

AKtion2

Working Together Agreement

Aboriginal Kidney Care Together- Improving Outcomes Now

Collaboratively written by the AKtion2 Team

Acknowledgement of Sovereignty Unceded

We acknowledge the Kurna people as the Traditional owners, carers of the Tarntanyangga, (Adelaide Plains, South Australia) where AKtion began. We acknowledge all Aboriginal and Torres Strait Islander Peoples of Australia whose sovereignty remains unceded.



We acknowledge First Nations People worldwide and pay our deepest respect to you and your families.

We also acknowledge AKtion2 community supporters, researchers and health professionals, effective allies who know when to step aside, step up and step back to ensure our voices are amplified to lead change..

Purpose of this agreement

This agreement guides the entire AKtion2 project from April 2021 to March 2026. It is a living agreement over the life of AKtion2, reviewed at the start of each year and at the end of each year to check we're doing what we said we'd do and date stamped to track our progress. Consider its purpose like you would a memorandum of understanding (MOU) that keeps us individually and collectively accountable to each other, the vision and our principles (page 3).



At each review and when significant changes are made, these will be discussed and approved by AKtion2 Reference Team (A2RT), followed by approval and acknowledgement from AKtion2 partner Teams.

This agreement provides a clear vision, principles and guidelines about how we work 'Wirikara' way (Barkindji: alongside each other), to decolonise processes respectfully, work through disputes and co-design together.

This agreement acknowledges partner organisations in their various roles and capacity who support AKtion2.

Process of developing this agreement

This agreement was collaboratively developed by APT, in consultation with A2RT and reviewed and signed off by all AKtion2 Teams.



Definitions

Aboriginal	Many First Nations People living in South Australia prefer the term Aboriginal, and when used in in this agreement includes Torres Strait Islander people also living in South Australia.
AKction1	A Health Translation SA project (2019-2020) that established strong and respectful collaboration between Aboriginal community members, renal health services and researchers, and identified Aboriginal peoples' priorities for improvements in urban, rural and remote areas.
AKction2	10 Aboriginal kidney patient experts and carers who guide AKction2 (3 members are Chief
Reference Team (A2RT)	Investigators). This group also includes Elders (academic and cultural advisors).
Colonisation	Referring both to the occupation of land and the corresponding manipulation of the mind where the final goal is the monopolization of power, agency, and selfhood. The colonizer therefore appears in many roles: as the settler, the patriarch, the exploitative capitalist, a combination of these etc.
Decolonising Methodologies	Approaches to research that acknowledge the ongoing experiences of colonisation, the silence(s) about its implications and shifting/sharing of power and control.
Elder	An Aboriginal or Torres Strait Islander Elder is someone who is held in esteem by their community for their wisdom, cultural knowledge, spiritual and moral leadership, and community service
First Nations People	Refers to Aboriginal and/or Torres Strait Islander People, acknowledging the place and many different owners/carers of country across Australia for millennia before colonisation.
Health	Aboriginal health means not just the physical wellbeing of an individual but refers to the social, emotional, cultural and spiritual wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.
Indigenous Sovereignty	Having the freedom to make one's own decision and be in control of one's own life, freedom to partake in cultural practices and passing down knowledge. Associated with self-determination and a responsibility to Country.

Acronyms

AKction	Aboriginal kidney care together improving outcomes now
ANS	Adelaide Nursing School
AMS	Adelaide Medical School
AHMS	Adelaide Health and Medical Sciences
ANZDATA	Australia & New Zealand Dialysis and Transplant Registry
CNARTS	Central Northern Adelaide Renal & Transplantation Service
NIKTT	National Indigenous Kidney Transplantation Taskforce
Purple House	Western Desert Nganampa Walytja Tjuta Palyantjaku Aboriginal Corporation - an Indigenous owned and run non-profit kidney dialysis and health service based in Alice Springs
SAHMRI	South Australian Health & Medical Research Institute
WTA	Working Together Agreement





AKction1 into AKction2

The *Aboriginal Kidney Care Together – Improving Outcomes Now* (AKction) 2 is a five-year NHRMC¹ Ideas Grant funded research project, extended the AKction1 MRFF² project based at the Adelaide Nursing School, University of Adelaide (figure 1, page 7).

AKction 1 aimed to improve the experiences and outcomes of kidney care for and with First Nations patients, carers, families and community members and kidney health services in South Australia. AKction2 builds on this work to strengthen Indigenous Governance, reposition and centre Aboriginal peoples' voices and lived experiences to create brave spaces for shared decision making and culturally safe and timely access to kidney health care services.

AKction2 Vision

First Nations Peoples in South Australia who experience kidney disease are strong, are speaking back to the health system, are engaged and leading decolonising practices, in a culturally safe, anti-racist health system supported by effective, respectful partnerships with communities, health professionals, researchers and allied health services.

AKction2 Principles

To achieve our vision, AKction2 Teams and partners agree to:

- Privilege the voices, experiences, and expertise of the AKction2 Reference Team (A2RT)
- Maintain confidentiality (not your story, not your business) about personal journeys and any stories shared across the teams. Be mindful and keep private conversations out of public spaces.
- Meaningfully and respectfully contribute to complex discussions about the impact of colonisation, power, racism, and systems inequities
- Celebrate regularly, the small steps, our resilience
- Be flexible at times, and go with the flow about how we meet
- Work together using cycles of Look and Listen, Think and Discuss, Take Action Together, Evaluate and Reflect
- Humour is AKction2's Superpower- be prepared to 'Style up' have fun, and laugh together

¹NHMRC: National Health and Medical Research council ²MRFF: Medical Research Future Fund





Working Forward: Research Plan for AKction2

Together we will: co design strategies for improvements in kidney care in line with the new SA Health Care Action Framework for Aboriginal and Torres Strait Islander People (2013-2023), the inaugural National Aboriginal and Torres Strait Islander renal clinical guidelines (CARI), NSQHS & AHPRA Guidelines³⁻⁴.

There are four sub studies of AKction2, based on experiences, priorities and reflections of Aboriginal kidney patients and their families, and the challenges experienced by renal services when attempting to provide holistic, culturally safe care. The four interwoven sub studies are shown in Figure 2 (page 7) and described in more detail.

We will achieve this by:

- increasing support for Aboriginal people, informed by their lived experience of kidney disease;
- promoting effective communication, collaboration, anti- racism approaches and partnerships between patients, carers, clinical and support staff, and allied health services;
- utilising patient experiences and feedback for guidelines implementation;
- initiating timely service and health systems responses; focusing on both clinical and culturally safe care;
- Centring and extending the role of First Nations patients and community members from advisory, leadership and governance, with active positions in key research decision making and health care re-design;
- First Nations patients and family members positioned as Chief Investigators, supported by the AKction2 Reference Team, and multidisciplinary partner teams of community managers, coordinators, medical, nursing, allied health, and support staff.

³ NSQHS User Guide for Aboriginal and Torres Strait Islander Health (2017).

<https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-User-Guide-for-Aboriginal-and-Torres-Strait-Islander-Health.pdf>

⁴ AHPRA The National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020-2025

<https://nacchocommunique.files.wordpress.com/2020/02/aboriginal-and-torres-strait-islander-cultural-health-and-safety-strategy-2020-2025-1.pdf>





AKAction2 Teams

There are four AKAction 2 teams. APT, A2RT, Networks, and Investigators. Each team has a different responsibility, with some team members belonging to multiple teams. Members are recruited through AKAction2 members' relational networks and people who express an interest to be involved.

A2RT

AKAction2 Reference Team & Elders

Formerly the AKAction1 Reference Group. A community team of Aboriginal renal patient experts, carers, and family members in South Australia guiding all aspects of this movement.

Elders are male and female, providing cultural/academic guidance, advice and healing activities to the teams.

AKAction2 Chief & Associate Investigators

The team working to facilitate the collaboration of the project across SA. Includes Chief Investigators (CIs) and Associate Investigators (AIs) listed on the NHRMC Ideas Grant application.

APT

AKAction2 Project Team & Students

Staff employed by the University of Adelaide to carry out and coordinate the project. Postgraduate and undergraduate students who are undertaking research within the AKAction Project.

Networks

Community, Researchers, Clinicians, & Stakeholders

Aboriginal community-controlled health organisations, researchers, and clinicians in South Australia who are actively involved in kidney care, First Peoples health care and improving Aboriginal health journeys. We keep networks informed of AKAction2 work to seek feedback and advice whether we're on the right track or not. This is the main group we need to keep accountable to.

Meetings and Sharing Information

Co Leaders and the Coordinators will provide a movement update before and at each group meeting. The A2RT will meet every month from July 2021 to June 2025 at a comfortable, easily accessible venue. Key decisions can be made providing there is a minimum of 5 members. Decisions are made by members of the group in attendance. Meetings are by agenda and minutes are recorded. A light meal is provided each time A2RT meet. APT to be added as a standing item on all team agendas to ensure a cyclical communication of updates and actions from the AKAction2 teams (Figure 3).

Supporting A2RT

Nunga Space (First Nations):

As required, A2RT can decide to discuss issues in a closed team space (without health service representation/ involvement) and such decisions will be respected by all AKAction2 teams and partners.

A2RT Members:

The maximum number is 10. It's important to have a gender balance and youth representation.

A2RT Support:

Each time the meetings are held, members are paid \$30 per hour. There are two options for payment (this will be individual choice):

- Payment is paid into each participant bank account 2 weeks after the meeting (pay cycle of Adelaide university) - Please provide us with your banking details.

OR

- A payment voucher is provided on the day

Travel:

Cab vouchers are provided to cover travel from metro areas, or mileage reimbursement (72cents per KM-with the pay cycle of Adelaide Uni) is provided for regional travel in your private vehicle, including parking. Please provide bank account details if you choose this option.

Knowledge Exchange, Knowledge Translation:

Knowledge exchange and knowledge translation is an important factor in this project, we aim to promote and bring awareness to the community, health services and research space the important work we are all doing. From time to time a presentation and/or article will be written and published for external reading, the APT will inform all members when this happens.

Permissions:

AKAction Project Team (APT) requires permission from each member, to use their image or words of wisdom for all forms of media (including photos, videos, interviews, quotes, stories, artwork, and poetry). Each member can decide whether they'd like their photos to be used into the future.

There is a separate photo permission form for members to complete that provides a place to sign. This ensures consent is given to use photos for continued advocacy and resource development after a person has passed. This option is offered to honour and respect the work members achieve in their lifetime to improve kidney care for Aboriginal and Torres Strait Islander people in consultation with their families.

Data Sovereignty

AKAction supports Data Sovereignty by First Nations People having involvement, ownership, and control of their knowledge at all stages of data collection, analysis, interpretation, and dissemination. For example, A2RT members hold roles as co-researchers and co-authors, and may choose to be identified in publications to acknowledge their ownership of their knowledge and position data belonging to a real identifiable person. This also acknowledges that First Nations ways of knowing, being and doing belong to individuals, their families, and communities.



Figure 1: AKAction1 to AKAction2 Research Plan

AKAction 1 extended into AKAction 2

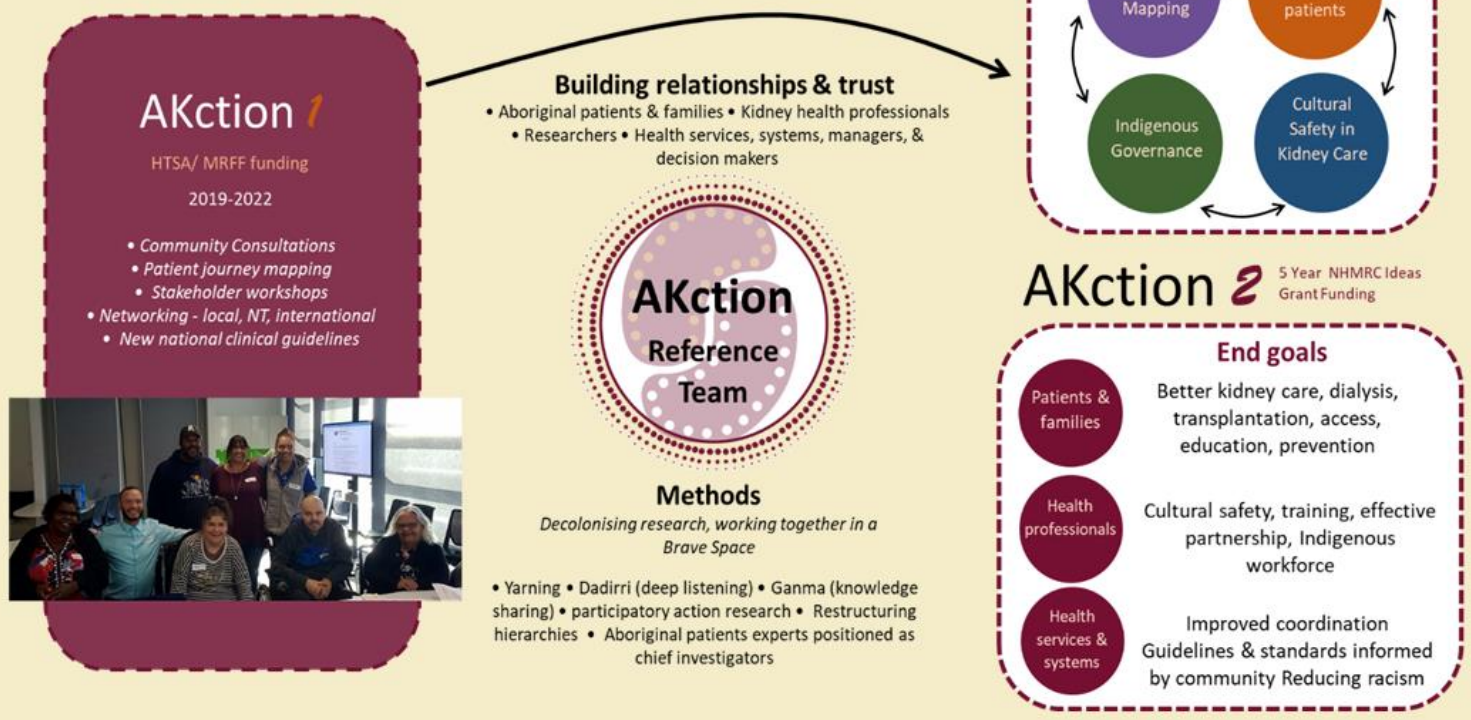


Figure 2: AKAction2 Four substudies with their aims, methods, and planned outcomes

AKAction2: 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

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

Figure 3: AKAction2 Team Meetings Schedule

M	T	W	T	F	S	S
		APT	A2RT			
		APT	Investigators			
		APT	Networks			
		APT		Newsletter		

A2RT: meet monthly at a comfortable easily accessible venue

APT: meet Wednesday mornings

Investigators: meet monthly, one week after A2RT

Networks: meet monthly

AKAction newsletter: emailed to networks monthly

* Example meeting schedule, days of week may vary

Figure 4: AKAction2 Request Form Guide

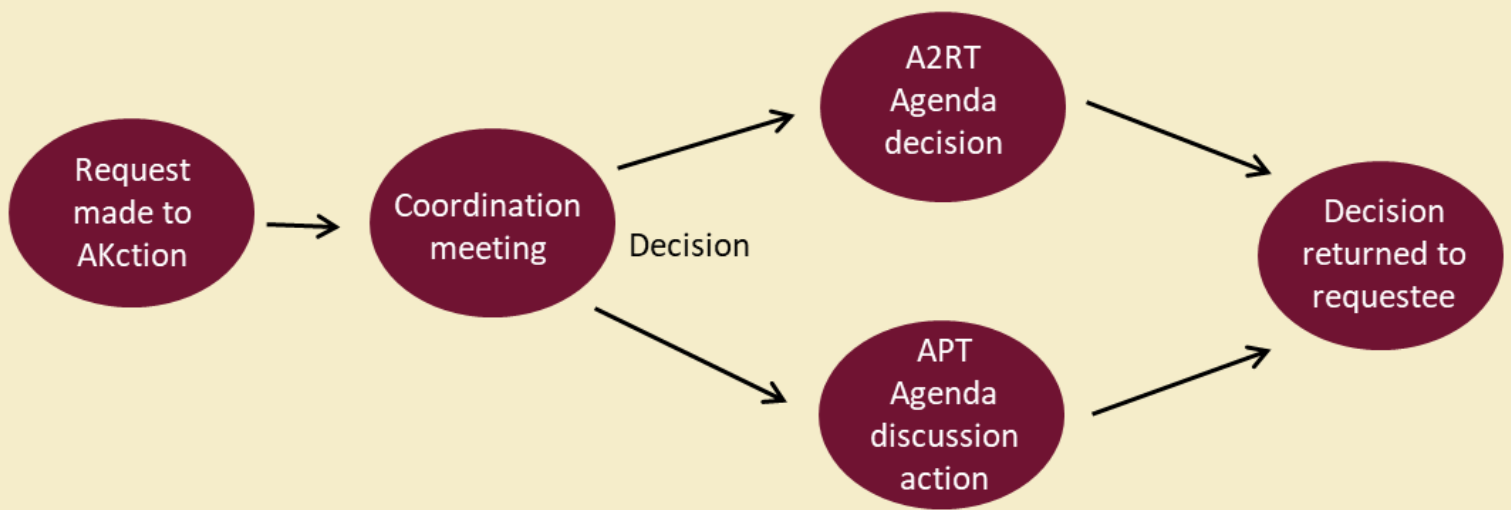


Figure 5: AKAction2 Timeline

Activity	2021 April	2022	2023	2024	2025	2026 March
Project establishment Recruitment, training, ethics, data collection tool development						
Sub study 1 Indigenous governance Yarning , Dadirri, interviews, capacity building analysis						
Sub study 2 Peer support Interviews, patient navigator pilot and evaluation						
Sub study 3 Kidney Journey Mapping						
Sub study 4 Cultural safety Training needs analysis, education with pre and post surveys,						
Rural and remote sites Employment, training, selection of sub studies and activities						
Synthesis, recommendations and dissemination Key stakeholder workshops, site roundtables						



'Shared Care' by Rhanee Lester and Jared Kartinyeri (AKAction members with lived experience of kidney disease), made from kidney haemodialysis consumables.

This memorial Kidney Art piece is in honour of our loved ones passed Sister Alice and Brother Matt. The letters A & M represent the two of them and the white pieces that are around them represent the circles of support that cared for them. The white pieces with red centres that are surrounding them represent their blood flow and dialysis journey. The small clear pieces that lead from the letters in towards the centre star represent A & M's spiritual journey back to our Ancestors where they are being embraced by Creator Spirit. The white bits of paper shooting out from the centre star represents their continued story reaching back into the community. The small blue and white pieces that connect back into the outer kidney shape represent their story continuing to have an impact in the Aboriginal Kidney Health Space and all the affiliated services and people that work together in the kidney space. The small blue intricate pieces represent the delicateness and fragility of their kidney journeys as well as the small veins within our kidney that support good flow. The 4 blue half circles that face towards each other represent the many yarning sessions they attended to help bring about change and awareness in the Aboriginal Kidney Health space as they shared their stories of courage and resilience of the challenges and triumphs they faced along the way.

AKAction logo by Kiki Designs

Aboriginal and Torres Strait Islander Flag Image Page 1, Retrieved from <https://naisda.com.au/cultural-protocols/>

Growing Plant Image Page 1, Retrieved from https://www.nicepng.com/ourpic/u2e6r5i1u2q8q8t4_grow-png-hd-plant-growing-cartoon/