The AKction 2 Research Project

Aboriginal Kidney care together - improving outcomes now

Presentation: RFDS 15 July 2022

A Prof Janet Kelly & Amy Graham

Acknowledgment to 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

Janet Kelly

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

Amy Graham

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

What is the AKction2 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

AKction 1 extended into AKction 2

AKction 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

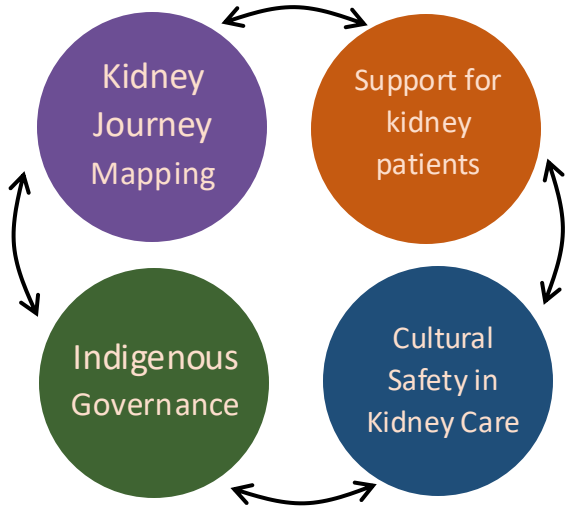
AKction Reference Team

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



AKction 2

5 Year NHMRC Ideas Grant Funding

End goals

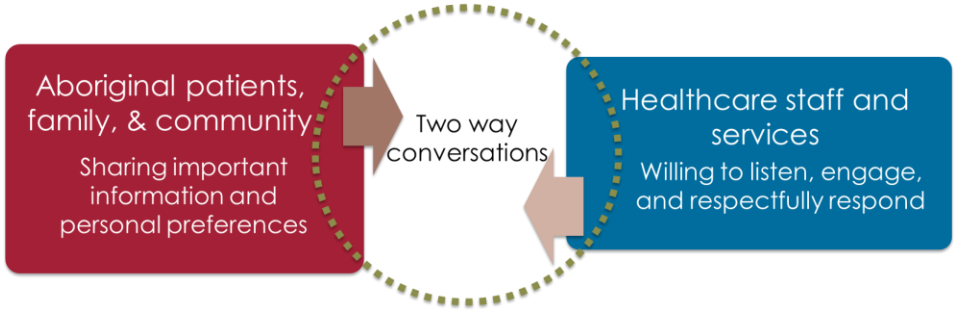
Patients & families	Better kidney care, dialysis, transplantation, access, education, prevention
Health professionals	Cultural safety, training, effective partnership, Indigenous workforce
Health services & systems	Improved coordination Guidelines & standards informed by community Reducing racism

Methodology: Decolonised PAR

- AKction 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

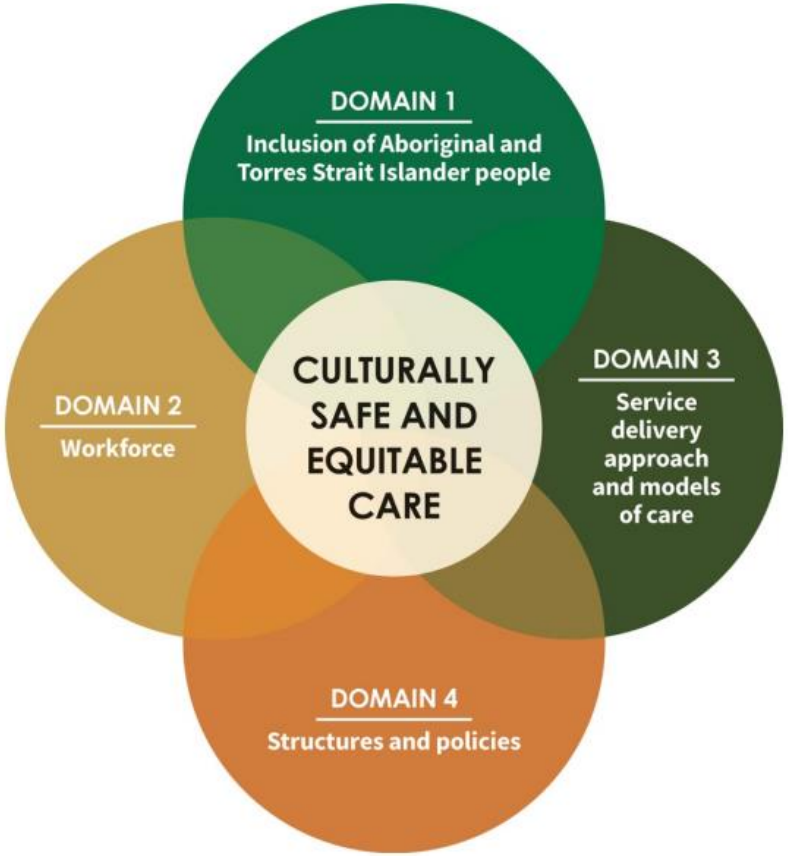
Health*Info*net Review of Kidney Health

- 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://healthinfonet.ecu.edu.au/healthinfonet/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

Croakey Health Media

- 3 Sponsored articles on AKction 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

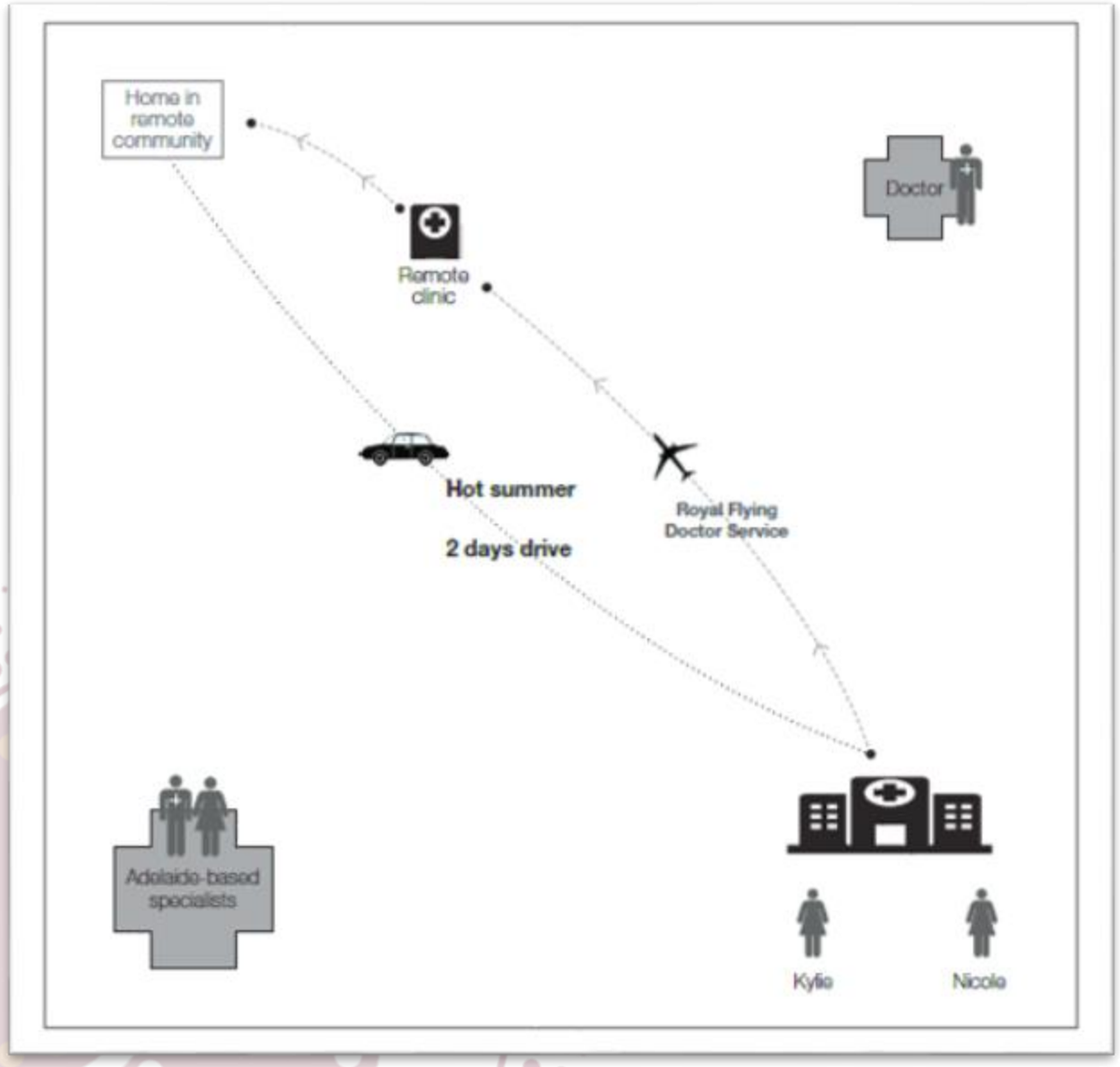
- Funded by the Lowitja Institute
- 3 tools with different purposes, to be used in healthcare settings
- To map health journeys, identify strengths and gaps in care, plan, strategise, continuous quality and improvement (CQI), support cultural safety
- Resources follow principles safety, equity and partnership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

HJM Tools

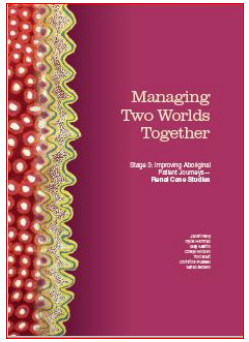
HJM Principles

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

Managing Two Worlds Together



RFDS role in supporting the deteriorating patient from Port Augusta:
Aboriginal people at the end of kidney care returning to family and country (MTWT 2015)



RFDS – current challenges - ramping

Journeys into hospital for acute illness and injury used to be smooth and lead to rapid admission
Now, due to ramping, there are significant delays.
This is impacting patients, families, RFDS, health services.

Could mapping

- identify different perspectives, gaps & responsive strategies
  - eg rural hospitals preparing patients for lengthy delays rather than rapid admission
- strengthen RFDS messaging about the impacts

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
Collect Information What are the priorities and needs for this person? From whose perspective?	**Interpret Information** How can these needs be supported, and who can support them?	**Stop, Think, Act** What actions will/have been taken to support these needs, and who is making them?	**Evaluate, Think, Learn** 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.	**Action plan: What strategies will be put in place and who will implement them?** Organise peer navigators to work with Mrs Brown. Book a female interpreter. Contact family when admission date is known.	**Did it work, and from whose perspective?** 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 & interpreter helped with informed consent.
		Actions taken: What strategies have been achieved, and by whom? Female interpreter booked, and attended treatment option meeting. Niece involved in care during admission.	**What else needs changing?** Better visual resources to help with explaining complex procedures (from Mrs Brown & peer navigators)
			What have you learned for next time? Linking patients with peer navigator via video conferencing, prior to going to the city, works well.

LOWITJA INSTITUTE
Australia's National Institute for Aboriginal and Torres Strait Islander Health Research

Detailed Mapping Tool

Kiki Designs

Stage 1: Look & Listen

Whose Journey: Mrs Brown **

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

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 orignially 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 informaiton will be shared with (Karen) and how.	1 Cultural safety 2 Access 3 Food security 4 Comphrensive health & wellbeing needs 5 Financial 6 Physical and biological 7 8 9

	Stage 2: Think & Disucss			Stage 3 : Take Action Together		Stage 4: Review Effectiveness		
Focus (Select a focus from the drop down menu)	**Collect** What is happening? Gather data from patients, staff, case notes, other sources	**Interpret** What does it mean? Compare to relevant standards, policies, prorities, 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 refered to her as "Mrs Brown" as promted 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 resepect 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 asssist 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

Whose Journey: Mrs Brown''

What is your planned approach?	How you will ensure the process is respectful, safe, collaborative & fair?	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 yarn with Mrs Brown and her daughter Bessie over a cuppa. Yarning will be in Mrs Brown's first language	Mapping with Mrs Brown and her daughter Bessie using oral, written and visual mapping to enhance two-way communication and analysis Mapping will focus on Mrs Brown's strengths and what she has surrounding to receive care	1 Living in remote community	Jun-20		remote community
		2 Initital treatment or diagnosis	Sep-20		remote community, ACCHS
		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
		9			
		10			
		11			
		12			
		13			
		14			

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

Think and Discuss: What is happening?

Health care journey What happened for the patient/client at this stage of the journey?	Family & carer's journey What happened for family members at this stage of the journey?	Life principles What was happening outside of healthcare interactions? e.g. personal, family, community, cultural, study, employment, financial, wellbeing
Living in remote community in her homelands. Developed diabetes, decreased mobility, started using a walker in town	Living together in a remote community Caring for community and Country together	Aboriginal Elder living in remote community
Mrs Brown became more unwell. Went to local ACCHS, was visiting kidney doctor [peripheral] and was diagnosed with kidney disease. Referred to city for more tests. Kidneys biopsy confirmed kidney failure.	Family very concerned. Her daughter Bessie travelled to the city with her, with 2 of her children. Bessie is an Aboriginal Education Officer at the remote community school	Bessie working for some time in city in the city. Mrs. Brown, Bessie, and children stayed with another family member for a while
Mrs Brown has a fistula made, ready to start dialysis when it is healed/matured. However, she became more unwell and started dialysis via central venous [CVC] line in her chest	Bessie supported Mrs Brown and assisted with recording interpretation and communication with staff.	Two young children went to stay with another family member, as there were no many hospital visits. Mrs Brown and Bessie went to the Aboriginal hostel where there was staff and transport support
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. Bessie 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 move away from her remote community. Mrs Brown and Bessie are staying with family, but the house is very crowded Mrs Brown is having difficulties accessing Centrelink and money
Mrs Brown has an upcoming admission in a city hospital for replacement cardiac leads	Mrs Brown's family is unable to travel to the city and help her with her admission.	Bessie has just started her new job, and it is difficult for her and her children to find somewhere to stay in the city
In hospital for replacement cardiac leads Has dialysis as an inpatient at city hospital	Terri supported Mrs Brown in the city hospital	Terri was able to juggle study timetable and Mrs Brown's needs
Mrs Brown was discharged and returned to regional remote six bus	Terri rang Bessie to check she would meet the bus	Terri had an exam and was unable to travel on the bus with Mrs Brown
Mrs Brown was living with diabetes, kidney disease and dialysis and heart condition, and is adjusting to living in	Bessie has ongoing work in the regional school.	Mrs Brown has more suitable accommodation. Bessie and her two children are living with her also supporting her.

Think & Discuss: What can be improved?

Patient/client/family/carer perspective			Health carer/ service perspective			Together
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?
Trusting connection between sisters Mrs Brown's health and wellbeing needs are being met by local ACCHS	Casual walk on far Hard to walk in sand hills	Family helped with transport	Clinic can pick up Aboriginal Health Professionals/ RN training about diabetes	Change over of RN, many agency nurses	Longer consults	Longer term health professionals
Health care in city - can see kidney doctor Bessie was with Mrs Brown at all appointments.	Accommodation support. Cost of stay in hostel with children. Confused about kidney care and options. Not enough time to make a decision with family	More accommodation options. Include other family members in discussions - video link. More diagrams to explain what is happening.	Rapid assessment and diagnosis of kidney disease	Transport assistance is offered appointments. Booking interpreters for appointments.	Cab vouchers, patient transport Use phone or video link for interpreters Include peer navigators in carer early	Transport assistance to enable access to health care Clear communication and understanding about new diagnosis of kidney disease Opportunity to discuss in First Language
Mrs Brown has a fistula made, ready to start dialysis when it is healed/matured However, she became more unwell and started dialysis via central venous [CVC] line in her chest	Bessie supported Mrs Brown and assisted with recording interpretation and communication with staff.	Two young children went to stay with another family member, as there were no many hospital visits. Mrs Brown and Bessie went to the Aboriginal hostel where there was staff and transport support	Peer navigator spent time with Mrs Brown and Bessie talking about the fistula and CVC line. Bessie was able to attend most appointments with Mrs Brown	Mrs Brown felt she was not always treated with respect, did not receive same gendered care, did not always understand what hospital staff are saying	Inclusion of family in all appointments and discussions	Fistula made and matured well	Rapid dialysis in health. Required CVC line.	Possible earlier fistula to prevent having to use CVC line access.
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. Bessie 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 move away from her remote community. Mrs Brown and Bessie are staying with family, but the house is very crowded Mrs Brown is having difficulties accessing Centrelink and money	Bessie is working a transfer to the local regional school so that she was stay with Mrs Brown and continue working	Carers' accommodation Missing appointments as extended family are unable to drive her to all appointments	Seeking other housing options Bessie is moving up for a car. Help organising transport to and from dialysis and appointments as Bessie's	Mrs Brown received help from nurses and peer navigator 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 to attend dialysis regularly	Housing Transport Ongoing coordination Support to attend dialysis 3 x week
Mrs Brown has an upcoming admission in a city hospital for replacement cardiac leads	Mrs Brown's family is unable to travel to the city and help her with her admission.	Bessie has just started her new job, and it is difficult for her and her children to find somewhere to stay in the city	Getting support from peer navigator and nurses at regional dialysis unit Bessie supporting Mrs Brown at health care	Bessie is unable to travel to city to be with Mrs Brown	Mrs Brown's niece Terri is studying in the city, and lives near the hospital and could attend some appointments and support Mrs Brown	Planned admission for cardiac investigations	Mrs Brown needs family support, but Bessie unable to travel to the city for this admission	Ensure city staff know to contact Terri and include her in conversations when Mrs Brown requests this.	Communication and support
In hospital for replacement cardiac leads Has dialysis as an inpatient at city hospital	Terri supported Mrs Brown in the city hospital	Terri was able to juggle study timetable and Mrs Brown's needs	Mrs Brown had family and communication support while in the city hospital	Mrs Brown's mobile phone stopped working [fell off the bed and broke]	Terri had an old phone she was able to bring in	Mrs Brown had family and communication support	Had all staff know how to call if they can book phone interpreter Face to face interpreter asked for also were signals to help explain	Better resources to help interpreters explain procedures	Effective communication and informed consent
Mrs Brown was discharged and returned to regional remote six bus	Terri rang Bessie to check she would meet the bus	Terri had an exam and was unable to travel on the bus with Mrs Brown	Terri was able to help Mrs Brown get on the bus before going to her exam	It was very difficult for Mrs Brown to get up the steps of the big bus	Different transport options - private car or maybe smaller bus	City hospital rang regional dialysis unit to coordinate discharge and dialysis care Dialysis sessions and transport booked	Delay in discharge when returning to regional dialysis service	Electronic transfer of discharge notes	Transfer of discharge information, updated medication list
Mrs Brown was living with diabetes, kidney disease and dialysis and heart condition, and is adjusting to living in	Bessie has ongoing work in the regional school.	Mrs Brown has more suitable accommodation. Bessie and her two children are living with her also supporting her.	Bessie 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 dietician	Improved accommodation Diagnosis and treatment of chronic conditions	The house has two front steps which are difficult for Mrs Brown to get up.	Liaise with housing to speed up process of getting a ramp for Mrs	Suitable access to home - falls prevention Specific dietary advice, patient

Act: What will we do next?

Action plan		Action taken
What are we going to do to fill the gap?	Who will do it and how?	What has been done, and by when?
AHP take greater role in diabetes education and management	Elder's group met to discuss and talked to clinic manager	Clinic considering how local AHP's can be more involved in comprehensive care
Consider options available (book appointments on same day to prevent multiple trips to hospital) Include peer navigators earlier, particularly for people from remote areas.	Dialysis unit assessment clinic nurse Peer navigator Renal educator who is working alongside peer navigators	Individualised care plan included transport considerations Peer navigators included earlier
When Mrs Brown has her next admission to a city hospital, handover will include culturally safety information, her needs and priorities	Will include clinical map in handover notes, flag Mrs Brown's needs	Clinical map was handed over to staff at the city hospital
Complete detailed mapping tool to identify problems Arrange ACCHS pick up for dialysis on workdays Other transport needed for Saturday dialysis	Peer navigator to book pick up with ACCHS Nurse to answer taxi numbers for Saturdays	ACCHS dialysis bus has been booked for Tues, Thurs pick up. Carried address for pick up. Taxi number for Sat pick up
Ensure city staff know which family member to contact. Pre book interpreter for informed consent discussion. Phone interpreter for other	Nurse to include in transfer notes	Nurse included clinical mapping tool in transfer notes
Clear interpreter policy and process Source patient education resources with clear diagrams	CM - as ward	CM investigated options

Review: What have

Evaluate How the situation improved? For whom?	Improve What else needs to be
AHP's now more involved in care planning and providing continuity of care Clearer care plans	Each patient has a plan, so that their needs are continued regardless of
Increased transport assistance from missed appointments Improved linking with peer navigators and interpreters [when available] Mrs Brown was able to talk through her options	Review transport options for remote patients Improved access to interpreters - better and wider options in
On ground visit to city hospital and staff supported Mrs Brown and she felt more energised	Greater uptake of
Mrs Brown has been able to attend all dialysis sessions with increased transport support	Link Mrs Brown with services that may
Terri was included in key discussions about informed consent	Review current
Clear that Mrs Brown has been able to attend dialysis sessions with increased transport support Can continue specialist appointments via video link Mrs Brown has been able to receive care closer to her home	Check when her next specialist appointment is Can continue specialist appointments via video link Can continue to receive care closer to her home
Ensure that any questions Mrs Brown and Bessie have about Mrs Brown's complex care needs are answered	

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