

# Indigenous 'Yarning Kidneys'

Report: Port Augusta Consultation, February 2019

Dr Janet Kelly, Ms Tahlee Stevenson, A/Prof. Shilpa Jesudason & Ms Dora Oliva on behalf of the Aboriginal Kidney Care Together: Improving Outcomes Now (aKction) Project and Kidney Health Australia.

**Consultation meeting to inform the development of the KHA-CARI Guidelines for Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islander Peoples and the Aboriginal Kidney Care Together: Improving Outcomes Now (aKction) Project**



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**Please be aware that this report refers to feedback from and may contain the images and names of Aboriginal and Torres Strait Islander participants who may have since passed away.**

# **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 Reference Group and Port Augusta community who provided valuable guidance for the Port Augusta community consultation:

- Ms Nari Sinclair and Ms Inawintyji Williamson
- Ms Rhoda Tjitatyi, Ms Kani George and Mr Brown

## **1.2 Stakeholders**

Kidney Health Australia and the University of Adelaide established a productive partnership with Central Northern Adelaide Renal & Transplantation Service (CNARTS), South Australian Health and Medical Research Institute (SAHMRI), and the Aboriginal Chronic Disease Consortium, Pika Wiya and Port Augusta Dialysis Unit 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
- Ms Tahlee Stevenson
- Ms Dora Oliva
- Ms Kylie Hermann
- Ms Laurel Dodd
- Ms Anne Marie Fawcett
- Dr Susan Crail
- Associate Professor Shilpa Jesudason
- Ms Gloria Mejia
- Ms Roxanne Sambo
- Prof Stephen McDonald
- Ms Eleanor Garrard

## 1.3 National Advisory Group

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 alphabetical order):

- Professor Alan Cass, Menzies School of Health Research
- Dr Martin Howell, KHA-CARI Office
- Dr Jaquelyne Hughes, Menzies School of Health Research
- Dr Janet Kelly, University of Adelaide
- Dr Odette Pearson, South Australian Health and Medical Research Institute (SAHMRI)
- Ms Rochelle Pitt, Metro South Health
- Ms Jess Styles, Aboriginal Health Community Controlled Health Organisation (ACCHO)

## 1.4 Funding

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

### **Yarning Kidneys consultation**

The Government of Australia provided funding to Kidney Health Australia for the development of 16 consultations across metropolitan, rural and remote communities of Australia (excluding communities in the Northern Territory, which have been involved in the Catching Some Air Project). Consultation costs including interpreting services, local co-facilitator, acknowledgement of Country, catering, patient transportation, printing, art supplies and artist assistance were paid through this grant.

### **Improving Aboriginal Kidney Care Together (IAKCT)**

The IAKCT project was funded as Medical Research Future Fund as a Rapid Applied Research Translation for Health Impact Grant Scheme Grant, through Health Translation SA. Funding from this project was used to support Aboriginal Reference Group members and researchers

to attend planning meetings and the consultation, for resources development, transport, accommodation and catering costs.

## **Pika Wiya – Hosts of the Port Augusta community consultation**

We would like to thank the Pika Wiya Health Service for welcoming us and assisting with preparation and organisation of the consultation, including transport arrangements. A special thank you to Ms Laurel Dodd and Ms Anne Marie Fawcett from Pika Wiya, Mr Alan Morris the CEO who came each day to welcome us and acknowledge local custodians. We would also like to thank SA Country Health Dialysis Manager Ms Kylie Herman for encouraging and supporting community participation, providing and preparing the dialysis machine for the women to paint, and connecting us with local and Country Health SA media.

## **Artwork**

A special acknowledgement to the Artist Inawintji Williamson, a Pitjantjatjara and Yankunytjatjara Woman, kidney patient and member of the SA Aboriginal Community Reference Group. Ina painted the story of her life on an old renal dialysis machine, with help from her nieces, Ms Kani George and Ms Rhoda Tjitayi (photo below and next page)



## 2. Abbreviations and definitions

CNARTS – Central Northern Adelaide Renal & Transplantation Service

CKD – Chronic Kidney Disease

aKction – Aboriginal Kidney Care Together: Improving Outcomes Now Project

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.



Photo: Ms Inawintji Williamson paints the story of her life on an old renal dialysis machine, with help from her nieces, Ms Kani George and Ms Rhoda Tjitayi. Photos courtesy of The Transcontinental.

### **3. Executive summary and recommendations**

The priorities identified by community members focused heavily on the prevention and early detection of kidney disease. There was an emphasis on providing information and educating community about the kidneys, how to keep them healthy and where and when to go to get a check. The preference is to increase awareness by educating young people and developing educational materials in appropriate language that include pictures and diagrams.

The need for improved access to care was highlighted, specifically the need for access to dialysis in Coober Pedy. Systems and supports ought to be put in place to facilitate dialysis patients traveling home and to community, giving them a chance to receive their treatment without being confined to one health care facility. Transport and accommodation remain forefront issues, the need for reliable services in these areas is paramount.

Community members expressed the desire to have greater access to allied health and support services. The needs of patients receiving renal care and dialysis go beyond that of the medical and having someone to help them navigate the challenges and anxieties of making such large changes in their lives was welcomed.

#### **Key messages and recommendations from community members**

<b>Prevention</b>
<ul style="list-style-type: none"><li>• Implement and support specific health promotion activities that focus on how the kidneys work and how to keep them healthy.</li><li>• Target children and youth with programs that encourage them to care for their kidneys, to keep them healthy and to know when and where to go for help.</li><li>• Deliver information and prevention campaigns through social and visual media, including TV advertisements</li></ul>
<b>Early Detection</b>
<ul style="list-style-type: none"><li>• Implement an early detection campaign that encourages periodic and routine kidney health checks.</li><li>• Educate people on warning signs and symptoms and increase awareness about where to go for support.</li></ul>

<b>Information and Education</b>
<ul style="list-style-type: none"> <li>• Create education campaigns that promote health and increase understanding of CKD</li> <li>• Provide specific education about lifestyle modification for CKD patients</li> <li>• Provide education and consultation regarding treatment and care options including peritoneal dialysis, haemodialysis and transplant</li> <li>• Allow time for patients to develop an understanding of the treatment and to make an informed choice, provide information more than once</li> <li>• Deliver education and information on TV as video advertisements</li> <li>• Include pictures and diagrams with written information to make it easier to understand</li> <li>• Have experienced patient experts in kidney disease, dialysis and transplant working alongside health professionals so that they can both provide information to new kidney patients.</li> </ul>
<b>Access</b>
<ul style="list-style-type: none"> <li>• Increase the number of dialysis chairs available and create dialysis chairs in rural and remote areas</li> <li>• Facilitate travel and make 'holiday bookings' a possibility</li> <li>• Increase the availability of the dialysis bus and expand the span of where the bus will travel to</li> <li>• Increase the number of accommodation options that are available</li> <li>• Provide transport assistance to people that need to travel to get to dialysis or other kidney care appointments</li> <li>• Create shareable information in relevant languages, free of clinical jargon</li> <li>• Support Aboriginal health professional roles, encourage uptake and ensure that services are available to all Aboriginal patients</li> <li>• Increase the availability and accessibility of allied health professionals in rural and remote locations.</li> </ul>
<b>Cultural Safety</b>
<ul style="list-style-type: none"> <li>• Encourage continuity of care, aiming to keep care providers as consistent as possible.</li> <li>• Provide cultural safety training for all staff involved in providing kidney care, encourage providers to be open minded in the way in which they approach and deliver care.</li> </ul>

<b>Transplant</b>
<ul style="list-style-type: none"> <li>• Provide dedicated transplant education for renal patients.</li> <li>• Provide additional support, both financial and emotional for transplant recipients – equip them with the necessary means to be able to travel to wherever required when a transplant becomes available.</li> <li>• Increase awareness pertaining to living donors and the processes involved in this – provide support for the donors and their families and friends that are also involved in the transplant process.</li> </ul>
<b>Additional Support</b>
<ul style="list-style-type: none"> <li>• Implement a Peer navigator system to connect renal patients, assist them throughout their transitions and provide support to one another.</li> <li>• Include mental health care as a component of routine kidney health care or treatment</li> <li>• Support transition back to employment for CKD patients, having these patient navigator roles as paid employment could be a great avenue through which to achieve this.</li> <li>• Provide transport to and from dialysis treatment.</li> </ul>

## **4. Background**

### **4.1 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.

The Adelaide consultation is the first of 16 community consultations that Kidney Health Australia will undertake in metropolitan, regional and remote areas of Australia.

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.

### **4.2 Aboriginal Kidney Care Together: Improving Outcomes Now (aKction) Project**

aKction 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. 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.

## 4.3 Partnerships

Kidney Health Australia and the aKction research project led by Dr Janet Kelly, University of Adelaide, have partnered with each other and local health services and community members in Adelaide and Port Augusta 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.

### Improving Aboriginal Kidney Care Together

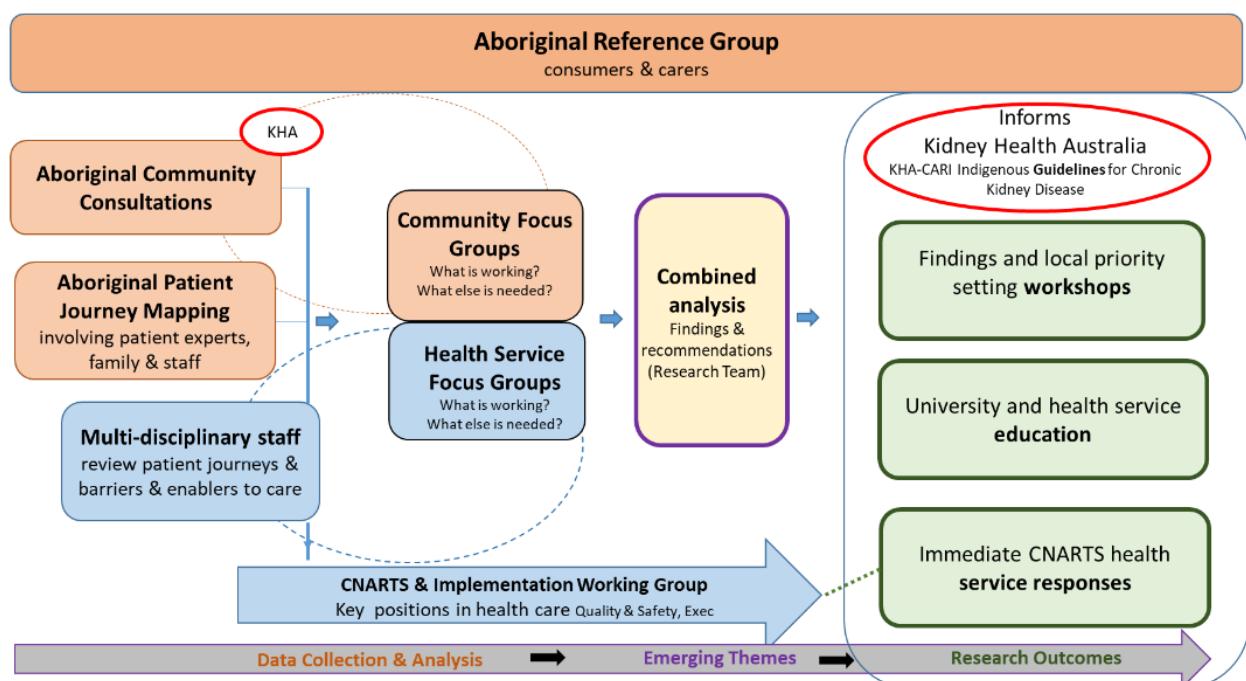


Figure 1: aKction Project model.

## **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 – Ganna.
- 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.

### **5.1.2. Ethical approval**

The aKtion 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.

## 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 the first consultation

We sought feedback from the Aboriginal Community Reference Group and participants of the first consultation held at Kangawoddli in December 2018 to guide us in planning the next consultation.

### Working with local care providers

We also contacted Laurel Dodd from Pika Wiya Aboriginal Health Service and Kylie Herman who manages the Port Augusta Dialysis Unit to discuss how best to hold a consultation in their area, with local kidney patients, their families and community members.

We modelled the structure of the Pt Augusta Community consultation upon that of the earlier consultation, in conjunction with feedback from this consultation and input from Pt Augusta local patients and staff. In the planning phase we liaised frequently with and other health care workers and nurses at from Pika Wiya in order to ensure the consultation was structured appropriately.

It was decided that the consultation would be held over two days, the first of which would be an open session in which participants would be encouraged to share their stories and engage in artwork activities. It was decided that this session would be facilitated by research staff only, and not feature the presence of clinical staff, in the hope that this would foster open sharing and relationship building. The second day would then be the more structured of the two, in which clinical staff would assist to facilitate and conversations would be centred on the pre-determined Kidney Health Australia priorities and questions.

### The role of clinical champions and renal services

As with the initial Adelaide consultation held at Kangawoddli in December 2018, nephrologists, medical staff, renal nurses and Aboriginal health workers were identified and contacted to be part of this initiative and played a crucial role in engaging Aboriginal kidney patients. 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.

## **Key stakeholders**

Key Indigenous and non-Indigenous stakeholders in Port Augusta assisted in the promotion of the consultation. The Aboriginal Community Controlled Health Organisation (ACCHOs) Pika Wiya Health Service Aboriginal Corporation hosted the consultation.

This report was disseminated among key partners to inform about the outcomes and recommendations from the consultation, to share with their community members, and also for transparency.

## 6. Participants



### **Patients, carers and family members      Local Researchers and Clinical Staff**

Ms Inawinytji Williamson

Dr Janet Kelly

Ms Angela Karni George

Ms Dora Oliva

Ms Rhoda Tjitayi

Ms Kylie Herman

Ms Cissie

Ms Anne-Marie Fawcett

Ms Joan Lang

Ms Susan Crail

Ms Kerry Alison Coulthard

Ms Tahlee Stevenson

Ms Sonia Champion

Ms Gloria Mejia

Mr Francis Ivan Dare

A/Prof. Shilpa Jesudason

Mr Robert Brown

Professor Stephen McDonald

Ms Raylene Buzzacott

Ms Eleanor Garrard

Ms Noleen Lester

Mr Chris Forbes

Mr Sandy Curtis

Ms Roxanne Sambo

Ms Shila Curtis

Ms Kanakiya Tjanyari

Ms Rosslyn Coukthard

Mr Douglas Walker

Ms Maureen Marks



## 7. Indigenous 'Yarning Kidneys' session

### 7.1 Participants

The consultation meetings in Port Augusta were conducted across two days, the 6th and 7th of February 2019. A total of seventeen Aboriginal community members attended, including those experiencing renal dialysis and transplant, and their carers and family members.

### 7.2 Consultation format

Both consultation sessions commenced with Acknowledgement of Country delivered by Mr Alan Morris, Pika Wiya Health Service, Chief Executive Officer.

The first session on the 6th of February was designed to be for community members only, in which participants were invited to share their stories and experiences through discussion and art.

Dr Janet Kelly, Principal Investigator, aKction research, University of Adelaide, and Ms Dora Oliva, National Manager, Indigenous Kidney Health, Kidney Health Australia, explained the purpose of the meeting and how the outcomes of the consultation will 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 shared their experiences in small groups, with facilitators recording key points in their discussion. In addition, an old dialysis machine was provided by Ms Kylie Herman, Nurse Unit Manager, Renal Unit, Port Augusta Hospital & Regional Health Services and the Port Augusta dialysis Unit, for participants to paint their kidney journey story on. A local

newspaper reporter came and spoke to community members and facilitators and took photos of the group and painted machine, and an article was published that week to increase kidney health awareness in the community.

The second session was held on the 7th of February and involved community members and kidney health staff from Port Augusta and, and Kidney Health Australia representatives, other key stakeholders, such as the Primary Health Network.

Following Acknowledgement of Country by Mr Alan Morris, Aboriginal Health Professional Roxanne Sambo, Royal Adelaide Hospital, introduced the aKction project and explained the Kidney Health Australia community consultations and guidelines using the whiteboard. A video from Ken Wyatt AM, MP, Minister for Aged Care and Minister for Indigenous Health was shown to inform the participants that funding that had been received and commitment made to improving kidney care for Aboriginal patients Australia wide.

Participants moved into smaller working groups for in depth discussion. A series of questions identified by Kidney Health Australia and modified following the Adelaide consultation at Kangawoddli hostel, guided the conversations. These questions explored the 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. Following these discussions, everyone came in a large group to share what had been discussed and to identify key themes, priorities and recommendations.

Throughout both sessions, Ms Rhoda Tjitayi interpreted the information into local languages, with the assistance of Ms Ina Williamson. Notes were taken throughout the consultations and discussions were recorded and transcribed for accuracy.

## 7.3 Discussion of themes

Notes were taken during the consultation and discussions were audio recorded and transcribed for accuracy. A level of analysis was undertaken within each small group, and also across the entire group using the white board in the final session. Each group were invited to discuss their most important points, with the facilitator inviting one point from each group around the room, and then repeating the process, with discussion and confirmation of these across the larger group. This interaction enabled a level of prioritisation through verbal and non-verbal responses. A draft version of the 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

### Prevention

The need for more information to enable community members to understand about what kidneys do and to prevent kidney disease, was highlighted across both days.

A lot of discussion focused on the need to prevent kidney disease in young people, and this was seen as a priority.

*'Getting into schools, raising awareness and getting kids thinking about their kidneys and how to keep them healthy' (Aboriginal participant).*

Almost all participants were initially unaware that kidney disease could also affect young people, leading to dialysis.

*'Even as a dialysis patient I didn't know that it was something that kids could be on, especially healthy and fit ones' (Aboriginal participant).*

Participants identified that there are targeted prevention campaigns for other chronic illnesses such as heart disease and smoking related illnesses, but they knew of nothing that highlights the severity and prevalence of CKD. They suggested visual media and TV advertisements as effective ways of communicating messages and getting information out to community.

They highlighted the need for improved education and targeted preventative initiatives that increase awareness of chronic kidney disease (CKD), about what the kidneys do within the body and how to keep kidneys healthy. Participants said this would provide community with the knowledge and understanding so that they would be able to identify warning signs and seek medical care when early warning signs and symptoms first appear. They could then prevent the development of kidney disease.

## **Early detection**

Participant discussions highlighted the link between prevention and early detection throughout the two days of consultation and the role that education played in both. Many participants shared similar stories of only finding out they had kidney disease as an incidental finding when in hospital for something else, or because they had family members with kidney disease and had learned from them what the symptoms might mean.

*'I only knew what to look out for after seeing other family members with the same thing' (Aboriginal participant).*

*'We don't know when it is best to get further information or a 'kidney health check', or even how to do this' (Aboriginal participant).*

There was a large gap in knowledge between those who found out about kidney disease from their own or other family members with kidney disease, and the rest of the community.

Many participants raised concerns that even when they find out they have kidney disease, they are only told what to avoid but there is little or no focus on what can be done to care for the kidneys or halt disease progression.

## **Information and education**

There was an overall preference for more education that focused on increasing knowledge about signs and symptoms and promoting health

*'We need more information about what is happening, where to go for help and when to do this' (Aboriginal participant).*

Many participants rely on the lived experience of family and friends, and while this was useful it also shaped the way in which CKD and the treatments were viewed, especially when they had witnessed or heard about negative or scary experiences.

There was a lot of discussion about the need for more information about transplants, and how it would be good to have transplant recipients and health professionals working together to explain about the transplant journey.

*'I put off going for transplant two times when I got the call because I had heard from other community members how scary it was' (Aboriginal participant).*

The need for education that focuses on positive life style changes was also stressed. Participants highlighted that there is a lot of information about what kidney patients should avoid or cut from their diet, but little there about what to aim for, such as exercise. If they received this information, it could encourage and inform them to make positive changes in their lives.

The need for increased awareness and information about treatment options and choices was also highlighted. Many participants spoke of how they wished that treatment options had been explained to them more thoroughly before they started treatment, and while having ongoing treatment. They wished to understand what the different drugs they were being prescribed were for and how they worked, and how dialysis works. Many participants also expressed a desire to know more about peritoneal dialysis and whether it would be appropriate for them.

*'I want to know more about [the medications] I am taking, about dialysis and my options (Aboriginal participant).*

*'Is peritoneal dialysis something I can have? I don't know (Aboriginal participant).*

Participants indicated that a lot of information could be shared on TV or video for the community generally. Written information and educational materials should include pictures and diagrams to increase understanding. There is also need for more time with kidney health professionals to explain treatments and options, and that this might need to be repeated over time.

## **Access**

Issues associated with accessing care and services featured quite prominently throughout discussion. The need for better access to dialysis in rural and remote areas, specifically in Coober Pedy was highlighted. The travel and relocation associated with accessing dialysis

treatment is one of the major barriers. Many participants discussed how emotionally taxing it can be to leave not only community and social supports and how this can influence treatment choices.

*'As if the pain from the kidney machines isn't bad enough, we already broken hearted from being away from home' (Aboriginal Participant).*

Committing to receiving treatment in a certain area it can make it incredibly hard to access treatment elsewhere, for example finding a 'holiday chair' or accessing the mobile dialysis bus.

*'We can't go home, we can't go anywhere, we get trapped' (Aboriginal Patient).*

Transport and accommodation were also discussed, with many patients stating that being able to physically get to and from treatment and having somewhere to live throughout can be significant barriers. Whilst there is often accommodation available to patients it isn't always appropriate to their needs, for example it can be challenging to find somewhere to stay if there are children or family members coming with you. Also having to wait for accommodation to be found can significantly delay the time it takes to actually commence dialysis.

*'A lot of people are in hardship, the pension isn't enough, if we have to pay to travel there isn't enough left to get food' (Aboriginal Participant).*

The availability of allied health professionals and services providers in rural and remote locations was also discussed. Many participants expressed interest in these services but struggled to access them when not in the metropolitan setting.

*'Unless you are in the big hospital, you don't get the services' (Aboriginal Participant).*

Cultural and language accessibility concerns were also raised. Avoiding medical jargon and incorporating traditional languages when giving information and explanations was highlighted as something that could be incredibly beneficial. It was also highlighted that the accessing Aboriginal health professionals such as liaison officers and support workers is not always an option, and that better linkages here could be beneficial.

## Cultural safety

The issue of whether or not the care being provided is always culturally safe and appropriate was also raised. Many participants spoke about the importance of familiar staff and local champions in their care; having people that know their journey and their family and were willing to be flexible in the way in which they approached care made engaging in care much more appealing. There was a clear desire to increase the number of Aboriginal individuals within the renal care workforce, with many encouraging the idea of upskilling those who are already carers or nurses to work specifically within the renal space.

*'We should educate our young people, they could become nurses and doctors and go back to community and work in renal care' (Aboriginal Participant).*

It was again raised that within Aboriginal culture there is a spiritual element to kidney care and that the possibility of this needs to be acknowledged by staff. Time needs to be taken to adequately explain to patients what dialysis is and what it does to the body, in order for people to become comfortable with the treatment they are receiving.

*'People don't need to know specifics, they just need to be aware that diversity is out there and that it needs to be acknowledged' (Aboriginal Participant).*

## Transplantation

A lot of discussion centred on the transplant process and the confusion and angst surrounding it. Many of the participants had quite varied experiences and understandings of the process and many stories were shared. Many found that the education and information surrounding transplant is inadequate, for example it was questioned as to why some people receive transplants before others and why some patients aren't eligible for transplant at all.

*'They just told me that I had to lose weight to stay on the transplant list, not how much weight or why just that I had to' (Aboriginal Participant).*

Some participants shared that it was never explained that the wait for transplant could take years, but simply unrealistically reassured that 'it could be any day now' when they asked. Many participants emphasized the panic that surrounds the entire process, in particular the 'wait for the call'.

*'There's' a real panic, must always have your phone on and charged and in reach, can't let the grandkids play with it in case they decline that call'* (Aboriginal Participant).

Another theme that emerged was the lack of awareness surrounding living donors and the lack of support available for people involved in that process. One participant shared with us her experience in which her husband had donated his kidney to their daughter and the turmoil that she had experienced throughout.

*'I was told you better say goodbye before surgery, just in case they don't come out – as a family we were offered no support, I felt useless like I wasn't a part of the journey and couldn't do anything to help'* (Aboriginal Participant).

## **Additional supports**

The desire to access additional supports was raised by almost all participants. One of the most common suggestions was the development and implementation of a peer navigator or buddy system in which previous or current but experienced renal patients connect with new patients and assist them to navigate and overcome the challenges associated with commencing treatment. Moving to receive treatment can be a very intimidating and confounding factors such as learning the layout of a new town or hospital can add additional pressures.

*'Moving to Adelaide is confusing, it is very different from the country. You have to learn about the buses and where the supermarkets are, all that extra stuff'* (Aboriginal Participant).

Assistance with moving and the associated costs and logistics was another common theme. Many participants shared their experience of being told they needed to relocate but having no idea where to start. Having someone to help throughout this process or even somewhere constant to go to find information and support would be welcomed.

*'Maybe doctors and nurses could help us to find services in Adelaide, they know how it works there'* (Aboriginal Participant).

Another point which was raised was that of going back to work following a transplant or whilst on dialysis. One participant shared the story of wishing to return to work once she had stabilised on peritoneal dialysis but found that many work places were apprehensive to hire her. Many people are required to give up their jobs in order to commence dialysis treatment.

*'Everyone was scared I would get sick and need more time off, they thought I wouldn't be able to do my job anymore' (Aboriginal Participant).*

Many renal patients highlighted that kidney disease generally impacts negatively their mental health, often causing depression. Patients indicated that it would be beneficial to offer social and emotional support services to renal patients, especially to those who have just started dialysis or recently relocated and are away from family. Some participants indicated that kidney treatment impacts on their work and social life, which also affect their emotional wellbeing.

*'That is when depression starts because you don't know what is happening. I used to work, but I don't anymore, I was exhausted, tired. Sunday was my only day off, because I attended dialysis for 5/6 hours a day, three times a week.' (Aboriginal participant).*

## **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. They also prioritised certain topics which are considered to be most important, for example prioritising educating young people, identifying and treating kidney disease early, and providing additional information and support for people with end stage kidney disease.

## **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 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.

## 9. Appendix One: Workshop Flyer



In consultation with:

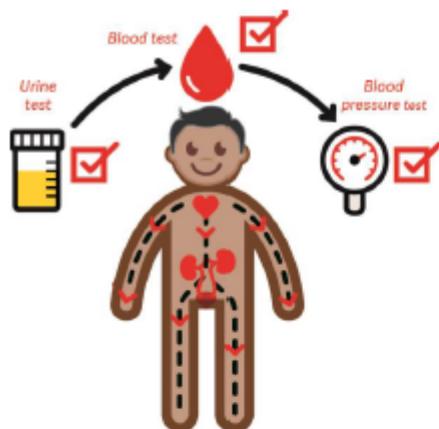


### Indigenous Voices Yarning 'Kidney Health'

In Australia and New Zealand there are Guidelines (instructions) that are used by doctors, nurses and other health professionals to know how best to treat kidney diseases. Currently these Guidelines do not include cultural aspects of care or specific needs or challenges that may occur for Aboriginal and Torres Strait Islander Peoples.



Kidney Health Australia and the 'Improving Aboriginal Kidney Care Together' Research are holding community consultations in South Australia: Adelaide and Port Augusta. We invite you to attend the consultations to tell us what should be in these guidelines, how we should use them, and give us ideas about improving kidney care locally and how to provide the information back to you.



Aboriginal and Torres Strait Islander Peoples and their family members have the opportunity to discuss what is most important regarding their kidney health, kidney care and personal, family and community experiences with kidney treatments. The consultation will be recorded and written up, and then shared with all who attended, to get their feedback. Names of those attending will not be written on the consultation report unless permission is given.

**Art Session:** Wednesday, 6 February 2019, 12:30pm – 4:00pm at Pika Wiya Health Service (40-46 Dartmouth Street Port Augusta, SA).

**Yarning Kidneys:** Thursday, 7 February 2019, 12:30pm – 3:30 pm at Pika Wiya Health Service (40-46 Dartmouth Street Port Augusta, SA).

**Food and transportation will be provided.**

**Please RSVP and book your transport** with Laurel Dodd on 8642 9930 or Kylie Herman on 8668 7737 **by Monday 4 February 2019.**

For more information call: Dora Oliva on 0406 809 712, Janet Kelly on 0428 891 286 or Laurel Dodd on 8642 9930.

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## Disclaimer:

The recommendations contained in this report were formed from feedback obtained through consultation with Aboriginal renal patients, carers, family and community members. It is designed to provide information and assist decision-making. The authors assume no responsibility for personal or other injury, loss or damage that may result from the information in this publication.