

Indigenous ‘Yarning Kidneys’ Report: Ceduna Consultation, June 2019



Participants of the Ceduna community consultation, shared with permission of all members.

Photo courtesy of the West Coast Sentinel

Ms Tahlee Stevenson, Dr Janet Kelly & Dr Kim O Donnell on behalf of the *aKction* Project and Kidney Health Australia.

Consultation meeting to inform the *aKction – Aboriginal Kidney Care Together, Improving Outcomes Now* project and the development of the Guidelines for Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islander Peoples

Ceduna, South Australia
June 2019

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1 Acknowledgements

1.1 Aboriginal Consumer Reference Group, co-facilitators and artists:

We would like to acknowledge the contribution of the members of the SA Aboriginal Community, Nari Sinclair and Inawinytji Williamson and the aKtion Reference Group for their guidance throughout this project.

We would also like to extend a special thankyou to Roxanne Sambo, an Aboriginal Health Practitioner Candidate, member of our research team and Ceduna local for her invaluable support in planning, organising and conducting the consultation.

1.2 Stakeholders

The University of Adelaide and Kidney Health Australia established a productive partnership with Central Northern Adelaide Renal & Transplantation Service (CNARTS), South Australian Health and Medical Research Institute (SAHMRI), the Aboriginal Chronic Disease Consortium, Pika Wiya and Port Augusta Dialysis Unit, Ceduna District Health Service and Koonibba Health Service for the organisation and follow up of the South Australia consultations, and would like to acknowledge their contribution.

Special acknowledgement to the local researchers, clinicians and members of the working group, who provided leadership, helped to facilitate the consultation, and contributed in the analysis and writing of this report:

- Dr Janet Kelly
- Dr Kim O'Donnell
- Ms Tahlee Stevenson
- Ms Melissa Arnold-Chamney
- Ms Roxanne Sambo
- Dr Susan Crail
- Associate Professor Shilpa Jesudason
- Ms Amanda Biddle
- Ms Roxanne Sambo
- Mr Andrew Lane
- Ms Geraldine Ware

1.3 National Advisory Group providing advice for community consultations

A national Advisory Group has been established to provide expert advice for Kidney Health Australia regarding consultation for the KHA-CARI CKD management in Aboriginal and Torres Strait Islander Guidelines. This group includes

- Associate Professor Shilpa Jesudason (Chair)
- Ms Dora Oliva (Project Manager)
(group members in alphabetic order):
- Professor Alan Cass
- Dr Martin Howell
- Dr Jaqui Hughes
- Dr Janet Kelly

- Dr Odette Pearson
- Ms Rochelle Pitt
- Ms Jess Styles

1.4 Funding

The following funders are acknowledged for their generous contribution through the following initiatives:

aKction – Aboriginal Kidney Care Together, Improving Outcomes Now Project

The aKction project was funded as Medical Research Future Fund as a Rapid Applied Research Translation for Health Impact Grant Scheme Grant, through Health Translation SA (formerly known as IAKCT – Improving Aboriginal Kidney Care Together) . Funding from this project was used to support community members and researchers to attend the consultation, for resource development, transport, accommodation and catering costs.

Kidney Health Australia

We would like to thank Kidney Health Australia for their continued support and guidance as well as their financial contribution toward the facilitation of the Ceduna consultation.

Ceduna Partners

We would like to thank Andrew Lane, Director of Nursing and CEO of Ceduna District Health Service, for inviting us to Ceduna and the Ceduna Hospital, and for hosting our consultation. We also thank Ceduna Koonibba Aboriginal Health Service for welcoming us, encouraging community participation and assisting with organisation of the consultation, including transport arrangements.

Ethics

The aKction project applied for and received ethical approval from the Aboriginal Health Research Ethics Committee of South Australia AHREC Protocol #: 04-18-796 for both the consultation activities and the research project as a whole. In addition to this we have ethics approval from the University of Adelaide: UoA #33394 and SA Health (CAHLN and Country Health): CALHN #: R20190124

2 Abbreviations and Definitions

CNARTS – Central Northern Adelaide Renal & Transplantation Service

CKD – Chronic Kidney Disease

aKction – Aboriginal Kidney Care, Improving Outcomes Now

KHA – Kidney Health Australia

KHA-CARI – Kidney Health Australia – Caring for Australasians with Renal Impairment

SAHMRI – South Australian Health and Medical Research

The authors acknowledge that Australian Indigenous communities include Aboriginal and/or Torres Strait Islander Peoples. In this consultation, participants only identified as Aboriginal and therefore the term Aboriginal is respectfully used throughout this South Australian report.

3 Executive Summary and Recommendations

Those involved in this consultation focussed heavily on the importance of education for illness prevention, and the importance of coming together as a community to support each other and keep each other strong. Participants highlighted that the focus should really be on improving life as a whole, rather than just improving life whilst on dialysis. Many participants discussed how being part of a community played a central role in keeping strong as individuals and families. Sharing knowledge, experiences and resources were all important for wellbeing.

When discussing health education and illness prevention, the focus shifted from just providing education in schools, to educating the whole community and talking about living healthy lives. Community members were interested in attending activities and gatherings where health providers talked about how to keep healthy. The importance of having interpreters readily available for clinical discussions, and having access to resources and information in language was also emphasized.

Many participants discussed issues of access, highlighting the need for improved transport, not only for dialysis treatment, but also to enable them to get home to family, and to be involved in cultural activities, collecting bush tucker and making artefacts. There were specific challenges relating to the remote location of Ceduna with no regular or reliable transport options west of the town. There was also a shortage of accommodation options in Ceduna, resulting in some people unable to dialyse locally as they had nowhere to live.

Key messages and recommendations from community members are as follows;

<p>Prevention</p> <ul style="list-style-type: none"> • Prevention needs to focus on understanding and supporting people, no matter their circumstances or history; avoid using a punitive approach. • Educating young people about holistic wellbeing and what they can do to keep themselves healthy.
<p>Early Detection</p> <ul style="list-style-type: none"> • Demystify CKD, teach people about what it is and show that there are options. • Offer incentives for those who partake in a kidney health check. • Give patients time to process and make decisions, rather than rushing into treatment as soon as illness is diagnosed.
<p>Information and Education</p> <ul style="list-style-type: none"> • Provide regular times and spaces for meetings with health care providers, ensuring that the dialogue remains open. • Provide education about treatment options such as peritoneal dialysis, help patients to dialyse at home or closer to home. • Ensure the availability of interpreters and language appropriate educational materials. • Provide education visually, using videos, pictures and people sharing stories. • Target some of the educational programs to young ones, but also ensure that there is also community education programs that are open to everyone.
<p>Access</p>

<ul style="list-style-type: none"> • More housing and improved access to long term housing in Ceduna for dialysis and renal patients • Provide consistently available transport services that are able to get patients to and from their dialysis appointments • Seek housing options in Adelaide for patients traveling there for procedures or appointments • Improve the availability of holidays chairs and help to facilitate patients travel or holiday plans and needs
<p>Cultural Safety</p> <ul style="list-style-type: none"> • Create Aboriginal Health Practitioner roles in the Ceduna Hospital, specifically within the renal section, with training in the provision of dialysis • Support and assist patients being able to return to country on non-dialysis days, to engage with community and family, and be involved in activities that can provide income (artefact making) • Seek reliable transport options that enable people to return home to country over the weekend and come back into town at the beginning of the week for dialysis
<p>Transplant</p> <ul style="list-style-type: none"> • Ensure Kanguwodli is able to continue to support patients travelling to Adelaide to receive transplant • Financially support transplant recipients to travel and ensure that extra stress isn't created by facing out of pocket expenses. • Support a family member to travel to Adelaide with the transplant recipient to provide them with social and emotional support. • Ensure the availability of interpreters for conversations pertaining to transplant. • Give patients time to process their options and make decisions.
<p>Additional Support</p> <ul style="list-style-type: none"> • Provide patients with 'something to do' whilst they are on dialysis, such as colouring or artwork. • Hold regular consultations and creating a space for consumers and their families to give feedback about the service and how it could be improved.
<p>The Role of Community, Strength and Empowerment – as described by community members</p> <ul style="list-style-type: none"> • Keeping strong for yourself and those around you • Put on events that encourage the community to come together and learn about keeping themselves healthy, such as cooking and health days • Social events specifically for dialysis patients and their families • Supporting families to be more involved in care • Speaking up for yourself and your needs and helping those around you to do the same

4 Background

4.1 Aboriginal Kidney Care, Improving Outcomes Now Project- AKTION

The aKtion project is a two-year Rapid Applied Research Translation for Health Impact Grant Scheme research project funded by the Medical Research Future Fund through Health Translation SA. Formerly known as the IACKT project we have updated the name upon recommendation of our Aboriginal reference group. It will provide opportunities for Aboriginal kidney patients, their family members, health professionals, health services, academics and researchers to work together to improve renal care in South Australia.

This project aims to identify and respond to the needs of Aboriginal patients and their families and to work with Kidney Health Australia and Central Northern Adelaide Renal & Transplantation Service (CNARTS) to inform both a local and national response to the disparities in care provision and to improve the coordination and delivery of renal care.

The research methods include community consultations, focus groups, patient journey mapping, identification of barriers and enablers, and effective implementation of strategies for improvement. Research outcomes include priority setting and knowledge translation workshops, education package development for staff and students and an opportunity for patients, family members and health professionals from South Australia to contribute to national guideline development. The process through which this will be accomplished is outlined in figure 1.

4.2 New Guidelines for management of Chronic Kidney Disease (CKD) among Aboriginal and Torres Strait Islander Communities

In 2018, the Honourable Ken Wyatt, MP, Federal Minister for Indigenous Health, awarded a grant to Kidney Health Australia to conduct extensive consultation with Aboriginal health experts, consumers, community members, service providers and peak bodies around Australia to ensure the new clinical guidelines are aligned with community preferences and needs.

Three communities in the Northern Territory and Thursday Island have already been involved in similar community consultations through the [Catching Some Air Project](#).

Kidney Health Australia has funded 16 community consultations that will be undertaken in metropolitan, regional and remote areas of Australia. Thus far there have been consultations in Adelaide, Port Augusta, Perth and Kalgoorlie. The consultation held in Ceduna was in addition to these 16 and will allow for the inclusion of a remote South Australian site in the writing of the guidelines.

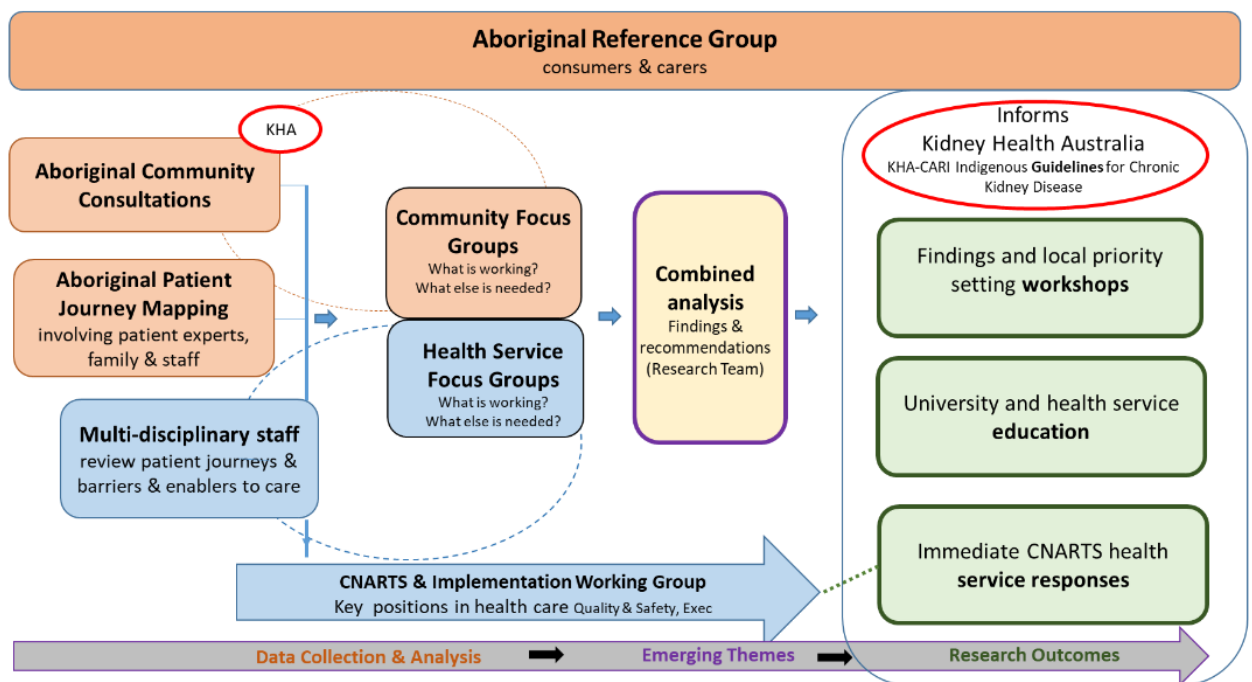
These community consultations aim to seek feedback and advice regarding:

- the focus and content of the proposed KHA-CARI clinical guideline for the Management of CKD among Aboriginal and Torres Strait Islander peoples; and
- the opportunities for translation of the new clinical guidelines into culturally-safe community information, tools and education materials.

4.3 Partnerships

The AKTION research project led by Dr Janet Kelly, University of Adelaide, and Kidney Health Australia have partnered with each other and local health services and community members in Adelaide, Port Augusta and Ceduna to develop the structure for the community consultations. This collaboration enabled community members' time and input to inform both the new guidelines and local and state-based improvements in renal care, as depicted in Figure 1 below.

Figure1: Improving Aboriginal Kidney Care Together Project model.



5 Consultation Methodology and Strategies for Community Engagement

5.1 Methodology

The consultation was based on a collaboration action research approach and methodology (Kelly et al 2019) specifically designed with Aboriginal community members for cross cultural projects. This involves repeated cycles and multiple layers of observation and listening, reflection and discussion and targeted action as described below:

- **Look and Listen**
 - observing and listening with your eyes, ears and heart, paying attention to both verbal and non-verbal communication
 - using community consultations, interviews, focus groups, yarning circles, artwork sessions, storytelling and informal discussions
 - non-judgemental observation, deep listening – Dadirri
- **Think and Discuss**
 - analysis involving community members, health care providers, researchers and other key stakeholders , individually and collectively
 - critical self-reflection and respectful discussion
 - bringing together knowledge across cultures to create new knowledge – Ganma
 - exploring culturally, work-related and ethically accepted ways of discussing and sharing ideas to create new knowledge
- **Take Action Together**
 - Working out priorities and goals in common
 - Identifying who will undertake which task
 - Completing tasks, including problem solving

5.2 Strategies for Community Engagement

The following strategies were used to engage Aboriginal and Torres Strait Islander kidney patients, carers, family and community to attend the community consultation.

Learning from prior consultations

We sought feedback from the aKtion Reference Group and participants of the first two consultations held at Kanggawodli in December 2018 and Port Augusta in February 2019 to guide us in planning of this consultation. We adjusted the structure and the content of the consultations as advised by people in Ceduna, to ensure that they were appropriate and could provide a safe space to yarn.

Working with local care providers

Throughout the planning of this consultation we were regularly in contact with Andrew Lane from Ceduna hospital and Geraldine Ware from Koonibba Health Service. We worked with them to ensure we designed a consultation that would suit the needs of those within the community. This resulted a 'closed' session in the morning, in which patients and their families shared their stories without health care professionals present. This was then followed by an open, more structured session in the afternoon in which clinical staff attended and the conversation centred around health care priorities and questions.

5.3 The Role of Clinical Champions and Renal Services

As with the prior Adelaide and Pt. Augusta consultations, nephrologists, medical staff, nurses and Aboriginal health workers were identified and contacted and invited to partake in the consultation and played a crucial role in engaging Aboriginal kidney patients within the local community. This group of renal experts supported the facilitation of the consultation and contributed with the analysis of the information collected through the session.

The same local clinicians and researchers will be involved in the consultation follow up to ensure the recommendations provided by the community are appropriate and remain relevant and that actions that have been identified and implemented to improve the delivery of kidney care at the state and local levels are plausible and fit for purpose.

5.4 Stakeholders

Key Aboriginal and non-Aboriginal stakeholders in Ceduna assisted in the promotion of the consultation and the Ceduna District Health Service hosted the consultation.

This report was disseminated among key partners to share the outcomes and recommendations, to distribute to community members, and for transparency.

6 Participants

[photo]

Patients, carers and family members

- Sherrie Jones
- Elma Lawrie
- Hedley Martin
- Marlene Lawrie
- Marilyn Jebydah
- Anne Ginger
- Melinda Jebydah
- Wanda Miller
- Steven Carr
- Alison Carr

Local Researchers and Clinical Staff

- Roxanne Sambo
- Kim O'Donnell
- Janet Kelly
- Su Crail
- Melissa Arnold Chamney
- Tahlee Stevenson
- Eleanor Garrard
- Amanda Bittle
- Andrew Lane
- Emma Collins
- Tina O'Driscoll
- Tracey Vincent
- Jodie Milne
- Geraldine Ware

[photo]

7 Indigenous ‘Yarning Kidneys’ session

7.1 Participants

The consultation in Ceduna was held on the 12th of June 2019 across two sessions. A total of ten Aboriginal community members attended, including those experiencing renal dialysis and or who had received a transplant, their caregivers and family members. An additional fourteen local health workers, clinical staff and researchers also attended at different times throughout the day.

7.2 Consultation format

The morning session was designed to be for community members only, in which participants were invited to share their stories and experiences through discussion. However, health care providers from the local Koonibba health service were welcomed by the participants and thus took part in the session.

Dr Janet Kelly, Dr Kim O’Donnell and Ms Roxanne Sambo explained the purpose of meeting and how the information discussed within the consultation would help inform the aKction project and new Indigenous Guidelines for management of CKD, as well as improvements in healthcare at state and local levels.

Participants talked about their experiences with kidney health and care, as well as sharing stories about how they keep strong within themselves and continue to support those around them. The local health workers talked about how the provision of kidney care has changed within Ceduna and the struggles that they face when it comes to supporting people through treatment.

The afternoon session involved community members and healthcare workers talking together. Staff from the Ceduna Hospital were present, as well as stakeholders from the local aged care facility and other SA Health representatives. Again Dr Kelly, Dr O’Donnell and Ms Sambo introduced the project and discussed the purpose for the consultations and how the information obtained throughout them would be used.

Following the preferences of those present, we remained in a large group throughout this session. A series of questions identified by Kidney Health Australia that had been modified following the Adelaide and Pt Augusta consultations, guided these conversations. Questions explored participants’ experiences with kidney disease, their opinions on how access, information and care for kidney disease could be improved, best ways to communicate health messages and share information and what they thought health professionals should be taught in regard to kidney care and caring for Aboriginal patients. There was also open discussion about what participants thought was important in addition to these points.

Notes were taken throughout both sessions of the consultation and discussions were recorded and transcribed for accuracy.

A reporter from the local newspaper came and spoke to community members, local health professionals and facilitators and took photos of the group. These conversations and pictures were used to create and publish an article about the community consultation and to generally increase kidney health awareness in the community.

7.3 Analysis

Notes were taken throughout the consultation and discussions were audio recorded and transcribed for accuracy. Discussions remained within the larger group throughout both sessions, which enabled all participants an opportunity to share and hear what was said. At the conclusion of each session, participants were asked to share what they felt was the most important point. This helped to prioritise the issues discussed throughout each session, in accordance with community priorities. A draft version of this report was shared with small group facilitators and emerging Aboriginal Community Reference Group members. Relevant quotes from participants were included in each theme.

7.4 Outcomes and Emerging Themes

In addition to priorities already highlighted by KHA and previous consultations the participants identified additional priorities throughout the course of the consultation.

Prevention

The participants emphasised that for prevention to be effective in this setting it needed to focus on helping people to understand and support them through their journey, rather than punishing 'wrong doings'.

'Patients need to be empowered, not scolded when something goes wrong. Why would they want to engage with the health service if they are just going to get in trouble' (Aboriginal participant).

Examples given related to food choices, fluid intake and alcohol use. The group suggested that it would be valuable to talk about the concept of moderation because 'just banning things' does not work and realistically creates bigger issues.

Similar to previous consultations, there was much discussion about the value of targeting prevention and education campaigns for young people and to start doing this in schools. Discussion centred around the value of a healthy diet and how this would impact on health now and into the future and how talking about this in school is a good way to reach many young people. Suggestions were made about involving both health providers and community members in such campaigns and how they could come together to encourage health and wellbeing and demonstrate the value of such preventative initiatives.

'Kids gotta understand that you need to be healthy now to be healthy later' (Aboriginal participant)

There was value placed on teaching young ones how to keep their kidneys and their whole bodies healthy. There was also a need to make clear the link between keeping healthy and preventing the development of chronic illness. It was suggested that a real shift in perception could be encouraged, so that individuals knew they could influence their own health by making healthy choices (as much as possible taking into account the impact of the social

determinants of health). Sometimes family members might feel that getting diabetes or kidney disease was inevitable due to high rates of chronic illness among their family members.

Early Detection

When talking about detecting Kidney disease early the participants highlighted the fact that one of the most influential factors on doing so is the fear and uncertainty that surrounds the condition. Many people have family that had experienced CKD and as a result have preconceptions and perceptions about what having the condition will mean for them. For example, people that have seen a family member have a negative experience with dialysis or pass away from the condition may be reluctant to engage with care or even attain a diagnosis.

'Kidney failure is scary, we know that it can be a death sentence or mean that you'll be stuck on dialysis for the rest of your life' (Aboriginal participant).

Some participants suggested that educating people about the value of early detection and demystifying the condition may make it less frightening for them to seek help when a problem is suspected or emerges. One idea was that incentives could be offered to encourage people to engage with specific Kidney Health checks. This strategy is currently being used to promote other health checks and has proven successful.

Patients reported that sometimes doctors made assumptions about what they wanted, or how ready they were to engage in conversation, and at times they felt rushed into making decisions before they are ready. There was also discussion about how to convey the urgency and need to change behaviour or seek treatment, to patients when they were seriously unwell. Sometimes patients were not ready to listen, and this led to a worsening in their condition.

'When I found out my Kidneys were sick, I didn't want to listen to the doctors, information just went in one ear and out the other' (Aboriginal participant)

The discussion continued; whilst it is undoubtedly important to provide treatment for patients, healthcare providers may find that it takes time for the patient to decide what they would like to do and what treatment is most appropriate to their needs and desires. Often staff were expected to take a flexible approach to supporting patients throughout this time, really listening to what they needed and giving them time to process and make decisions.

Information and Education

One of the conversations that emerged throughout both sessions was the desire to have regular meeting times, and community events to talk more about kidney health. Participants were interested in coming together in a safe space to meet with health providers to talk and learn about what is new with kidney care. Community members wanted more education about treatment options such as peritoneal dialysis and information about the things that could help them to dialyse at home. There is a need to have information in appropriate languages and for interpreters to be more available.

'We need to translate health literacy not only health language' (Aboriginal participant)

There was a clear preference for visual education resources. Participants suggested educating people about what the kidneys look like and what they do and what happens when they become damaged. The importance of starting in schools and targeting campaigns to young children, teaching them about overall health and the small things they can do to make a difference to their health and wellbeing, was highlighted.

'We have to teach real life skills in our schools, not just be healthy' (Aboriginal participant)

A lot of the conversation about education focused on teaching not only children, but the whole community about healthy eating and how to do so affordably. Participants suggested having cooking lessons as a part of social events or community days. Others highlighted the value of having Elders and community members sharing their stories to educate others about living with kidney disease and making healthy choices.

Access

Issues surrounding accessing treatments and services featured prominently, similar to previous consultations. In Ceduna, the issues of housing and transport was focused on. Some transport and accommodation services are only available short term (such as Step Down) and is vulnerable to staffing shortages. Many participants talked about how challenging it can be to find stable accommodation and how long it takes to do so. Staff identified that previous accommodation pressures had led to patients having to return to Adelaide to dialyse, even when they had access to a chair here in Ceduna, closer to home. The issues surrounding travelling to Adelaide to receive treatments or for appointments were also raised. For example, Kanggawodli can only provide short term accommodation and even then, only if they have the room to do so, and no children are travelling with them.

The role of Native Title offices in supporting transport for medical care was highlighted, with many patients only being able to travel for treatment if they were supported by the office. This is was unique to the Ceduna consultation and highlighted just how challenging it can be for people to make the trip to Adelaide, raising the question whether the long distance and financial impact for these patients was underestimated by city services because they were still coming from within South Australia .

The concept of 'holiday chairs' was raised. Participants spoke of how it can be incredibly challenging to organise a change in regimen or access a chair in another location temporarily. There was also the possibility that this could jeopardise their chair in Ceduna.

'I am a country man, I need to be able to move and travel to keep myself healthy' (Aboriginal participant).

Cultural Safety

When discussing cultural safety, the emphasis was firmly placed upon just how important it is to have Aboriginal staff available within the renal space. The value of positions like the Aboriginal Health Practitioners in the RAH was reinforced with participants suggesting that they would like to see similar roles in place in the dialysis unit in Ceduna. This idea was supported by staff also, with many expressing interest in having Aboriginal Healthcare providers trained to provide dialysis.

There was also discussion about how important it is for dialysis patients to return home to country - it enriches their quality of life as a whole opposed to just when on dialysis. Returning to community gives people time to connect with others and receive social support and can also provide the opportunity to engage in activities like painting or weaving, that can be used to make money to support themselves. This is vitally important for wellbeing. However, whilst Ceduna may be closer to home than Adelaide is, many participants spoke of their home as being communities up to as far as 200km out of the Ceduna. They expressed just how hard it is for them to get out there.

'Going back to the bush is good for the heart and the mind' (Aboriginal participant)

'Its difficult to keep our spirits up without spending time on country and with our family and loved ones' (Aboriginal participant).

Many people spoke of how easily they can get back to community over the weekend via the local bus service but then struggle to return at the beginning of the following week for treatment as the bus only runs on certain days.

Renal Transplantation

When talking about transplantation and care pre and post-transplant, the importance of support services was highlighted. Many participants spoke about the Kanggawodli as providing transplant recipients a safe stable place to stay in a supportive environment. This positively influenced their experience and stay in the city.

One participant shared their transplant journey, talking about the hardships faced before transplant, what helped them through the process and what moving forward has been like. They spoke about being able to take a family member with them to Adelaide and how they believed that their journey would have been incredibly negative and stressful without them.

The cultural safety of the process was also discussed, highlighting how services such as interpreters can significantly impact upon patients desire to pursue transplantation. Without this service, the complexity of the concepts and medical language make it seem inaccessible. It was suggested that employing more Aboriginal health workers is the most critical health service improvement needed to support transplant candidates and recipients, and enable them to thrive rather than just survive. There was also discussion about the fact that transplant isn't always what people want immediately and that they may need time to process and make decisions about their options and preferences.

Additional Supports

During the consultation patients talked about what they would actually like to do whilst they were on dialysis. Participants expressed a desire to have interactive activities like painting or colouring available, as well as different movies or TV programs available and having the TV's themselves closer to the chairs. Some of these things were being discussed already within the dialysis unit. There was also a suggestion to have other appointments scheduled during this time. Participants were open to the idea of having consultations with other health care providers whilst on dialysis in order to give them more time outside of their treatment schedule. Confidentiality was possible in the current configuration of the dialysis unit.

The idea of ongoing patient/community consultations regularly and having a platform for feedback was also raised. It was suggested that this would help to get people involved and make the unit more inviting and better suited to the needs of families.

The Role of Community - Strength and Empowerment

One of the themes that featured prominently throughout both sessions was the importance of 'community' and of keeping yourself and those around you strong. When talking about the prevention and early detection of CKD one of the things suggested was to hold community wide events or days that encouraged everyone to come together to learn about kidney health and healthy living. Having services providing health checks and cooking demonstrations that focused on low cost, healthy food preparation was suggested.

Social events specifically for the dialysis patients and their support networks were also suggested, allowing time for people to come together and socialise, debrief and support one another in a non-clinical environment. Involving support and family networks in the provision of care more frequently, encouraging them to be present at specialist consultations and involving them in educational initiatives was also raised.

'We moved here to support my uncle, but we need just as much support to know what we should be doing' (Aboriginal participant).

Many participants talked about what motivates them to keep strong and how they go about it. People shared stories about how they have learned to take control and speak up about their health and wellbeing and how this has helped them to take control of their own journey. They spoke of the value of teaching people about their bodies and illness, to equip them with knowledge so that they can make decisions that will benefit their health.

'I am ultimately responsible for my own health, I have the incentive' (Aboriginal Participant).

We discussed harnessing this ability and developing a community support program, in which people that have experience 'taking control' are able to go out into the community and support others that may be facing challenges.

'We have to stop this dependence on other people to solve problems, people need to be empowered' (Aboriginal participant).

This was discussed as being an internal community led initiative that took into account issues of equity and the reality of the social determinants of health.

Community priorities

When asked to reflect on the priorities, participants identified education for young people, identifying and treating kidney disease early, providing additional information and support for the whole of community as well as for people with end stage kidney disease, addressing accommodation and transport shortages, and improving access to nearby home communities and 'country' between dialysis sessions. There was also interest in community driven initiatives to help people stay strong while on dialysis.

Guidelines

Participants agreed that all the themes raised during the consultation could and should be shared with the Guidelines Working Group to guide the writing process.

8 Dissemination

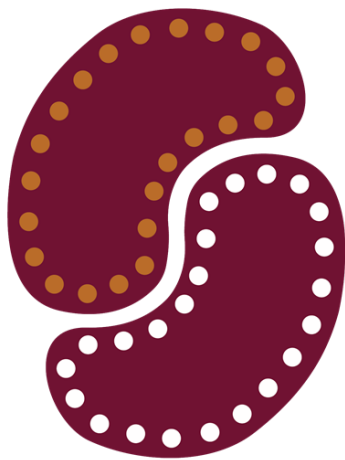
The draft report was shared with participants for accuracy.

The participants have approved the release of this report and it has been disseminated with:

- The Guidelines Writing Group
- Clinical Champions and local renal services
- Key Aboriginal and Non-Aboriginal partners
- Funding agencies

A short version of this report was provided to all community members who attended this meeting.


This report is produced as part of the aKction project, based at University of Adelaide, funded through a Medical Research Future Fund grant.



aKction

Aboriginal kidney care together - improving outcomes now

9. Appendix One: Workshop Flyer



In consultation with:

aKction Aboriginal Kidney Care Together, Improving Outcomes Now!

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

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

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

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

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

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



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

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

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

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

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

Please RSVP to Geraldine Ware on 8626500 or Andrew Lane on 86262110 by **Monday 4th of June 2019**. You can discuss transport needs with Geraldine.

For more information please call: Roxanne Sambo on 0475 3453 68, or Janet Kelly on 0428 891 286 or Tahlee Stevenson on 0411 307 297

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Disclaimer:

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