



# 'Yarning Kidneys'

Report: Mount Isa

30 January 2020

Consultation meeting to inform the development of the Kidney Health Australia - Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines for Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islander Peoples



*Photo: Reproduced with permission. Participants of the Mt Isa 'Yarning Kidneys' Community Consultation at Ibis Styles Mt Isa Verona on the 30 January 2020.*

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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 North West Hospital and Health Service*

Kidney Health Australia acknowledges the valuable contribution and leadership of the North West Hospital and Health Service (NWHHS).

We would like to acknowledge and thank local Elders, community leaders and clinical nurses, especially Checille Naig, Cleofe Madryga and Odreh Sambamo who supported this initiative and helped co-facilitate the consultation.

Our greatest acknowledgement and thanks goes to all the patients, family members and carers who participated in the Yarnings.

## *1.2 Kidney Health Australia Yarning Kidneys Advisory Group*

An Advisory Group was established to provide expert advice for the Kidney Health Australia Yarning Kidneys initiative to ensure the consultations are conducted in a culturally safe way and the outcomes are followed up.

This group includes:

- Associate Professor Shilpa Jesudason (Chair)
- Ms Kimberly Taylor (Project Manager)

Group members in alphabetical order:

- Professor Alan Cass, Menzies School of Health Research, NT
- Dr Martin Howell, Senior Researcher, KHA-CARI, NSW
- Associate Professor Jaquelyne Hughes, Menzies School of Health Research, NT
- Dr Janet Kelly, University of Adelaide, SA
- Professor Suetonia Palmer, Chair, KHA-CARI Steering Committee, NZ
- Dr Odette Pearson, South Australian Health & Medical Research Institute (SAHMRI), SA
- Ms Rochelle Pitt, Metro South Health, QLD
- Ms Jess Styles, National Aboriginal Community Controlled Health Organisation (NACCHO), ACT

### *1.3 Funding*

Kidney Health Australia acknowledges the contribution from the Government of Australia for the generous funding provided to develop multiple community consultations across metropolitan, rural and remote communities of Australia, excluding communities in the Northern Territory and Thursday Island which have already been consulted by the Catching Some AIR – Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease Project.

## *2 Abbreviations and Definitions*

**AHW** – Aboriginal Health Worker

**AIATSIS** – Australian Institute of Aboriginal and Torres Strait Islander Studies

**ALO** – Aboriginal Liaison Officer

**CKD** – Chronic Kidney Disease

**CNC** – Clinical Nurse Consultant

**ESKD** – End Stage Kidney Disease

**KHA** – Kidney Health Australia

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

**NWHHS** – North West Hospital and Health Service

**TSANZ** – Transplantation Society of Australia and New Zealand

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 report.

### *3 Background*

In 2018, the Honourable Ken Wyatt AM, MP, former 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 for 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.

The over-arching principles and methodology for these consultations has been [published](#)<sup>1</sup> and is designed to be wide and encompassing to facilitate maximum input from the people who are most likely to use and be affected by the use of the planned Guidelines. The consultation is intended to focus on what is relevant to the planned Guidelines.

The consultation is designed to complement and recognise the decades of activities by many others across Australia in the area of Indigenous Kidney Health research and community engagement.

As outlined in this joint statement on methodology, the consultation findings will complement the Catching Some Air project and align with the KHA-CARI Guidelines development principles.

### *4 Ethical Considerations*

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) provided waiver of ethics for the Yarning Kidneys consultation implemented in Mount Isa.

A copy of this report will be submitted to AIATSIS.

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<sup>1</sup> D Duff, S Jesudason, M Howell and JT Hughes. A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease. *Renal Society of Australasia (RSA) journal* 2018; 14 (3): 84-88

## *5 Community Engagement and Participants*

The Mount Isa community consultations that were conducted on the 30<sup>th</sup> January was attended by twelve Aboriginal community members. Participants represented a mix of patients with diabetes, heart disease, CKD patients receiving dialysis, a kidney transplant patient, family members, carers and community members with an interest in chronic diseases.

The North West Hospital and Health Service (NWHHS) invited participants to the session. Event flyers were developed and given to patients directly when attending appointments and also placed in waiting rooms and clinics to encourage community members to attend the session (see Appendix).

Nurses and Aboriginal Health Workers at NWHHS helped with the promotion of the event by personally inviting their clients and community members who were experiencing other chronic diseases with or without concurrent CKD.

Transport was coordinated by NWHHS to help assist patients in attending the Yarning session.

## *6 Format and Methodology*

The Kidney Yarnings were introduced by Kimberly Taylor, the National Indigenous Project officer for Kidney Health Australia. Vanessa Nemo of Kalkadoon Nation provided the Welcome to Country.

The session was co-facilitated by Ms Checille Naig and Ms Kimberly Taylor. At the start of the session patients and support staff sat in a circle and introduced themselves to one another. This gave community members the opportunity to become comfortable with the Kidney Health Australia facilitator and the topic at hand to be discussed. Emotional support was available to attendees if required through the attendance of local NWHHS nurses and an Aboriginal Health Worker.

Participants were encouraged to base discussions around a set of pre-established questions (developed through previous Yarning consultations) regarding kidney care and other CKD related diseases. This general discussion was not however limited to these questions, rather it was free-ranging and led by participants.

Attendees were then placed into three smaller sub-groups to discuss their views and priorities to inform the new guidelines. Local NWHHS nurses and Aboriginal Health Worker, Checille Naig, Cleofe Madryga and Odreh Sambamo assisted to co-facilitate the session within each group, which included a designated note-taker.

Lunch was then provided where further discussions occurred and notes taken. After lunch, two short videos regarding the Perth community consultation showcasing renal patient stories were played to explain how the consultations will inform the new guidelines. <https://kidney.org.au/yarning-kidneys-consultations>. Upon showing this footage to the group one of the patients volunteered to also participate in a video clip for the promotion and feedback of the Kidney Health Australia Yarning Kidneys community consultations for Mount Isa.

Key themes and suggestions were presented at the end of the session. The event concluded with the participants' approving once again to use the feedback from the session to develop the consultation report and the group photo to be used for the front cover of the report.

## *7 Yarning Kidneys – Outcomes, Key Themes and Recommendations*

There were ten themes identified during the consultation which are discussed in more detail below including associated recommendations.

### **Key Themes and Recommendations include:**

|           |  |
|-----------|--|
| <b>1.</b> | <b>The impact of being diagnosed with kidney disease</b> <ul style="list-style-type: none"><li>• Provide additional support to patient's immediate family members to reduce family breakdowns and reduce stress and burden for the individual living with CKD.</li><li>• This could include ensuring the spiritual and psychological impact of kidney disease diagnosis is addressed proactively at the time of diagnosis.</li><li>• Increase the provision of renal services in rural and remote areas of Doomadgee and further communities surrounding Mt Isa region to avoid patients' separation from family and disconnection from country and community.</li></ul> |
| <b>2.</b> | <b>Navigating treatment options</b> <ul style="list-style-type: none"><li>• Provide culturally appropriate education around renal treatment options through videos.</li></ul>  |

|           |   |
|-----------|---|
|           | <ul style="list-style-type: none"> <li>• Provide kidney checks to achieve early detection of kidney disease which will allow patients (and family or carers) to participate in education programs and prepare for future treatment.</li> <li>• Give patients the chance to decide on their treatment plan to empower them and take responsibility regarding their health, which will result in better health outcomes and more positive community engagement with health care professionals and services.</li> </ul>  |
| <b>3.</b> | <p><b>Local services and workforce support</b></p> <ul style="list-style-type: none"> <li>• Employ more permanent GPs and nurses at NWHHS with a preference for more targeted positions e.g. AHW's.</li> <li>• Encourage more visits from clinical nurse consultants (CNC's) and diabetic nurses and/or employ more trained staff.</li> <li>• Government to provide training to community members who are interested in knowing how to care for patients on dialysis. <ul style="list-style-type: none"> <li>○ For example, community information sessions held within a trusted health service or culturally safe organisation.</li> </ul> </li> <li>• NWHHS to discuss with the State Government the implementation of haemodialysis machines in remote communities of Doomadgee and further communities surrounding Mt Isa help patients to return to their country.</li> <li>• Establish targeted Aboriginal and Torres Strait Islander traineeships within NWHHS to support the local communities, build professional capacity of local people and promote positive engagement between services and community.</li> <li>• Refer also section 7.9.</li> </ul> |
| <b>4.</b> | <p><b>Relocating for dialysis treatment</b></p> <ul style="list-style-type: none"> <li>• Treatment "closer to home" must be a priority for better health outcomes for patients and family impacted by end-stage kidney disease and dialysis treatment.</li> <li>• NWHHS to discuss with the State Government the implementation of additional kidney clinics in rural and remote communities of Doomadgee and further communities surrounding Mt Isa to alleviate the need for relocation and to help patients to return to their country.</li> </ul>   |
| <b>5.</b> | <p><b>Transplantation</b></p> <ul style="list-style-type: none"> <li>• Deliver culturally appropriate education on pre and post-transplantation, well before ESKD develops.</li> <li>• Ensure that patient family members are adequately informed and involved in the whole transplantation work-up and process</li> </ul>  |
| <b>6.</b> | <p><b>Education and prevention</b></p> <ul style="list-style-type: none"> <li>• Implement better health promotion tools/campaigns around CKD</li> <li>• Bring in more health programs that teach patients and community members the importance of holistic health care. <ul style="list-style-type: none"> <li>○ Emphasis more importance on foot care, oral hygiene, heart health and mental health.</li> </ul> </li> <li>• Implement a localised campaign/program to prevent diabetes and kidney disease targeting children and youth.</li> </ul>   |

|     |   |
|-----|---|
| 7.  | <p><b>Communication barriers</b></p> <ul style="list-style-type: none"> <li>• Employ interpreters to help renal patients understand their condition and treatments and relay information back to doctors to reduce misunderstandings. <ul style="list-style-type: none"> <li>◦ Two-way interpretation as miscommunication isn't always from the patient's perspective</li> </ul> </li> <li>• Use plain language during appointments and dialysis sessions</li> <li>• Provide straight forward, easy to remember messages and information on caring for kidneys and CKD management.</li> </ul> |
| 8.  | <p><b>Cultural awareness training</b></p> <ul style="list-style-type: none"> <li>• Implement a comprehensive and ongoing cultural awareness training in the healthcare system.</li> <li>• Cultural training should include local Indigenous history, customs, lore, language and the status of health and wellbeing at the grass-root level.</li> </ul>   |
| 9.  | <p><b>Aboriginal workforce: men's and women's business</b></p> <ul style="list-style-type: none"> <li>• Increase the number of Aboriginal Health Workers delivering haemodialysis.</li> <li>• Employ adequate numbers of male and female Aboriginal workers to address cultural sensitivities working with Aboriginal and Torres Strait Islander men and woman.</li> </ul>  |
| 10. | <p><b>Ongoing community meetings</b></p> <ul style="list-style-type: none"> <li>• The government to provide funding to NWHHS to implement and facilitate regular meetings with the local community members affected by CKD.</li> <li>• Provide funding to help establish a community advisory group regarding Kidney issues in the local community, similar to the South Australian framework for the aKction Reference Group.</li> </ul>   |

## *7.1 The impact of being diagnosed with kidney disease*

Participants expressed that when they first found out they had kidney disease it was "life shattering" and for some it took a while to come to terms with. Other participants expressed how this information not only affected them, but potentially affected the rest of their family and in some cases, the community.

*"It made me sad, when I first got the news my kidneys were bad I started crying, being depressed that I won't be around my grannies anymore. I remember being really very frightened and scared."*

Participants agreed strongly that kidney disease disrupted every part of their life and caused major interferences within their relationships with family, friends and community. It greatly impacted work commitments, community roles and responsibilities and caused substantial lifestyle changes. For some participants the interference and impact of kidney disease was

so great it caused the family unit to break down completely and left massive gaps in wider extended families.

*"We had to leave our community, it was especially hard for us as a married couple and we are separating because my wife needs to move to be on dialysis."*

Understanding the disease and trying to explain what kidney disease was to family and community members was a concern experienced by most patients. For new patients, this was especially hard as they themselves were learning and trying to understand the information and then relay it back to family and community members. Participants all agreed that it would be a lot easier if more people knew about kidney disease and understood how dialysis treatments worked.

*"Bring in training for family and carers, teach family how to do dialysis."*

Attendees mentioned how useful it would be to have this support in place and expressed that there needs to be more support to help educate and train younger family members and members of the community who are interested in caring for people living with CKD.

*"Teach them while they are young. Bring in more trainees."*

Consistent with feedback from previous sessions, participants highlighted how difficult it is to separate from family, community and country to access treatment. Participants highlighted how crucial it is for the health system to provide the Mt Isa communities with rural and remote renal treatment and conduct training on their country to avoid separation from family and disconnection from their land.

*"Had to leave my community when I got really sick, I let it go too far and had to move here for treatment, I felt very alone."*

## *7.2 Navigating treatment options*

Prior to this consultation some of the participants indicated they weren't aware of the different treatment options when they were first diagnosed and didn't have the opportunity to choose an alternative that suited their needs and preferences. It was evident that, for some, they weren't given any options at all, just informed they had to go on dialysis immediately. This left some patients confused and unhappy about the care they were receiving. Participants agreed that being able to decide on their care and treatment plan could result in better health outcomes and increased compliance.

*"They asked me if I wanted to go on the bag, but I said no because my elder sister she was on the bag and she didn't last long. Even my sister before me she was on the bag, didn't last long." (Aboriginal participant)*

As in previous consultations, participants indicated that providing culturally safe education around different treatment options through videos will help patients understand each alternative and help to choose the one that is best for them, which will also empower them to take control of their health.

### *7.3 Local services and workforce support*

Participants are thankful for the ongoing support and dedication from the renal nurses and healthcare staff at the North West Hospital and Health Service. They all expressed how much the renal team support the local community by thoroughly explaining information to them such as how diabetes, blood pressure and certain lifestyle habits can affect the kidneys.

*"A lot of people feel comfortable around you and the other nurses too, you know." (Aboriginal participant)*

Community members noted however the growing need for an increased workforce in the diabetes and kidney clinics along with more communication between the wards and healthcare staff. Participants are aware that there are only a small number of chairs in Mt Isa and have expressed that this is a major issue and concern for the local community members who need a spot as well as other patients travelling from remote communities surrounding Mt Isa. Patients do not like having to move for dialysis treatment but most understand that it is required if they want to stay well.

*"The government needs to put more renal unit into communities - especially in Doomadgee and Nash so people can be in their own hometowns." (Aboriginal participant)*

Attendees suggested NWHHS discuss with the Government to implement dialysis machines in remote communities such as Doomadgee and further communities on the outskirts of Mt Isa to help patients stay on their own country.

*"People should be in their own hometowns, so they can enjoy their life with families, go out bush and all that, keep to traditions." (Aboriginal participant)*

The need for more Aboriginal health trainees in the hospital and kidney clinics was also discussed. For all the people that attended the session this was an extremely important focus and many questioned why there aren't more aboriginal trainees employed within NWHHS and suggested it be something the service looks into and advocates for the local community.

*"Bring in more aboriginal trainees teach them while they are young."*

## *7.4 Relocating for dialysis treatment*

Upon being first diagnosed participants were not aware that they had to relocate to receive treatment due to the limited number of dialysis chairs available in hospitals and kidney clinics. It was expressed with great disdain, the whole ordeal of travelling and relocating for treatment which wasn't a good experience and often left people uprooted and their lives disrupted.

*"I was pretty shocked about it all, I wasn't too happy about it because it took me away from a lot of things. I'm used to living and working on the cattle station, the bush and can't go out there no more and on weekends. I can't stand living in town and all that, living here in Mt Isa was the worst place you know. Every couple of weeks now I go bush."* (Aboriginal participant)

The question was raised by all who attended as to why there isn't more chairs available in the hospital, why there isn't more kidney clinics set up in rural and remote communities so people don't have to relocate to access treatment, have to worry about the burden and financial stress of travelling or the spiritual and cultural disconnection from country.

*"Pretty unhappy about it, I had to go to Townsville you know. We had to stay around families places a lot of the time, going from this place to that place. Didn't like Townsville, I had to stay there for about 12months."* (Aboriginal participant)

## *7.5 Transplantation*

During the session participants asked about the processes involved in receiving a kidney transplant. Some of the patient questions included:

- How they get on the transplant list?
- What is the age limit for receiving a transplant?
- How long the operation and healing takes and how it impacts them and their families?
- What happens after receiving a new kidney?

It was explained to them thoroughly by the nurses who helped facilitate the session.

During the session participants asked about the processes involved in receiving a kidney transplant and these were discussed by the nurses who helped facilitate the session. Much of the discussion centred around the lack of culturally appropriate education on transplantation, both before commencing the transplant journey and while navigating transplant workup and assessment. It was proposed that transplant education should begin long before a person progresses to end-stage kidney disease and that these discussions

would be more valuable if they occurred in a community setting encompassing all community members (including children and adolescents).

## *7.6 Education and prevention*

It was very clear that patients, their family and community members alike did not have a complete understanding of CKD and why it has affected them. It was raised within this Yarning session that, for a number of Indigenous people with serious health problems like kidney disease that there is a belief that illness is inevitable, especially in some rural and remote communities where education is lacking and understanding that healthy lifestyles, regular check-ups and eating better can improve overall health and reduce the chances of being diagnosed with CKD and other kidney related health problems.

*“A lot of people think it can’t be avoided like your numbers come up, if you’re going to get it, you’re going to get it. They don’t understand if you follow all these rules. Tell people what they can do, the right things and avoid it.”*

Participants expressed the overwhelming need for other programs and information that take a holistic approach to kidney care and healthy lifestyles. Many participants were concerned and disappointed at the lack of information given to them by multiple doctors and nurses regarding adequate foot care, oral hygiene, diet and healthy lifestyle choices, heart health and looking after mental health and wellbeing. Attendees agreed that there needs to be more information and focus on other areas of kidney care and not just diabetes management. There needs to be integrated holistic care.

*“They always talk to us about diabetes and what not to eat but they never tell us about all the other stuff that affects our kidneys and how we care for them better.” (Aboriginal participant)*

Many participants were concerned that there isn’t enough information available that targets young people to better understand and be aware of all the factors that contribute to CKD and other related diseases. It was suggested during the session that there should be more educational programs available in schools and local community events that raise awareness and teach the younger generation about the importance of taking care of the kidneys.

*“Go to the schools and provide educational programs for kids to learn about kidneys and diabetes, teach the young ones the right foods to eat and how to care for their kidneys’.*

## *7.7 Communication barriers*

Participants highlighted that communication barriers existed between patients and doctors. One participant reported that their initial awareness and understanding of CKD was minimal but they understood all the information that was given to them. However, when expressing their concerns to their doctor, the doctor was unable to understand the patient, causing substantial distress to the patient.

*“He said something to me and when I told the doctor, the doctor couldn’t understand me. I knew what he was saying but I didn’t think he knew what I was saying, it was very frustrating you know.”*

Participants strongly agreed that interpreters should be available in the health system at all times to help overcome language barriers. Participants indicated that non-compliance is usually associated with a lack of understanding due to communication barriers and the use of medical jargon. Participants suggested more plain language and straight forward messages within hospitals, health clinics, dialysis clinics and during appointments and information sessions provided by health and medical staff.

## *7.8 Cultural awareness training*

Mt Isa is a small town and there are not many permanent GPs with health professionals often visiting from other sites. Many patients expressed how difficult it can be at times interacting, trusting and communicating with different doctors and nurses who come from all different backgrounds, understanding and beliefs, especially when they are transient and unfamiliar.

*“We see a lot of new faces and sometimes we get scared about what the doctors are going to do to us, how they are going to treat us when we have an operation or something.”*

Additionally, participants recommended that the renal service staff undertake a formal induction and cultural awareness training before commencing work in the Mount Isa region. The training should also include local Indigenous history, customs, lore, language and the status of health and wellbeing at the grass-root level.

## *7.9 Aboriginal workforce: men’s and woman’s business*

As in previous community consultations, participants recommended the health system to employ Aboriginal and Torres Strait Islander communities to deliver renal services. Participants are disappointed that their isn’t more AHW’s employed with NWHHS in Mount Isa to deliver haemodialysis and Aboriginal Care Coordinators to support renal patients; participants suggested that NWHHS and KHA advocate to have more AHW’s employed in

renal health. Additionally, participants suggested it is crucial to create a culturally safe environment within the hospital and kidney clinics. Additionally, it is important to acknowledge the cultural sensitivities around male workers caring for male patients and female workers looking after female patients.

*“We need more Aboriginal Health Workers here at NWHHS that understand us and can help explain things in a different way and don’t make us feel shame.” (Aboriginal participant).*

### *7.10 Ongoing community meetings*

The need for Indigenous kidney community support groups was discussed. Participants acknowledged that Kidney Health Australia’s community consultation provided a great opportunity to meet people who are experiencing the same treatment and associated challenges who otherwise they would not normally have met. Participants emphasised the importance of having regular opportunities to engage with other members of the kidney community as well as peak bodies such as Kidney Health Australia, TSANZ and others associated with this Yarning; one-off consultations are not enough. Some attendees suggested that NWHHS could facilitate regular sessions such as the Kidney Health Australia Yarning Kidneys gathering. Participants were aware of funding restraints and the limited capacity of the renal team at NWHHS but all that attended expressed great hope that something like this may be implemented soon.

## *8 Dissemination*

Key participants and Aboriginal health workers who attended the consultation read the report and provided feedback.

This report was approved to be disseminated to:

- The Kidney Health Australia Yarning Kidneys Advisory Group;
- The KHA-CARI Guidelines Writing Group;
- The Australian Institute of Aboriginal and Torres Strait Islander Studies;
- The North West Hospital and Health Service, Renal Champions;
- Kidney Health Australia Website and
- Funding Agencies.

## 9 Appendix

### 9.1 KHA Yarning Kidney's Mount Isa Flyer



In consultation with:



## Indigenous Voices Yarning 'Kidney Health'

Thursday, 30<sup>th</sup> January 2020, from 10:00 am to 2:30 pm at

Ibis Styles Mount Isa Verona,

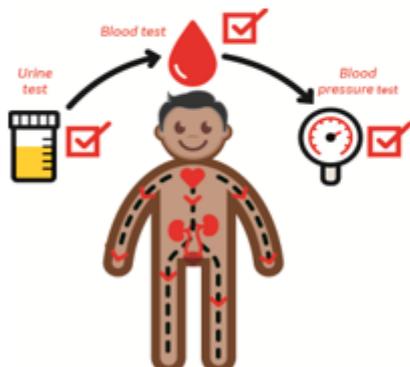
Corner Rodeo Dr and, Camooweal St, Mount Isa.

**Food, transportation and sitting fees will be provided.**

Kidney Health Australia with support from North West Hospital and Health Service invite you to attend the **Mount Isa 'Yarning Kidneys' Community Consultations**.

Aboriginal kidney patients, carers, family and community members with interest in Kidney Health are invited to attend this event to:

- Talk about their kidney journey
- Discuss what information should be in the new Indigenous Kidney Health Guidelines (instructions for doctors and nurses about best care for Indigenous Australians with kidney problems)
- Best ways to improve kidney care
- How to share information about the meeting back to you.



Aboriginal and Torres Strait Islander community members in Mount Isa can discuss what is most important regarding their kidney health, kidney care and personal and community experiences with kidney treatments.

**Sitting Fees will be provided.**

Please confirm your attendance with Chez Naig on 0406 809 712 by **Thursday, 16 January, 2020**. For more information call: Kimberly Taylor on 0400 602 437.

## 9.2 KHA Yarning Kidneys Community Consultation Questions

### **KHA Yarning Kidneys Community Consultations Questions**

#### **1. When did you know you had a kidney problem?**

- Felt sick, swollen feet, puffy, shortness of breath, high blood pressure?
- From your Doctor/hospital
- Referred to kidney doctor from GP

#### **2. When you got told you had a kidney problem (sick kidneys) how did this information make you feel?**

- Why me? shocked, unhappy, scared, fear, thinking about the future
- How can we address these feeling on the above?

#### **3. Did you understand all the information the doctors/kidney team explained to you?**

- Why this has happened to you?
- Other medical conditions
- Other risk factors (smoking, lifestyle, over weight, high blood pressure, physical activity)
- Nutrition (diet changes, salt intake, traditional foods)

#### **4. How does your kidney issues affect you and family/friends?**

- Less or no time with family, socially, had to leave community, feeling sad
- Financially can't do as much
- Support from your family, friends or carer?

#### **5. How did you decide on which dialysis treatment option suited you?**

- Did you feel informed to make your own decision?
- HD hospital/satellite, HD at home, PD or kidney transplant?
- Have you tried a number of the treatment options?
- Are you aware of receiving a kidney transplant?
- How did you become aware of receiving a kidney transplant?
- How can we make access to kidney transplant easier for people in remote communities?

**6. Have you experienced any issues that made you feel uncomfortable whilst receiving dialysis treatment?**

- Not being listened to?
- Not happy with decisions being made about you whilst not being involved in that conversation?
- Not happy with treatment?

**7. Did you have to leave your community?**

- How did you feel about leaving your traditional country?
- Connection to your traditional country, spiritually, traditional foods, family gathering, hunting & gathering

**8. How do you think we can find kidney issues early in our community?**

- Early Prevention
- Health Promotion Strategies
- Renal Buddy (one on one)
- Renal Patient Leadership
- Have our own local Indigenous network?

**9. How important do you think health professionals should complete cultural awareness training?**

- Given we have 95% of patients who identify as Aboriginal or Torres Strait Islander or both?
- Should cultural training be mandatory on a yearly basis or every 5 years?

**10. What are the best ways to engage community for**

- Caring for kidneys?
- Educate about kidneys?

**11. How can we do kidney care better for you and our community?**

- Find a GP in the community?
- Link in better with primary health care professionals?
- Have more networking amongst our patients?
- Share your journey to other CKD patients?

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Kidney Health Australia

PO Box 9993

Melbourne VIC 3001

Kidney Helpline: 1800 454 363

[Kidney.Helpline@kidney.org.au](mailto:Kidney.Helpline@kidney.org.au)

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## *11 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.