

# **‘Yarning Kidneys’**

## **Report: Perth Consultation 2019**

**Consultation Meeting to inform of the development of the new  
Guidelines for Management of Chronic Kidney Disease in  
Aboriginal and Torres Strait Islander Peoples**

***Artwork: ‘My Kidney Journey’ by Inawinytji Williamson***



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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 Stakeholders

Kidney Health Australia established a productive partnership with Derbarl Yerrigan Health Service Aboriginal Corporation and the Aboriginal Health Council of Western Australia (AHCWA) to plan, organise and follow up the Perth Yarning Kidneys Consultation. The authors would like to acknowledge their significant contribution to guide the consultation and ensure a culturally appropriate process based on community preferences.

Derbarl Yerrigan Health Service Aboriginal Corporation provided valuable guidance in the organisation of the event and engaged appropriate representative to conduct the Welcome to Country. Additionally, they hosted the event, engaged renal patients and community members to attend the consultation and provided culturally-safe and healthy catering.

AHCWA contributed in the organisation and implementation of this initiative and guided Kidney Health Australia to ensure all ethical considerations were met accordingly.

Special acknowledgement to the local leaders, researchers, clinicians and members of the working group, who provided leadership, help to facilitate the consultation, and contributed in the analysis and writing of this report (alphabetical order):

- Dr Ashley Irish
- Mr Brett Walley
- Dr Christine Clinch
- Dr Depak Naran
- Ms Jackie Oakley
- Ms Jenny Bedford
- Ms Keisha Calyun
- Ms Kili Krishnan
- Ms Laurel Houghton
- Mr Luke Austin
- Dr Marianne Wood
- Dr Paula Edgill
- Ms Suzanne Taylor
- Ms Tara Rowe

## 1.2 Local Aboriginal Renal Community Reference Group

The authors would like to acknowledge the valuable contribution and guidance provided by the Members of the Aboriginal Community Reference Group in Perth, who led all the stages of the consultation (alphabetical order):

- Mr Brett Walley
- Ms Cheryl Augustsson, Co-Facilitator of the Art Session
- Ms Kili Krishnan
- Ms Laurel Houghton
- Mr Lindsay Calyun
- Ms Lyn Dimer, Co-Facilitator of the Yarning Kidneys Consultation

### 1.3 Advisory Group

A National Advisory Group has been established to provide expert advice for Kidney Health Australia regarding consultation for the Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines for Management of Chronic Kidney Disease (CKD) for Aboriginal and Torres Strait Islander Peoples. This group includes:

- Associate Professor Shilpa Jesudason (Chair)
- Ms Dora Oliva (Project Manager)

Group Members in alphabetical order:

- Professor Alan Cass
- Dr Janet Kelly
- Dr Jaquelyne Hughes
- Ms Jess Styles
- Dr Martin Howell
- Dr Odette Pearson
- Ms Rochelle Pitt
- Professor Suetonia Palmer

### 1.4 Funding

The authors acknowledge the Government of Australia for the generous funding provided to Kidney Health Australia to develop 16 community consultations across metropolitan, rural and remote communities of Australia (excluding communities in the Northern Territory and Thursday Island, who have already been consulted by the Catching Some AIR – Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease Project). Consultation costs including local facilitator, catering, art supplies, patient transportation and sitting fees were covered through this grant.

The authors would like to acknowledge the Hon. Ken Wyatt AM, MP, Minister for Aged Care and Indigenous Health, who attended the consultation and delivered a welcome message to thank community members for voicing their opinions and preferences for the development of the new Guidelines for Management of CKD for Aboriginal and Torres Strait Islander Peoples.



*Photo: Minister for Aged Care and Indigenous Health, Hon. Ken Wyatt AM, MP welcoming participants*

## 1.5 Artwork

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

The artwork was created specifically for the community consultations and will be used across consultation documents with her permission.



### ***“My Kidney Journey” – Inawinytji Williamson (pictured presenting the artwork)***

*‘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 clean 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

**AHCWA** – Aboriginal Health Council of Western Australia

**AHW** – Aboriginal Health Worker

**CKD** – Chronic Kidney Disease

**KHA** – Kidney Health Australia

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

The Author acknowledges 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 Western Australian report.

### 3. Executive Summary

Participants highlighted the fact that being away from Country and family interferes with cultural obligations and negatively affects patient's spiritual, social and emotional wellbeing. Therefore, strong emphasis was given to increase rural and remote dialysis treatments in Western Australia.

Concerns were raised about Aboriginal people not being equally represented on the transplantation waiting list. Attendees collectively advised to allocate funding to improve access and outcomes of kidney transplantation.

Education and prevention of kidney disease and other chronic diseases should be implemented to target children and youth through community-centred health promotion approaches, in partnership with Elders.

CKD is commonly associated with death; therefore, efforts should be focused on reducing fear by increasing awareness that kidney disease can be prevented. Antenatal education was suggested to ensure expectant mothers understand the care required for proper kidney development and how this will help prevent CKD.

It is essential that the health system improves the way in which renal care is delivered by implementing patient-centred approaches, providing ongoing cultural awareness training to staff and employing interpreters to reduce language barriers. Peer support by Aboriginal experienced renal patients to assist new patients was also recommended.

Increasing the Aboriginal workforce is crucial to meet the needs of renal patients in WA; and therefore, Aboriginal Health Workers should be upskilled to deliver culturally safe kidney prevention, early detection and treatment.

The need for the Government to prioritise and provide funding to improve Aboriginal kidney health was highlighted with clear recommendations about the provision of affordable accommodation, reliable transport services for patients who relocate for treatment and the implementation of funding schemes to support patients on home dialysis and patient carers.

### 4. Recommendations from Community Members

<b>Kidney disease impacts social, emotional and spiritual wellbeing</b>
<ul style="list-style-type: none"><li>• The health system must recognise and acknowledge that kidney disease affects social, emotional, cultural and spiritual wellbeing of Aboriginal renal patients.</li><li>• Provide culturally safe social and emotional support services to Aboriginal renal patients, especially for people who relocate from rural and remote communities to access treatment.</li><li>• Provide renal treatments in regional and remote communities, so that patients can stay on Country, feel culturally safe, be with family and meet cultural obligations.</li></ul>
<b>Kidney disease is a financial burden</b>
<ul style="list-style-type: none"><li>• Establish a funding scheme to support Aboriginal renal patients who perform home dialysis.</li><li>• Support financially, family carer/members looking after renal patients.</li><li>• Provide adequate, affordable and culturally-safe accommodation for rural and remote renal patients living away from home.</li><li>• Renal patients in Western Australia to explore the possibility of using local royalty money to build and run culturally safe accommodation in major cities for patients who relocate to access renal treatment.</li></ul>
<b>Nutrition</b>
<ul style="list-style-type: none"><li>• Provide education for renal patients about healthy economical foods, including easy to follow recipes and culturally-safe food alternatives available in the metropolitan area.</li></ul>

<b>Prevention and Early Detection</b>
<ul style="list-style-type: none"> <li>• Reduce fear about kidney disease by increasing awareness that CKD can be prevented and discuss ways to prevent it through culturally safe education, in collaboration with community leaders and renal patients.</li> <li>• Conduct antenatal education and awareness programs so that expectant mothers understand the care required for proper kidney development and how this will help prevent CKD.</li> <li>• Increase early awareness and early detection of CKD by encouraging Aboriginal and Torres Strait Islander Peoples to access regular kidney checks, even when they feel well.</li> </ul>
<b>Community Engagement and Education</b>
<ul style="list-style-type: none"> <li>• Implement culturally safe kidney health education through visual and animated materials, in first language and contextualised to culturally diverse groups and local preferences.</li> <li>• Engage Aboriginal community members to talk about kidneys through yarning circles, art and music sessions, in collaboration with renal community leaders.</li> <li>• Invite Aboriginal Elders to talk about kidney health when taking kids out bush to learn about culture.</li> </ul>
<b>Cultural Awareness</b>
<ul style="list-style-type: none"> <li>• Conduct ongoing cultural awareness training with healthcare providers to reduce racism and discrimination towards Aboriginal people and culture.</li> <li>• Increase cultural training in primary and tertiary education.</li> </ul>
<b>Language Barriers</b>
<ul style="list-style-type: none"> <li>• Ensure the availability of trained interpreters in the healthcare system.</li> </ul>
<b>Aboriginal Workforce</b>
<ul style="list-style-type: none"> <li>• Increase Aboriginal workforce and train them to deliver kidney prevention, education and care in rural and remote communities to meet the needs of Aboriginal people in Western Australia.</li> </ul>
<b>Consideration about Dialysis</b>
<ul style="list-style-type: none"> <li>• Increase the number of dialysis chairs in rural and remote communities of WA, so that patients can return to their family and Country.</li> <li>• Provide culturally safe education about the renal treatments available, especially to new patients, and address fears about peritoneal dialysis.</li> <li>• Ensure reliable transport services are consistently available for renal patients.</li> </ul>
<b>Consideration about Transplant</b>
<ul style="list-style-type: none"> <li>• Provide funding to undertake research about premature death among Aboriginal transplant patients and identify culturally safe ways to improve access and outcomes of kidney transplantation for Aboriginal people.</li> <li>• Identify models of peer support for renal transplant patients to provide culturally safe education about the process and implications of kidney transplant and to help them navigate through the different systems.</li> </ul>

<b>Considerations about Conservative Treatment</b>
<ul style="list-style-type: none"> <li>• The decision of renal patients to opt for end of life should be respected by family and community members.</li> <li>• The healthcare system should understand the cultural implications of an end of life decision for family carers/members and Aboriginal health staff and raise awareness among healthcare providers about their role in helping family understand this decision.</li> <li>• The healthcare system should provide culturally safe social and emotional support services for family carers/members of renal patients who decide to discontinue dialysis treatment.</li> </ul>
<b>Management of Co-Morbidities</b>
<ul style="list-style-type: none"> <li>• Develop and implement holistic education and awareness about chronic diseases by engaging community in culturally meaningful health promotion activities to encourage lifestyle changes, in collaboration with experienced renal patients.</li> </ul>
<b>Guidelines</b>
<ul style="list-style-type: none"> <li>• The Guidelines should be holistic.</li> <li>• Involve Aboriginal renal patients and carers in the guidelines writing process.</li> <li>• Share draft guidelines with patients for feedback and disseminate the final guidelines in easy to understand format.</li> </ul>
<b>Government Funding and Support</b>
<ul style="list-style-type: none"> <li>• Increase the number of dialysis chairs in regional and remote communities of Western Australia.</li> <li>• Implement a funding scheme to subsidise all costs associated with home dialysis.</li> <li>• Implement a funding program to support family carers.</li> <li>• Ensure that the workforce is properly trained in the delivery of renal services, particularly around cultural safety and increase the Aboriginal workforce in the renal health sector.</li> <li>• Increase the number of trained interpreters in the healthcare system.</li> <li>• Increase funding to conduct research regarding transplantation and better outcomes for Aboriginal people.</li> <li>• Provide consistent and reliable transport services for renal patients to attend dialysis.</li> <li>• Provide affordable and culturally-safe accommodation for renal patients who need to relocate to major cities to access treatment.</li> </ul>

## 5. Background

In 2018, the Hon. Ken Wyatt AM, MP, Federal Minister for Aged Care and 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 KHA-CARI Guidelines for Management of CKD for Aboriginal and Torres Strait Islander Peoples are aligned with community needs and preferences.

The aim of the consultations is to seek feedback and advice regarding:

- the focus and content of the proposed KHA-CARI Clinical Guidelines 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.



## 6. Community Engagement

### 6.1 Collaboration Approach

The consultation was based on a collaboration action approach (Kelly et al 2019) specifically designed with Aboriginal community members for cross cultural projects, which was trialled with the Adelaide and Port Augusta consultations. This involves repeated cycles and multiple layers of observation and listening, reflection and discussion and targeted action.

### 6.2 Strategies for Community Engagement

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

#### 6.2.1 Aboriginal Renal Community Reference Group

An essential component of the planning for the community engagement was the establishment of the Aboriginal Renal Community Reference Group in Perth (Reference Group) to provide local Aboriginal governance.

The members of the Reference Group were involved in all aspects of the planning of the consultation and met after the event to evaluate the process and discuss the outcomes.



*Photo: Members of the Perth Aboriginal Renal Community Reference Group*

#### 6.2.2 Key Stakeholders and Clinical Champions

Local clinical champions and Aboriginal Health professionals, including nephrologists, Aboriginal General Practitioners, Renal Nurses, Social Workers, and Aboriginal Liaison Officers became involved in this initiative and played a crucial role in engaging Aboriginal kidney patients. Some local clinicians and Aboriginal health professionals assisted with the facilitation of sub-group discussions and contributed to the co-analysis process and provided feedback on the report.

Local clinicians and other medical staff continued to be involved to disseminate the consultation outcomes so that the recommendations provided by community members are implemented.

## 7. Participants

Patients, Carers and Family Members	Local Leaders, Clinical Staff and Organisers
<p>Mr Alfie White            Mr Alvin Edney            Ms Annette Uhl            Ms Barbara McGillina            Ms Benita Indich            Mr Cedric Passenger            Ms Cheryl Augustsson            Ms Corina Abraham            Ms Dot Henry            Ms Enid Jackson            Mr Ernie Dimer            Ms Esther Fullgrate            Ms Fay Farmer            Mr Gail H.            Ms Grace Smith            Mr Harold Thomas            Ms Hilda Flamin            Ms Hilda Flann            Mr Ian Gore            Mr Ignatius Gill            Ms Irene Nannup            Ms Irene Passenger            Mr Ivan Waytt            Mr James Hones            Mr Jarod Minniecon            Mr Joseph Cranbell            Joy Benny            Julie Fland            Kathleen Farrell            Kathy            Laura Farmer            Mr Lindsay Calyun            Lou Nannup            Marlene Davis            Marlene Goodji            Nancy White            Nina Chadd Rivervale            Mr Rod Con            Rosie Gove            Mr Sam Hart            Shirley Thorne            Tasha Davis            Mr Ted Hart            Terence Mungyl</p>	<p>Dr Ashley Irish            Dr Christine Clinch            Mr Chris Forbes            Dr Depak Naran            Ms Dora Oliva            Mr Evan Hill            Ms Jackie Oaaskley            Ms Jenny Bedford            Ms Keisha Calyun            Mr Ken Wyatt            Ms Kili Krishnan            Ms Lyn Dimer            Dr Marianne Wood            Ms Natalie Jetta            Mr Nick Way            Mr Ramsay O'Neil            Dr Paula Edgill            Ms Ronda Clarke            Ms Suzanne Taylor</p>

## 8. Yarning Kidneys

### 8.1 Participants

Forty-four Aboriginal community members attended the consultation conducted on 20 March at Derbarl Yerrigan Health Service Aboriginal Corporation, representing a mix of patients with CKD, diabetes and heart diseases. Some of the CKD patients were on dialysis or have a kidney transplant. Family members, carers and community leaders with an interest in kidney health also attended the meeting.

### 8.2 Consultation Format

Members of the local Reference Group agreed that it would be beneficial to allocate time to conduct a closed art session to allow participants the opportunity to freely yarn about their kidney journey, given there are pre-established questions to cover due the afternoon yarning session.

The Acknowledgement of Country was delivered by a representative of Derbarl Yerrigan Health Service Aboriginal Corporation, followed by The Art Session: 'My Kidney Journey', which was co-facilitated by Ms Cheryl Augustsson. Ms Augustsson had a kidney transplant five years ago, and is passionate about sharing her experience to help others to beat kidney disease.

During this session, participants shared their personal and family journeys with kidney disease, while developing artwork. Participants gave permission to include photos of the artwork they produced:

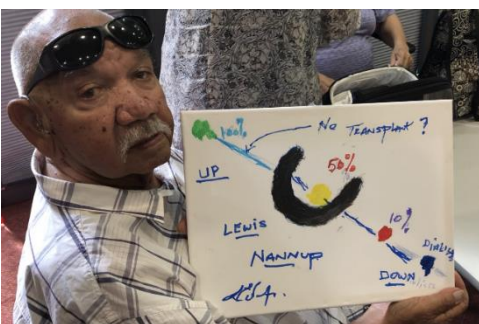
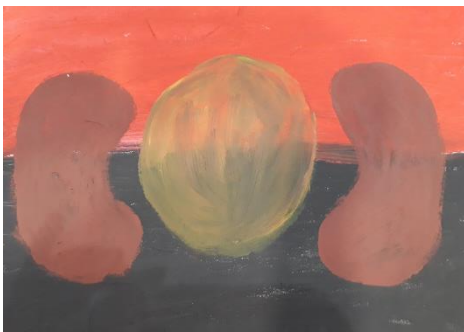
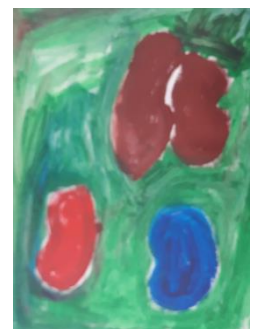


Photo: Lewis Nannup sharing his Kidney Journey





Participants interacted with each other and chatted to Minister Ken Wyatt, representatives from Derbarl Yerrigan Health Service Aboriginal Corporation, Aboriginal Health Council of Western Australia, Kidney Health Australia, renal clinicians and health staff during lunch.

The afternoon yarning session started with a welcome message delivered by the Minister for Indigenous Health, The Hon. Ken Wyatt AM, MP, who thanked participants for their contribution. Minister Wyatt encouraged attendees to voice their opinions and preferences for the development of the new clinical guidelines. During the opening, some attendees raised some issues and concerns which Minister Wyatt addressed accordingly.

Ms Jackie Oakley, Chair of the Board, Derbarl Yerrigan Health Service Aboriginal Corporation, and Mr Chris Forbes, CEO, Kidney Health Australia, delivered a speech to welcome attendees and highlight the ways in which the outcomes of the consultation will inform new guidelines and identify improvements in the renal healthcare system.

Participants re-organised into sub-groups to discuss kidney themes with local facilitators. Ms Lyn Dimer co-facilitated the introduction of this session. A set of pre-established themes and key questions were discussed to ensure relevant topics were covered.

### 8.3 Discussion

Each sub-group designated a note-taker, who helped synthesize the priorities and recommendations. The notes were transcribed and a level of analysis was undertaken within each sub-group, but there was no final whole-group discussion due to limited time and participant fatigue. The analysis of the main themes was conducted by the organisers and local clinical champions, with input from the Members of the local Reference Group. Relevant quotes from participants were included in this report.

## 9. Outcomes

### 9.1 Kidney Disease Impacts Social, Emotional and Spiritual Wellbeing

Participants highlighted that kidney disease has impacted negatively on the way they practice their culture. There are negative cultural implications that patients face when they have to move away from land, including not being able to follow kinship systems and not meeting cultural obligations, such as attending Sorry Days. Community members usually feel culturally unsafe, which also affects their emotional and spiritual wellbeing.

*'When we are diagnosed with kidney disease, we become medical refugees'  
(Aboriginal participant).*

Participants highlighted that rural and remote community members who move away from Country to access renal treatment and leave family and community behind constantly feel stressed and isolated, which significantly affects their mental health and sleep patterns.

*'When we move away from our land, we feel sad and depressed – our spirit is taken away from our Country' (Aboriginal participant).*

Participants stated it would be beneficial for patients who relocate to be able to access social and emotional support services, but highlighted that their preference is to access renal treatment in their Country.

## 9.2 Kidney Disease is a Financial Burden

Participants indicated that kidney disease causes a significant financial burden to patients and families, given that relocation and dietary changes are costly. Additionally, renal patients are often forced to give up work and live on Centrelink payments, as employers are usually unsupportive.

*'Employers don't understand and there are not enough sick days for kidney treatment'  
(Aboriginal participant).*

Participants on home dialysis advised that electricity bills have increased substantially and they cannot access any financial support that helps alleviate the financial burden imposed by having renal treatment at home. Community members suggested that State Government should subsidise all the costs associated with home dialysis.

It was evident that family members who provide care for renal patients experience substantial financial burden, given there are extra costs related to transport and accommodation that need to be covered in order to provide support and care for their family member.

Participants suggested there should be specific funding for family carer/members to help them continue with the caring role and not have to worry about all the costs associated with relocation and constant travel for treatments. Some attendees mentioned that Kidney Health Australia could help by talking to the Government about establishing funding or support for Aboriginal family carer/members looking after renal patients.

The need for adequate housing was mentioned as a priority for rural and remote patients who relocate to Perth in order to access renal treatment. Participants agreed that the Government should provide adequate, affordable and culturally safe accommodation for rural and remote patients.

Another solution identified by participants was the option of renal patients in Western Australia exploring the possibility of using local royalty money to build and run culturally safe accommodation in major cities and provide accommodation to patients who relocate to access renal treatment.

## 9.3 Nutrition

Some participants advised that having to relocate not only affects their social and emotional wellbeing and cause a financial burden, but also impacts their nutrition. Patients who move away from their Country are not able to access bush tucker (and bush medicines), and cannot cook food in a culturally safe way, as fires cannot be built in metropolitan areas.

Participants highlighted that dieticians and healthcare providers may be unaware that dietary and water restrictions for renal patients are difficult to follow and costly to maintain. These restrictions and the cultural responsibility to feed big families on a limited budget are crucial when making decisions about food.

Participants suggested that education about healthy economical foods and easy to follow recipes would be extremely useful. Some attendees suggested that dieticians, Aboriginal Medical Services and other healthcare services could deliver talks to share easy to follow recipes and discuss the availability of culturally safe food in metropolitan areas to help patients and their families to find ways to eat healthier.

## 9.4 Prevention and Early Detection

Participants advised that there are very limited efforts to prevent and detect kidney disease early, particularly in rural and remote areas. Attendees agreed that there is no specific education around kidney disease in most communities of Western Australia. It was also agreed that there is no culturally appropriate information about energy drinks/soft drinks and the damage they cause to kidneys.

Community members advised that using pictorial materials with basic information in first language about kidney disease and the role of the kidneys would encourage community members to look after them.

Some community members mentioned that kidney disease is silent and the absence of symptoms may mean that people do not visit clinics to undertake a kidney check. For instance, participants in one sub-group mentioned a member of the community who passed away due to a kidney failure, who wasn't aware he had kidney disease.

*'Feeling of wellness causes people don't visit Doctors. A person had heart attacks, and family was told later he died because of kidney failure – this came as a surprise'*  
(Aboriginal participant).

Attendees agreed that doctors can help detect kidney disease early by encouraging Aboriginal people to have regular medical checks even when they are feeling well. Some community members have never heard about kidneys, and for those who are aware, it is usually because of family history of kidney disease.

Participants agreed that fear may stop people from accessing health checks or attending clinics, and therefore, using positive messages in first language to communicate that kidney disease can be prevented, will encourage Aboriginal people to undertake regular kidney checks.

Antenatal education was suggested by participants as an important way to increase awareness about proper kidney development to prevent CKD.

## 9.5 Community Engagement and Education

Attendees agreed that community education about kidney health should be performed through visual and animated materials, which should be contextualised to culturally diverse groups and local preferences.

Resources should cater for audiences with low literacy levels, using models to visually explain the stages of kidney disease.

Participants highlighted that healthcare providers should be innovative when it comes to kidney education among Aboriginal communities. The use of visual materials in different formats and first language was strongly suggested.

*'Lots of visual materials about dialysis, animation, cultural diverse materials in own language and use apps'* (Aboriginal participant).

Participants stated that yarning circles, art and music lessons in which community perform songs are highly regarded by Aboriginal people, therefore should be used to engage communities to talk about kidney health.

Attendees advise that kidney education should start at school by building the person's confidence and self-esteem, and should ultimately focus on empowering community to make the right decisions for their health (and their kidneys).

*'It is a two-way learning – enable to take responsibilities, empowering to do this.'*  
(Aboriginal participant)

Participants agreed that it would be appropriate to invite Elders to include kidney health talks when taking kids out bush to learn about culture.

## 9.6 Management of Chronic Diseases

While chronic diseases are linked, participants stated that there isn't comprehensive education about how the diseases are linked and are managed separately.

Participants agreed that culturally safe education on all chronic conditions, including CKD and risk factors is needed in regional and remote communities in collaboration with Aboriginal expert renal patients.

A member of the Perth Aboriginal Community Reference Group highlighted the importance of General Practitioners to recommend lifestyle changes rather than the use of medications to manage diabetes.

*'The prolonged use of medications can affect kidney function and therefore education about lifestyle changes should be conducted before prescribing any medications'*  
(Aboriginal participant.)

Participants agreed that lifestyle changes are difficult to achieve and suggested that a culturally safe and community driven program should be implemented to help Aboriginal people to lose weight through dietary changes and physical activity.

## 9.7 Cultural Awareness

Participants highlighted that the lack of understanding of cultural practices often resulted in Aboriginal patients experiencing racism, judgement and discrimination. Participants highlighted that doctors, nurses and other health professionals should avoid stereotyping, judgemental attitudes and behaviours towards Aboriginal culture and people.

Attendees stressed the importance of conducting cultural training to healthcare staff in the health system, so that health professionals understand cultural reasons for non-compliance.

*'Services have to understand cultural reasons for non-compliance and not because patient doesn't want to go'* (Aboriginal participant).

Additionally, community members suggested Aboriginal culture education should start at primary schools, and be reinforced at tertiary education.

## 9.8 Language Barriers

Miscommunication from health professionals to patient and families are caused by language barriers and the use of medical jargon. Participants stressed the importance of hiring trained interpreters in the healthcare system and stated this will help Aboriginal people to feel culturally safe and understand their condition, treatment options, care plans, medication and other aspects of their care.

Participants agreed that non-compliance is, in the majority of cases, associated with a lack of understanding of the condition and poorly explained care plan. In the view of the participants, the use of interpreters in the renal sector will result in better compliance.

## 9.9 Aboriginal Workforce

Participants advised that Aboriginal health professionals should be employed in rural and remote communities to address the needs of Aboriginal communities.

*'Need more Aboriginal health professions on the ground to meet the needs of kidney health for our people.'* (Aboriginal participant)

Additionally, participants recommended that Aboriginal Health Workers should be trained and supported, so that they are able to provide kidney education and care in local communities of Western Australia.

*'There is need for specialised Aboriginal Health Worker Workforce in kidney disease'*  
(Aboriginal participant).

## 9.10 Considerations about Dialysis

There is a need to provide culturally safe and appropriate information and education about treatment options, including peritoneal and haemodialysis, and the implications of each alternative. Participants advised that there are some concerns and fears about peritoneal dialysis, and appropriate education is required to address these concerns.

Participants collectively agreed that the number of dialysis chairs in regional communities of Western Australia is not enough to fulfil the needs of renal patients.

*'I got sick, came to Perth, found out here I have kidney problems. Now have to stay here and can't go home. This all majorly affects emotional and spiritual wellbeing in a bad way'*  
(Aboriginal participant).

It was strongly suggested this report should include a recommendation about increasing the number of chairs, which in the view of attendees, should become a priority for the Government and Community Controlled Health Organisations to address in order to support kidney patients to return to their Country.

Participants mentioned that renal patients face difficulties to attend dialysis due to the lack of transportation, and therefore support for reliable transport should be increased.

## 9.11 Considerations about Transplant

Understanding the process, medication and compliance, as well as the signs of rejection and infections were all considerations raised by the participants who suggested that more culturally safe education is required around transplantation.

Participants repeatedly mentioned the need to increase donation and transplant rates among Aboriginal people. Attendees advised that there is frustration because Aboriginal people are not equally represented on the transplantation waiting list and there isn't enough and adequate information about the reasons some patients are eligible for a transplant and others are not, as well the reasons as to why some patients need to wait longer than others.

*'We want HONESTY about transplant, yes or no? If no, why'*  
(Aboriginal participant).

Participants indicated that patients on the waiting list need to undertake lifestyle changes that are difficult to achieve, such as dietary restrictions, reducing weight, increasing exercise and regular check-ups with the kidney doctor and GP.

Attendees agreed that it would be useful if experienced kidney transplant patients can explain to new patients about lifestyle and other changes that need to happen. It was suggested that a peer network be established that also can help them navigate through the different systems to access housing, health, education, Centrelink, DCP, etc.

*'Waiting a long time sitting at bottom of list. Need to lose more weight, Drs always saying, but it is hard, so many things to do, feel like in limbo and need support'*  
(Aboriginal participant).

Some attendees advised that there are community concerns about the high number of deaths within Aboriginal transplant patients who die due to infections. It was agreed that greater research should be undertaken in this area.

Participants mentioned that, in their view, renal doctors constantly cause fear about premature death to Aboriginal transplant patients. It was agreed that further research and adequate Government funding should be provided to identify culturally appropriate solutions to improve access and outcomes of kidney transplantation for Aboriginal people.



## 9.12 Considerations about Conservative Treatment

Participants talked about the negative cultural implications for family member carers and Aboriginal health staff when Aboriginal renal patients opt for end of life and decide to discontinue dialysis treatment.

Attendees agreed that community should respect patients' rights to make the decision to end their treatment, and understand their reasons and support them.

Aware of the negative cultural implications that the end of life decision will have on the family member carer and Aboriginal health staff, attendees suggested that kidney doctors or GPs should be aware of cultural consequences and their role in helping family to understand this decision. It was suggested that healthcare and social support staff should support the patients who decide to stop treatment and also support their families. Emphasis was given about the importance of renal doctors and GPs communicating with the family of the patient who decides to discontinue dialysis treatment to ensure family and community are aware that the carer and any Aboriginal health worker providing care are not responsible for the decision, and therefore shouldn't be held accountable.

Some Members of the Local Reference Group mentioned the story of Jason Bartlett, who agreed to produce a video to raise awareness about his journey with diabetes and kidney disease to promote lifestyle changes within Aboriginal people in Western Australia. Jason opted to end his kidney treatment and passed away in 2017. (Permission was granted by his family to include a link to the video in this report <https://www.youtube.com/watch?v=RcbQmILeDTs>)

The Members of the Reference Group mentioned Jason's story to highlight the right of renal patients to end treatment and the need for family and community to understand and respect his decision.

Additionally, participants highlighted that culturally safe social and emotional support services should be made available in these cases, especially to support carers and family members during this time.

## 9.13 Guidelines for Management of CKD for Aboriginal and Torres Strait Islander Peoples

Participants collectively agreed that all the themes, priorities and recommendations raised during the Perth consultation should be shared with the Guidelines Working Group to guide the new Guidelines for Management of CKD for Aboriginal and Torres Strait Islander Peoples writing process.

It is extremely important that the Guidelines are holistic and include Aboriginal renal patients and carers in the process of writing it. Attendees recommended that the draft guidelines be shared with consumers for discussion.

Participants would like to be informed about the outcome of the consultation and receive a copy of the final Guidelines in easy to understand format.

## 9.14 Government Funding and Support

Participants noted that to improve kidney health for Aboriginal people, there needs to be specific support and funding from the Government to increase renal treatment in rural and remote communities of WA, the provision of affordable accommodation and reliable transport for patients who relocate for treatment and to increase and train the Aboriginal workforce.

## 10. Dissemination

The Members of the Perth Renal Community Reference Group and organisers approved the release of this report and it has been disseminated with:

- The KHA-CARI Guidelines Writing Group;
- Aboriginal Health Community Controlled Organisations, Clinical Champions, renal services in Western Australia; and
- Funding Agencies.

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

## 11. Workshop Flyer – Appendix 1



# Indigenous Voices Yarning 'Kidney Health'

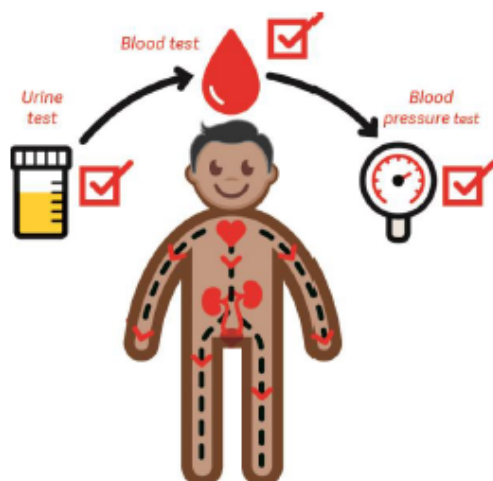
Wednesday, 20 March 2019, from 10:30 am to 3:30 pm at  
Derbarl Yerrigan Health Service Aboriginal Corporation, 156-172 Wittenoom  
Street, East Perth, WA.

*Food and transportation will be provided.*

Kidney Health Australia in partnership with Derbarl Yerrigan Health Service Aboriginal Corporation and the Aboriginal Health Council of WA (AHCWA) invite you to attend the **Perth 'Yarning Kidneys' Community Consultation**.



We invite Aboriginal kidney patients, carers, family and community members to attend the consultation to tell us what should be in the new Indigenous Kidney Guidelines (instructions for doctors and nurses about best care for Indigenous people with kidney problems), how to use them, give us ideas about improving kidney care locally and how to share 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.

Please RSVP and book your transport with Dora on 0406 809 712 **by Thursday, 14 March, 2019**  
For more information call: Dora Oliva on 0406 809 712.

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## Disclaimer

The recommendations contained in this report were formed from feedback obtained through consultation with Aboriginal renal patients, carers, and 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.