

Prevent, Detect, Support.

Indigenous 'Yarning Kidneys'

Report: Adelaide Consultation 2018

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

**Consultation meeting to inform the development of the 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**

Artwork: 'My Kidney Journey' by Inawinytji Williamson



Table of Contents

| | |
|---|----|
| 1. Acknowledgements | 3 |
| 1.1 Local Aboriginal Community Reference Group:..... | 3 |
| 1.2 Stakeholders | 3 |
| 1.3 Advisory Group | 4 |
| 1.4 Funding | 4 |
| 1.5 Ethics | 5 |
| 1.6 Artwork..... | 5 |
| 2. Abbreviations and Definitions | 6 |
| 3. Executive Summary | 7 |
| 4. Background | 11 |
| 4.1 New Guidelines for management of Chronic Kidney Disease (CKD) among Aboriginal and Torres Strait Islander Peoples | 11 |
| 4.2 Aboriginal Kidney Care Together: Improving Outcomes Now - aKction | 11 |
| 4.3 Efficient partnership | 12 |
| 5. Consultation methodology and engagement | 13 |
| 5.1 Methodology | 13 |
| 5.2 Strategies for Community Engagement..... | 13 |
| 6. Participants | 17 |
| 7. Indigenous ‘Yarning Kidneys’ session | 18 |
| 7.1 Participants | 18 |
| 7.2 Consultation format | 18 |
| 7.3 Analysis..... | 18 |
| 7.4 Outcomes..... | 19 |
| 8. Dissemination | 27 |
| 9. Appendix One: Workshop Flyer | 28 |

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 Local Aboriginal Community Reference Group:

The authors would like to acknowledge the valuable contribution and guidance of the members of the SA Aboriginal Community Reference Group for the Adelaide community consultation:

- Ms Nari Sinclair
- Ms Inawinytji Williamson
- Mr Richard Brooks

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 for the planning, organisation and follow up of the South Australia consultations. We would like to acknowledge their significant contribution and support. 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
- Associate Professor Shilpa Jesudason
- Professor Stephen McDonald
- Dr Susan Crail
- Dr Samantha Bateman
- Dr Andrea McKivett
- Ms Tahlee Stevenson
- Ms Gay Martin
- Ms Serena Frasca
- Ms Lisa Hanson
- Ms Tiffany Whittington

1.3 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 alphabetic order):

- Professor Alan Cass
- Dr Martin Howell
- Dr Jacquelyne 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:

1.4.1 Yarning Kidneys Consultation

The Australian Government has provided funding to Kidney Health Australia for the development of 16 community consultations across metropolitan, rural and remote communities of Australia (excluding communities in the Northern Territory and Thursday Island, who have already been involved in the Catching Some Air Project). Consultation costs including interpreting services, local co-facilitators, acknowledgement of Country, catering, patient transportation and printing were supported through this funding.

1.4.2 Aboriginal Kidney Care Together: Improving Outcomes Now (aKction) Project

The aKction project is funded by a Medical Research Future Fund - Rapid Applied Research Translation for Health Impact Grant through Health Translation SA. This project has supported Aboriginal Community Reference Group members and researchers to attend planning meetings and the consultation, and provided funding for resource development.

1.5 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.

1.6 Artwork

A special acknowledgement to the Artist Inawinytji Williamson, a Pitjantjatjara and Yankunytjatjara Woman, kidney patient and member of the SA Aboriginal Community Reference Group. Ina developed the artwork included in the front cover of this report, which depicts her kidney journey.

This artwork was created specifically for the community consultations and research project and will be used across future consultations and documents with her permission.



'My Kidney Journey' - Inawinytji Williamson

"The white circles in the centre represent all Aboriginal kidney patients coming together to have a yarn about kidney health with doctors and nurses, talking about the plans for the future and sharing what they want to see happening to improve kidney health for their people.

The outside circles represent patients on dialysis to help cleaning their body to keep healthy.

There are two footpaths that represent the journey of Aboriginal kidney patients. Wild flowers and grass

are represented by purple, white, black, orange and green dots."

2. Abbreviations and Definitions

CNARTS – Central Northern Adelaide Renal & Transplantation Service

CKD – Chronic Kidney Disease

aKction – Aboriginal Kidney Care Together: 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

The priorities identified by community members include kidney disease prevention and early detection through Aboriginal Health Services, with greater emphasis to be given to rural and remote education involving family camps, face-to-face workshops and storytelling. The preference is to increase awareness among Aboriginal young people about kidney disease, and for schools, parents and people who have experience of kidney disease to be involved in delivering this education.

Suggestions were made about: improving access to healthcare, having treatment options available 'on country', improving continuity of care, stabilising the local workforce, encouraging the availability of Aboriginal expert kidney patients to provide peer education, improved availability of interpreters and resources in a range of languages, and reliable transportation to dialysis services.

Providing culturally safe care was also regarded as a priority (often described by community members as 'cultural awareness'), highlighting the importance of cultural training for health professionals. Community members identified that health care providers need a deeper understanding of how Aboriginal peoples comprehend and relate to kidney disease, and how this impacts upon their understanding of, and considerations regarding, renal transplant and dialysis

Aboriginal community members identified the need increased funding for kidney health prevention and treatment, and have clear suggestions for the development of holistic Indigenous guidelines for the management of chronic kidney disease.

Key messages and recommendations from community members

| |
|--|
| Prevention |
| <ul style="list-style-type: none">• Deliver kidney education to young people (kids).• Offer cooking and shopping lessons, as well as family camps to educate community about taking care of kidneys.• Deliver culturally-safe and comprehensive kidney prevention education and health promotion in metropolitan, rural and remote communities, in collaboration with Aboriginal and mainstream primary healthcare services, schools and community members with kidney disease. |
| Early detection and CKD management |
| <ul style="list-style-type: none">• Utilise kidney patients to encourage family members to conduct regular kidney checks.• Implement an early detection campaign, including periodical kidney checks routinely performed as part of the annual health check for kidney patients' family members.• Provide culturally-safe information to people with early stages of CKD to increase the understanding of kidney disease and the ways to prevent and slow progression of kidney disease. |
| Information and education |
| <ul style="list-style-type: none">• Deliver kidney education and make written resources available in Aboriginal languages.• Implement culturally-safe and peer education around treatment options, especially to be provided by someone who themselves has kidney disease and various treatments.• The most effective way to educate and communicate is through videos, followed by face-to-face education and storytelling by Aboriginal people.• Renal health services should employ Aboriginal expert renal patients as Patient Navigators and Mentors to assist and support new patients. |
| Management of co-morbidities |
| <ul style="list-style-type: none">• The health care system needs to communicate more effectively to reduce the need for multiple appointments and travel to and from disconnected health services for co-morbidity care.• Aboriginal Medical Services need support and resources to enable them to incorporate kidney prevention, management and treatment as part of the approach to chronic disease prevention within Aboriginal and Torres Strait Islander communities. |

| |
|--|
| <ul style="list-style-type: none"> • Better coordinate overall care of co-morbidities in a patient-centred approach, rather than health system focused approach. |
| <p>Access</p> |
| <ul style="list-style-type: none"> • Supporting connection with land and family is important. • Kidney treatment options should also be available in rural and remote communities across Australia and delivered in collaboration with Aboriginal community input. |
| <p>Cultural awareness</p> |
| <ul style="list-style-type: none"> • Health professionals need to acknowledge and accommodate the important roles, commitments and responsibilities that Aboriginal peoples have and adjust the care plan based on these needs. • Interpreters should be available to attend clinics, so that Aboriginal peoples are able to understand and communicate. • Improve and increase cultural awareness of doctors, nurses and other health providers about heterogeneity among Aboriginal people and communities • Given the spiritual considerations in relation to dialysis and transplant, a better understanding of how Aboriginal peoples interpret kidney issues should be acquired and applied to renal programmatic and guideline initiatives. |
| <p>Considerations about transplant</p> |
| <ul style="list-style-type: none"> • Transplant is often perceived to be the cure for kidney disease rather than a treatment option. • Deliver culturally-safe information and education around transplant as a treatment option, as well as medication and costs associated with this option. |
| <p>Considerations about Dialysis</p> |
| <ul style="list-style-type: none"> • Increase understanding of cultural and geographical preferences regarding dialysis treatment options (dialysis centres in metropolitan areas versus home dialysis in rural and remote areas). |
| <p>Continuity of care and stable workforce</p> |
| <ul style="list-style-type: none"> • Ensure continuity of care and stable workforce for Aboriginal kidney patients. |
| <p>Transport</p> |
| <ul style="list-style-type: none"> • Transport services should be reliably provided alongside the dialysis services for both Aboriginal and non-Aboriginal patients who need to access them. |

Guidelines

- Guidelines should be comprehensive and include management of lifestyle risk factors, prevention of kidney disease and treatment options.
- Community members need to be meaningfully involved in determining priorities for guidelines as is happening. They also to receive information about the final version of the guidelines, in ways that are accessible and understandable.

Government funding and support

- Concern that the Government is not listening to the community about kidney health priorities, and important support services are not being adequately resourced.
- Kidney health has not been given the funding and priority it requires to cover the needs for all patients.
- There should be equitable allocation of resources to prevent, manage and treat kidney diseases among Aboriginal and Torres Strait Islander Peoples.

4. Background

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

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 research project - aKction

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.

4.3 Efficient partnership

Kidney Health Australia and the aKtion research project led by Dr Janet Kelly, University of Adelaide, have partnered with each other and local health services 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.

Aboriginal Kidney Care Together: Improving Outcomes Now (aKtion) Project

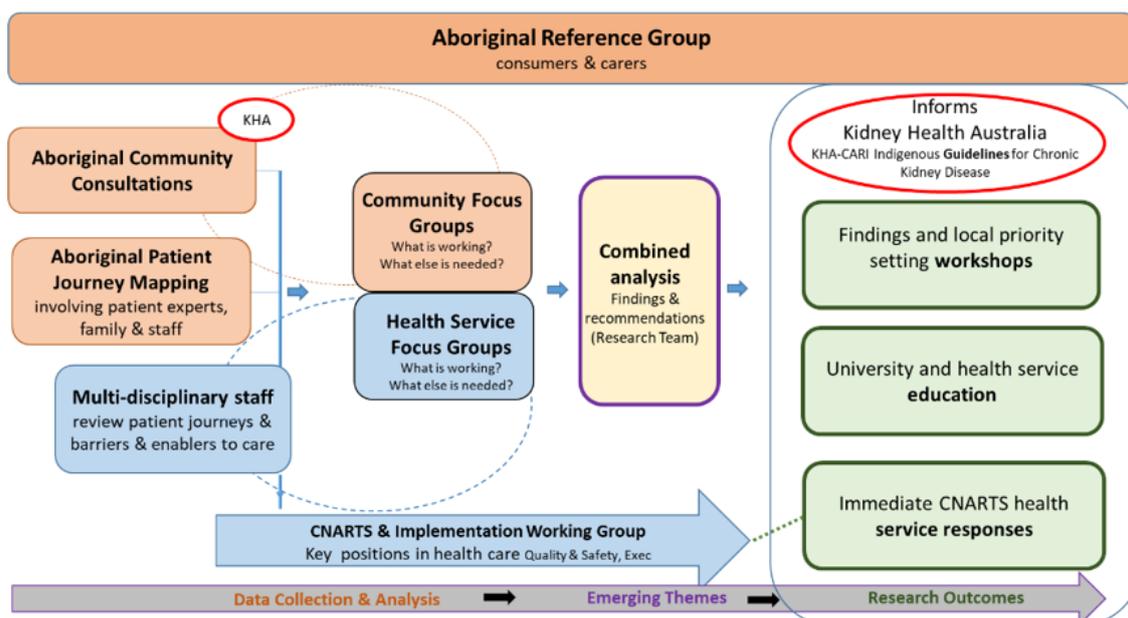


Figure1: Aboriginal Kidney Care Together: Improving Outcomes Now (aKtion) Project model.

5. Consultation methodology and 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 three strategies were used to engage Aboriginal and Torres Strait Islander kidney patients, carers and family members, as well as Elders, community members and religious leaders to attend the community consultation.

5.2.1 Aboriginal Community Reference Group

An essential component of planning successful community engagement was the establishment of the SA Aboriginal Community Reference Group who provided local Indigenous governance. This group was comprised of Indigenous kidney patients who are passionate about supporting their community and preventing kidney disease in other members of their community, by sharing their kidney journey.

Ms Ina Williamson, Ms Nari Sinclair and Mr Richard Brooks combined their unique knowledge and experience to provide guidance for the planning, facilitation and follow up of the consultation. The meetings conducted with the Aboriginal Community Reference Group are described below:

1. **Initial meeting:** Discussed the Reference Group's role and expectations about the upcoming consultation, and discussed an earlier consultation workshop conducted in June 2018 at Kanggawodli. The group identified the need to disseminate the themes that will be discussed at the consultation in advance, which were subsequently incorporated onto the flyer.
2. **Meeting 2 to discuss progress:** Obtained feedback about the proposed questions and themes for the consultation, and the benefit of engaging Ms Inawinytji Williamson as interpreter. A list of key patients and community members to be invited were identified, as well as a culturally-safe venue chosen.
3. **Meeting 3 to finalise arrangements:** Engaged Ms Nari Sinclair to conduct the Acknowledgement of Country, and co-facilitate as needed. Negotiated agreement regarding reimbursement for their contribution, and Ms Inawinytji Williamson agreed to present the Aboriginal artwork she created for the consultation and research projects at the consultation.
4. **Meeting 4 evaluation:** Discussed feedback to identify changes to improve upcoming consultations, as well as guidance on the analysis of the information and the draft report. Some members agreed to continue providing guidance for the Port Augusta consultation and to work with Dr Janet Kelly to progress patient journey mapping, focus groups and other initiatives as part of the aKction research project.



Photo: Inawinytji Williamson and Nari Sinclair, members of the SA Aboriginal Reference Group.

5.2.2 The Role of Clinical Champions and Renal Services

Local clinical champions including nephrologists and other medical staff, renal nurses and dialysis managers, and Aboriginal health professionals were identified from the Royal Adelaide Hospital and Central and Northern Adelaide Renal and Transplantation Service (CNARTS).

These health professionals became involved in this initiative and played a crucial role in engaging Indigenous kidney patients and supporting them to attend. They also assisted with the facilitation of the consultation and contributed to the co-analysis process during the session.

Local clinicians and researchers will continue to be involved following the consultations to ensure that the recommendations provided by the community are considered by renal services, and that responsive actions are identified and implemented to improve the delivery of kidney care at state and local levels.

5.2.3 Stakeholders

Key Indigenous and non-Indigenous stakeholders in Adelaide assisted in the promotion of the consultation. Aboriginal Community Controlled Health Organisations (ACCHOs), Aboriginal hostels, Aboriginal Elder Villages, art centres and the local church were informed and invited to be part of the consultation. The following stakeholders assisted in inviting Aboriginal community members to attend the event:

- Aboriginal Health Council of SA (AHCSA)
- Nunkuwarrin Yunti of South Australia
- Wonggangga Turtpandi
- Kanggawodli
- Luprina
- Aboriginal Elders Village
- Adelaide Congress Ministry.

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

Inawinytji Williamson
Greg Sinclair
Nari Sinclair
Bobbo Sumner
Adam Tunkin
Margaret Wintina
Thomas Tjilya
Rev Dean Whittaker
Alice Abdula
Barbara Baker
Kerry-Ann Edwards
Penny Wells
Richard Pearce
Carolyn Dunn
Richard Brooks
Tjimpuna Dunn
Margaret Richards
Purky Edwards
Tjulyata Tjilya

Local Researchers and Clinical Staff

Janet Kelly
Shilpa Jesudason
Gay Martin
Serena Faser
Susan Crail
Samantha Bateman
Tahlee Stevenson
Lisa Hansen
Dora Oliva
Eleanor Garrard
Anjana Prabu



7. Indigenous 'Yarning Kidneys' session

7.1 Participants

Nineteen Aboriginal community people attended the consultation conducted on 13 December 2019 at Kanggawodli, Adelaide; representing a mix of patients experiencing diabetes and/or heart diseases, are or had been on dialysis, and have received a kidney transplant. Family members and carers, as well as the local religious leaders also attended the meeting.

7.2 Consultation format

The consultation session started with the Acknowledgement of Country delivered by Ms Nari Sinclair, followed by a short video message delivered by the Minister for Indigenous Health, The Hon. Ken Wyatt AM, MP, to welcome participants.

Dr Samantha Bateman delivered a short presentation about the role of the kidneys and how to keep them healthy. Dr Janet Kelly and Ms Dora Oliva then explained the purpose of the meeting and how the outcomes of the consultation will help inform the new Indigenous Guidelines for management of CKD as well as improvements in the healthcare at state and local levels.

Participants re-organised themselves into sub-groups to discuss kidney themes with local facilitators. Ms Nari Sinclair co-facilitated a small group discussion during the session and Ms Ina Williamson provided Pitjantjatjara interpreting.

A set of themes and key questions developed by the working group with feedback from the SA Aboriginal Community Reference Group, were used to ensure all important topics for the guideline development were covered.

7.3 Analysis

Notes were taken during the consultation and discussions were audio recorded and transcribed for accuracy. A level of analysis was undertaken within each sub group, but not across the entire meeting due to participant fatigue. The analysis of the main themes

was conducted by the organisers and researchers, with input from the Local Aboriginal Community Reference Group. Relevant quotes from participants were included in each theme.

7.4 Outcomes

7.4.1 Prevention

The importance of prevention was discussed across all four sub-groups, highlighting community concern that kidney education isn't readily available or appropriately discussed for those in rural and remote communities.

'If you want to talk about kidneys, you have to come to the city' (Aboriginal participant).

A level of frustration was evident, with participants discussing that heart disease and diabetes prevention initiatives are available in some rural and remote communities and at schools, but kidneys and kidney health is usually ignored by those conducting prevention, education and other health promotion initiatives.

Attendees believed that Aboriginal Medical Services, Aboriginal health workers and other health professionals hold a responsibility to ensure kidneys and kidney care are included in their regular community workshops and events.

Participants agreed that education should start within schools and that parents play an important role in assisting their children to learn about kidney health and kidney disease. One activity that was suggested to increase awareness about kidney disease is to bring children to dialysis units and the dialysis truck to see patients on dialysis. This potentially incorporates storytelling and intergenerational learning processes into discussions around kidney illness prevention.

Culturally appropriate ways of raising awareness about risk factors were also discussed, and attendees agreed that cooking and shopping lessons and family camps are highly regarded by the community to learn about the negative consequences of fast food and sugary drinks, as well as learning how to cook healthy food on budget. Educational cooking videos for kidney patients were also considered to be an effective way to raise awareness about healthy eating.

'The dietitians come and see you, but they don't give a lot of help' (Aboriginal participant).

Participants indicated that a greater emphasis is usually given to food education, but health workers should acknowledge that the use of tobacco, alcohol and other drugs are also significant risk factors. Therefore, a comprehensive approach to community education should be implemented in regional and remote areas.

One participant indicated he quit smoking prompted by the graphic warnings on the cigarette packs, and suggested a similar approach to educate about the negative effects of sugary drinks and fast food.

'Including ugly pictures on the Coca-Cola bottle may be useful to inform Indigenous peoples about the consequences of sugary drinks and fast food' (Aboriginal participant).

7.4.2 Early Detection and CKD management

Early detection was considered to be one of the most important factors by the community members that attended the consultation. The majority of those who were renal patients stated that they were shocked when they were first diagnosed with a kidney condition, having had no previous warning signs. This is consistent with national statistics reflecting that 90% of the patients experiencing CKD don't have any symptoms until they have lost most of their kidney function.

'I was shocked when the doctor rang me to say I should start dialysis the next day' (Aboriginal participant).

Most attendees agreed that doctors should recommend that kidney patients encourage their family members to get checked to detect any early signs of kidney disease. Only one participant mentioned that their family members get a kidney check annually. Other participants indicated that they would encourage their family members to get kidney checks if the doctor ask them to do so.

There is a clear need for more information about; the signs and symptoms for CKD, when is it time for a check-up, and where to go. Participants stressed the importance of educating people in the early stages of CKD about things they can do to manage and slow the progression of their condition.

7.4.3 Information and education

The general preference was that education should be delivered in Aboriginal languages, and written materials that can be easily translated into Aboriginal languages.

'There are materials in Italian, Greek and other languages, but there is nothing in our languages – yet we are the Traditional owners of the land' (Aboriginal participant).

Peer education was highlighted as a priority, particularly to explain treatment options and what is involved, especially for new patients.

'The hospital should employ an [Aboriginal experienced kidney patient] to explain Aboriginal people about dialysis and what is a kidney transplant, and what are the consequences of these treatments' (Aboriginal participant).

This comment highlights the need of culturally-safe and peer education being provided by someone who themselves has kidney disease and has experience of various treatments.

Participants identified that the most effective way to educate and communicate with the majority of Aboriginal peoples is through videos, which can then be made available on DVDs, in clinic waiting rooms and on television, including National Indigenous Television. This was closely followed by face-to-face education and storytelling, which is particularly effective if shared by known Aboriginal people, rather than external people coming from outside areas.

Participants indicated that videos should incorporate music, dancing and local Aboriginal faces.

'I reckon sharing her experience would be good – hearing about what other people have gone through would be helpful' (Aboriginal participant).

7.4.4 Management of co-morbidities

There is an evident need to better encourage kidney prevention and early detection initiatives and manage the treatment of multiple co-morbidities as part of the national chronic disease strategy.

Participants provided the example of the Trachoma Community Clinics, that are focused on eyes only, rather than incorporating education of other chronic disease conditions.

'Aboriginal Medical Services only focus in one disease, but do not include kidneys, dialysis, diabetes, etc. – they could be teaching about other organs while teaching about the eyes' **(Aboriginal participant).**

Many Aboriginal people spoke about having multiple appointments for different co-morbidities and how difficult it was for them to navigate these, because different parts of the health system weren't communicating with each other effectively.

7.4.5 Access

The importance and connection with land and family was extensively discussed. People who moved far from home in order to access kidney care stated that they constantly thought about and missed their family. All participants agreed that kidney treatment options should be available 'on country'.

'Family is important to us and homesickness is a big issue' **(Aboriginal participant).**

'We are all worried, long away from all. My mum is diabetic, and my brother has problems. All my other family have cancers, heart problems, diabetics, that is why I am worried [about them]' **(Aboriginal participant).**

7.4.6 Cultural awareness

Participants agreed that dialysis is a foreign concept to many, and that blood has a spiritual connotation for many Aboriginal peoples – for some groups blood and kidneys are considered sacred. A better understanding of how Aboriginal peoples comprehend kidney disease and treatments should be acquired and applied to any renal intervention, including any programmatic and guideline initiatives.

Conversations highlighted the need for increased cultural awareness about heterogeneity among Aboriginal peoples for doctors, nurses and other health providers. Participants agreed that doctors and nurses should talk to patients in the same way they themselves would like to be talked to, with consideration of cultural and personal preferences.

Participants identified that hospitals and health services should have interpreters that are readily available to attend clinics, so that Aboriginal peoples are able to understand and communicate their opinions accordingly. It was also communicated that there is a need for

health workers to acknowledge that Aboriginal peoples have extensive roles, commitments and responsibilities within the community, and may need designated family or community members to make decisions regarding their treatment, care and medication, and other aspects of their health.

7.4.7 Considerations about transplant

Participants indicated that they knew very little about transplant and transplant options. Community members perceive that Doctors often tell people to just do things that are in fact very difficult to achieve, in order to get a transplant:

'My mum was given the chance of a transplant, but needed to lose weight, which was really difficult' **(Aboriginal participant).**

Participants on dialysis would like to get a transplant to go back home:

'I want to go home with a transplant, rather than going home in a coffin' **(Aboriginal participant).**

Community members believe that transplant is the cure for kidney disease, therefore, more information about transplant as a treatment option, medications and the cost should be provided.

7.4.8 Considerations about Dialysis

Community members indicated that there is constant fear about kidney disease and dialysis:

'Aboriginal people back home [on country] need to know that dialysis is OK' **(Aboriginal participant).**

While participants acknowledged that treatment preferences may be different for people who live in regional and remote areas, they agreed that patients in metropolitan areas of South Australia prefer to attend a renal unit to be dialysed to 'socialise and chat' with other patients.

On the other hand, dialysing at home, which seems a preferred option for people in rural and remote areas, may give the wrong impression that patients can still have unhealthy lifestyle behaviours, as they are able to dialyse in their own and at any time.

'I know someone who regularly drank alcohol because he was able to dialyse at home – he died recently' (Aboriginal patient).

Participants who are on dialysis stated that needles are more painful when nurses are not trained well:

'Nurses sometimes are careless with set up and rush the procedure, and needles are more painful' (Aboriginal participant).

Dialysis patients agreed that it would be appropriate that appointments are organised before dialysis.

7.4.9 Continuity of care and stable workforce

Participants indicated that they want one person or a dedicated team of people that work with the one community for a set period of time:

'The chopping and changing of health care providers is really problematic, because when they start in the community it takes them a long time to establish trust and familiarize themselves with the problems' (Aboriginal participant).

7.4.10 Transport

Having adequate transport options to enable people to attend kidney treatments was raised by all participants. Patients on dialysis indicated that they don't want to miss appointments, but the lack of transportation options sometimes makes it difficult for them to attend.

One of the participants mentioned that she is aware of two kidney patients who have recently passed away; they had both recently missed dialysis appointments due to a lack of transportation.

'Transport should be available to all patients, and not only to Aboriginal patients – all of us need it' (Aboriginal participant).

When there are not clear processes in place to facilitate transport, Aboriginal people are unable to attend dialysis, and sometimes become so sick that an ambulance is needed to transport them. This can end up costing more than a regular transport service would.

One of the participants indicated that Aboriginal people often have to move from their home community to receive treatment; this is at a huge personal cost. In comparison, transport is a relatively minor cost and should be made more accessible.

'Many people come from home communities where we are leaders and have important roles and responsibilities. When we have to leave that behind to access treatment in the city and there is not transport for us, we feel like rubbish, and we are treated like we are unimportant' (Aboriginal participant).

Community members perceive that providing transport options is a simple way to show that health system cares and are concerned for Aboriginal kidney patients' wellbeing.

Lack of transport services interferes with treatment plans and options. One of the participants mentioned that he is on a waitlist for transplant and needed to go to an appointment for transplant education, but missed it because there was no transport arranged or available.

7.4.11 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, the need for a greater focus on nutrition.

'Aboriginal and Torres Strait Islander peoples just want to 'fill up', they don't care if it's healthy' (Aboriginal participant).

'If kids see their parents eating certain things, they're going to want to eat the same things to be 'part of the mob'. It is history repeating itself' (Aboriginal participant).

Participants emphasized that it is extremely important that the Guidelines are holistic and include prevention of kidney disease, dialysis, transplant and organ donation.

Participants also would like to be informed of the final Guidelines.

7.4.12 Government funding and support

Participants are concerned that the Government is not listening to the community about kidney health priorities, and important support services are not being adequately resourced. For example:

'The Cancer Council provides a full wraparound service for cancer patients, including dedicated accommodation and support services. Why can't KHA do the same?' (Aboriginal patient).

'There is imbalance regarding the funding allocated to drugs prevention, cancer and kidney' (Aboriginal patient).

Participants believe that kidney is not given the funding and priority it requires to cover the needs for all kidney patients.

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.

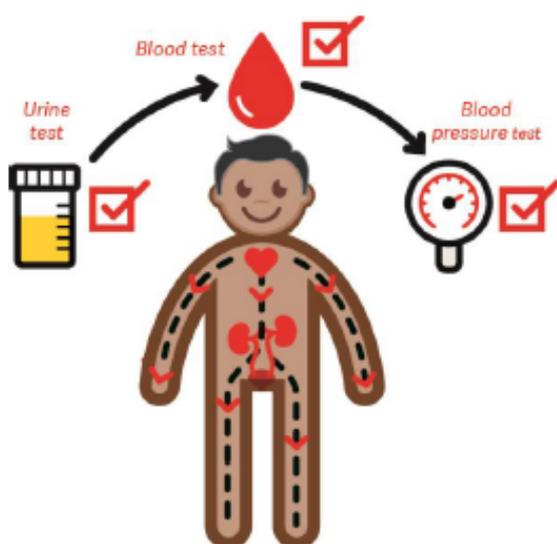
Kidney Health Australia and the 'Improving Aboriginal Kidney Care Together' Research are holding community consultations in South Australia: Adelaide and Port Augusta. We invite you to attend the consultations to tell us what should be in these guidelines, how we should use them, and give us ideas about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

Chronic Kidney Disease (CKD) Management in General Practice

Guidance and clinical tips to help identify, manage and refer patients with CKD in your practice



Prevent, Detect, Support.



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.

Let's Yarn 'Kidney Health':

Thursday, 13 December 2018 2:15 - 5:00 pm
Kanggawodli, 16-22 Clements St, Dudley Park

Food and transportation will be provided.

Please RSVP and book your transport with Dora on 0406 809 712 by **Monday 10 December, 2018**

For more information call:

Dora Oliva on 0406 809 712, Janet Kelly on 0428 891 286 or Nari Sinclair on 0401 844 024

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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.