

Research Spotlight Seminar: Aboriginal and Torres Strait Islander Kidney Health Research



THE UNIVERSITY
of ADELAIDE

AKtion – Aboriginal kidney care together – improving outcomes now

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Adelaide Nursing School



Acknowledgment of Country

I 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.



First Nations people experience a higher rate and burden of kidney disease

Overrepresented in all stages of chronic kidney disease

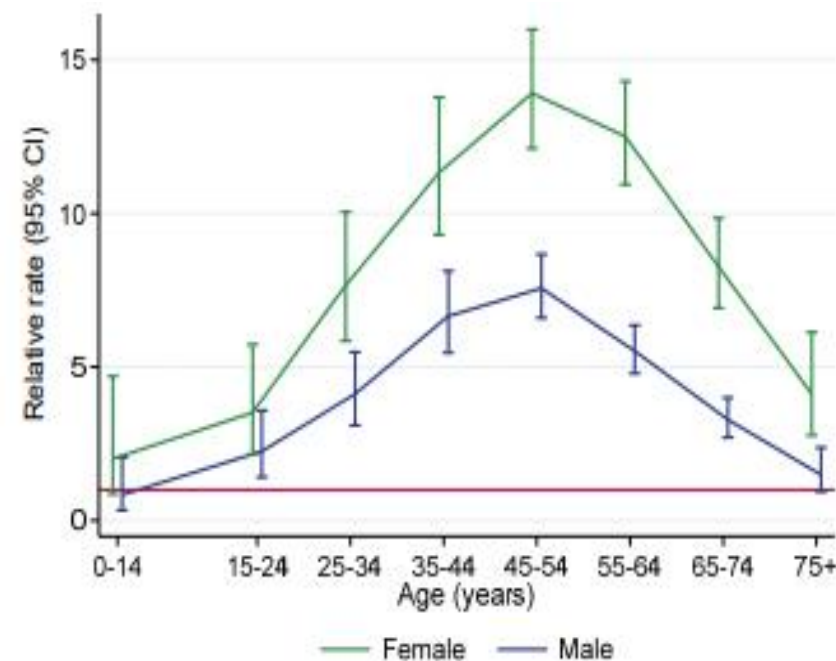
- Increased incidence & prevalence
- Increased progression of disease

Increased kidney failure rates 2-13x higher

Poorer access to dialysis and transplantation

Perceived poor outcomes

Relative rate of treated kidney failure; First Nations and non-Indigenous Australians 2016 -2020



“Disparities between Indigenous and non-Indigenous patients with end-stage kidney disease in access to kidney transplantation are not explained by patient or disease related factors. Changes in policy and practice are needed to reduce these differences.”

Khanal et al. 2018

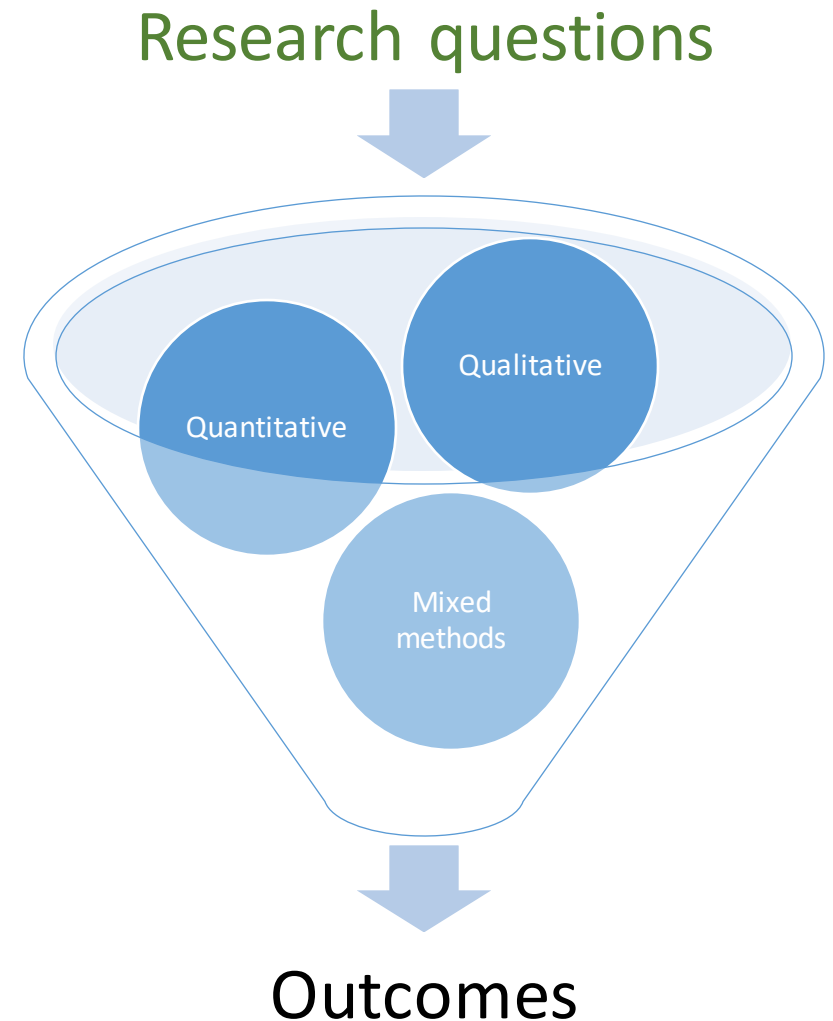
Different research approaches

Approaches

- Quantitative
 - numbers, statistics
- Qualitative
 - experiences, reasons behind statistical results
- Mixed methods
 - using both qualitative and quantitative

Questions

- What is working well and where are the gaps?
- From who's perspective?
- How best to address gaps in care?
- How to evaluate effectiveness?



Aboriginal health research

- Aboriginal people have been doing complex and longitudinal research for tens of thousands of years
- With colonisation – Western ‘scientific’ research was done ‘on’ Aboriginal people, often without any individual or community recognition or benefit, and often to their detriment.
- Research became known as a dirty word in Aboriginal communities



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The Repatriation of Aboriginal Ancestral Remains

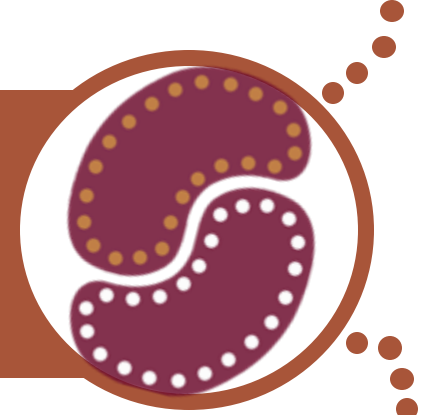
From the late-19th Century, researchers from the University of Adelaide actively studied and documented the lives of Aboriginal peoples and their customs in their community. In some cases, fieldtrips to communities or to urban redevelopment sites involved the removal of cultural items and human remains. These were kept as scientific collections by the Adelaide Medical School and the Adelaide Dental School.

Some of these collections remained at the University until they were relocated to the SA Museum for safekeeping through a formal repatriation program which began in 2017.

This University is one of many institutions now seeking to understand the ramifications of these practices and acknowledging the impact on Indigenous communities worldwide.

Our university has been significantly involved ...

Meaningful approaches



- Acknowledge Aboriginal people as experts of their own lives, health and wellbeing needs and priorities
- Prioritise Aboriginal knowledges, ways of being, knowing and doing
- Flips typical colonial hierarchies on their heads e.g. community members as chief investigators

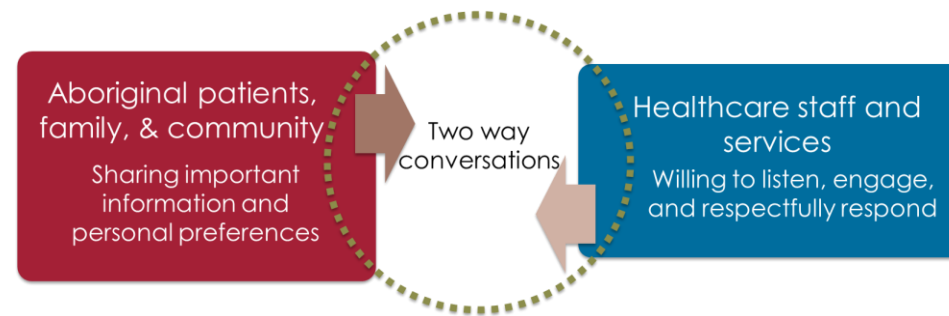
Top down

What often happens in healthcare & research

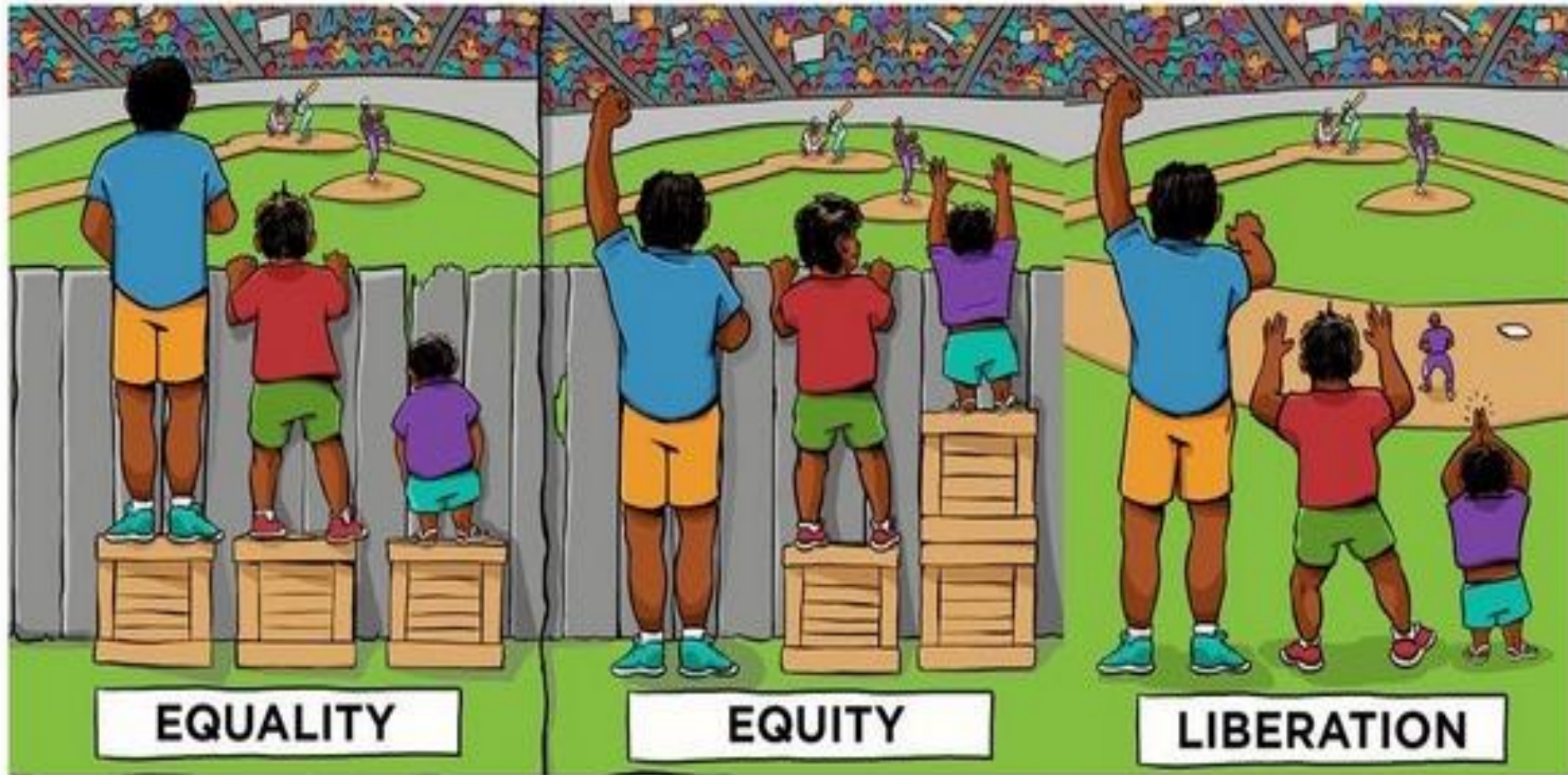


Co creation & codesign

What should happen in healthcare & research



Addressing power differentials Moving beyond “treating everyone the same...”



(Ogilvie 2018)

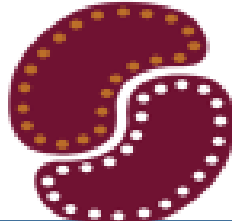


AKction

Aboriginal Kidney Care Together
– Improving Outcomes Now



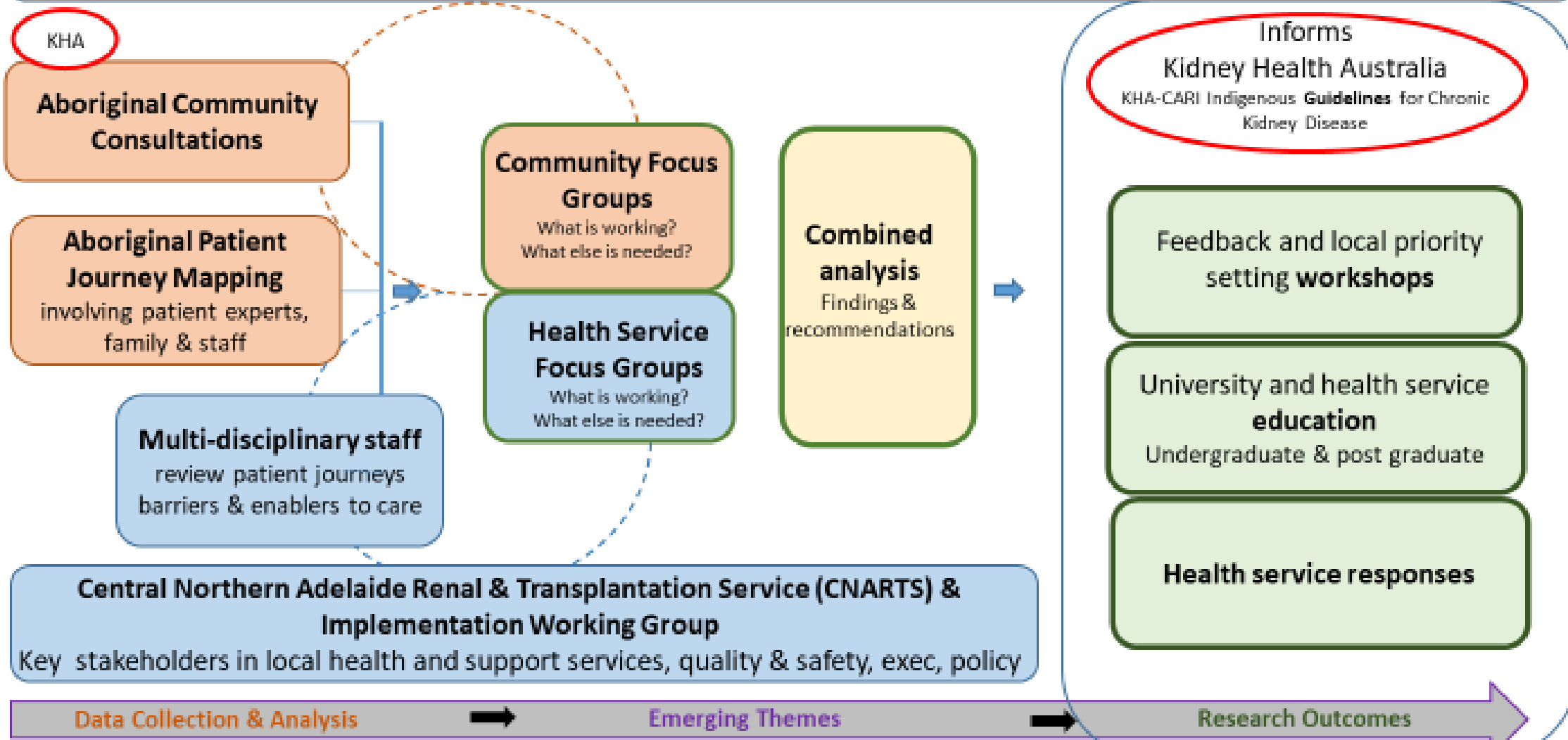
- Aboriginal patient experts as chief investigators & project leads
- Aboriginal health practitioners, nurses, and doctors working alongside community members to improve care



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



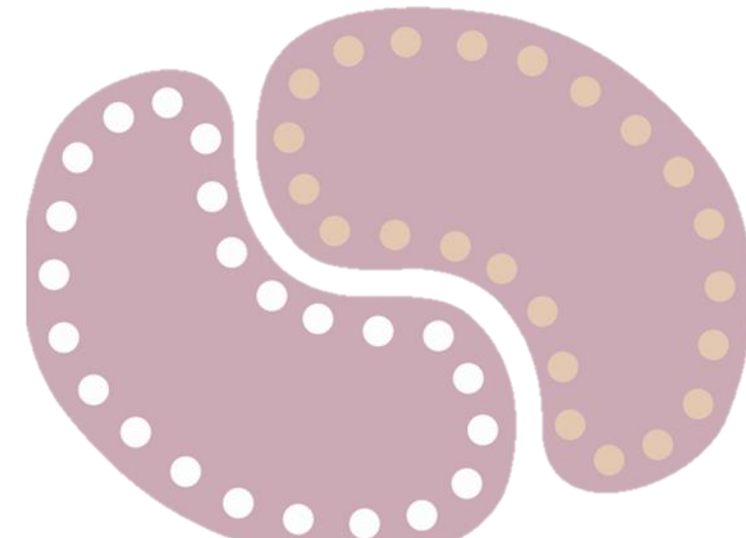
AKtion2 - Focus

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

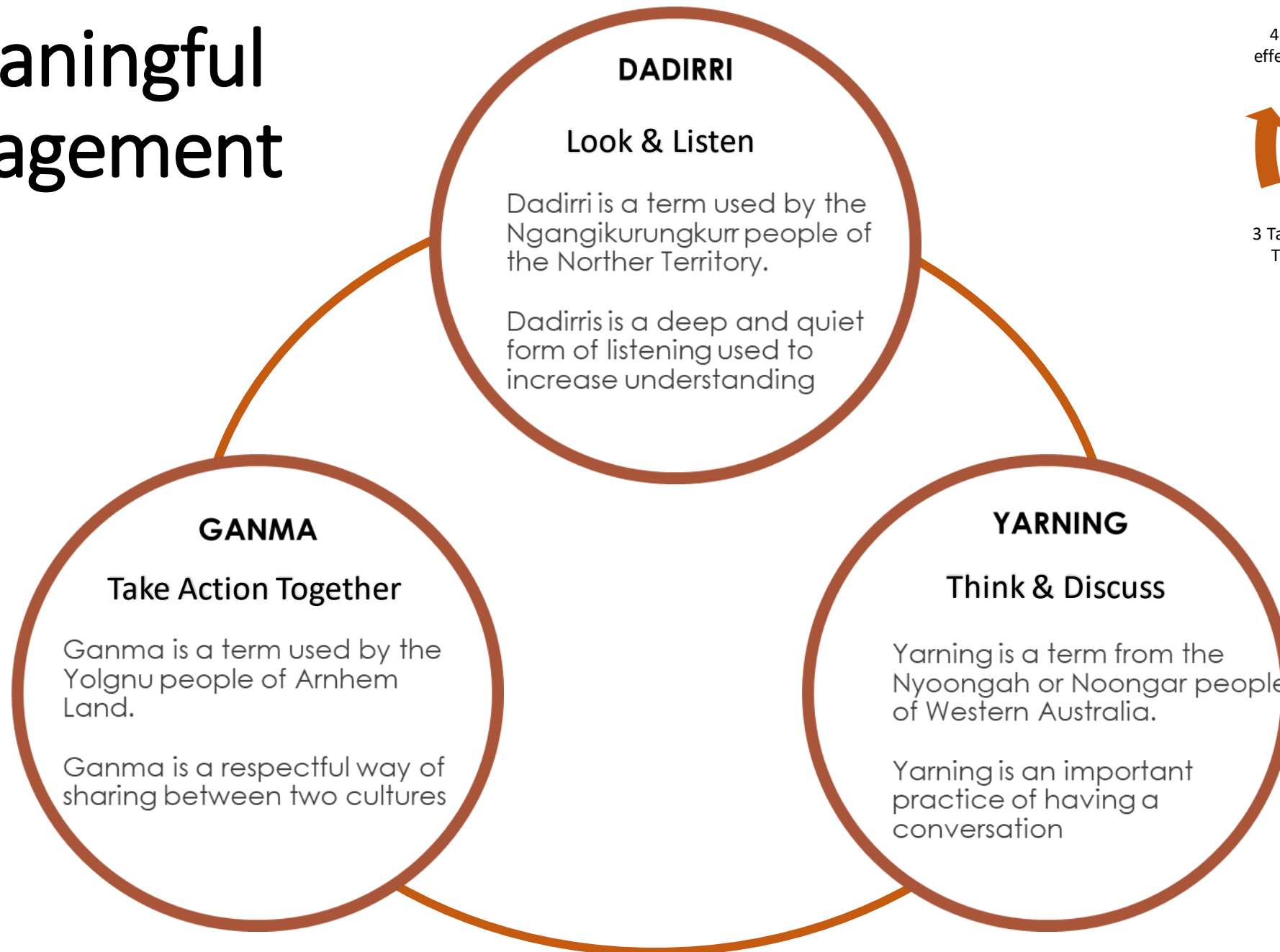


1. **Indigenous governance** *“We are more than our disease!”*
2. **Support for Aboriginal kidney patients** *“We know what it is like”*
3. **Kidney journey mapping** *“No one else should have to experience this”*
4. **Cultural Safety in Kidney Care** *“Sometimes they just don’t get it”*

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



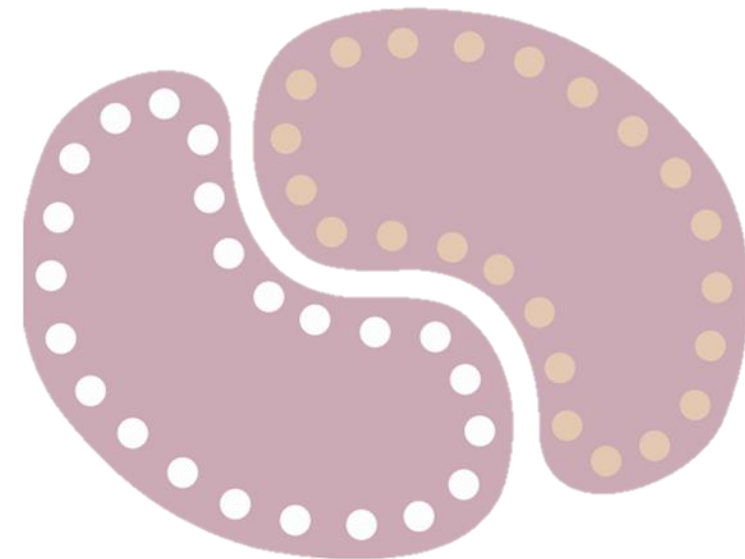
Meaningful engagement



DADIRRI – Look & Listen

- a deep and quiet form of listening to increase awareness and understanding.
- Shared by the Ngangikurungkurr people near the Daly River in the Northern Territory
- an active, respectful process of listening
- taking time to listen, process and reflect on the information

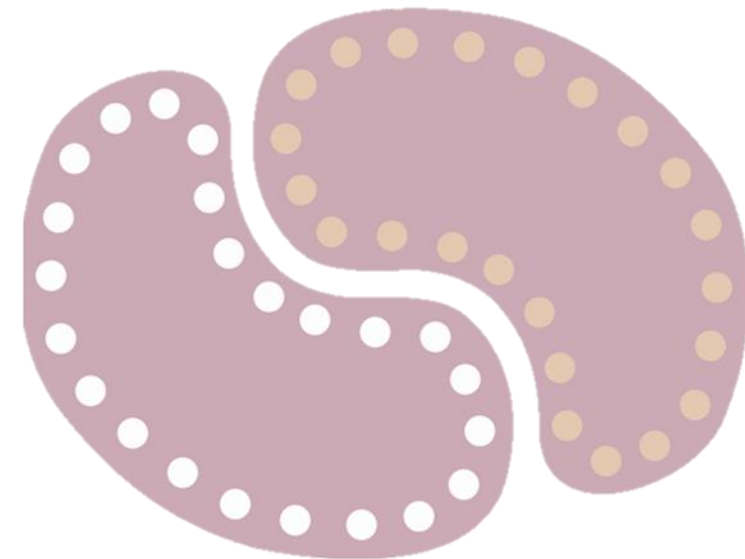
Sharmil, 2021, p.5; West et al, 2012, p.1584



YARNING – Think & Discuss

- a culturally safe way of talking for First Nations people.
- Shared by Nyoongah /Noongar in Western Australia
- Social Yarning; Collaborative Yarning; Research Topic Yarning; and Therapeutic Yarning
- Clinical Yarning: social, diagnostic management
- Frames the lived experience of people - truly hear what people have experienced.
- Take time to process information that has been expressed through lived experience and detailed stories.
- Can take place through oral or written conversation.

Bessarab and Ng'andu, 2010, p.38



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

GANMA – Take AKtion Together

- The respectful way of sharing cultural knowledge between people
- Shared by the Yolgnu people of Arnhem land, Northern Territory.
- On Yolgnu land there is place on Country where two kinds of water meet, a river and the sea, they flow together becoming one.
- The term *Ganma* comes from the process, when the two meet and create a foam that represents a new kind of knowledge.
- This naturally occurring phenomenon has been used as metaphor to improve knowledge exchange between two cultures.





Health journey mapping tools & resources

- Collaborative research, from the ground up
- Flexible, adaptable, can be scaled up or down
- Pragmatic, problem solving
- Helps identify, plan, support and record what cultural safety looks and feels like in practice

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

Research leading to significant improvements in care

Kanggawodli dialysis chairs & National Clinical guidelines



More responsive models of care

<https://kidney.org.au/get-involved/advocacy/yarning-kidney-consultations/cari-guidelines-recommendations-for-culturally-safe-kidney-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** • TRANSPORTATION
• ACCOMMODATION NEEDS
- 4** • 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
• KIDNEY-FAILURE
• TRANSPLANTATION

 **CARI** GUIDELINES
CARING FOR AUSTRALIANS & NEW ZEALANDERS

www.cariguideines.org
[@cariguideines](https://twitter.com/cariguideines)

New national clinical guidelines

Opportunities for students



3rd year health and medical sciences students

- Service mapping
- Mapping 'typical' journeys
 - To dialysis
 - To kidney transplantation

Honours students

- Service mapping
- Mapping kidney journeys
 - Kidney transplantation
 - COVID impacts
 - Strengths and resilience

PhD students

- Cultural safety
 - Clinical guidelines
 - Scoping review
 - Surveys
- Models of care

To be part of a large research project that is changing lives

AKtion team acknowledgement



Thank you to Aktion team members

Chief investigators: Kim O'Donnell, Janet Kelly, Kelli Owen, Nari Sinclair, Rhanee Lester, Sam Bateman, Josee Lavoie,

AKtion Reference Team: Nari Sinclair, Kelli Owen, Rhanee Lester, Jared Kartinyeri, Lili Simo, Denise Champion, Shallander Champion, Ramon Gadd

Associate investigators: Odette Pearson, Tamara Mackean, Melissa Arnold-Ujvari, Shilpa Jesudason, Stephen McDonald, Richard Le Leu, Kylie Herman, Lisa Jamieson,

Project team: Amy Graham, Kynesha Temple Varcoe, Alyssa Cormick, Tahlee Stevenson, Liz Rix

Janet's journey

British &
German
ancestry



Grew up on
Kangaroo Island

Hospital trained
nurse

Community
health nursing

Working with
Aboriginal
colleagues &
community
members

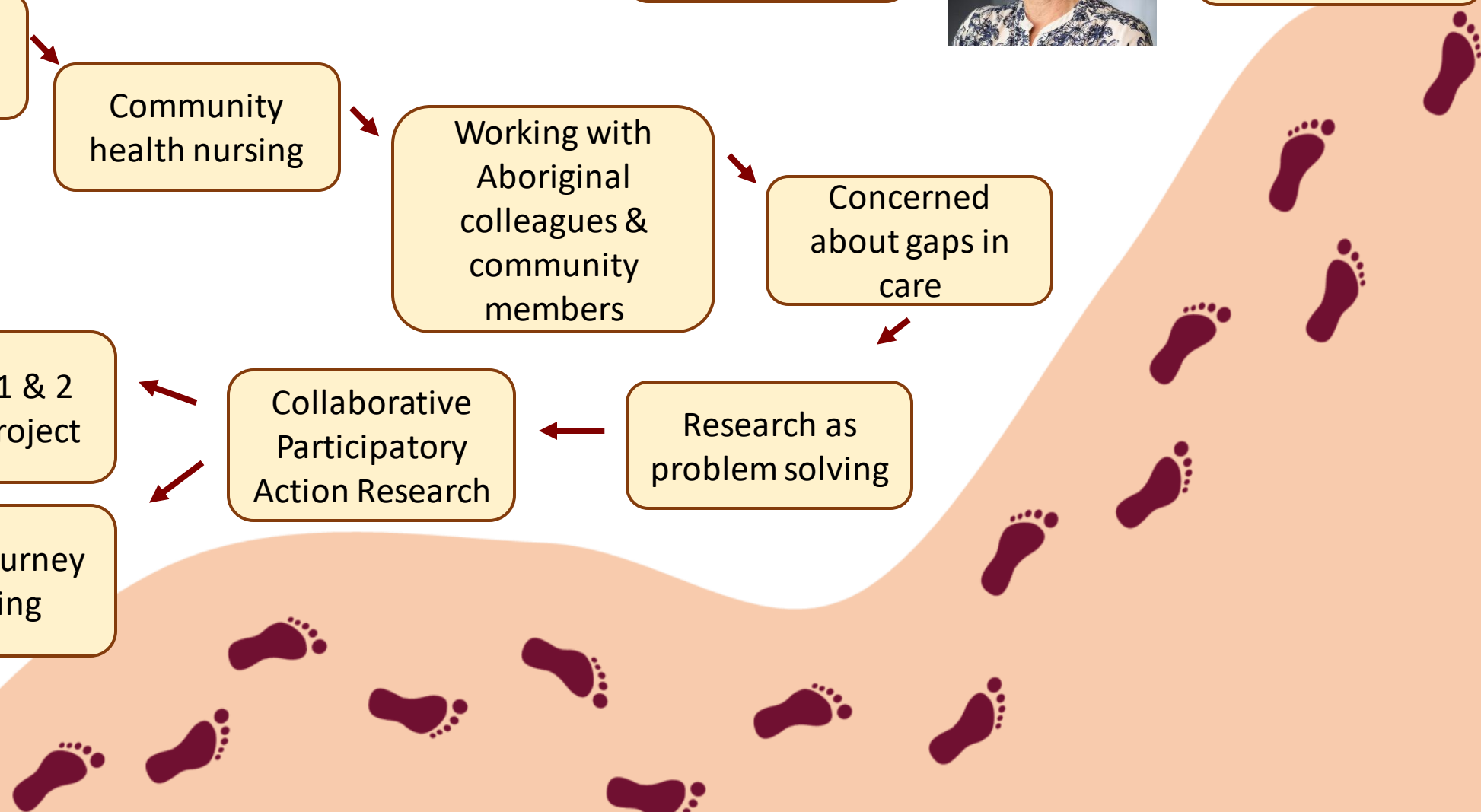
Concerned
about gaps in
care

AKtion 1 & 2
Kidney Project

Collaborative
Participatory
Action Research

Research as
problem solving

Health Journey
Mapping



Nakutha!

Thank you for Listening!

