

## Meaningful engagement with Aboriginal people

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### Aboriginal people driving healthcare improvements

Janet Kelly & Amy Graham



THE UNIVERSITY  
*of* ADELAIDE



# 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.

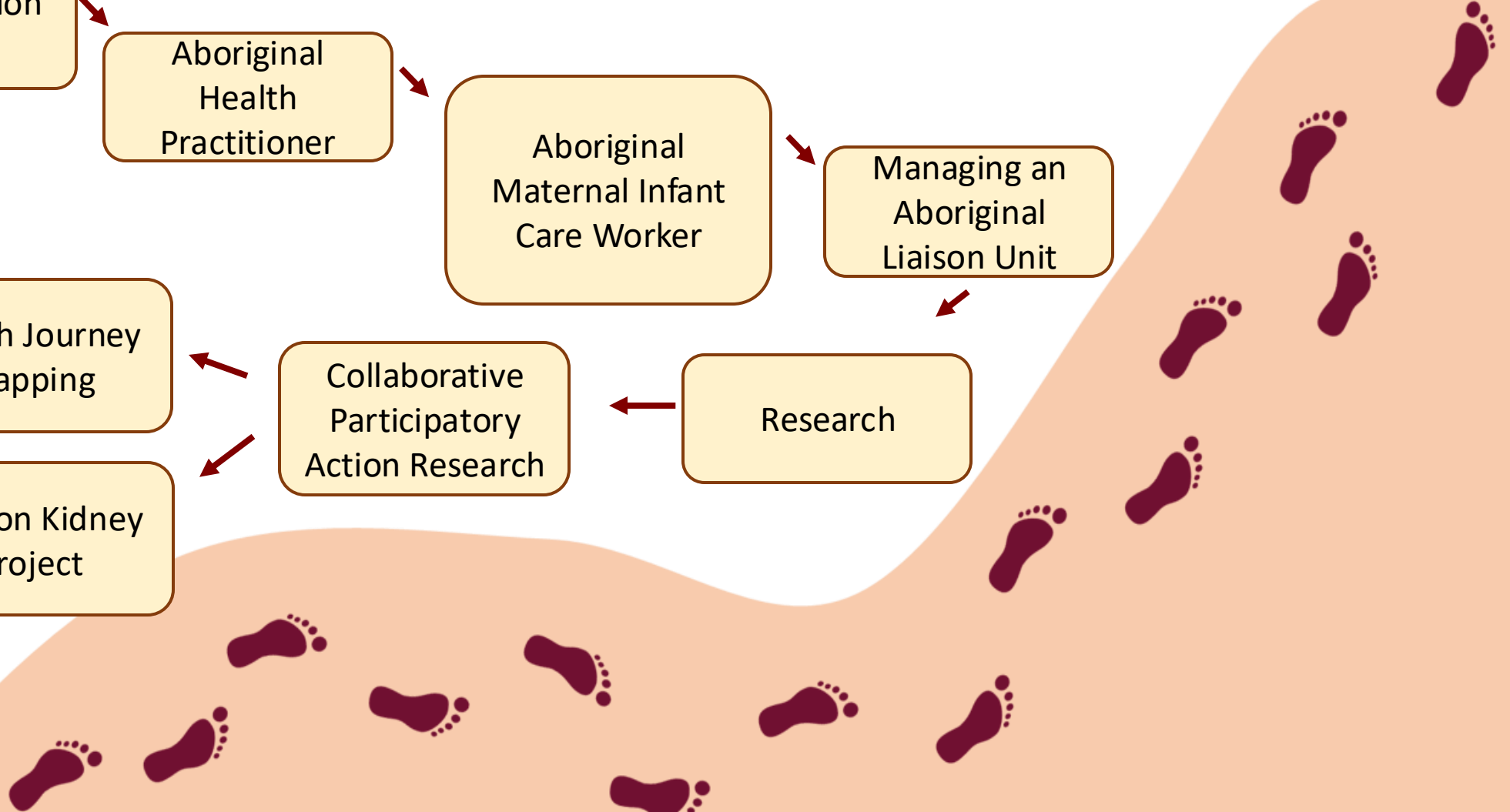
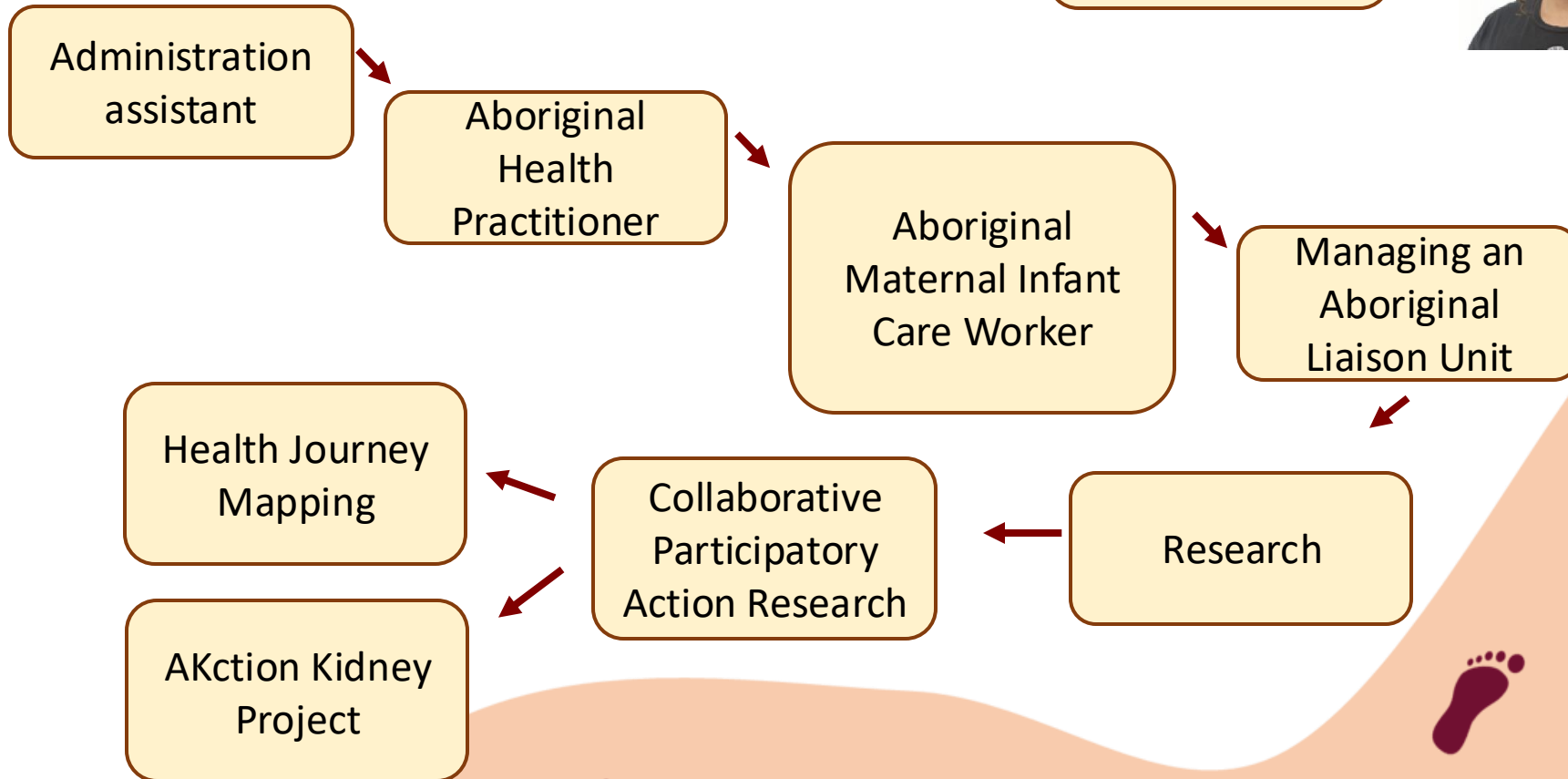


# Amy's journey

Kurna  
Narungga  
woman



Grew up in  
Adelaide

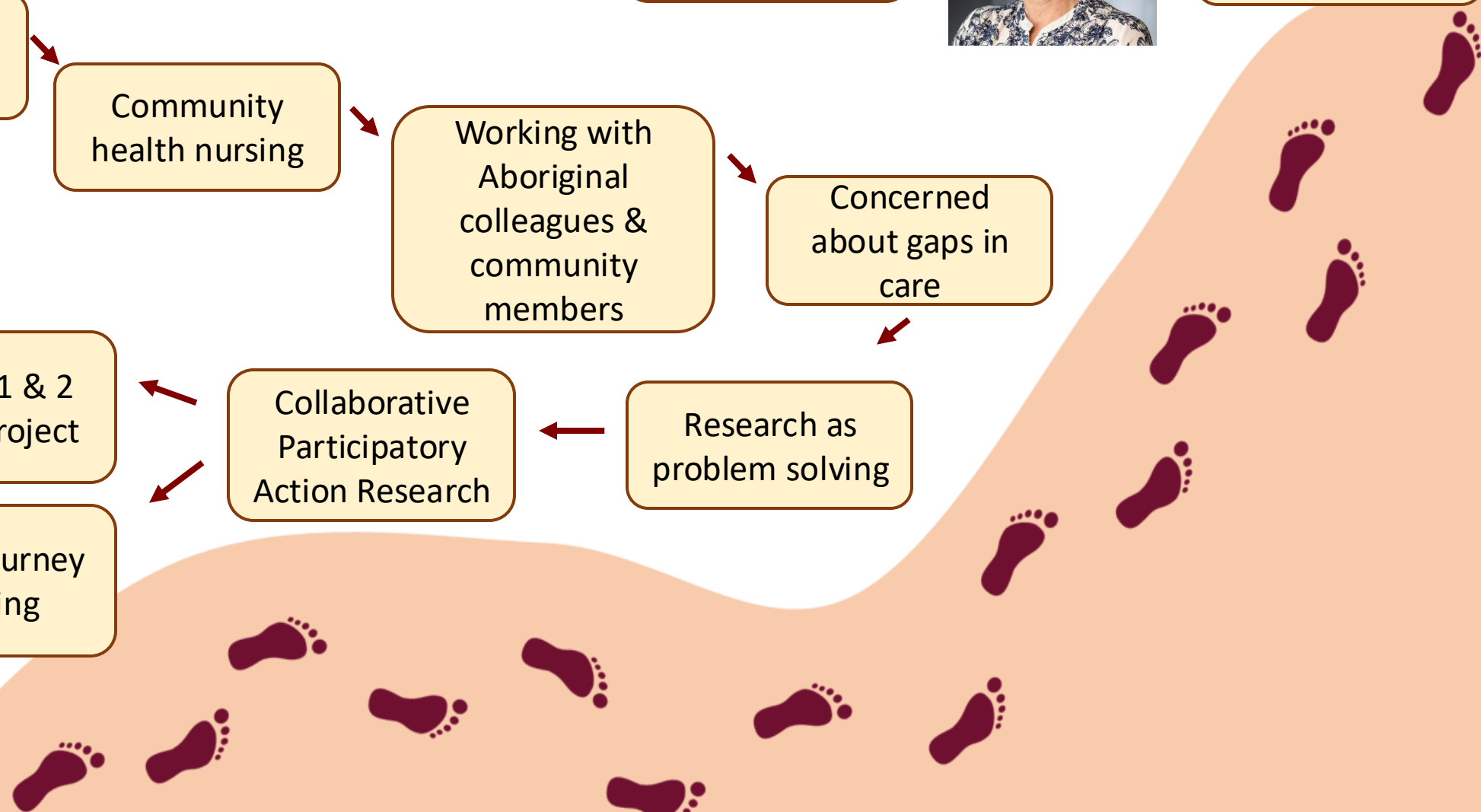


# Janet's journey

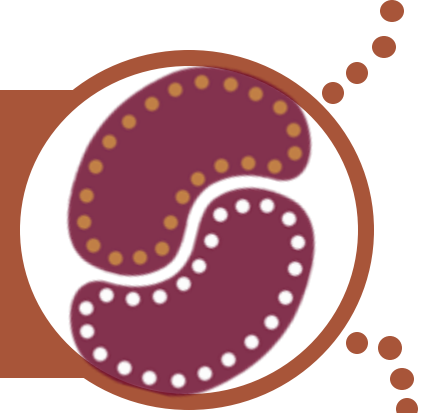
British &  
German  
ancestry



Grew up on  
Kangaroo Island



# Meaningful approaches



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

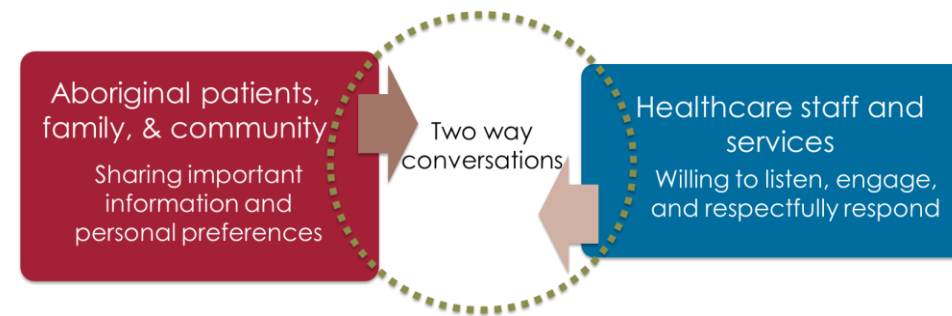
## Top down

What often happens in healthcare & research



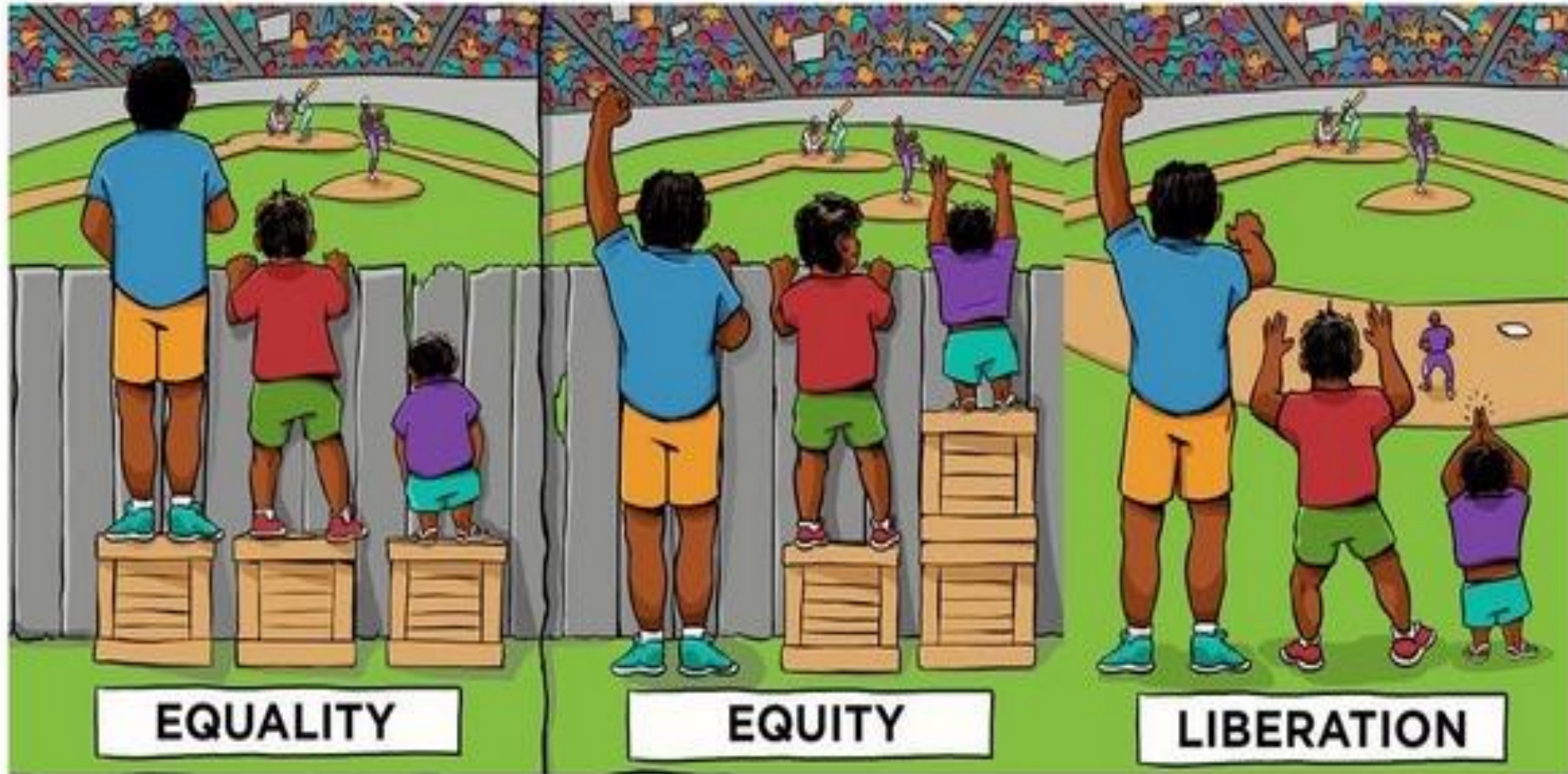
## Co creation & codesign

What should happen in healthcare & research



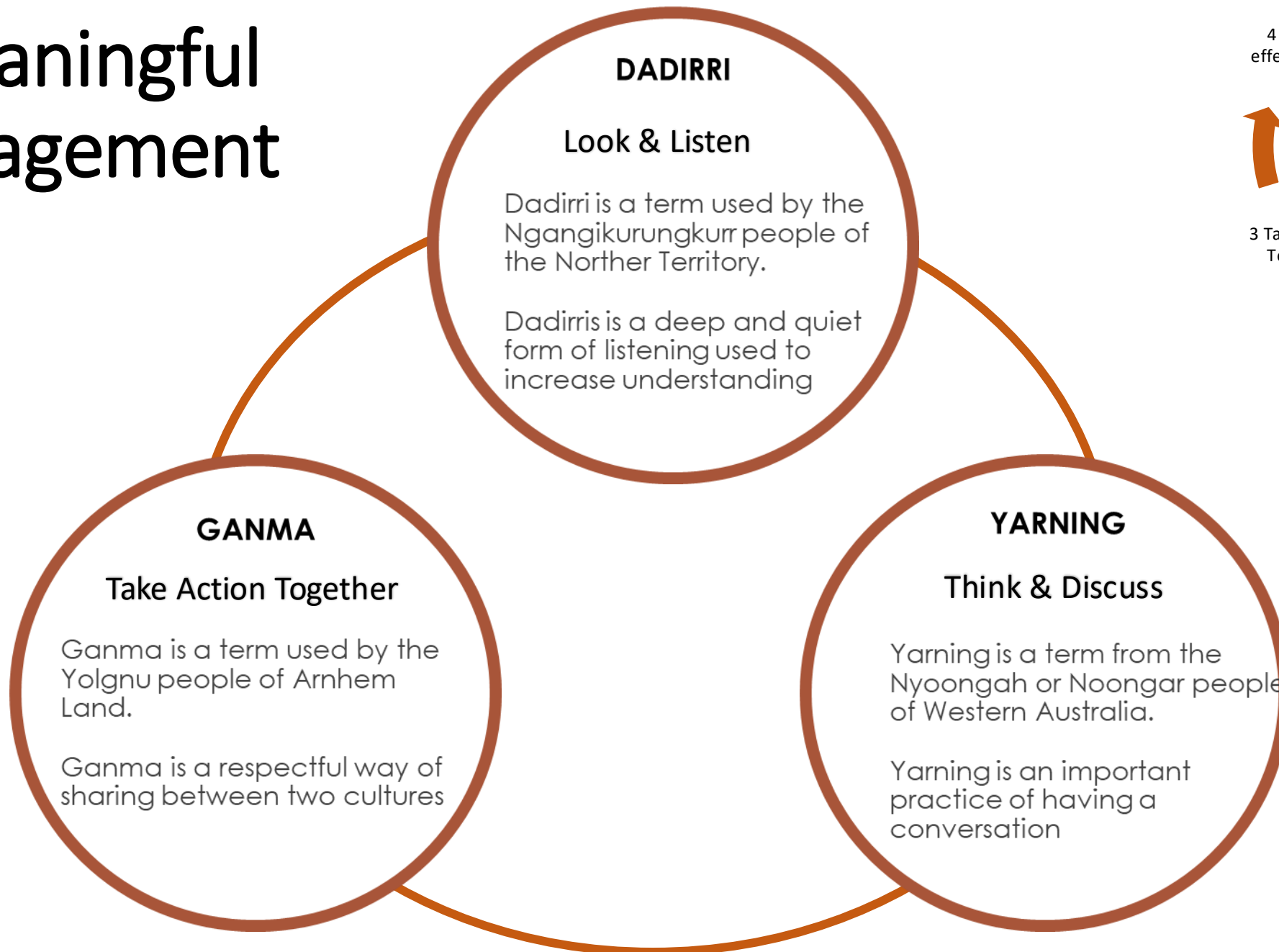


# Addressing power differentials Moving beyond “treating everyone the same...”



(Ogilvie 2018)

# Meaningful engagement





# 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>



# 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

## 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.	<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.	<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 & interpreter helped with informed consent.
		<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.	<b>What else needs changing?</b> Better visual resources to help with explaining complex procedures (from Mrs Brown & peer navigators)
			<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.

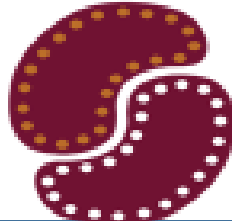


## AKction

Aboriginal Kidney Care Together  
– Improving Outcomes Now



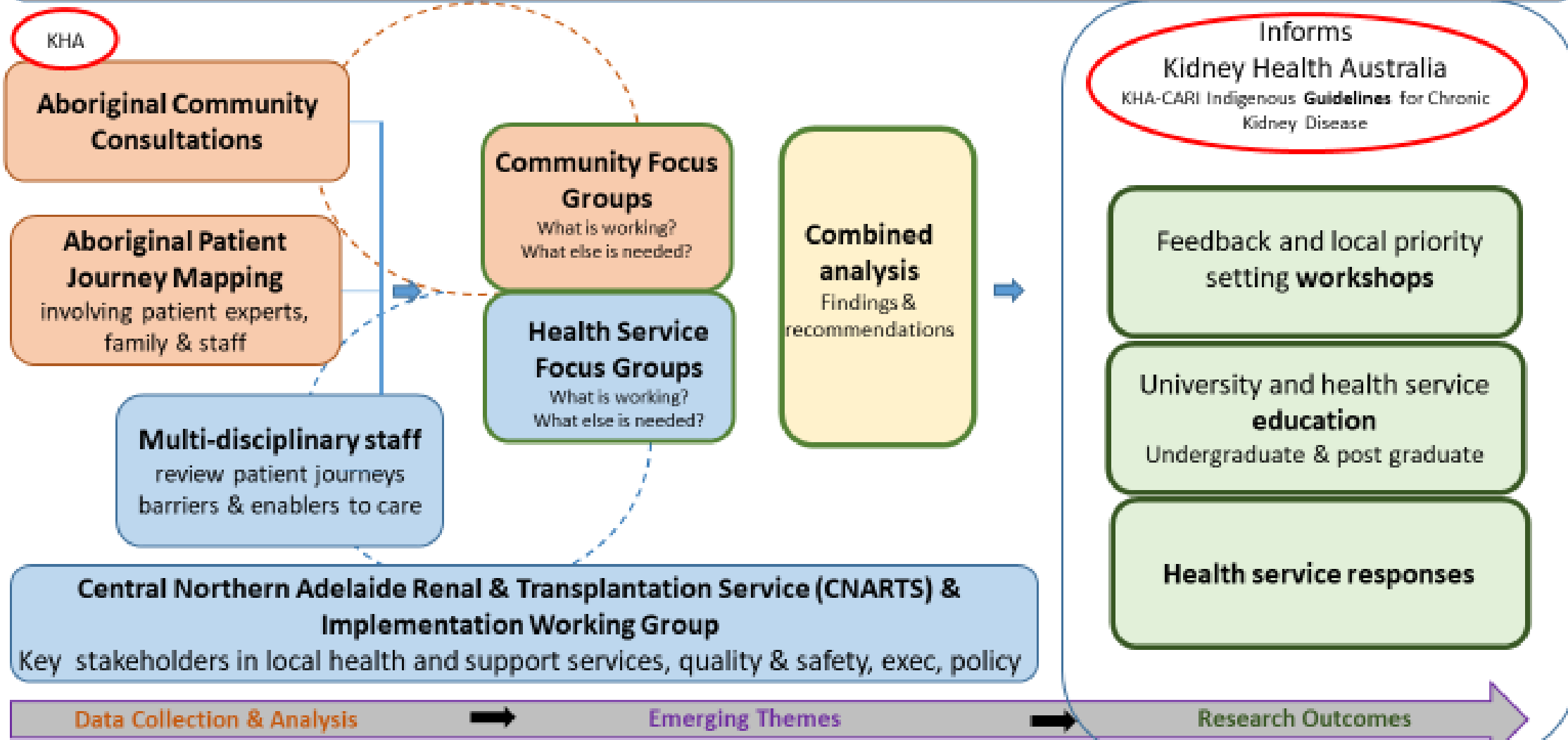
- Aboriginal patient experts as chief investigators & project leads
- Aboriginal health practitioners, nurses, and doctors working alongside community members to improve care



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





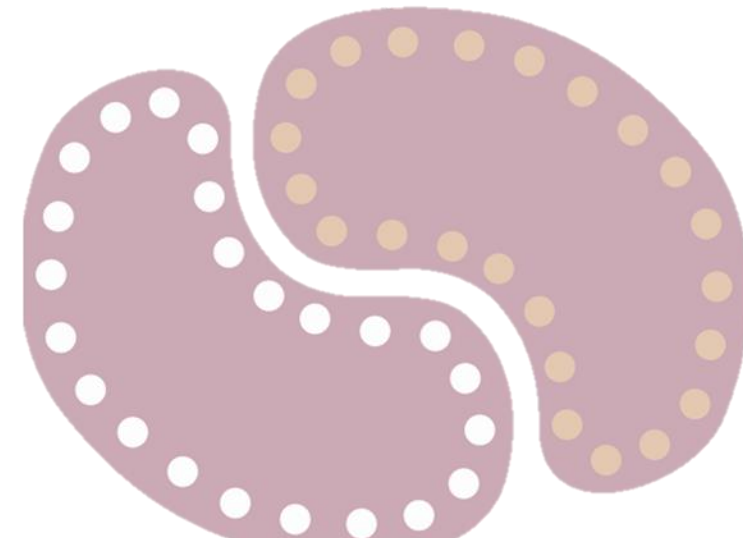
## AKction2 - Focus

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



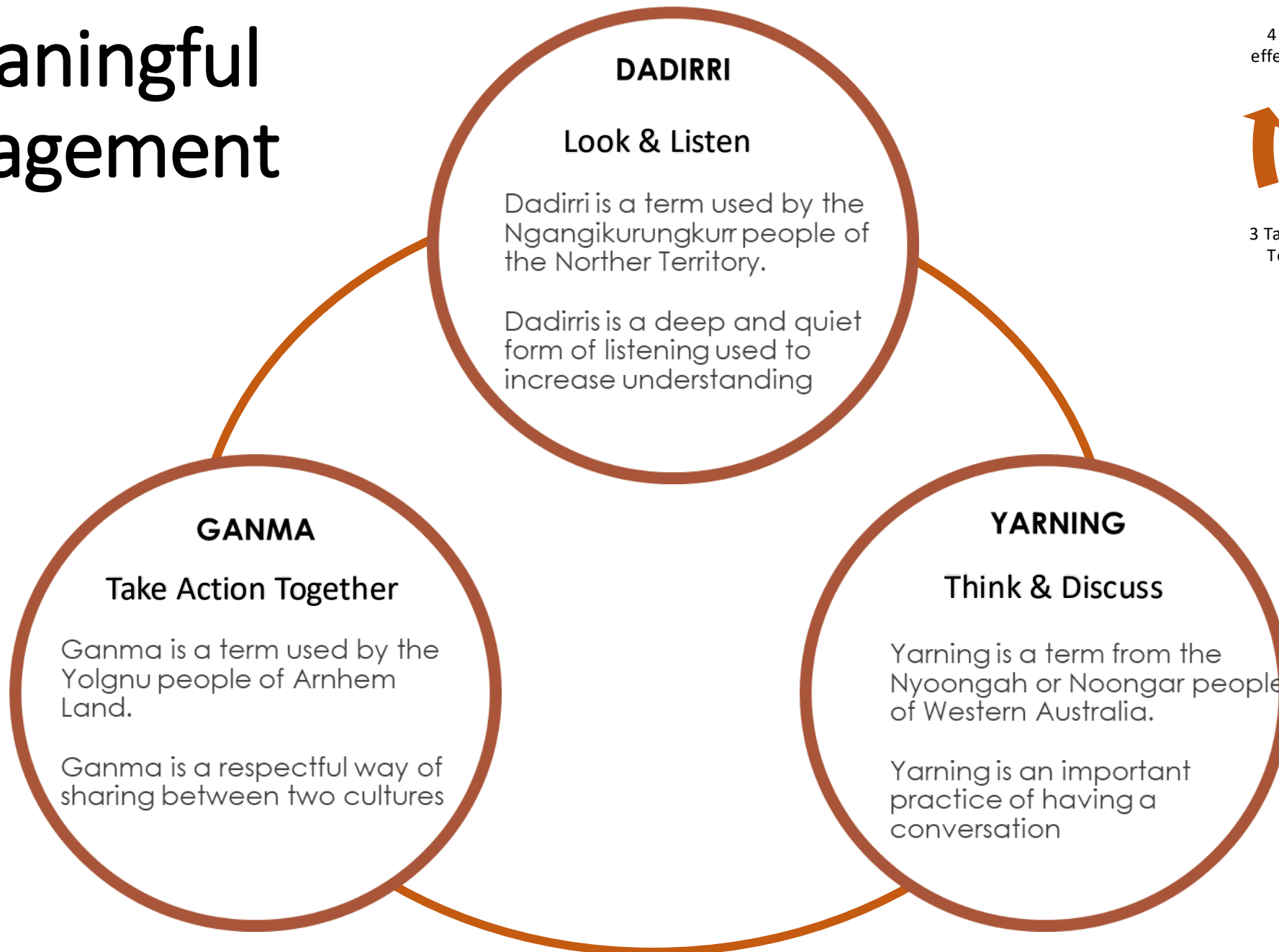
1. **Indigenous governance** *“We are more than our disease!”*
2. **Kidney journey mapping** *“No one else should have to experience this”*
3. **Support for Aboriginal kidney patients** *“We know what it is like”*
4. **Cultural Safety in Kidney Care** *“Sometimes they just don’t get it”*

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





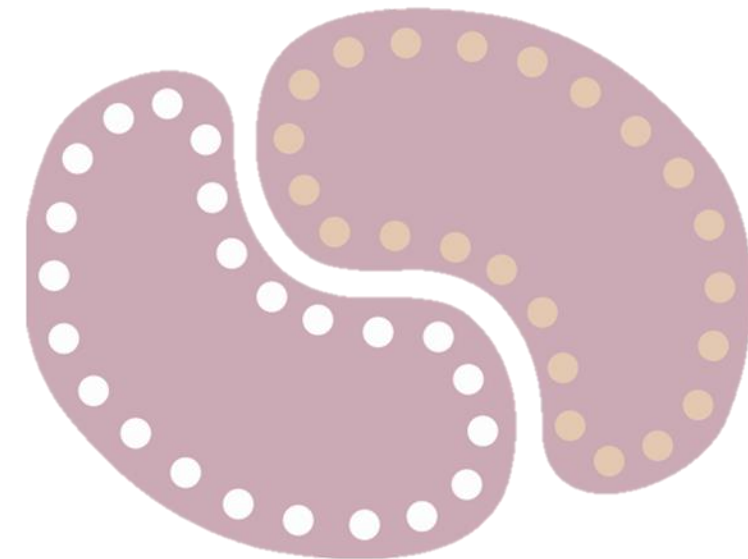
# Meaningful engagement



# 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



# Flyers

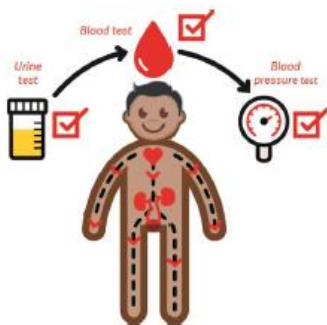


## Indigenous Voices Yarning 'Kidney Health'

In Australia and New Zealand there are Guidelines (instructions) that are used by doctors, nurses and other health professionals to know how best to treat kidney diseases. Currently these Guidelines do not include cultural aspects of care or specific needs or challenges that may occur for Aboriginal and Torres Strait Islander Peoples.



Kidney Health Australia and the 'Improving Aboriginal Kidney Care Together' Research are holding community consultations in South Australia: Adelaide and Port Augusta. We invite you to attend the consultations to tell us what should be in these guidelines, how we should use them, and give us ideas about improving kidney care locally and how to provide the information back to you.



Aboriginal and Torres Strait Islander Peoples and their family members have the opportunity to discuss what is most important regarding their kidney health, kidney care and personal, family and community experiences with kidney treatments. The consultation will be recorded and written up, and then shared with all who attended, to get their feedback. Names of those attending will not be written on the consultation report unless permission is given.

**Art Session:** Wednesday, 6 February 2019, 12:30pm – 4:00pm at Pika Wiya Health Service (40-46 Dartmouth Street Port Augusta, SA).

**Yarning Kidneys:** Thursday, 7 February 2019, 12:30pm – 3:30 pm at Pika Wiya Health Service (40-46 Dartmouth Street Port Augusta, SA).

**Food and transportation will be provided.**

Please **RSVP** and book your transport with Laurel Dodd on 8642 9930 or Kylie Herman on 8668 7737 by **Monday 4 February 2019**.

For more information call: Dora Oliva on 0406 809 712, Janet Kelly on 0428 891 286 or Laurel Dodd on 8642 9930.



## AKtion-Aboriginal-Kidney-Care-Together, -Improving-Outcomes-Now!

You are invited to a consultation workshop to talk about kidney care for Aboriginal people in Ceduna. There are two sessions on Wednesday, 12<sup>th</sup> June 2019 at Ceduna Hospital (3-Eyre Highway, Ceduna-SA).

**Yarning session for kidney patient and family members: 10:00am – 12:00pm**

We are inviting Aboriginal and Torres Strait Islander People with kidney disease, their family members and anyone who would like to, to discuss what is most important about their kidneys and health care.

**Open discussion for patients, families, staff and services: 1:00pm – 3:00pm**

This session is open to everyone in Ceduna who would like to talk about how to improve Aboriginal kidney care.

The information from these sessions will be used in three ways:

- To inform kidney care locally in Ceduna, and at a state level
- To inform the AKtion project
- To inform new national clinical guidelines (instructions) about how to care for Aboriginal and Torres Strait Islander peoples experiencing kidney disease.



The 'AKtion' research brings together the Central and Northern Adelaide Renal and Transplantation Service, The University of Adelaide, Kidney Health Australia, the SA Aboriginal Chronic Disease Consortium and SAHMRI.

Consultations have also been held at Kangawodli in Adelaide and Pika Wiya in Port Augusta.



We invite you to attend a consultation in Ceduna and share your experiences. We will record the consultation and write a report, which will be shared back with you all. Names of those attending will not be written on the consultation report unless permission is given. This report will then be shared with community members, healthcare and support providers and the government.

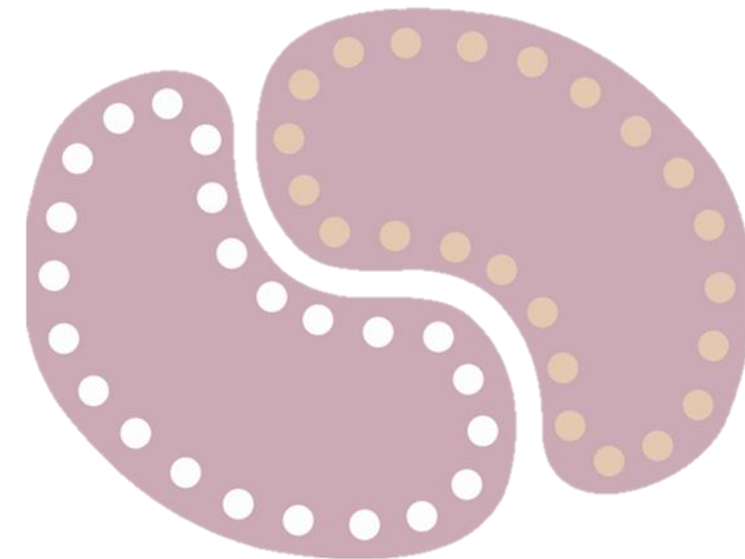
**Transport to the event can be arranged. Lunch will be provided.**

Please RSVP to Geraldine Ware on 8626500 or Andrew Lane on 86262110 by **Monday 4<sup>th</sup> of June 2019**. You can discuss transport needs with Geraldine. For more information please call: Janet Kelly on 0428 891 286 or Tahlee Stevenson on 0411307297

# 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.
- tale 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.



# Kanggawodli dialysis chairs & National Clinical guidelines



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

# 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

# Nakutha!

Thank you for Listening!

