

# Real Ways of Working Together: co-creating meaningful Aboriginal community consultations to advance kidney care

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*We respectfully use the term First Nations to describe the people of colonised countries such as Australia, New Zealand, Canada and the United States of America who have ancestral, cultural and community ties to the pre-colonial/pre-settler societies of that country. In Australia, this includes Aboriginal and Torres Strait Islander peoples. In South Australia, the First Nations contributors identify as Aboriginal Australians and prefer the term Aboriginal is used when referring to community members involved in the AKction project.*

First Nations people of colonised countries such as Australia, New Zealand, Canada and the United States of America (USA) share a common history of forced disconnection from land, community, and culture.<sup>1,2</sup> While colonisation processes and reconciliation strategies of the four nations differ, the lasting colonial effects of disempowerment, marginalisation, disproportionate social disadvantage and disparity in health outcomes persist for First Nations people.<sup>3</sup> In Australia, Aboriginal and Torres Strait Islander people experience kidney failure at 10 times the rate of non-Indigenous peers and for people living in rural or remote areas, the rate of difference is up to 30 times higher.<sup>4,5</sup> Unexamined colonising and racist beliefs continue to underpin the perceptions, attitudes and practices of non-Indigenous Australians towards Aboriginal and Torres Strait Islander Australians in government policies, society and health care.<sup>6</sup>

## Abstract

**Objective:** To describe a process of meaningful Aboriginal community engagement that repositioned and valued community members' knowledge(s) and lived experiences while strengthening relationships, research processes and outcomes.

**Background:** Aboriginal Australians have the oldest continuous culture in the world, yet due to effects of colonisation, experience some of the world's poorest health outcomes. The AKction [Aboriginal Kidney Care Together – Improving Outcomes Now] project brought together Aboriginal people with lived experience of kidney disease, clinicians and researchers to improve kidney care.

**Methodology:** Using Aboriginal methodologies of Ganma and Dadirri within community-based participatory action research (cb-PAR), a core advisory group of Aboriginal people with lived experiences of kidney disease worked closely with clinicians and researchers.

**Results:** Three community consultation workshops that deeply valued Aboriginal knowledge(s) were co-created. Community members formed a reference group, established partnerships and influenced health research, policy and service provision. Non-Indigenous researchers engaged in critical self-reflection and levelling of Western-Aboriginal and clinician-consumer power imbalances.

**Conclusions:** Deeply respectful community engagement is possible through co-creation and cb-PAR. It results in multiple positive impacts and beneficial relationships between community members, clinicians and academics.

**Implications for public health:** Meaningful consultation with Aboriginal communities guides culturally safe research processes, health policy and service delivery.

**Key words:** Chronic kidney disease, community engagement, co-creation, Aboriginal and Torres Strait Islander Health

There is increasing recognition that meaningfully including minority populations in governance structures, decision making and care provision are key attributes to achieving health equity.<sup>7</sup> Western research has too often been conducted on First Nations people in paternalistic, punitive and

exploitative ways,<sup>8</sup> without their permission, consultation or involvement.<sup>9</sup> Little value has been placed on First Nations knowledge, ways of knowing and knowledge sharing<sup>8</sup> and a deficit view of First Nations people and culture remains.<sup>8</sup> Unique research methods developed by First Nations people over

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centuries through collective observation, discussion, piloting and evaluation have largely been ignored,<sup>8</sup> leading to deep feelings of distrust, animosity and resistance towards Western research and researchers.<sup>9</sup> In Australia and internationally, meaningful consumer engagement in both research and health care services is increasing.<sup>8,10</sup> Australian health service accreditation requires health services to 'build effective and ongoing relationships with Aboriginal and Torres Strait Islander communities',<sup>11</sup> reinforcing the concept 'nothing about me, without me'.<sup>10,12</sup> National kidney care guidelines for the care of Aboriginal and Torres Strait Islander peoples are being written for the first time, informed by community members with lived experience of kidney disease, in addition to expert clinicians. Initiatives such as these are leading to increasing levels of engagement and consultation with Aboriginal communities, but the degree to which this is achieved varies between research projects and health services.<sup>13</sup>

The South Australian population is approximately 1.77 million people, of whom 2% identify as Aboriginal and/or Torres Strait Islander.<sup>14</sup> The population is culturally and geographically diverse with many unique Aboriginal language groups.<sup>15</sup> While the majority reside in the major urban city of Adelaide, 30% of Aboriginal South Australians reside in regional or remote communities,<sup>14</sup> some of which are many hundreds of kilometres from the closest urban centre. The Central Northern Adelaide Renal and Transplantation Service (CNARTS),

is a government-funded health service that provides clinical care to 732 dialysis patients and 872 renal transplant recipients across South Australia, eight per cent of whom are Aboriginal and/or Torres Strait Islander.<sup>4</sup> CNARTS strives to provide responsive, well-coordinated care,<sup>16</sup> but is often challenged in achieving this for Aboriginal and Torres Strait Islander patients with complex clinical needs, in a culturally safe way.

In 2018, the AKction (Aboriginal kidney care Together – Improving Outcomes Now) project funded through Health Translation South Australia, aimed to identify and respond to the needs and priorities of Aboriginal people living with kidney disease. AKction worked with Kidney Health Australia (KHA), a national patient support organisation and CNARTS to improve coordination and delivery of kidney care within South Australia. A collaborative network involving community members and nine academic, research, not-for-profit and health care agencies within South Australia initiated meaningful and respectful community consultations, drawing on past experiences and other relevant kidney projects; Indigenous Patient Voices<sup>17</sup> and Catching Some Air.<sup>18</sup> We aimed to privilege Aboriginal knowledge and governance, identify community priorities to guide research, health care policy and guideline development, and provide reciprocal process and outcome benefits for community members.

This paper describes the process of developing and implementing community consultation and engagement workshops

within the AKction project. This work aims to elevate and value Aboriginal ways of knowing, being and doing. In doing so, we provide a guide for non-Indigenous researchers and health professionals to establish respectful and meaningful collaboration, 'real ways of working together'.

## Methods

### *Theoretical framework: Aboriginal methodologies embedded within collaborative community-based participatory action research*

Collaborative community-based participatory action research (CB-PAR) methodology guided the consultation process. This respectful, intercultural approach was co-designed between Aboriginal community women and a non-Indigenous nurse researcher during earlier collaborative studies and was shown to be a culturally safe and effective way to achieve meaningful collaboration.<sup>19</sup> The approach combines concepts of Dadirri; deep listening and Ganma; knowledge sharing into PAR cycles of Look and Listen, Think and Discuss and Take Action Together (Figure 1).

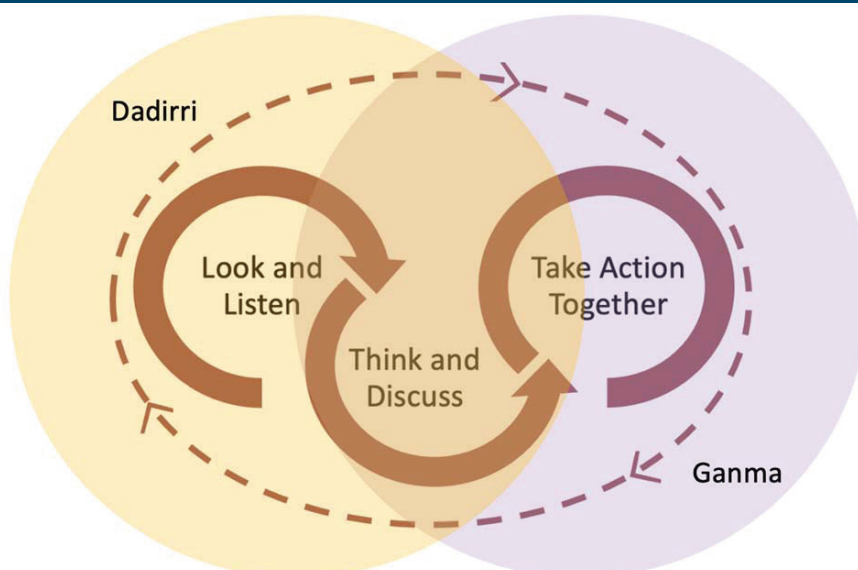
### *Look and listen*

The importance of observing and listening with one's eyes, ears, and heart, and paying attention to non-verbal cues in contemplative and reciprocal relationships has been described by the Ngangikurungkurr people of Daly River region in the Northern Territory of Australia as Dadirri.<sup>20</sup> Understanding of Dadirri has grown and been incorporated into research, particularly where complex cultural, personal and power imbalances require deeper investigation.<sup>21</sup> Dadirri reminds and teaches non-Indigenous researchers of the importance of creating brave and respectful spaces that enable Aboriginal people to share their stories; recognising ongoing and damaging effects of tokenism, marginalisation, colonisation, white fragility and racism.<sup>22</sup> It provides a framework to undertake liberation project work that promotes change<sup>23</sup> and helps establish professional and personal relationships between Aboriginal and non-Indigenous peoples.

Ungunmerr describes Dadirri as:

*... another special quality of my people ... Dadirri. This is the gift that Australians are thirsting for [...].inner deep listening and quiet*

Figure 1: Community-based participatory action research process.



*still awareness—something like what you call contemplation.*<sup>20</sup>

Embracing the concept and practice of Dadirri was a critical step toward building relationships and this research project. Two community members, a project officer and nurse researcher began building respectful relationships. This expanded to include community members (n=10), staff from CNARTS (n=12) University of Adelaide (n=6), KHA (n=2), the Transplantation Society of Australia and New Zealand (TSANZ) (n=2), and the South Australian Health and Medical Research Institute (SAHMRI) (n=2) in meetings, informal discussions, interviews, focus groups, Yarning circles, artwork sessions and storytelling (Table 1) over a period of two years.

### Think and discuss

The perspectives of community members, health care providers, researchers and other key stakeholders were brought together to co-create new knowledge, informed by Ganma. This Northern Australian Yolngu philosophy values and acknowledges the significance of each person's unique knowledge.<sup>24</sup> It enables a deeper understanding of who we are and what knowledge we bring, the value of different knowledges and how we can engage in respectful two-way relationships.<sup>24</sup>

Ganma is both a metaphor and a philosophy of what happens where a river of water from the sea (Western knowledge) and a river of water from the land (Aboriginal knowledge) mutually engulf each other, flowing together and becoming one.<sup>24</sup> The forces of the streams (knowledge) combine and lead to deeper understanding and truth and the foam produced when the saltwater mixes with the fresh water represents a new kind of knowledge. Ganma is a place where knowledge is (re)created.<sup>21,25</sup>

Ganma informed the consultations, data analysis and critical self-reflection (Table 1). We recognised the need for Indigenous-only spaces when Western and clinical dominance shut down Aboriginal-led conversations. We introduced a two-step process over two days that enabled Aboriginal participants to share stories and experiences between themselves, before speaking with a collective voice in a larger, mixed forum on the second day. Non-Indigenous participants also needed time and space to examine the challenges of whiteness, intercultural work, and recognising and addressing systemic racism that has such

a profound impact on the lives of Aboriginal people.<sup>26-28</sup> This required the ability to reflect inwardly on one's own assumptions, privilege and unconscious bias.<sup>29</sup> These processes enabled a deeper level of engagement and co-analysis within the consultations (Table 1).

### Take action together

The third phase involved a collaborative approach to identifying key themes, writing the consultation reports and sharing results; this put the new knowledge, the Ganma foam into action.

Large group preliminary data analysis occurred at the end of each consultation. Further analysis and interpretation was conducted by both the AKction reference group and research team. Member checking with each community consultation participant then occurred to ensure the findings remained true and accurate. Concurrent 'spirit checks' followed up on the health and wellbeing of individuals and partner organisations. The results were finalised and key messages shared through a range of knowledge translation mechanisms including local newspapers, radio interviews, artworks and formal report writing.

### Ethical approval

Ethics approval was provided by the Aboriginal Health Research Ethics Committee (#04-18-796), the University of Adelaide (ID: 33394) and the Central Adelaide Local Health Network (HREC/19/CALHN/45).

### Results

The AKction group facilitated consultations at three locations in South Australia (Figure 2) involving 46 Aboriginal community members and 37 key stakeholders. The key elements for successful Aboriginal community engagement are summarised in Table 2 and discussed in detail below.

### Working with key stakeholders

Our process of co-creation began as the lead researchers approached two Aboriginal kidney patients who were vocal advocates. These two women formed a core advisory group, which later grew to become the AKction Reference Group. Simultaneously, KHA-CARI (Kidney Health Australia - Caring for Australasians with Renal Impairment) were commencing a national project (KHA Yarnings) to inform a best practice

guideline for the management of chronic kidney disease for Aboriginal and Torres Strait Islander people and were seeking input from the advisory group. A pragmatic and respectful decision was made to work together, and a flexible and effective community consultation approach was co-created.

Establishing each consultation required more time and investment in relationship building with community members, local Aboriginal health staff and organisations than is often recognised by funders and employers. We worked collaboratively, pooling resources, and drawing on relational networks within communities and health care.

### Seeking Community permission and support

Community permission and support for the consultations was sought prior to any logistical planning in all three sites. Elders, representatives from local Aboriginal Community Controlled Organisations and local Aboriginal health professionals were widely consulted and involved in the planning process. Both community members and health professionals provided guidance regarding who needed to be included, where the consultations should be held and the best strategies for successfully engaging with community. We sought to create safe Aboriginal spaces and brave sharing spaces, recognising that each site had unique requirements. Advertising the consultation and inviting participants was community driven and health service supported, utilising pre-existing social and community networks and dialysis clinics. Promotion by known and trusted clinical staff with strong pre-existing relationships with patients and the community was effective.

Consultations were held at Kanggawodli, an Aboriginal hostel in Adelaide, Pika Wiya Aboriginal Community Controlled Health Service in the regional town of Port Augusta and the district hospital in the very remote town of Ceduna (Figure 2). This enabled a broad level of representation and understanding of the issues faced by Aboriginal Australians living with kidney disease. Each community chose their preferred consultation setting.

### Logistics and budget

Transport support is crucial for access and equity. This required a specific budget and

**Table 1: Step-by-step guide for meaningful community consultation using a collaborative, community-based, participatory action research methodology.**

Process	Practical considerations
<b>Planning the consultation</b>	
Look and Listen	<p>Engage key stakeholders -- Community</p> <ul style="list-style-type: none"> <li>Approach the Aboriginal Liaison Unit, Aboriginal Chronic Disease Consortium and renal staff to identify community members who may be interested</li> <li>Engaging a small number of interested people at this stage is all that is required</li> </ul> <p>Engage key stakeholders -- Service Providers</p> <ul style="list-style-type: none"> <li>Seek partnerships with people/organisations that already have the respect and trust of the community</li> <li>Health care providers: medical, nursing and allied health staff with a key interest</li> <li>Patient advocacy groups e.g., Kidney Health Australia (KHA)</li> <li>Key research and policy advisers: state/territory health departments, Aboriginal community-controlled health organisations (ACCHOs), research institutions</li> <li>Ethics committee: seek advice from local ethics committee about area specific considerations and gain support, may require formal ethics application</li> </ul>
Think and Discuss	<p>Meet engaged community members at a time and place of their choosing</p> <ul style="list-style-type: none"> <li>Deeply listen to the stories of the community members, to the issues these stories raise, to what and how things need to be done, to who needs to be involved</li> <li>Introduce the project concept and invite feedback; does the concept address community issues?</li> <li>Be prepared to have these discussions evolve over several meetings; ideas, concepts and feedback will need to be taken back to the wider community and rediscussed</li> <li>Invite community to create branding for the consultation process: name, artwork, themes – ensure all reproducible works are commissioned and copywritten with appropriate remuneration</li> </ul> <p>Meet with key stake holders (community and service providers) to discuss how to best work together to achieve mutual goals</p> <ul style="list-style-type: none"> <li>Facilitate a small group meeting consisting of Aboriginal community members, patient-experts, Elders; project coordinators; key service providers</li> <li>Contact and invite other key stakeholders as suggested by community members</li> <li>Discuss options for consultation: budget and funding, location, participants, time, transport, facilitation, interpreters, catering</li> <li>Identify themes and questions to be discussed</li> </ul>
Take Action	<p>Ensure ethical approval obtained</p> <p>Cultural safety training to be provided for all staff prior to the event</p> <p>Finalise time and place</p> <ul style="list-style-type: none"> <li>Discuss with venue manager; seeking their knowledge and suggestions for site specific considerations to achieve effective collaboration</li> <li>Arrange transport, have support people to assist with this process including on the day (a phone number to ring when things go wrong)</li> <li>Prepare discussion and education resources and materials, any available merchandise e.g., patient advocacy group merchandise</li> </ul> <p>Get the word out</p> <ul style="list-style-type: none"> <li>Community members can drive recruitment using existing social and cultural networks</li> <li>Inclusive recruitment strategy; approach as many people accessing the health system as possible e.g., advertise through dialysis, Aboriginal Liaison office, clinical staff</li> </ul>
<b>Implementing the consultation</b>	
Look and Listen	<p>Community members to co-facilitate the consultation and provide language interpretation</p> <p>Getting settled</p> <ul style="list-style-type: none"> <li>Welcome people as they arrive, invite into the space, orientate to amenities and refreshments</li> <li>Provide a range of seating options so that people can sit in their preferred friendship, family, cultural and/or gender groups</li> </ul> <p>Community governance</p> <ul style="list-style-type: none"> <li>Acknowledgement of country</li> <li>Self-introductions of core advisory group, and introduce the research team</li> <li>Present community branding; name, themes, artwork</li> </ul> <p>Setting the scene</p> <ul style="list-style-type: none"> <li>Co-facilitators to describe the purpose and general overview of the consultation</li> <li>Include detailed description of the potential uses of the information gathered</li> <li>Staff/stakeholders may present key background information</li> </ul> <p>Gain permissions</p> <ul style="list-style-type: none"> <li>Inform of any proposed photography, video and/or audio recordings, gather written consent</li> </ul>
Think and Discuss	<p>Small group discussion</p> <ul style="list-style-type: none"> <li>Health service staff to join small groups and ensure appropriate introductions</li> <li>Record and take notes about the themes, content, and quotes of discussion</li> </ul>
Take Action	<p>Each group prioritises key messages</p> <p>End of session</p> <ul style="list-style-type: none"> <li>Opportunity to report findings back to the group</li> <li>Research team write up notes</li> </ul>

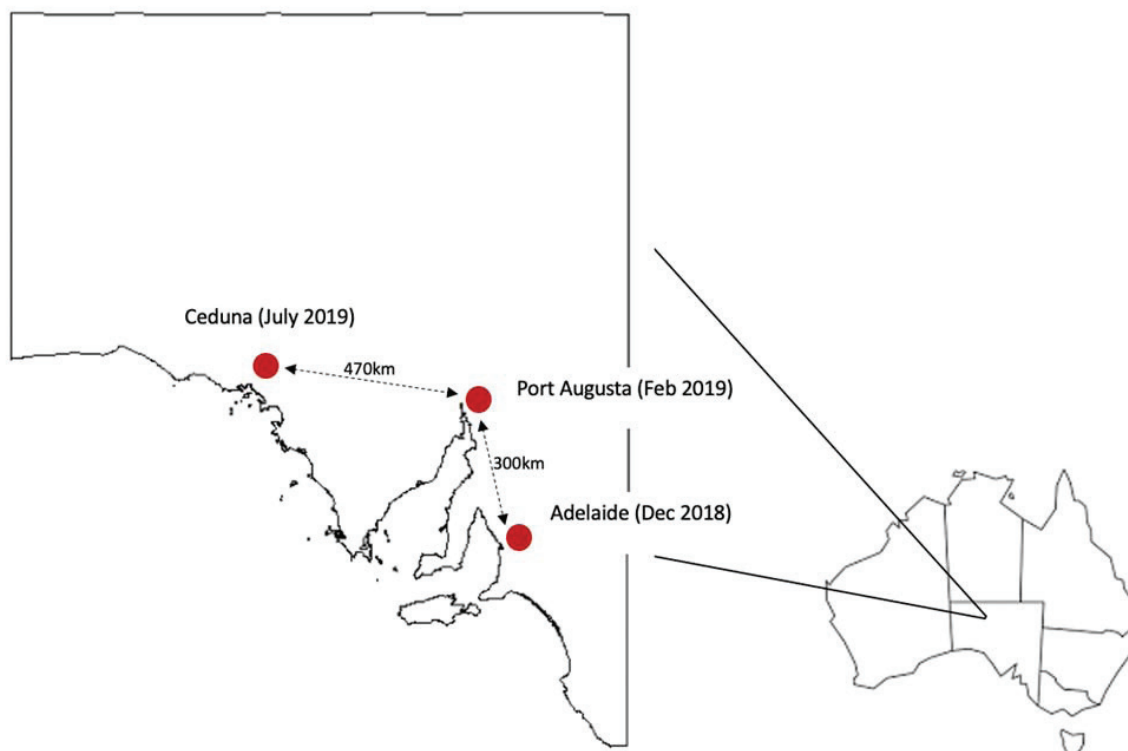
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**Table 1 cont.: Step-by-step guide for meaningful community consultation using a collaborative, community-based, participatory action research methodology.**

Process	Practical considerations
<b>Analysis, Reporting and Translation</b>	
Look and listen	The perspectives of the different groups are brought together for analysis
Think and Discuss	<p>Analysis of findings</p> <ul style="list-style-type: none"> <li>Initial analysis during the consultation with participants in small groups</li> <li>Continued by the research team following the consultation</li> </ul> <p>Checking back</p> <ul style="list-style-type: none"> <li>Clarify emerging themes with participants (member checking) to ensure correct interpretation and shared understanding</li> <li>Spirit check to ensure participants have support for their physical and emotional well-being</li> </ul> <p>Reporting</p> <ul style="list-style-type: none"> <li>Community to be given opportunity to contribute to report writing</li> <li>Consider which reports need to be produced and for whom (community, consumer groups, staff, academic literature)</li> <li>Consider how community voices can be heard more broadly e.g., media interviews, infographics</li> </ul> <p>Reflection</p> <ul style="list-style-type: none"> <li>Reflect on what worked well and what needs changing for subsequent consultations</li> <li>Consider applications for urban, rural, and remote locations                             <ul style="list-style-type: none"> <li>safe spaces for First Nations-only discussion</li> <li>balance of information sharing</li> </ul> </li> </ul>
Take Action	<p>Write reports, checking back with each group before final version is completed</p> <p>Plan knowledge translation activities</p> <ul style="list-style-type: none"> <li>Key stake-holder workshops</li> <li>Advocacy in health service planning and delivery</li> </ul> <p>Feedback findings</p> <ul style="list-style-type: none"> <li>To community members, clinical staff, health services and other key stakeholders</li> </ul> <p>Next consultation</p> <ul style="list-style-type: none"> <li>Incorporate feedback from initial consultation,</li> <li>Location and community specific considerations</li> </ul>

Notes:  
 Abbreviations: ALO: Aboriginal Liaison Officer; ACCHO: Aboriginal Community-Controlled Health Organisation.

**Figure 2: Urban, regional and remote community consultation.**



local knowledge of what worked best. Budgets ensured appropriate remuneration of community members who co-facilitated, provided interpretation services, peer support and/or art activities. Budget constraints prevented monetary remuneration of participants for their time, but substantial catering (particularly for those attending following dialysis), and educational materials were provided enabling reciprocity.

### The consultations

Key engaged community members co-designed and co-facilitated each consultation. Interpretation was provided by community members with lived experience of kidney disease. Time was taken to be clear and transparent when explaining the purpose of the consultation, how information would be used and the intended (but not overpromised) outcomes of each

consultation. Individual written consent with permissions to take notes, audio record and/or photograph was gained.

The first consultation was held in the major city of Adelaide over a single day and involved community members, health professionals and other key stakeholders meeting together at an Aboriginal operated hostel. The consultation began as a large group, then participants met in small groups with an Aboriginal and non-Aboriginal facilitator. Prompt questions (Supplementary File 1) were used to identify priorities and the strengths, weaknesses and gaps in kidney care from the perspectives and experiences of the community. Conversations were audio-recorded and a facilitator took notes. A spokesperson from each group fed back to the larger group. Following the event, community members identified that the consultations needed more time, Aboriginal-

only spaces and increased choice of small group facilitators.

The Port Augusta workshop was held over two days and facilitated by an experienced Aboriginal Health Practitioner. Day one involved Aboriginal kidney patients and family members talking together and sharing their experiences. Some participants painted their kidney journey on an old dialysis machine donated for the consultation, which was then used for health promotion. On the second day, local health professionals, specialist clinicians, researchers and key stakeholders attended. Themes from the previous day were shared and small group discussions followed. At the end of the consultation, the themes were prioritised by the large group. This collaborative analysis enabled subsequent reports to reflect the priorities of each community more accurately.

A similar format was used in the remote town of Ceduna, with increased flexibility to accommodate people's dialysis schedules, community movement, transport arrangements and staff availability. Numerous informal discussions were held with community members and service providers around the town who were unable to attend the consultations.

### Analysis and dissemination

Notes and recordings from each consultation were transcribed by members of the AKAction research team and KHA. These were shared back with community members to check accuracy and interpretation and adjusted as required. A full report, plus an additional summarised community version from each consultation was produced and shared extensively.<sup>30-32</sup>

Local newspapers were invited to the regional and remote consultations, with articles published the following week.<sup>33,34</sup> This had multiple positive impacts: sharing findings of the consultations, providing a health promotion opportunity regarding the impact of kidney disease and publicly valuing the knowledge and expertise of Aboriginal people with lived experience of kidney disease. Following the three consultations, one of the community members, an Aboriginal Health Professional and the project lead spoke on the government run regional radio station about the consultation process, experiences of kidney disease and kidney care.

**Table 2: Key elements for successful Aboriginal community engagement.**

Community identified priorities and governance	<ul style="list-style-type: none"> <li>Consider whether this is, and, how this is, an issue of importance for the community.</li> <li>Ensure the community retain ownership of data and outcomes and govern dissemination and implementation.</li> </ul>
Decolonising approach	<ul style="list-style-type: none"> <li>Recognise and include Aboriginal community members as co-researchers acknowledging their unique knowledge, skills, and approaches</li> <li>Focus on relationship building and respectful processes of engagement</li> <li>Utilise Aboriginal methodologies such as Dadirri; deep listening and Ganma; knowledge sharing</li> <li>Engage in critical self-reflection, recognise one's own assumptions and gaps in knowledge</li> <li>For non-Aboriginal participants – recognise white supremacy, implicit bias, white privilege and racism and take active steps to diminish their impact</li> </ul>
Community consent	<ul style="list-style-type: none"> <li>Seek consent and agreement from Aboriginal Elders, Aboriginal health services and/or key community stakeholders. Permissions may be required to enter the community, engage with community members, and conduct the consultation.</li> <li>Assess the need to adjust the consultation approach and scope specific to the requirements of the community.</li> </ul>
Local approach and facilitation	<ul style="list-style-type: none"> <li>Recognise that every community is unique. Each consultation must be guided by local people, and respect local processes and preferences.</li> </ul>
Collaboration	<ul style="list-style-type: none"> <li>Engage in respectful and inclusive collaboration with local and community-based organisations.</li> <li>Enable pooling of resources and recognise the time and efforts of community members and organisations.</li> </ul>
Brave spaces	<ul style="list-style-type: none"> <li>Consider the need for Aboriginal only spaces. Different conversations occur in these spaces.</li> <li>Take guidance from community about where, when, and how consultation participants should come together and who might facilitate.</li> </ul>
Equitable access	<ul style="list-style-type: none"> <li>Promote an inclusive approach, spread the word broadly through a range of formal and informal networks.</li> <li>Provide transport assistance and/or appropriate remuneration. Find out what works best in each location.</li> </ul>
Reciprocity	<ul style="list-style-type: none"> <li>Utilise community organisations to build capacity and local employment and benefit.</li> <li>Allow time and space for community networking, sharing of stories and peer support.</li> <li>Incorporate health promotion, knowledge sharing and dissemination activities within the consultation.</li> </ul>
Flexibility	<ul style="list-style-type: none"> <li>In timing, location, and process, while maintaining scientific rigor and essential deadlines.</li> </ul>
Transparency	<ul style="list-style-type: none"> <li>Clearly identify what the consultation will and will not include, and possible impacts</li> <li>What will happen to the information the community choses to share,</li> <li>What actions and/or improvements can be expected as a result of their sharing of knowledge and time.</li> </ul>

### **Continuing Aboriginal governance**

A key enabler in ensuring that the consultations met community needs and expectations was the formation of the AKction Reference Group (ARG). The two Aboriginal women who formed the initial core advisory group were joined by other highly engaged Aboriginal community members during and after the initial consultation. They provided cultural and community perspectives, advice and guidance for the consultations. Advising on how best to approach and include community members, co-facilitate and share findings and recommendations more effectively. This group continues to provide community governance in the AKction project; they are supported by an experienced Aboriginal AKction research team member and are growing in strength and role in co-designing new models of care.

### **Discussion**

The importance of meaningful community participation and consultation is increasingly being recognised.<sup>18</sup> From a community perspective, the act of coming together, sharing stories and developing networks of peer support is particularly significant. Aboriginal-only spaces enable community members to meet and discuss their lived experiences together, resulting in a collective voice, and a safer way of providing feedback and addressing inherent power imbalances.<sup>35</sup> The AKction community consultation model was shared with KHA and locally adapted for the eight remaining national KHA Yarnings.<sup>36</sup>

#### **Lifting voices; being heard**

Community members have engaged with national and international projects, extending the breadth of the community voice. The consultations are directly informing the national guideline on the management of chronic kidney disease for Aboriginal and Torres Strait Islander people. A delegate group from the ARG travelled to the National Indigenous Dialysis and Transplantation Conference in Central Australia. This conference brought Aboriginal community members from across the country together with health professionals, researchers and policymakers to discuss issues at a national level.

At a state level, the ARG and research team co-created and facilitated a series of kidney

health service and policy planning workshops drawing on the priorities that emerged from the consultations. In late 2019 and again in 2020, the workshops enabled Aboriginal community members to work alongside health executives and key stakeholders in statewide health and social policy co-design strategies to respond to issues raised. As a direct result, a dialysis service model was piloted at Kanggawodli Aboriginal hostel with the aim of providing dialysis care in a more culturally-safe environment, while also addressing significant dialysis transport issues. Incorporation of dental services are now also underway.

At a local urban, regional and remote level, priorities discussed in consultations and recorded in consultation reports have been utilised by local health services and practitioners to identify health care gaps and plan responsive strategies. Changes in health service policy and delivery is a lengthy and often slow process. Working closely with community members from inception through to report writing and beyond has enabled this process to become more transparent and accountable. Copies of all reports were provided to community members involved, as well as health professional which aligns with ethical principles for conducting research with Aboriginal communities and provides the community and health care providers with a shared benchmark.<sup>37,38</sup>

#### **Shifting power and control**

The positioning of and relationships between ARG members, Aboriginal and/or Torres Strait Islander and non-Indigenous research team members have shifted and deepened over time. The result has been significant two-way learning, personal and professional development.

Several community-governed and mandated research projects have emerged from this two-year co-creation process. Each project developed in response to the priorities identified in the consultations and was enabled by the deep and trusting relationships that formed through co-creation. Aboriginal Kidney Care Together – Improving Outcomes Now 2 (Akction2) received National Health and Medical Research Council funding [APP 2004389] to position community members as chief investigators, driving a decolonising research agenda and a targeted response to community priorities. As part of the National Indigenous Kidney Transplantation

Taskforce,<sup>39</sup> a pilot project in the regional town of Port Augusta has responded to the need for increased peer support identified in the consultations. The project has successfully established a peer navigator and transplant coordination role within the health system, creating employment opportunities for Aboriginal people with lived experience of kidney disease and increasing the number of people on the kidney transplantation work up list.

#### **Creating brave spaces**

Co-creation is a process of continual learning and reflection. The value of relationship building, and maintenance must be acknowledged, as consumers and researchers work alongside one another to generate new knowledge.<sup>40</sup> This requires a fundamental understanding that power imbalances exist between the community and researchers/health care providers. Sustainable change is only possible through mutual trust and relationships that are built over time.<sup>40</sup> In our project, Aboriginal community and team members actively chose to re-engage with researchers and health professionals, yet again, hoping for better and different outcomes. Against a backdrop of tokenism, disrespectful Western research<sup>8,9</sup> and non-inclusive health care decision making processes,<sup>41</sup> this was a significant undertaking.

Non-Indigenous research team members were required to actively de-colonise Western research and mainstream medical approaches to effectively engage with community members. Given the impacts of unconscious and intergenerational colonising societal practices, this approach did not always come easily. By incorporating Aboriginal concepts and practices of Dadirri and Ganma the team learned how to enact power sharing, reciprocity and two-way learning. The research team were encouraged to take time and space to reflect and discuss all learnings, being careful to protect Aboriginal team members from further trauma. This was an important step toward embracing decolonisation and the co-creation of spaces where Aboriginal community members' voices could be heard and their knowledge respected. Together we created brave spaces<sup>42</sup> for meaningful involvement.

The process also required building reminders for non-Indigenous researchers and clinicians to slow down and deeply listen. This does not often occur in clinical settings. Extended time

spent listening and discussing was needed to understand and address underlying priorities, assumptions, and bias; a process that involves genuine humility and respect. Reflecting on the processes and outcomes of the community consultations, we recognise that at times the process was not as suitable or responsive as we hoped. Critical reflection and open and honest feedback enabled us to learn, adapt and grow in our knowledge and ability to work effectively together.

## Conclusion

We have demonstrated that meaningful and deeply respectful community consultation and engagement is possible using a co-created, collaborative, community-based participatory action approach. It can result in well-informed health service improvements. Researchers and service providers can reach out to the community but must prepare themselves to deeply listen, walk alongside and allow community to lead. Aboriginal leadership within the health service and/or research team can support this experience. This work is underpinned by a commitment to ethical and respectful research approaches and is informed by shared professional and personal experiences and the guidance of Aboriginal communities.

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## References

1. Alfred G. Colonialism and state dependency. *J Aborig Health*. 2009;5(2):42-60.
2. Tuffin K. Racist discourse in New Zealand and Australia: Reviewing the last 20 years. *Soc Personal Psychol Compass*. 2008;2(2):591-607.

3. Armitage A. Chapter 8: Similarities and Difference among Australia, Canada, and New Zealand. In: Armitage A, editor. *Comparing the Policy of Assimilation: Australia, Canada and New Zealand*. Vancouver (CAN): UBC Press; 1995.
4. Australian and New Zealand Dialysis and Transplant Registry. *ANZDATA 44th Annual Report 2021 (Data to 2020)*. Adelaide (AUST): ANZDATA; 2021.
5. Cass A, Cunningham J, Wang Z, Hoy W. Regional variation in the incidence of end-stage renal disease in Indigenous Australians. *Med J Aust*. 2001;175(1):24-7.
6. Marmot M. Social determinants and the health of Indigenous Australians. *Med J Aust*. 2011;194(10):512-3.
7. Institute for Healthcare Improvement. *Improving Health Equity: Make Health Equity a Strategic Priority. Guidance for Health Care Organizations*. Boston (MA): Institute for Healthcare Improvement; 2019.
8. Laycock AF, Walker D, Harrison N, Brands J. *Researching Indigenous Health: A Practical Guide for Researchers*. Melbourne (AUST): The Lowitja Institute; 2011.
9. Martin K, Mirraoopa B. Ways of knowing, being and doing: A theoretical framework and methods for indigenous and indigenist re-search. *J Aust Stud*. 2003;27(76):203-14.
10. Came H, Gifford H, Wilson D. Indigenous public health: Nothing about us without us. *Public Health*. 2019;176:2-3.
11. South Australian Health and Medical Research Institute Wardlapingga Aboriginal Research Unit. *National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander Health*. Sydney (AUST): Australian Commission on Safety and Quality in Health Care; 2017.
12. Funnell S, Tanuseputro P, Letendre A, Bearskin LB, Walker J. "Nothing About Us, without Us." How community-based participatory research methods were adapted in an Indigenous End-of-Life Study using previously collected data. *Can J Aging*. 2020;39(2):145-55.
13. Kowal E, Anderson I, Bailie R. Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research. *Aust N Z J Public Health*. 2005;29(5):468-70.
14. Australian Bureau of Statistics. *2071.0 - Census of Population and Housing: Reflecting Australia - Stories from the Census*. Casberra (AUST): ABS; 2016.
15. The Australian Institute of Aboriginal and Torres Strait Islander Studies. *Map of Indigenous Australia*. Canberra (AUST): AIATSIS; 2021.
16. Central Adelaide Local Health Network. *Shaping the Future of Health with World-class Care and World-class Research. Our Strategic Ambition*. Adelaide (AUST): State Government of South Australia Department of Health; 2021.
17. Hughes JT, Dembski L, Kerrigan V, Majoni SW, Lawton PD, Cass A. *Indigenous Patient Voices: Gathering Perspectives Finding Solutions for Chronic and End Stage Kidney Disease* [Symposium Report]. Darwin (AUST): Menzies School of Health Research; 2017.
18. L Mick-Ramsamy, J Kelly, D Duff, A Cass, L Ross, D Croker, et al. *Catching Some Air - Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease Project-The Final Report*. Darwin (AUST): Menzies School of Health Research; 2019.
19. Kelly J, Dwyer J, Mackean T, Donnell K, Willis E. Coproducing Aboriginal patient journey mapping tools for improved quality and coordination of care. *Aust J Prim Health*. 2016;23(6):536-42.
20. Ungunmerr M. Dadirri: Listening to One Another. In: Hendricks J, Hefferan G, editors. *A spirituality of Catholic Aborigines and the Struggle for Justice*. Brisbane (AUST): Catholic Archdiocese of Brisbane; 1993. p. 34-7.
21. Atkinson VJ, Graham J, Pettit G, Lewis L. Broadening the focus of research into the health of Indigenous Australians. *Med J Aust*. 2002;177(6):286-7.
22. Cox L, Judy Atkinson. *Trauma Trials, Recreating Song Lines: The Transgenerational Effects of Trauma in Indigenous Australia*. Melbourne (AUST): Spinifex Press; 2002.
23. West R, Stewart L, Foster K, Usher K. Through a Critical Lens: Indigenous Research and the Dadirri Method. *Qual Health Res*. 2012;22(11):1582-90.
24. Watson H, Chambers DW. *Singing the Land, Signing the Land: A Portfolio of Exhibits*. Geelong (AUST): Deakin University; 1989.
25. Pyrch T, Castillo MT. The Sights and Sounds of Indigenous Knowledge. In: Reason P, Bradbury H, editors. *Handbook of Action Research: Participative Inquiry and Practice*. London (UK): Sage; 2001. p. 379-85.
26. Gallaher G, Ziersch A, Baum F, Bentley M, Palmer C, Edmondson W, et al. *In Our Own Backyard: Urban Health Inequities and Aboriginal Experiences of Neighbourhood Life, Social Capital and Racism*. Adelaide (AUST): Flinders University; 2009.
27. Wilson AM, Kelly J, Jones M, O'Donnell K, Wilson S, Tonkin E, et al. Working together in Aboriginal health: A framework to guide health professional practice. *BMC Health Serv Res*. 2020;20(1):601.
28. Dwyer J, Willis E, Kelly J. Hospitals caring for rural Aboriginal patients: Holding response and denial. *Aust Health Rev*. 2014;38(5):546-51.
29. Krusz E, Davey T, Wigginton B, Hall N. What contributions, if any, can non-Indigenous Researchers offer toward decolonizing health research? *Qual Health Res*. 2020;30(2):205-16.
30. Kelly J, Oliva D, Jesudason S. *Indigenous 'Yarning Kidneys' Report: Adelaide Consultation 2018*. Melbourne (AUST): Kidney Health Australia; 2018.
31. Kelly J, Stevenson T, Jesudason S, Oliva D. *Indigenous 'Yarning Kidneys' Report: Port Augusta Consultation February 2019*. Melbourne (AUST): Kidney Health Australia; 2019.
32. Stevenson T, Kelly J, O'Donnell K. *Indigenous 'Yarning Kidneys' Report: Ceduna Consultation June 2019*. Melbourne (AUST): Kidney Health Australia; 2019.
33. Balsamo M. Kidney health consultation in Port Augusta. *The Transcontinental Port Augusta*. 2019 Feb;12;10:35am.
34. Cetta L. Ceduna hosts kidney health consultation. *Port Lincoln Times*. 2019 Jun;18;4:21pm.
35. Kelly J, Dent P, Owen K, Schwartzkopf K, O'Donnell K. *Cultural Bias Indigenous Kidney Care And Kidney Transplantation Report*. Adelaide (AUST): The Lowitja Institute; 2021.
36. Duff D, Jesudason S, Howell M, Hughes JT. A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease. *Renal Soc Australas J*. 2018;14(3):84-8.
37. National Health and Medical Research Council. *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders*. Canberra (AUST): NHMRC; 2018.
38. Jamieson LM, Paradies YC, Eades S, Chong A, Maple-Brown L, Morris P, et al. Ten principles relevant to health research among Indigenous Australian populations. *Med J Aust*. 2012;197(1):16-18.
39. Transplantation Society of Australia and New Zealand. *Performance Report National Indigenous Kidney Transplantation Taskforce*. Sydney (AUST): TSANZ; 2021.
40. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving research impact through co-creation in community-based health services: Literature review and case study. *Milbank Q*. 2016;94(2):392-429.
41. Taylor KP, Thompson SC. Closing the (Service) Gap: Exploring Partnerships between Aboriginal and Mainstream Health Services. *Aust Health Rev*. 2011;35(3):297-308.
42. Aroo B, Clemens K. From Safe Spaces to Brave Spaces: A New Way to Frame Dialogue Around Diversity and Social Justice. In: Landreman LM, editor. *The Art of Effective Facilitation: Reflections from Social Justice Educators*. Sterling (VA): Stylus Publishing; 2013.

## Supporting Information

Additional supporting information may be found in the online version of this article:

**Supplementary File 1:** Prompt Questions AKtion community consultation Port Augusta February 2019.