

Akction Project Update

CNARTS CRG Meeting 16 3 22

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On behalf of the Akction Research Teams

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**ABORIGINAL
KIDNEY
CARE** 
**TOGETHER
IMPROVING
OUTCOMES
NOW**



Aboriginal Kidney Care Together – Improving Outcomes Now: AKAction1 → AKAction2

Working Together

Community

Health, Renal & support services:
CNARTS
CALHN
NALHN

National Indigenous Kidney Transplant Taskforce

SAHMRI

Universities

Aboriginal Chronic Disease Consortium

Aboriginal Health Services

Kidney Health Australia

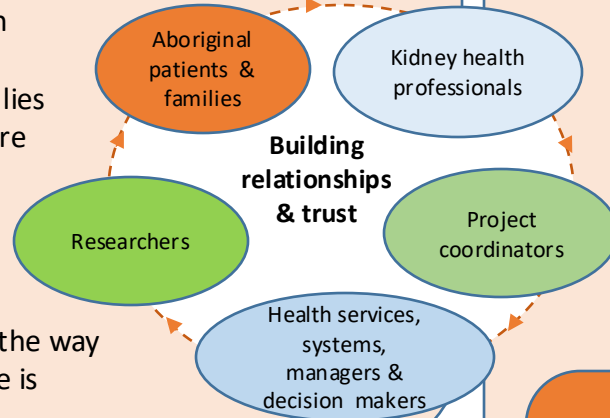
CARI guidelines

Purple House

AKAction1

- Aboriginal Reference Group
- Community Consultations
- Patient journey mapping
- Stakeholder workshops
- Networking - local, NT, international
- New national clinical guidelines

Building relationships and trust between Aboriginal patients, families and health care professionals



Changing the way kidney care is provided

HTSA/MRFF Funding

Working with

NIKTT: National Indigenous Kidney Transplant Taskforce

- IRG – Indigenous Reference Groups
- National Community Kidney Panel
- Peer navigators
- Cultural Bias report & policy document

AKAction2

Decolonising approaches & methodologies

Indigenous methods

Yarning – relaxed conversations
Dadirri – deep listening
Ganma - knowledge sharing

Interface – working in Brave Spaces

combining Indigenous and Western concepts
Co-design, collective decision making
Participatory Action Research
Look & Listen, Think & Discuss, Take Action Together

Western methods

Interviews, focus groups
Surveys, evaluation
Critical reflection

4 sub studies

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 care patients *“We know what it is like”*
4. Cultural safety in kidney care *“Sometimes they just don’t get it”*

What we want to achieve - our end goals

Patients & families

Better kidney care, dialysis & transplantation experiences & outcomes
Access, education & prevention
Peer support

Health professionals

Cultural safety training & tools
Effective partnerships with patients, families and communities
Increase Indigenous workforce

Health services and systems

Improved coordination of care - within and across health services & systems
Improvements in care processes and outcomes
Implementation of new guidelines & standards
Increased Indigenous workforce
Reducing racism

NHMRC Ideas Grant Funding

Aktion2

Bringing together Indigenous & Western approaches to research

Informed by AKtion1, Aboriginal patients, health carers standards & guidelines

Resulting in multi-level improvements in care processes and outcomes

AKtion2: using Decolonising Methodologies to co-create improvements in Aboriginal Kidney Care

Indigenous methods

Yarning: relaxed conversations
Dadirri: deep listening
Ganma: knowledge sharing

AKtion1 processes & findings - 2019-20

Aboriginal kidney patients, families and communities
Real world kidney health experiences & priorities.
AKtion1 Reference Group
Community consultations
Journey Mapping Tools

Working at the *interface* in Brave Spaces

Challenging conversations, racism anxiety
Co-creation, collective decision making
Participatory Action Research
Look & Listen, Think & Discuss, Take Action Together

Four interwoven sub studies

1 Indigenous governance

2 Kidney journey mapping

3 Patient support needs

4 Cultural safety in kidney care

Western methods

Interviews, focus groups
Surveys, Critical reflection
Implementation, Evaluation

Health carers, standards & guidelines

Renal health professionals
Health Action Framework
Cultural safety
Reducing racism
National Indigenous renal clinical guidelines

Outcomes

Patients: improved kidney health journeys, outcomes and quality of life, reduced readmissions

Health professionals & services: Aboriginal informed patient centred care & best practice evidence based framework, cultural safety training tools, partnerships with community, Indigenous workforce

Systems: improved coordination of care within and across health services, future research leaders

AKtion2: Aboriginal Kidney Care Together – Improving Outcomes Now

AKtion students & concurrent projects

Privileging Aboriginal ways of knowing, being and doing
Combining Indigenous and Western concepts & approaches
for responsive co-design & collective decision making

KHA CARI national clinical guidelines

Shilpa women, pregnancy, kidney disease

Sam's study

Kelli, Rhanee, Katie, Stephen - NIKTT

Kelli & Kate – RAH & Kanggawodli

Sub study 1: Indigenous Governance

1. Reference Team (RT) members' experiences
2. Health professionals perspectives of RT – in Australia & Canada
3. Reference group establishment & support needs
4. Working effectively at the interface/Brave space

Sub study 2: Kidney Journey Mapping

1. Map individual kidney journeys, needs & gaps
2. Identify coordination & communication gaps - health professionals
3. Improve coordination and communication within & between sites
4. Review findings, prioritise action

Sub study 3: Support for Kidney Patients

1. Identify patient & family unmet support needs
2. Identify what works in patient support & navigator programs
3. Investigate the feasibility of peer navigators
4. Peer support & information sharing

Sub study 4: Cultural safety in kidney care

1. Identify cultural safety training needs of staff
2. Review cultural safety education approaches in health care & universities
3. Co-create, trial & evaluate a kidney health cultural safety education package
4. Refine package through feedback from participants

Kelli's study

Cultural Bias report

Melissa's study

Kelli's study

Methods

1. 2. Yarning, Ganma, Dadirri, interviews & focus groups with community members & health professionals
3. Scoping Review
4. Critical Reflection journals
4. Ganma knowledge sharing with ART & research team members in workshops

Methods

1. Interviews, my kidney my journey mapping tools, photo voice & artwork
2. Mapping journeys against standards & guidelines. Calculate personal & \$\$ costs
3. Co-create kidney journey quality improvement tools
4. Key stakeholder workshops

Health journey mapping

Methods

1. Review journeys, workshop with ART, identify unmet needs
2. Focus groups with patient support /navigator programs
3. Co-create & evaluate a pilot peer navigator project. Adapt mapping tools for use.
4. Peer support & information workshops

Methods

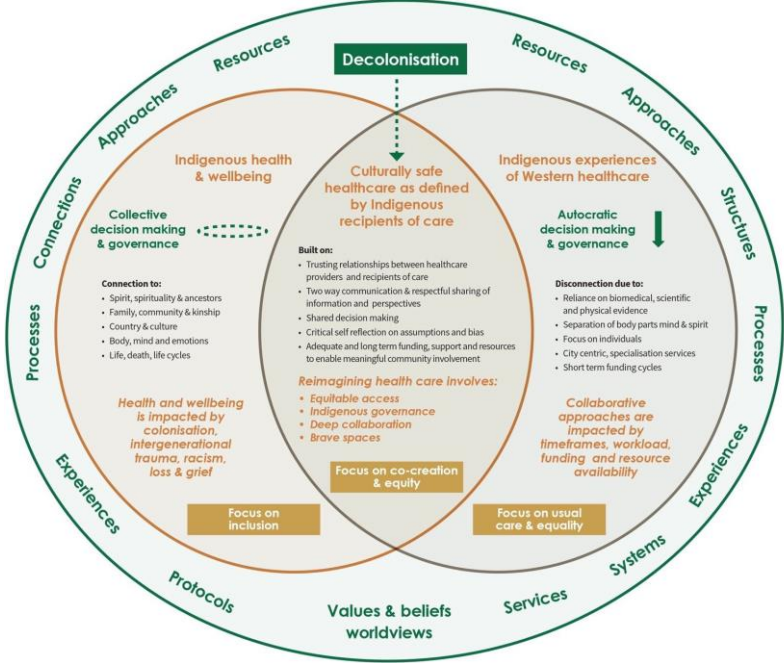
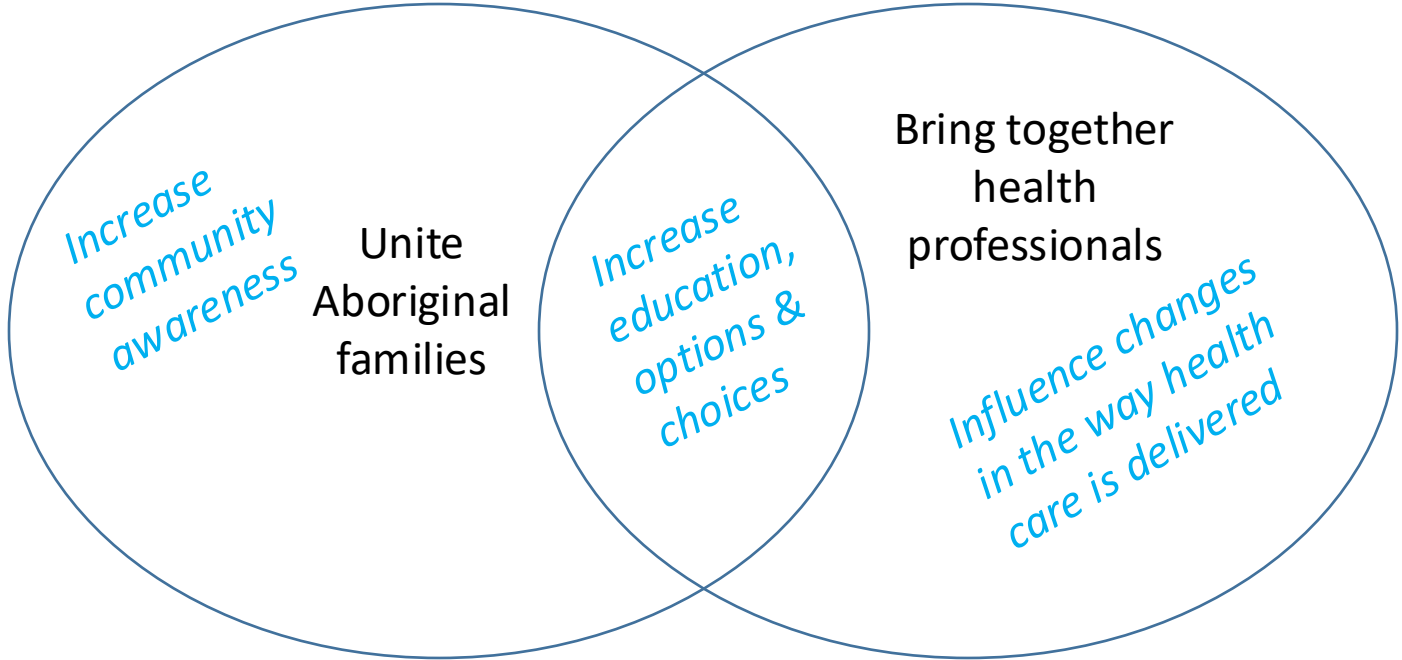
1. Survey kidney care staff - skills, knowledge & training
2. Scoping review
3. Review findings, refine & workshop package, participant evaluation, post training survey.
4. End user workshops

Melissa's study

Publications – articles

- Cultural Bias Report & Policy Brief
- Croakey – 2 published
 - <https://www.croakey.org/dreaming-big-building-a-movement-in-aboriginal-kidney-healthcare/>
 - <https://www.croakey.org/holding-that-space-game-changing-kidney-project-has-research-activism-at-its-core/>
 - 1 forthcoming
- 2 submitted & responding to reviewers' comments
 - Akction 1 process
 - Akction 1 findings
- 4 in progress
 - Alyssa's Honours – mapping Kelli's journey x 2 – process & findings
 - HJM tool development process
 - The history of cultural safety in kidney care in Australia

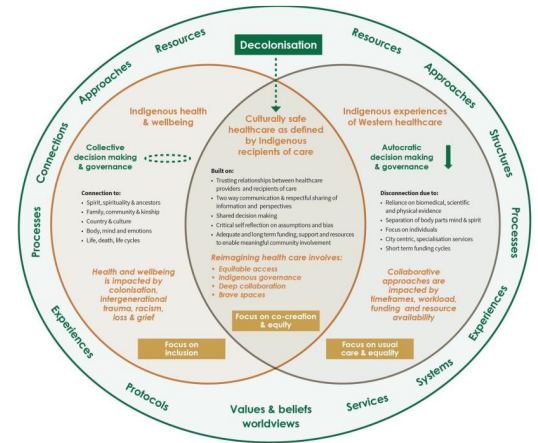
Creating new Brave Spaces in kidney care



Cultural Bias Document

Active decolonisation

- Shared vision
- Working out how to do things in decolonising ways
- AKAction Reference Group now a Reference Team
- Taking time needed to get the process right
- Time + respect = trust
- Working Together agreement
- Re-writing own Job Descriptions
- Expression of interest – Elders



Respectful and robust discussions

Critical reflection

Students

HDR

- Sam Bateman, PhD – Peer support, peer navigators Pt Augusta
- Melissa Arnold Chamney, PhD – Cultural safety education
- Kelli Owen, Masters – PhD – Indigenous Governance

Honours

- Ella Rigney (Public Health)
- Millie – kidney journeys -post transplant
- Ayleen - kidney journeys -post transplant
- Vera – kidney journeys – COVID & CKD journeys

Collaborations

- Dental & oral health
- NIKTT MRFF application
- The Kidney Mums Project: Advancing pregnancy planning and care for women with kidney disease

Context

- A lot happens in a week - sorry business and funerals, births,
- COVID
- Other projects, deadlines, floods
- Celebrations – making the time and space to celebration to keep spirit strong and achievements. Counter balance the negatives.