mrs Brown has a fistula made, ready to start dialysis when it is healed/matured. However, she became more unwell and started dialysis via another person (CVC) line in her chest.	Danni supported Mrs Brown and assisted with emergency interpretation and conversations with staff.	Two young children used to stay with another family member, as there were no other hospital visits. Mrs Brown and Danni used to be Aboriginal health worker there was staff and transport support.	Peer navigators spent time with Mrs Brown and Danni talking about the fistula and CVC line. Danni was able to attend most appointments with Mrs Brown.	Mrs Brown felt she was not always treated with respect, did not receive same grade of care, did not always understand what hospital staff were saying.	Inclusion of family in all appointments and discussions.	Fistula made and working well.	Rapid dialysis in health. Required CVC line.	Peer navigators to help information or feel better about what is going on at city hospital.	Did not always receive enough information or feel better about what is going on at city hospital.	When Mrs Brown has her next admission to city hospital, healthcare worker include culturally safe information, her needs and priorities.	Will include official map in healthcare notes, flag Mrs Brown's needs.	Official map was handed over to staff at the city hospital.	Official map was handed over to staff at the city hospital.	Official map was handed over to staff at the city hospital.	
Mrs Brown has started dialysis in a regional dialysis unit. However, she has missed a number of dialysis sessions over the past few weeks.	Mrs Brown is living with extended family. Danni and Mrs Brown returned home to their remote community for a funeral.	Mrs Brown is now living attending dialysis at the regional dialysis unit, which requires her to leave town for remote community.	Danni is working a transfer in the local regional hospital as well as her own stay with Mrs Brown and another working.	Correct accommodation. Planning appointments as extended family are unable to drive her to all appointments.	Seeking other housing options. Danni is making up for a year. Help organising transport and from dialysis and appointments as Danni is unable to drive her to all appointments.	Mrs Brown received help transfer from carer and peer navigators. Linked with support services for housing and transport assistance.	Mrs Brown has missed dialysis and risks becoming very unwell.	Detailed & holistic care planning to better support Mrs Brown in attending dialysis regularly.	Housing. Transport. Queuing considerations. Support to attend dialysis in work.	Other transport needed for Saturday dialysis.	Peer navigators to book pick up with RCCHS. However, to ensure last numbers. Transport for Saturday. Other transport needed for Saturday dialysis.	RCCHS dialysis has been booked for Mrs Brown. Transport for Saturday pick up.	Mrs Brown has been able to attend all dialysis sessions with increased transport support.	Mrs Brown has been able to attend all dialysis sessions with increased transport support.	Link Mrs Brown with services that may assist her in attending dialysis sessions.
Mrs Brown has an upcoming admission to a city hospital for emergency cardiac tests.	Mrs Brown's family is unable to travel to the city and help her with her admission.	Danni has just started her own job, and it is difficult for her and her children to find somewhere to stay in the city.	Getting support from peer navigators and some at regional dialysis unit. Danni supporting Mrs Brown at all appointments.	Danni is unable to travel to the city to be with Mrs Brown.	Mrs Brown's sister Terri is staying in the city, and there are other family members and support Mrs Brown.	Planned admission for cardiac investigations.	Mrs Brown needs family support, but Danni is unable to travel to the city for this admission.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Communication and support.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.
In hospital for emergency cardiac tests. Mrs Dialysis in an inpatient at city hospital.	Terri supported Mrs Brown in the city hospital.	Terri was able to provide stable and Mrs Brown's needs.	Mrs Brown had family and communication support while in the city hospital.	Terri had an old phone she was able to bring in.	Mrs Brown had family and communication support.	Had all staff know how to use the phone. Mrs Brown had family and communication support.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.
Mrs Brown was discharged and returned to regional dialysis unit.	Terri was supporting Mrs Brown in the city hospital.	Terri had an old phone she was able to bring in.	Terri was able to help Mrs Brown get on the bus before going to her room.	It was very difficult for Mrs Brown to get up the steps of the bus.	Different transport options private car or maybe smaller bus.	City hospital rang regional dialysis unit to coordinate discharge and dialysis care and transport booked.	Delay in discharge unless referring to regional dialysis service.	Electronic transfer of discharge notes.	Transfer of discharge information, updated medication.	Consider other transport options for the discharge and transfer of care home.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.	Emergency staff help to ensure Mrs Brown is safe and included her in conversations when Mrs Brown requires this.
Mrs Brown was living with diabetes, kidney disease and dialysis and heart conditions, and adjusting to living in...	Danni has ongoing work in the regional school.	Mrs Brown has more available accommodation. Danni and her two children are living with her, she supporting her.	Danni is able to help Mrs Brown with medications, food, cooking and daily...	The house has two front steps which are difficult for Mrs Brown to get up.	Need a ramp. Speak to health staff or dialysis.	Improved accommodation. Diagnosis and treatment of chronic conditions.	The house has two front steps which are difficult for Mrs Brown to get up.	Stairlift with housing support or process of getting a ramp for Mrs Brown.	Suitable access to home - falls prevention. Specialist dietary advice, patient...	Follow up on actions. Timing of dialysis appointments. Support Mrs Brown and Danni's...	Follow up on request for housing. Support Mrs Brown and Danni's...	Housing has been installed a suitable ramp. Dialysis was Mrs Brown and...	Mrs Brown was in suitable housing with support from family. Mrs Brown and Danni have been about Mrs Brown's...	Check if there are any services Mrs Brown can access with...	

# HealthInfoNet Review of Kidney Health

- A comprehensive review of key information on kidney health among Aboriginal and Torres Strait Islander people in Australia
- There are many improvements that can be implemented to ensure effective treatment and care are provided for Aboriginal and Torres Strait Islander Australians such as:
  - Providing holistic care that addresses social and cultural wellbeing needs
  - Ensuring programs are led by, or work in collaboration, with Aboriginal and Torres Strait Islander families, communities, health professionals and services.

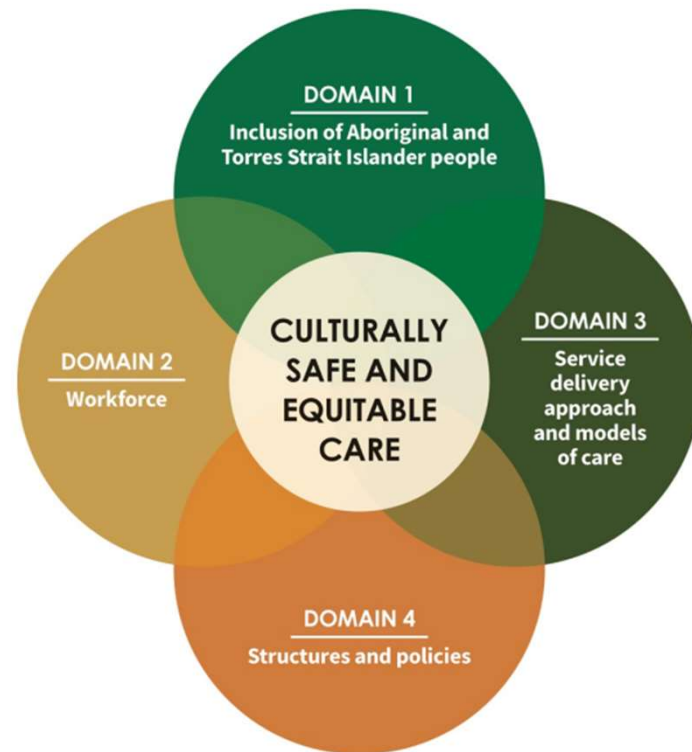
[https://healthinonet.ecu.edu.au/healthinonet/getContent.php?linkid=651687&title=Review+of+kidney+health+among+Aboriginal+and+Torres+Strait+Islander+people&contentid=41278\\_1](https://healthinonet.ecu.edu.au/healthinonet/getContent.php?linkid=651687&title=Review+of+kidney+health+among+Aboriginal+and+Torres+Strait+Islander+people&contentid=41278_1)



# Cultural Bias Report



- Developed with the Lowitja Institute for NIKTT (National Indigenous Kidney Transplantation Taskforce)
- Identifies 14 recommendations for improving kidney care & services for First Nations Peoples
- Policy document now informing Transplantation Units & kidney care



<https://www.lowitja.org.au/page/services/resources/health-services-and-workforce/cultural-safety/cultural-biasindigenous-kidney-care-and-kidney-transplantation-report>

# Community Consultations- KHA Cari Guidelines

- To respond to disparities in CKD outcomes for First peoples
- AKction helped conduct community consultations to develop KHA Cari Guidelines
- Aim is to improve cultural safety, responsive care, detection, management and outcomes
- Guidelines currently being reviewed by community for sign off

## 4 C's

- Community voice
- Cultural considerations
- Clinical evidence
- Costs - individual & health system





# Nukuta!

*See you later in Kaurna - we never use the word goodbye because we believe we will always see each other again either on earth or in the Dreamtime*