The AKction 2 & Health Journey mapping

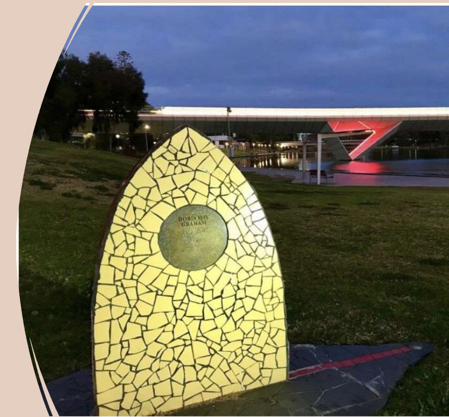
Aboriginal Kidney care together - improving outcomes now

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

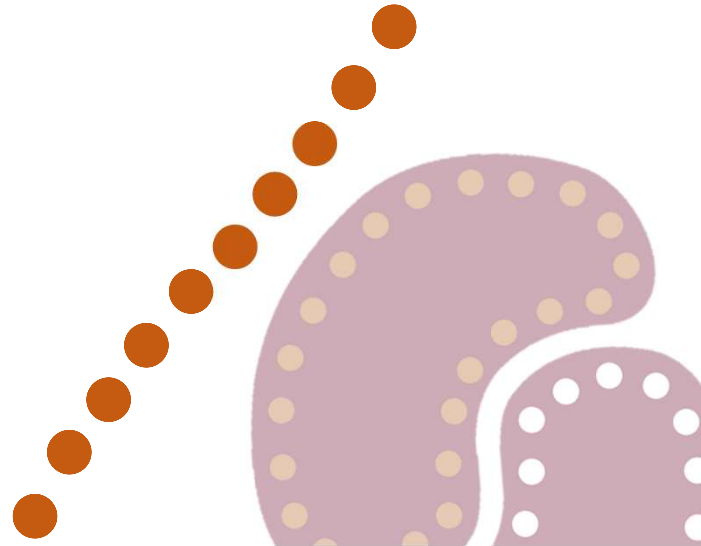
- Grew up in Adelaide, Kaurna, Narungga woman, Aboriginal Health Practitioner, AMIC Worker, Coordinate AKction Project.

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 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*

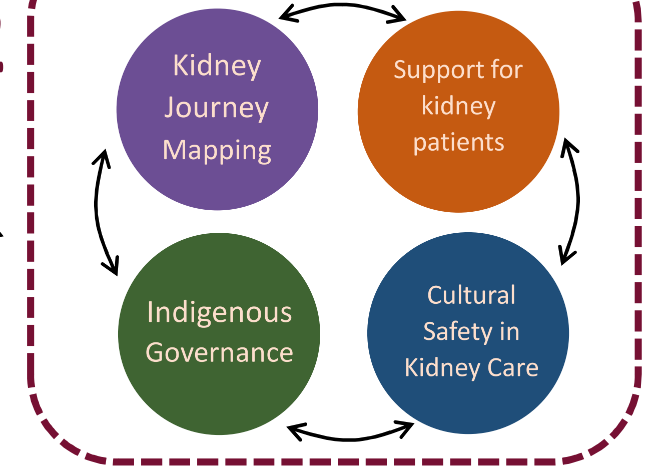
Building relationships & trust

• Aboriginal patients & families • Kidney health professionals • Researchers • Health services, systems, managers, & decision makers

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



AKction 2

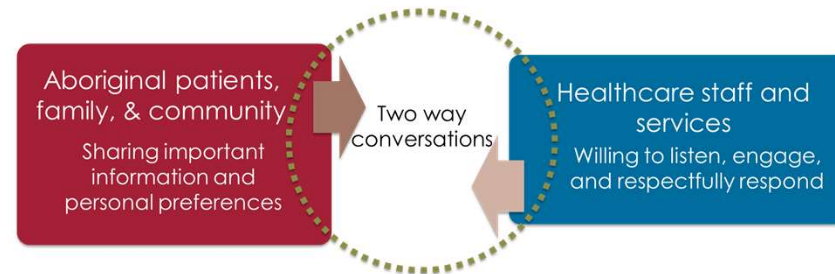
5 Year
NHMRC Ideas Grant Funding

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

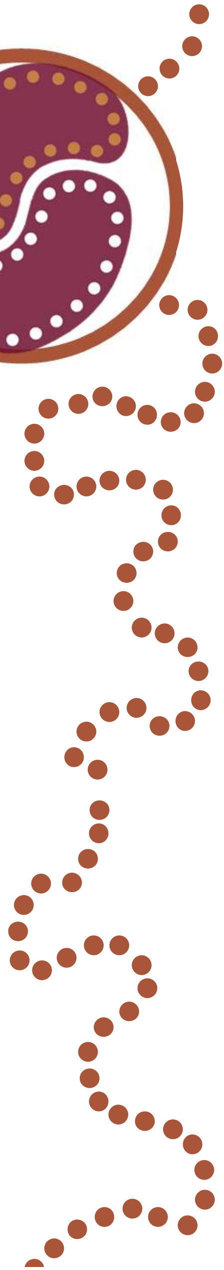
Co creation & codesign

What should happen in healthcare & research



Top down

What often happens in healthcare & research



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

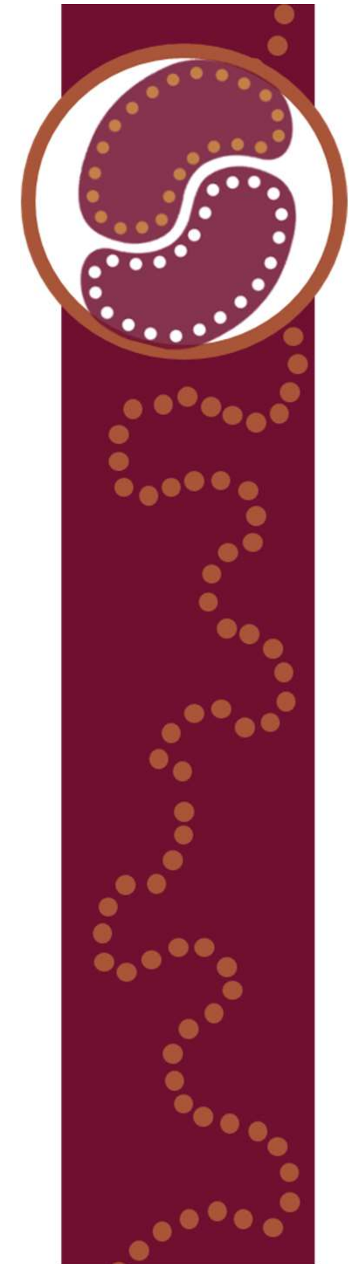
Dreaming big: building a movement in Aboriginal kidney healthcare

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

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.

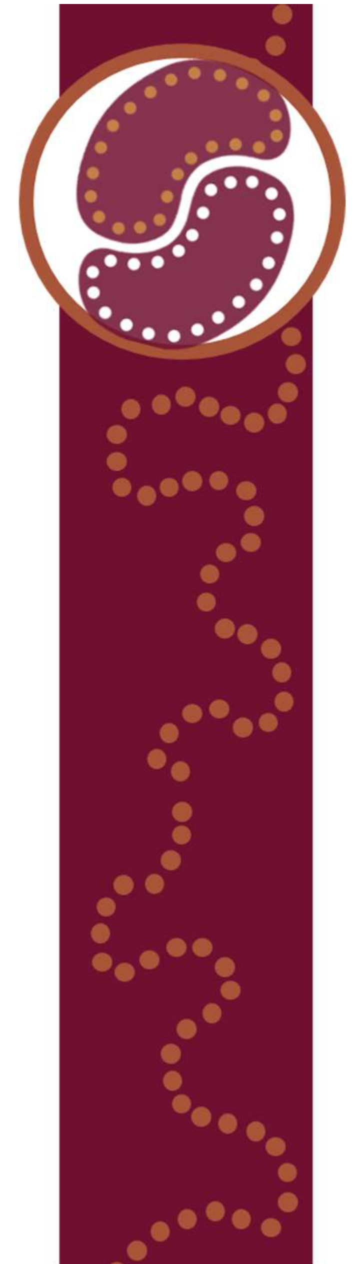
Detailed
A comprehensive care planning and evaluation tool, using look & listen, think & discuss, take action together, and review. Identifies areas to focus on; and strategies to best improve experiences and outcomes of care.

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

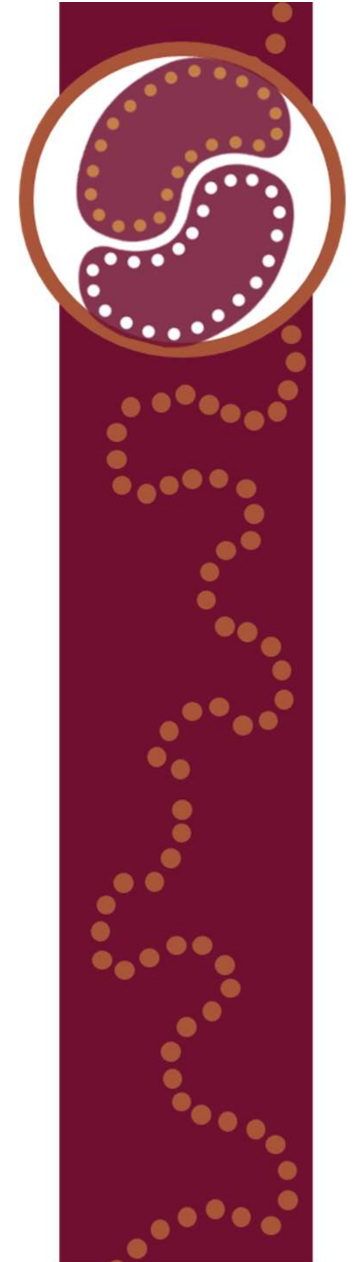
Work out which slides to use
? Embed video

Book side room for presentation

HJM Tools

HJM Principles

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



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. **Actions taken: What strategies have been achieved, and by whom?** Female interpreter booked, and attended treatment option meeting. Niece involved in care during admission.	**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. **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

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

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Strategic Mapping Tool

Look & Listen: Planning & Details

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 Hospita
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?

Think & Discuss: What can be improved?

Act: What will we do next?

Review: What have

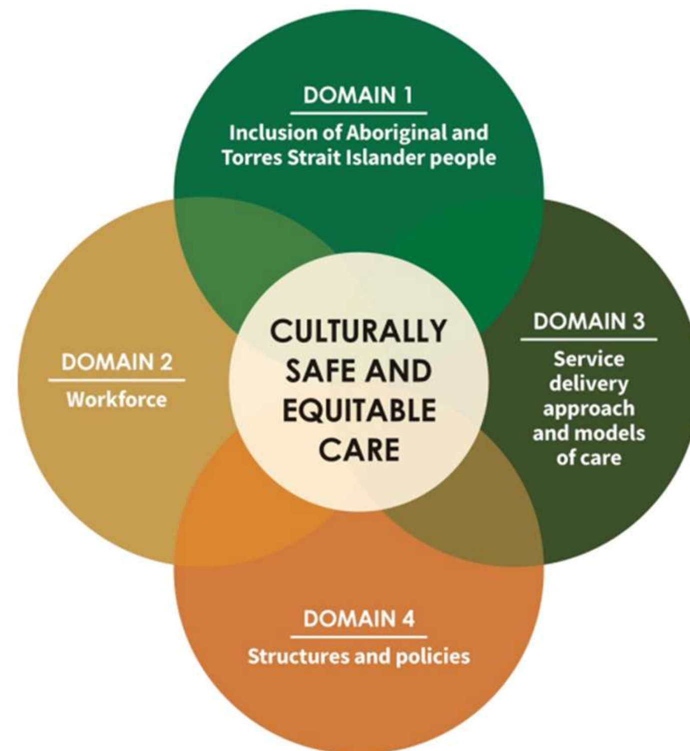
Health*Info*net Review of Kidney Health

- 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

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