



*Aboriginal Kidney Care Together  
Improving Outcomes Now -  
AKction2*

RESEARCH PROTOCOL

MARCH 2021

## Contents

Investigator details.....	2
Principal Co-Investigators .....	2
Chief Investigators .....	2
Associate Investigators .....	3
AKction Project Team – (Current as per January 2025) .....	5
Previous Project Team Members.....	5
Students .....	5
Abbreviations.....	6
Introduction .....	7
Background .....	9
Purpose .....	10
Anticipated start and finish dates.....	10
Project Design .....	11
Participants: .....	12
Methodology:.....	14
Methods.....	15
Research Sites .....	16
Sub Study 1: Indigenous Governance - “ <i>We are more than our disease!</i> ” .....	17
Sub study 2: Support for Aboriginal and Torres Strait Islander kidney patients “ <i>We know what it is like</i> ” .....	18
Sub study 3: Kidney journey mapping “ <i>No one else should have to experience this</i> ” .....	19
Study 4: Cultural Safety in Kidney Care- “ <i>Sometimes they just don’t get it</i> ” .....	21
Resources .....	22
Funding .....	22
Confidentiality, data storage and security.....	22
Publications.....	22
Ethical Considerations.....	23
Results, Outcomes and Future Plans .....	26
Plans for dissemination and publication of project outcomes .....	26
Project closure processes .....	27
Plans for sharing and/or future use of data and/or follow-up research .....	27
Targeted, Likely/Foreseeable and Incidental Participant Recruitment .....	27
References .....	28

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**Lili Simpson Lyttle** – Torres Strait Islander woman (Gadu, Suki Clan), lived experience of dialysis

**Waluwa Dono** - Torres Strait Islander woman (Gadu, Suki Clan), family and community representative

**Ramon Gadd** – Bajala man, lived experience of dialysis and transplantation

**Marissa Wilson** – Warlpiri and Anmatyerre woman with lived experience of dialysis

**Christine Franks** - descendant of the Yuin people, community representative

**Derek Forbes**- Kurna man with lived experience of dialysis and transplantation

**Trudy Reid** – Kokatha woman with lived experience of dialysis

**Denise Champion** - Adnyamathanha woman, lived experience of dialysis

**Shellander Champion** - Adnyamathanha woman, family and community representative

**Inawinytji Tjingilya (flower) Williamson** – Anangu, Pitjantjatjara and Yankunytjatjara woman with lived experience of dialysis (*Returned to the Dreamtime*)

**Nari Sinclair** - Ngarrindjeri and Yorta Yorta woman, with lived experience of dialysis and transplantation (*Returned to the Dreamtime*)

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## Previous Project Team Members

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## Abbreviations

ACCHO: Aboriginal Community Controlled Health Organisation

A2RT: AKction 2 Reference Team

APT: AKction Project Team

CPD: Continuing Professional Development

CNARTS: Central and Northern Adelaide Renal and Transplantation Services

CQI: Continuous Quality Improvement

SAHMRI: South Australian Institute of Health and Medical Research

# Introduction

This project brings together Aboriginal and Torres Strait Islander people living with kidney disease and failure, their families, health professionals, health services, academics and researchers to improve renal care and services in South Australia. AKction2 builds on the learnings and outcomes of AKction 1 where Aboriginal and Torres Strait Islander patients and their families were involved in community consultations and patient journey mapping, informing renal care and clinical guideline development for both culturally and clinically safe care.

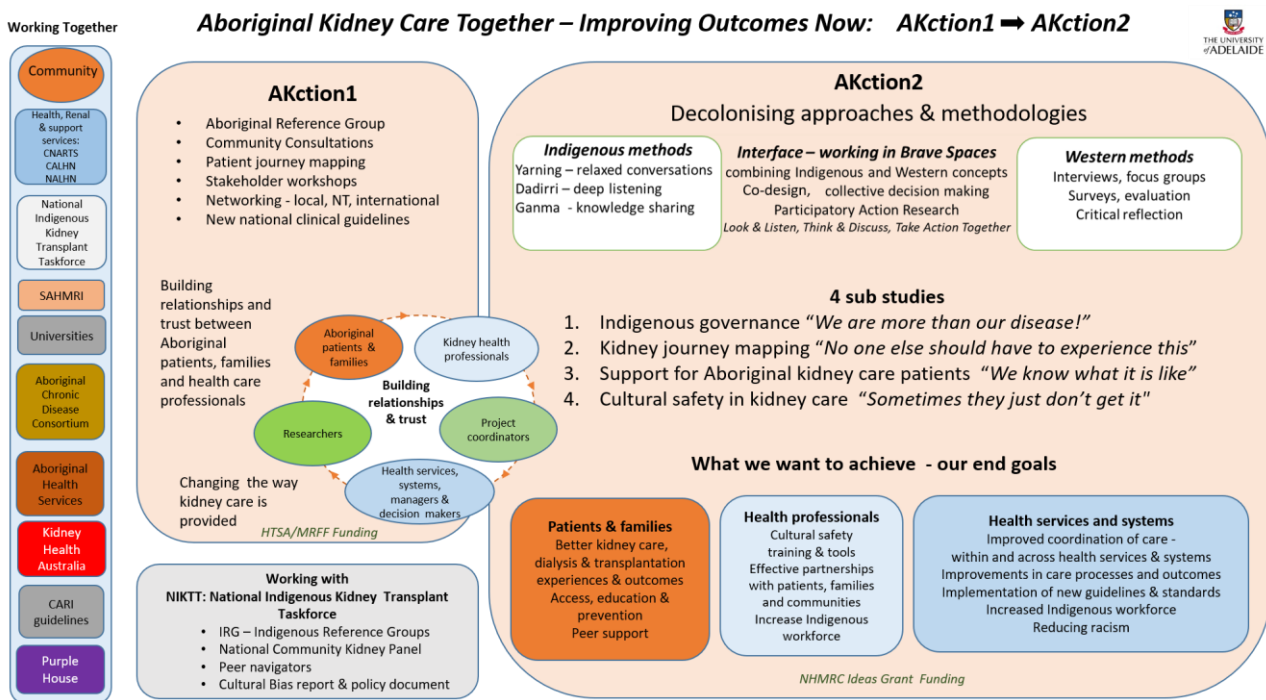
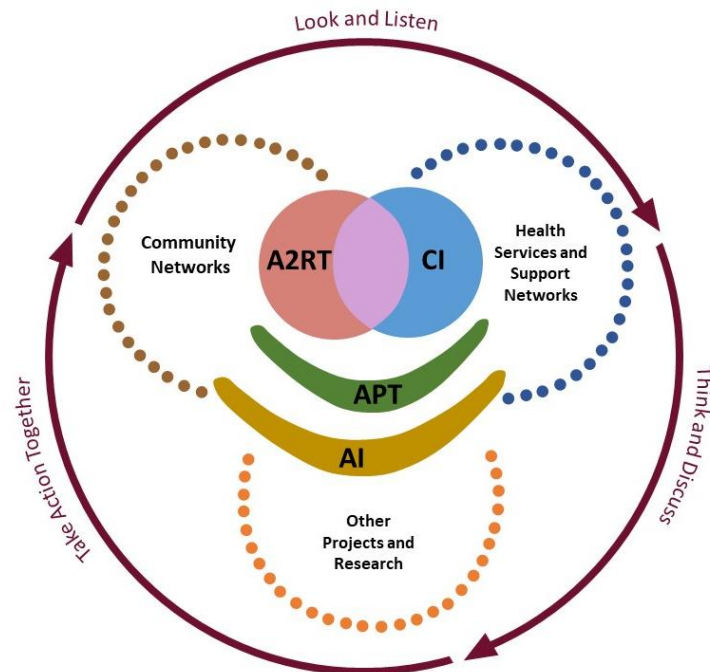


Figure 1: Moving from AKction 1 into AKction2



AKction2 extends and centres the role of Aboriginal and Torres Strait Islander patients and community members from advisory to leadership and Indigenous governance, with active involvement in key decision making, research and health care re-design. Aboriginal and Torres Strait Islander renal patients and family members are now positioned as Chief Investigators and AKction2 Reference Team (A2RT) members, supported by the AKction Project Team (APT), Associate Investigators and wider multidisciplinary managers, coordinators, medical, nursing, allied health and support staff and services (Figure 2).



**Figure 2:** AKction2 teams' structure

Together we are working as allies and partners to co-design innovative and responsive models of kidney care within and across health and support services. Our road map for action is underpinned by Durie's *working at the interface* principles of shared benefits, human dignity, discovery and innovation. We recognise the strength and resilience of Aboriginal and Torres Strait Islander people, and will utilise Indigenous methodologies (Yarning, Dadirri and Ganma), to better understand and respond to people's lived experience of kidney disease/failure. We also recognise the need to meaningfully address the ongoing impacts of colonisation and interpersonal and institutional racism. The AKction2 project is organised into four interconnected sub-studies that identify and promote effective collaboration and partnership between patients and clinical staff; and seeks to initiate new models of care and service and system responses; focusing on the need for both culturally and clinically safe care.

## Background

Kidney disease and failure, is a growing concern for many Aboriginal and Torres Strait Islander people, families and communities with significant health and wellbeing implications (1). Timely diagnosis, early detection and clear understanding of treatment options is vital (2). Care for kidney failure involves regular and lengthy dialysis sessions and visits with numerous specialists and multidisciplinary health professionals, placing a high cost on both community members and the health system (3). For Aboriginal and Torres Strait Islander people living in rural and remote locations, a diagnosis of kidney failure can mean having to leave their homes, families and Country in order to receive life-saving treatment in cities and regional hospitals (4). Many Aboriginal and Torres Strait Islander people experience kidney failure at younger ages (5), while raising children and meeting education and work commitments. They may also have other chronic conditions such as diabetes or heart disease (6). The challenge of navigating kidney and health care services while unwell and unsupported is huge, and often leads to missed dialysis, worsening health conditions and potentially emergency admissions (2), significant personal and health service costs (3) and, in the worse-case scenario, death (1). Regular dialysis and specialist appointments are key requirements for successful transplantation workup. If patients are unable or unsupported to attend dialysis and appointments, their chance of undergoing kidney transplantation is greatly reduced (7, 8) leading to further inequities, and feelings of hopelessness.

### *Current renal health care, policies, Acts and guidelines*

Nationally, Aboriginal and Torres Strait Islander people aged 25 to 64 experience rates of kidney failure ten times that of their non-Indigenous peers (1) and for those living in rural or remote areas this disparity rises up to 30 times (1, 9). In South Australia the Central and Northern Adelaide Renal and Transplantation Service (CNARTS) provides clinical care to over 600 dialysis patients and 800 renal transplant recipients across city and country South Australia, 8% of whom are Aboriginal and/or Torres Strait Islander. CNARTS strives to provide responsive and well-coordinated care, but is often challenged in achieving this for Aboriginal and Torres Strait Islander patients with complex clinical and cultural safety care needs.

All health care services are required to meet the 2017 National Safety and Quality Health Service accreditation standards (10). There are now an additional six specific actions to assess health services' ability to; work in partnership with Aboriginal and Torres Strait Islander patients, identify, and meet safety and quality priorities, accurately identify Aboriginal and Torres Strait Islander patients, provide a welcoming environment, and ensure cultural competency of staff (10). The 2020 Healthcare Action Framework for Aboriginal and Torres Strait Islander People (11) combines these actions with the need to reduce institutional racism, recognise race discrimination law, and establish cultural safety and decolonisation models and incorporate them into practice. Within South Australia, the SA Public Health Act 2011 is unique in that it specifically identifies the need to provide for, and support strategies and programs designed to, improve the health of Aboriginal and Torres Strait Islander people within communities (12). Currently, inaugural National Indigenous specific renal clinical guidelines are being written (13), informed in part by AKtion1 community consultations (14, 16) and journey mapping (17). Aktion2 will work alongside

CNARTS to devise effective ways of incorporating these standards and guidelines into everyday renal clinical care.

## Purpose

### **Overarching aim:**

This project aims to improve the experiences and outcomes of kidney care for and with Aboriginal and Torres Strait Islander patients, families and community members and kidney health services within South Australia.

### **Secondary aims:**

1- To identify the processes and resources required to enable the establishment and sustainability of effective Indigenous Governance and shared decision making in kidney health care.

2- To identify, pilot and evaluate a response to better meet the support needs of Aboriginal and Torres Strait Islander kidney care patients and family members as they begin kidney care journeys.

3-To identify, map and assess kidney patient journeys and care experiences to identify gaps and strengths and improve experiences and outcomes of care, and co-create new models of care.

4- To identify the cultural safety training needs of South Australian kidney health staff, and respond to these by developing, piloting and evaluating the effectiveness of new training tools.

### **Hypothesis:**

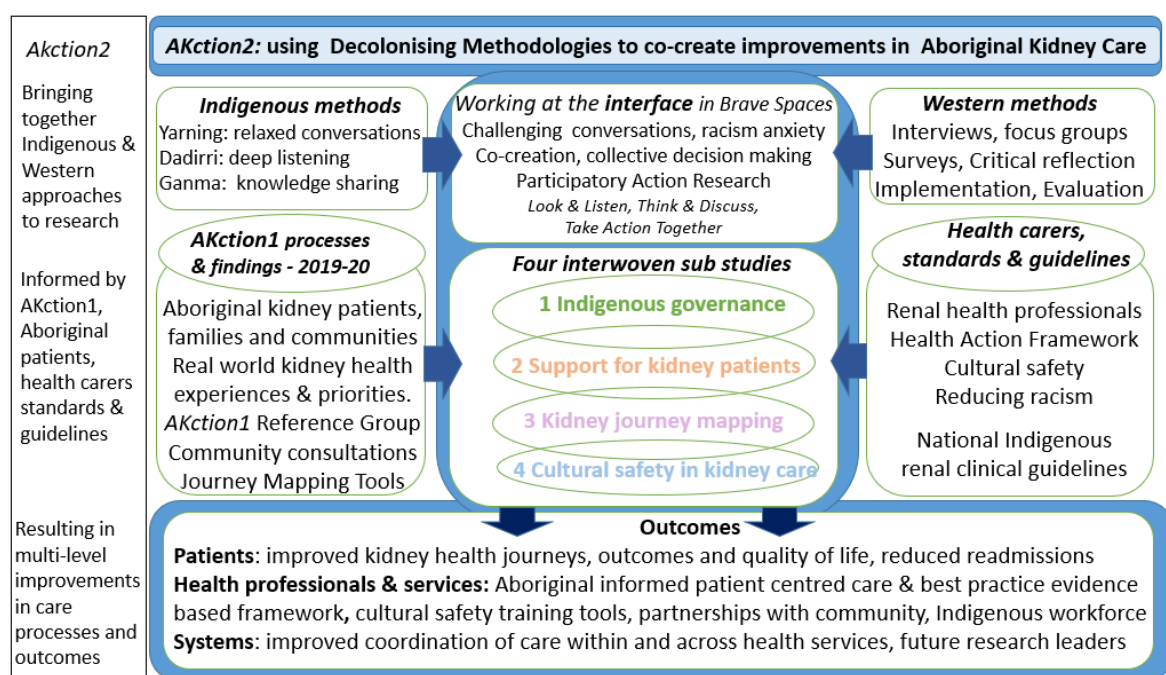
We hypothesize that the combination of decolonising methodologies and participatory research will enable Aboriginal and Torres Strait Islander patients, families, communities and kidney health services to co-create significant improvements that ensure people to thrive, opposed to just survive their kidney health journeys.

## Anticipated start and finish dates

1 April 2022 – 31st March 2026.

## Project Design

Participatory action research and four interconnected and concurrent sub-studies form the basis of the design of this project. Each sub-study is based on priorities identified in AKction 1 and reflect the lived reality of Aboriginal and Torres Strait Islander kidney patients and their families, and the challenges experienced by renal services when attempting to provide holistic, culturally safe care.



**Figure 3: Decolonising Methodologies**

**Sub-study 1** focuses on **Indigenous Governance**; aiming to identify and develop resources and processes required for the establishment and continued success of effective Indigenous Governance and shared decision-making structures. Semi structured interviews and focus groups will be conducted with A2RT members, using Yarning, Ganma and Dadirri to explore their experiences with AKction thus far and perceived challenges moving forward. Semi-structured interviews and focus groups will also be held with health care leaders, coordinators and key stakeholders to determine what is required for meaningful and effective involvement of Aboriginal and Torres Strait Islander community in health service co-design. This will be accompanied by critical reflection journaling for all involved, focusing on what has been learnt, how to successfully work together in these brave spaces and how to meaningfully respond to identified issues and inequities. A scoping review will examine how Indigenous kidney health reference groups have been established and supported across Australia so far.

**Sub-study 2** will build upon previous peer navigator and **peer support** studies, seeking to understand when and how peer-navigators can be beneficial within a kidney care journey. The participant journey stories from AKction 1 and sub study 3 will be

reviewed to identify strengths and unmet support needs, and where and how patient peer navigators may be the most effective. Existing literature and documents will be reviewed to identify essential elements for success, in consultation with established peer navigators and project coordinators. A pilot study involving kidney patient experts in a peer navigator program will be established, trialled with emphasis on how this program can be sustained within CNARTS. Regular focus groups will be held with the peer navigator team, kidney health professionals and health service staff to identify key strengths, weaknesses and long-term feasibility and benefit of continuing this type of program.

**Sub-study 3** focuses on **Mapping Kidney Journeys**. We will map between 15 and 20 kidney patient journeys using semi-structured interviews and inviting participants to share their experiences using Dadirri – deep listening. Prompt questions reflecting specific issues identified in AKtion 1 will also be used. Photovoice or artwork may supplement these journey stories, depending on participant’s interest and preferences. The resulting journey maps will identify the health and wellbeing needs and priorities of current kidney care patients and the extent to which these needs are being met. We will analyse individual kidney care journeys against the new Aboriginal and Torres Strait Islander Kidney care clinical guidelines, health standards and frameworks. Additional interviews and focus groups held with health professionals will collaboratively identify gaps in care within and between services. A health economist will be engaged to calculate the costs for both the client and the health service of planned versus unplanned admissions. These findings will be shared with key stakeholders in workshops; where data will be reviewed, and new continuous quality improvement and evaluation frameworks co-designed.

**Sub-study 4** will investigate the **cultural safety** training needs of South Australian kidney health staff. This will involve a survey of staff, as well as review of the mapped journeys and a scoping review of current cultural safety education approaches within health care. This data will be used to co-create a new cultural safety education package and materials to be delivered to healthcare staff and healthcare tertiary education students and evaluated by the A2RT. A pre and post education survey will identify levels of perceived benefit from the healthcare staff.

## Participants:

### i Inclusion

- Patient Experts: Aboriginal and Torres Strait Islander people who have or are receiving kidney care within CNARTS
- Family and community members. Any Aboriginal or Torres Strait Islander person who lives in South Australia and has family, friends or fellow community members experiencing kidney disease/failure.
- Health staff involved in the coordination or delivery of kidney care to Aboriginal and Torres Strait Islander patients.
- All participants must be over the age of 18 and capable of providing informed and voluntary consent.

## **ii Exclusion**

- Patients or family members aged under 18 years, or unable to be involved due to cognitive ability and/or those who decline to participate.
- Staff who decline to be involved.

## **iii Recruitment**

- Aboriginal and Torres Strait Islander patients, family and community members with experience of kidney disease/failure and kidney care will be invited to be involved in research activities via flyers, emails, A2RT and Project Team members, CNARTS and ACCHO staff, and through radio and social media.
- Staff: staff will be invited to be involved in this project via email, health service meetings and flyers.

## **iv Monetary reimbursement –**

A2RT members (x10) will be reimbursed (hourly rate) for attending monthly meetings, and providing Indigenous Governance to lead the project.

Patients and their family members will be offered travel assistance in the form of a taxi vouchers to support them attending meetings and workshops. This will also be extended to those with limited mobility with the provision of vouchers for access cabs.

Participants who choose to have their kidney journeys mapped will receive 2 gift vouchers (1x upon completion of their interview and 1x upon completion of checking the accuracy of the interview transcript with them).

Aboriginal and Torres Strait Islander community members who provide interpreting, facilitation or co-researcher services will be paid for their time (hourly rate).

Healthcare staff will not be reimbursed for their time. Rather this project will work with health services to ensure that outcomes are mutually beneficial. This includes arranging recognition and CPD accreditation for involvement in research activities where possible and sharing findings as part of health service CQI processes.

## **v Informed consent**

Each patient, family, community and health staff participant invited to be involved in the project will have the project and their potential involvement clearly explained, with diagrams showing the entire project and where their specific activity fits in. If they choose to participate, informed consent will be sought. Interpreters will be accessible and used if language is a barrier to fully informed consent. Either written consent, or verbal consent will be accepted. Patients may identify family members that they would like to be involved, and these family members will also be involved in an informed consent process if they are interested in participating.



## Methodology:

### **i Existing data**

Data collected within AKtion 1 community consultations, patient journey mapping and key stakeholder workshops has been published and/or used to identify the priorities for AKtion2.

### **ii Data collection**

Semi-structured interviews, focus groups and critical reflection will be led by members of the research team. Data from these sources may include audio and Zoom recordings which may then be transcribed. Field notes will also be taken.

Health journey mapping will be led by experienced researchers who will map patient's journeys from the patient and their family members' perspective. Aboriginal and Torres Strait Islander patient experts will also be involved in the mapping and data collection processes. SA Health/CNARTS/ACCHO staff will be involved in identifying gaps in care within and between health services in interviews and focus groups.

Pre and post cultural safety education surveys will be designed and conducted by research team members.

### **iii Existing tissue/samples**

Not applicable

### **iv Tissue / sample collection**

Not applicable

### **v Data – identifiable category**

Patient journey data will be re-identifiable - only information relevant to the project will be collected. Only researchers/investigators involved in the study data collection, analysis and reporting of results within a specific SA Health/CNARTS/ACCHO site will have access to the identifiable data. Any resulting case studies will be de-identified and checked back with the participant before being used outside of that SA Health/CNARTS/ACCHO site.

## Methods

Our unique approach brings together decolonising research methodologies and participatory action research by bringing community members and health services together to work collaboratively. This approach is a significant contribution to health services research. Our decolonising approach will ensure Indigenous worldviews are acknowledged and respectfully incorporated with western scientific worldviews; within this interface we will create an innovative and contemporary approach to kidney care and research. Distinctive knowledge systems will be carefully and respectfully combined to co-create new opportunities, understanding and responses. This will be a brave space where inequities can be addressed.

Indigenous research approaches of Yarning, Ganma and Dadirri will be used in conjunction with western research methods:

**Yarning:** an open conversational exchange, used to share information and build relationships. Yarning enables and encourages Indigenous participants to talk freely about their experiences, ideas and thoughts, whilst also enabling the researcher(s) to respectfully explore the topic in greater depth. This process supports Indigenous ways of working and sharing knowledge, resulting in the development of respectful partnerships and two-way exchange.

**Ganma:** provides a conceptual framework for effective and equal knowledge sharing between Indigenous and non-Indigenous people. Based on an Indigenous concept of different streams of water coming together to create foam; Ganma is a place where Indigenous and Western knowledge and experiences come together to re-create shared understanding.

**Dadirri:** is based on the importance of 'listening deeply' and respectfully. Dadirri acknowledges that although our experiences may be vastly different, truly listening to others facilitates learning and growing together. Reciprocity and reflexivity are key to this process, encouraging reflection on one's beliefs, influences, assumptions and choices.

Semi structured interviews and focus groups, surveys, critical reflection, key stakeholder workshops, co-design of new strategies, implementation of pilot projects and evaluation will be used across the four sub studies, as is shown in Figure 4. Details of each sub study activity are then provided in more detail.



## AKtion2: Aboriginal Kidney Care Together – Improving Outcomes Now

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

<p><b>Sub study 1: Indigenous Governance</b></p> <ol style="list-style-type: none"> <li>1. Reference Team (ART) members' experiences</li> <li>2. Health professionals perspectives of ART – in Australia &amp; Canada</li> <li>3. Reference group establishment &amp; support needs</li> <li>4. Working effectively at the interface</li> </ol>	<p><b>Sub study 2: Support for Kidney Patients</b></p> <ol style="list-style-type: none"> <li>1. Identify patient &amp; family unmet support needs</li> <li>2. Identify what works in patient support &amp; navigator programs</li> <li>3. Investigate the feasibility of peer navigators</li> <li>4. Peer support &amp; information sharing</li> </ol>	<p><b>Sub study 3: Kidney Journey Mapping</b></p> <ol style="list-style-type: none"> <li>1. Map individual kidney journeys, needs &amp; gaps</li> <li>2. Identify coordination &amp; communication gaps -health professionals</li> <li>3. Improve coordination and communication within &amp; between sites</li> <li>4. Review findings, prioritise action</li> </ol>	<p><b>Sub study 4: Cultural safety in kidney care</b></p> <ol style="list-style-type: none"> <li>1. Identify cultural safety training needs of staff</li> <li>2. Review cultural safety education approaches in health care &amp; universities</li> <li>3. Co-create, trial &amp; evaluate a kidney health cultural safety education package</li> <li>4. Refine package through feedback from participants</li> </ol>
<p><b>Methods</b></p> <ul style="list-style-type: none"> <li>• Yarning, Ganma, Dadirri, interviews &amp; focus groups with community members &amp; health professionals</li> <li>• Scoping Review</li> <li>• Critical Reflection journals</li> <li>• Ganma knowledge sharing with ART &amp; researchers in workshops</li> </ul>	<p><b>Methods</b></p> <ul style="list-style-type: none"> <li>• Review journeys, workshop with ART, identify unmet needs</li> <li>• Focus groups with patient support /navigator programs</li> <li>• Co-create &amp; evaluate a pilot peer navigator project. Adapt mapping tools for use.</li> <li>• Peer support &amp; information workshops</li> </ul>	<p><b>Methods</b></p> <ul style="list-style-type: none"> <li>• Interviews, my kidney my journey mapping tools, photo voice &amp; artwork</li> <li>• Mapping journeys against standards &amp; guidelines. Calculate personal &amp; \$\$ costs</li> <li>• Co-creation of kidney journey quality improvement tools</li> <li>• Key stakeholder workshops</li> </ul>	<p><b>Methods</b></p> <ul style="list-style-type: none"> <li>• Survey kidney care staff - skills, knowledge &amp; training</li> <li>• Scoping review</li> <li>• Review findings, refine &amp; workshop package, participant evaluation, post training survey.</li> <li>• End user workshops</li> </ul>
<p><b>Outcomes</b></p> <ul style="list-style-type: none"> <li>• Identification of the decolonisation processes required to establish and support Indigenous reference groups</li> <li>• A "How to Guide" for establishing and sustaining Indigenous Governance in projects and renal care</li> </ul>	<p><b>Outcomes</b></p> <ul style="list-style-type: none"> <li>• Better understanding of the key elements of an effective peer navigator program</li> <li>• Increased workforce capacity &amp; improved models of care</li> <li>• Increased support and recognition of the role of patient experts by experience</li> </ul>	<p><b>Outcomes</b></p> <ul style="list-style-type: none"> <li>• Kidney Specific mapping tools for patients, health professionals &amp; services to use in day-to-day clinical practice. CQI, and evaluation</li> <li>• Clearer identification of gaps in care, &amp; co-design of responsive strategies for improvement in coordination and care outcomes</li> </ul>	<p><b>Outcomes</b></p> <ul style="list-style-type: none"> <li>• Targeted cultural safety education for use within renal care</li> <li>• Updated cultural safety resources for use in tertiary education</li> <li>• Increased cultural safety in practice</li> </ul>

Figure 4: Activities, Methods and Outcomes.

### Research Sites

The AKtion project is based within the Adelaide University Nursing School and CNARTS within the Royal Adelaide Hospital. In addition to these sites, research activities and data collection will also take place at the following:

- Kangawoodli Aboriginal Hostel
- Hampstead Dialysis Clinic
- The Queen Elizabeth Hospital
- Port Augusta Hospital
- Pika Wiya Aboriginal Health Service
- Ceduna Hospital
- Ceduna, Yadu Health Aboriginal Corporation
- Yalata, Tullawon Aboriginal Health Service
- Murray Bridge Hospital
- Moorundi Aboriginal Health Service,

## Sub Study 1: Indigenous Governance - *"We are more than our disease!"*

**Aim 1:** To identify the processes and resources required to enable the establishment and sustainability of effective Indigenous governance and shared decision making in kidney health care.

### 1.1 A2RT

- Yarning, Ganma, Dadirri semi structured interviews and focus groups
- PAR - look and listen, think and discuss and take-action
- Analyse with A2RT members.
- Explore A2RT member experiences in AKction1, and their perceptions of the challenges, opportunities and resources required for them to be meaningfully involved in Indigenous Governance and decision making in AKction2 and beyond. Collectively analyse the data with A2RT members drawing out themes, findings, and strategies for action.

### 1.2 Discussions with health care leaders, coordinators, and key stakeholders in SA & Canada

- Yarning, Ganma, Dadirri.
- Semi structured interviews and focus groups.
- Explore the role of community members in kidney health care, research and policy development both within CNARTS and across other South Australian sites and Canadian sites (through CI Lavoie & the Canadian kidney health research team) to determine what is required for meaningful and effective involvement of Aboriginal and Torres Strait Islander community members in health service co-design.

### 1.3 Conduct a scoping review to determine how Indigenous kidney health reference groups have been established and supported across Australia

- Scoping review & workshop findings with A2RT.

### 1.4 Research Team members - critical reflection

- Critical reflection journals.
- Ganma knowledge sharing workshops to share our experiences and learning about working together in decolonising spaces.
- We will invite all AKction2 team members, CIs and AIs, to engage in deep discussion about how we work together effectively at the interface between Indigenous/Western, community/health care, health consumer/health professional/researcher/policy maker, and meaningfully respond to long term and complex issues related to colonisation, power, racism and inequities. Working in these 'Brave spaces' requires new approaches and mindsets.

## Sub study 2: Support for Aboriginal and Torres Strait Islander kidney patients “*We know what it is like*”

**Aim 2:** To identify, pilot and evaluate a response to the support needs of Aboriginal and Torres Strait Islander kidney care patients and family members as they begin kidney care journeys.

### **2.1 Review journeys, identify current supports and unmet support needs**

- Review kidney journey case studies from AKction 1 and Sub-study 3.
- Identify current supports and unmet support needs with A2RT members, Aboriginal and Torres Strait Islander kidney patients and their family members (analysis).
- Identify where patient peer navigators may be most effective (analysis).

### **2.2 Identify essential elements of success of existing programs**

- Document Review -review existing reports and documentation.
- Focus groups - online and face to face focus groups with peer navigators and coordinators in other established programs and pilot projects (Purple House in Darwin, and the National Indigenous Kidney Transplant Taskforce – NIKTT
- Identify essential elements of success (analysis).

### **2.3 Co-create a pilot peer navigator project \*\***

- Preparation - investigate the feasibility and impact of (a male and female) peer navigators operating in South Australian hospitals and dialysis centres.
- Engage 8 Aboriginal and Torres Strait Islander patient experts and provide training. Regular focus group meetings with AKction2 peer navigator team and kidney health professionals and health service staff (3 monthly) to identify key strengths and issues, collate and analyse these using Nvivo and work with the peer navigation team to co-author a pilot study report. There are currently few evaluation methods that accurately record the ‘behind the scenes’ and non-clinical support provided by existing pilot programs, making it difficult for such programs to be refunded or continued.

### **2.4 Peer support and information sharing – workshops road shows/ continuing the work begun in the consultations /peer support workshops**

- Hold community workshops that introduce AKction goals, team & activities.
- Identify patient, family, community support needs and provide responsive support, health information and education. Develop other supportive resources such as a webpage.

**\*\*Note:** *A comprehensive peer navigator project was subsequently funded and undertaken by the National Indigenous Kidney Transplantation Taskforce – within the COMPASS project.*

## Sub study 3: Kidney journey mapping “*No one else should have to experience this*”

**Aim 3:** To identify map and assess kidney patient journeys and care experiences to identify gaps and strengths and improve experiences and outcomes of care, and co-design new models of care.

### **3.1 Kidney journey mapping – patient focused Dadirri**

- 15 – 20 x kidney journeys mapped in a collaborative, patient centred process that identifies strengths, issues and solutions at an individual patient, service and systems level.
- Semi structured interviews, using Dadirri in Adelaide, Murray Bridge, Port Augusta/Whyalla and Ceduna/Yalata using my kidneys, my journey mapping tools to identify health and wellbeing needs, and the extent to which these have been met. Prompt questions about specific issues identified in AKction1, family and peer support, transport and accommodation, access to dental care, and the effectiveness of current resources and information.
- Photovoice & artwork can be used as an option to supplement the kidney journey mapping if participants are interested. This will enhance our understanding of what cultural safety means from patient and family member’s perspectives. We will invite each patient and family participant to visually record aspects of culturally safe care using artwork and/or photovoice.

### **3.2 identify gaps in care and opportunities for improved communication and coordination – with health professionals**

- Interviews and focus groups with clinicians, dialysis managers and Aboriginal and Torres Strait Islander Health Professionals in each location to identify gaps in care, within and between services; city and country; primary and tertiary; renal, allied health, Aboriginal Community Controlled and support services.
- Analysis of individual kidney care journeys against the new National Aboriginal and Torres Strait islander Kidney Clinical Guidelines, health care standards and frameworks to assess how each journey compares to ideal standards of care.
- Identify which patients experienced planned dialysis commencement versus emergency admission dialysis commencement and investigate the factors that influenced this.
- We will engage a health economist to calculate the cost to both patients and health services of unplanned emergency admissions and planned dialysis care, and the cost for people relocating from a rural or remote area to the city to commence dialysis.

### **3.3 journey quality improvement tools**

- Co-create kidney journey quality improvement tools for ongoing use within and between CNARTS urban, rural and remote locations – improve coordination & communication.

### **3.4 Review findings, take action – workshops and implementation**

- Key stakeholder workshops - we will hold workshops with Aboriginal and Torres Strait Islander patient experts, CNARTS clinicians and quality improvement teams to review the findings together and co-develop new tools and evaluation frameworks. We will work with CNARTS and SA Health to determine how to embed key elements of quality kidney care into existing health service records and monitoring for Aboriginal and Torres Strait Islander patients.

## Study 4: Cultural Safety in Kidney Care- *“Sometimes they just don’t get it”*

**Aim 4:** To identify the cultural safety training needs of South Australian kidney health staff, pilot and evaluate the effectiveness of new training tools utilising Aboriginal and Torres Strait Islander kidney journey case studies.

### **4.1 Survey of staff**

- We will survey kidney health staff in two urban hospital renal wards and two dialysis units, and rural and remote sites to identify their cultural safety knowledge, skills and training needs, utilising a well- recognised multi-disciplinary survey designed by Indigenous scholars (West et al).

### **4.2 Scoping review**

- Conduct a scoping review of cultural safety education approaches in health care and tertiary settings.

### **4.3 co-create a cultural safety education package**

- Bring together survey results, scoping review results, findings from journey mapping and photo voice from Sub study 3; Combine these three data sources with concepts of cultural safety that focuses on renal staff critical reflection, Aboriginal and Torres Strait Islander patient journey stories, and health service responses to racism and inequities.
- We will hold cultural safety education package development workshops with hospital and university educators and A2RT members to refine the package. Trial the education package in the same sites as the survey and invite participants to evaluate their experience of the training. Repeat the original survey with kidney health staff to measure pre and post training effectiveness (where possible due to staff turn-over). We will take the learning from this process to create both face to face and online options for undergraduate nursing and medical courses.

### **4.4 End user workshop**

- Hold a workshop with health service managers, educators and other relevant participants to discuss findings and ways of embedding and evaluating effectiveness of cultural safety training programs, and application in clinical settings.

## Resources

This research project has been developed by researchers from the Adelaide Nursing School (The University of Adelaide) in collaboration with CNARTS Clinical Research Group. Careful consideration has been and continues to be undertaken, to ensure that this project is mutually beneficial and not overly burdensome to any one site or organisation.

The resources necessary for the project to be conducted include:

- Aboriginal and/or Torres Strait Islander A2RT members, chief investigators, associate researchers and researchers
- Chief and associate investigators from University of Adelaide, SA Health and SAHMRI
- The Project coordinator, research assistants and higher degree research students within the University of Adelaide
- A Health Economist employed within the project
- My Kidneys, My Journey mapping tools – adapted from those developed in the Managing Two Worlds Together Project and the Health Journey Mapping Project with the Lowitja Institute
- A room/location (at each site as required) to conduct focus groups and interviews

## Funding

Ideas Grant Funding from the National Health and Medical Research Council has been awarded to support this project, Application ID 2004389.

## Confidentiality, data storage and security

Data storage during the study: All data collected in paper form will be stored securely at the University of Adelaide in a locked filing cabinet in a locked office. All data collected in electronic form will be stored on the University of Adelaide server or a password protected laptop which will be locked in a filing cabinet in a locked room when not in use. All data will be stored for 7 years then destroyed.

Data Storage post projected completion: All data collected in paper form will be stored securely at the University of Adelaide in a locked filing cabinet in a locked office. All data collected in electronic form will be stored on the r University of Adelaide server or a password protected laptop which will be locked in a filing cabinet in a locked room when not in use. All data will be stored for 7 years then destroyed.

Sample storage – not applicable

## Publications

Reporting of study results will be by publication in peer-reviewed public health, nephrology, nursing and education journals and by presentation at national and



international conferences. Results will also form the basis of higher degree research theses, at Honours, Masters and PhD level.

## Ethical Considerations

This project been reviewed by, and received approval from the Aboriginal Health Research Ethics Committee (approval number #: 04-22-944), the Central Adelaide Local Health Network Human Research Ethics Committee (HREC reference number: HREC/19/CAHLN/45, CAHLN reference number: R20190124) and the University of Adelaide Research Ethics Committee (UoA ID 33394).

### *The ACCORD*

The South Australian Aboriginal Health Research Accord was developed in 2014 in response to the Aboriginal and Torres Strait Islander community calling for reform in the way research is conducted within this space.

The AKtion project addresses each of the key principles as shown in the following table.

Key principles of the Accord	How this project addresses each principle
<p><b>PRIORITIES:</b> Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.</p>	<p>This project builds upon the priorities identified by Aboriginal and Torres Strait Islander kidney patients, their families and communities in AKtion 1. We are therefore focusing on Indigenous Governance, Kidney Journey mapping, Peer Support for Aboriginal and Torres Strait Islander Kidney Patients, and Cultural Safety in Kidney Care.</p>
<p><b>INVOLVEMENT:</b> The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.</p>	<p>Many Aboriginal and Torres Strait Islander people and organisations are involved in this research; Aboriginal and Torres Strait Islander patient experts and researchers have chief investigator roles and a reference team (A2RT) comprised of Aboriginal and Torres Strait Islander people guide the project. We are also working with Aboriginal community-controlled health care services and support services.</p>
<p><b>PARTNERSHIP:</b> Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.</p>	<p>This project is based on relational networks and partnerships that have been formed between Aboriginal and Torres Strait Islander patient experts, researchers and kidney care services. This collaborative research uses Indigenous concepts of Ganma and Dadirri to ensure Aboriginal and Torres Strait Islander kidney patients are heard, and inform changes within health services.</p>
<p><b>RESPECT:</b> Researchers must demonstrate respect for Aboriginal</p>	<p>This project embeds Aboriginal and Torres Strait Islander ways of knowing, being and</p>



knowledge, Aboriginal knowledge systems and custodianship of that knowledge.	doing into the way we do research. We acknowledge custodianship of knowledge and work with people to co-create a decolonising methodology.
COMMUNICATION: Communication must be culturally and community relevant and involve a willingness to listen and learn.	Respectful two-way communication with sufficient time and timeliness, including the use of interpreters when needed.
RECIPROCITY: Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.	This study identifies barriers and enablers to kidney care, and works with clinicians and health services to co-design new models of care.
OWNERSHIP: Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.	The mapping process will enable Aboriginal and Torres Strait Islander patients and their family members to have their perspectives heard and verified. They will retain 'ownership' of their own journey stories. They will be invited to approve final versions of any case studies produced, as well determining the use of these case studies for education, training and quality improvement.
CONTROL: Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.	Non-biological research materials include people's journey stories, and these will be recorded, given back, and shared to the extent to which, and in whatever format participants prefer
KNOWLEDGE TRANSLATION: Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.	The overarching aim of this project is to change the way kidney care is experienced, designed and delivered. The findings of this research will be shared with patient experts, their families and communities, health professionals, health service managers and executives, policy makers, peak bodies and other key decision makers.

### *Benefits of the study*

The primary benefit of this study for Aboriginal and/or Torres Strait Islander peoples is potentially improved kidney health journeys and outcomes.

The additional benefits of this study for health services will be the increased capacity of staff and service to provide responsive care for Aboriginal and Torres Strait Islander patients.

- identifying current care strategies and gaps for patients and family members, health care staff and services.

- providing Aboriginal and Torres Strait Islander patients and their family members with opportunities to be involved in evaluating and planning their own care.
- providing health care staff with additional knowledge, skills and resources to enable them to better meet the needs of this vulnerable patient group.
- Provide feedback from Aboriginal and Torres Strait Islander communities about how to improve kidney care – this can be utilised locally at each healthcare site, at a state level, and will inform the national guidelines writing group who are developing the first national guidelines for Aboriginal and Torres Strait Islander Renal Care.

The outcomes of this project will be used to improve patient care through increased awareness of clinical, cultural, coordination and communication needs and implementation of effective strategies.

*Risks* - nil

*Risk mitigation* - nil

*Responsibility for liability of injury* – not applicable

*Conflicts of interest* – none identified. All CNARTS investigators are involved in clinical care of the patient cohort as part of their employment. University of Adelaide and SAHMRI investigators are experienced Aboriginal and Torres Strait Islander health researchers and educators invested in improving health care and education.

*Other ethical issues* – none identified

## Results, Outcomes and Future Plans

The A2RT will provide vision and oversight of the entire project, and be actively involved in decision making, knowledge sharing, and interpreting and approving research outputs. Aboriginal and Torres Strait Islander community members who choose to be involved in Health Journey mapping will be invited to approve the final version of any case study or education material that draws on their experiences, including details of its use. De-identified case study may be used for community education and teaching nursing and medical staff, if approved by the individual participant.

Staff involved in health journey mapping activities will receive a copy of the completed case study and analysis. Staff involved in interviews and focus groups will be offered a copy of the transcript for member checking, and a final report of the research results. Participants in key stakeholder and networking meetings and forums will receive written reports of that activity.

Please refer to **Figure 4: Activities, Methods and Outcomes** on page 16 for the breakdown of research outcomes associated with each sub-study.

### Plans for dissemination and publication of project outcomes

This is a knowledge translation project, and opportunities throughout the will be sought throughout the project to translate and disseminate findings and enable rapid translation to practice, and kidney care improvements.

- The research team and A2RT members will share outcomes and findings at community events, community radio and through web based and social media to reach a wider community audience.
- The research team will present findings in written publications, conference presentations and grand rounds.
- Honours, Master's and PhD students will write theses and articles.

Other potential uses of the data at the end of the project

- The case studies and updated health journey mapping tools developed through this project may be used as local, relevant, culturally respectful case studies for use in SA Health training and in undergraduate and post graduate education, if the individual participant agrees to this. Multiple members of the research team are also University of Adelaide lecturers and course coordinators.
- The mapping tools may also be used by other areas within the health care sites, SA Health and research facilities for future projects.
- The cultural education programs developed will potentially be used by health services and universities for ongoing undergraduate, postgraduate and staff education.
- Sharing of processes regarding the establishment and continued support of Indigenous reference groups and Indigenous Governance – the development of a 'How to Guide'.

## Project closure processes

The funding for the project will end in March 2026, it is expected that the project will also conclude at this time, pending any extensions. All data will be safely stored in University of Adelaide as per the guidelines. CI B has an ongoing position and can ensure this occurs.

## Plans for sharing and/or future use of data and/or follow-up research

As outlined above, the resulting case studies and health journey mapping tools will be used in education and training, and to inform future research. Patient journey stories will only be used as the basis of case studies when the participant has given explicit consent for this to occur. Where appropriate, journey stories will be combined, with significant changes to details to protect the identity and privacy of the person involved (this was done successfully in previous Managing Two World Together studies). The research team will work together and with the CNARTS Research Group to identify the most appropriate follow up research.

## Anticipated secondary use of data

The data in this study will not be used in any way other than that described above, particularly in relation to patient journey stories.

## Targeted, Likely/Foreseeable and Incidental Participant Recruitment

This project specifically, and intentionally targets Aboriginal and Torres Strait Islander patients with kidney disease/failure, their family members and the health professionals who care for them.

We purposefully began this research ethics process by seeking AHREC approval first, due to the strong focus on Aboriginal and Torres Strait Islander health care and wellbeing.

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