‘Yarning Kidneys’

Report: Broome Consultation

15 August 2019

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

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. KAMS, KRS and Local Reference Group

Kidney Health Australia acknowledges the valuable contribution and leadership of the Kimberley Aboriginal Medical Services (KAMS) and Kimberley Renal Services (KRS). We would like to acknowledge and thank local leaders and clinical champions, especially and members of KAMS Board, Jenny Cutter, Henk Bruins, Kerrie Parker, Ronnie (Veronica) Lee, Brett Dean, Shane Bin Omar, Rae Gon Goo, Michelle McMahon, Coco Rahman and many others who supported this initiative, helped co-facilitate the consultation, and contributed in the analysis and writing of this report. We acknowledge the guidance provided by the members of the Broome Aboriginal Renal Community Reference Group: Ms Doreen Hester, Ms Ronnie Lee and Mr Brett Dean.

1.2. KHA Yarning Kidneys Advisory Group

An Advisory Group was established to provide expert advice for the Kidney Health Australia’s Yarning Kidneys initiative to ensure the consultations happen in a culturally safe way and the outcomes are followed up properly. This group includes:

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

Group members in alphabetical order:

- Professor Alan Cass, Menzies School of Health Research, NT
- Dr Janet Kelly, University of Adelaide, SA
- Dr Jaquelyne Hughes, Menzies School of Health Research, NT
- Ms Jess Styles, National Aboriginal Community Controlled Health Organisation (NACCHO), ACT
- Dr Martin Howell, KHA-CARI, NSW
- Dr Odette Pearson, South Australian Health and Medical Research Institute (SAHMRI), SA
- Ms Rochelle Pitt, Metro South Health, QLD
- Professor Suetonia Palmer, KHA-CARI Steering Committee, NZ
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.)
The costs related to the Broome consultation were covered through this grant, including local facilitator, catering, acknowledgement of country and participant sitting fees.

2. Abbreviations and Definitions

AHCWA – Aboriginal Health Council of Western Australia
AHW – Aboriginal Health worker
CKD – Chronic Kidney Disease
ESKD – End Stage Kidney Disease
KHA – Kidney Health Australia
KHA-CARI – Kidney Health Australia – Caring for Australasians with Renal Impairment
KAMS – Kimberley Aboriginal Medical Services
KRS – Kimberley Renal Services
NIKTT – National Indigenous Kidney Transplantation Taskforce
TSANZ – Transplantation Society of Australia and New Zealand
WAAHEC – Western Australian Aboriginal Health Ethics Committee

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.

4. **Ethical Considerations**

The Western Australian Aboriginal Health Ethics Committee (WAAHEC) provided waiver of ethics for the consultations implemented in Perth, Kalgoorlie and Broome. A copy of this report will be submitted to the WAAHEC.

5. **Community Engagement and Participants**

Twenty Aboriginal community members attended the consultation conducted on 15 July 2019, from Broome, Derby, Fitzroy Crossing and Bidyadanga. Participants represented a mix of patients with CKD, diabetes and heart diseases. Some of the CKD patients were on dialysis or had a kidney transplant. Family members, carers and community members with interest in chronic diseases also attended the meeting.

Participants were invited by KAMS, KRS and other Aboriginal Community Controlled Health Organisations. Event flyers were developed and placed visible in waiting rooms and clinics to encourage community members to attend the session (see Appendix).
KRS Aboriginal Health Workers and Aboriginal Care Coordinators helped with the promotion of the event by personally inviting their clients and community members who were experiencing chronic diseases. Aboriginal hostels were informed about the event and helped inviting their clients to attend the yarning session.

<table>
<thead>
<tr>
<th>Patients, Carers and Family Members</th>
<th>Local Leaders, Clinical Staff and Organisers</th>
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<tbody>
<tr>
<td>Ms Agnes Seela</td>
<td>Mr Brett Dean</td>
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<tr>
<td>Mr Allan Fafoutis</td>
<td>Mr Chris Forbes (KHA CEO)</td>
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<td>Ms Annette Riley</td>
<td>Ms Dora Oliva (KHA Program Manager)</td>
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<td>Mr Cyril Archer</td>
<td>Ms Eleanor Garrard (NIKTT)</td>
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<td>Mr Danny Jinderah</td>
<td>Ms Jenny Cutter</td>
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<td>Ms Dianne Appleby</td>
<td>Ms Kerry Parker</td>
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<td>Ms Dianne Manson</td>
<td>Ms Michelle McMahon</td>
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<td>Ms Doreen Hester</td>
<td>Ms Raelene Con Goo</td>
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<td>Ms Elaine Marr</td>
<td>Ms Serena Buckle</td>
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<td>Ms Faye Isbell Taylor</td>
<td>Ms Veronica (Ronnie) Lee</td>
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<td>Mr Ivan Pinda</td>
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<td>Ms Leah Dolby</td>
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<td>Ms Marea Barney</td>
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<td>Ms Noreen Edgar</td>
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<td>Mr Rod Ford</td>
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<td>Mr Shane Bin Omar</td>
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<td>Ms Suzette Edgar</td>
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<td>Mr Terence Mungul</td>
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6. Format

The yarning session initiated with an Acknowledgement of Country delivered by Dianne Appleby followed by a presentation about the purpose of the meeting by Ms Ronie Lee. A video regarding the Perth community consultation showcasing renal patient stories was played to explain how they will inform the new Guidelines. [https://kidney.org.au/yarning-kidneys-consultations](https://kidney.org.au/yarning-kidneys-consultations)

The session was co-facilitated by Ms Veronica Lee and Ms Dora Oliva. An art session took place during the morning to allow participants to paint their kidney story. After this session, participants presented the art and shared their journey with kidney disease. Emotional support was available to attendees who needed help.
The afternoon session followed lunch. Mr Chris Forbes, Chief Executive Officer, Kidney Health Australia, welcomed attendees and highlighted the purpose of the consultation. Ms Eleanor Garrard, TSANZ Executive Officer, highlighted that their feedback concerning access to kidney translation will support the work and initiatives of the NIKTT. Participants were encouraged to discuss a set of pre-established questions validated in previous consultations. Attendees gathered in sub-groups to discuss their views and priorities to inform the new Guidelines. KRS Aboriginal Health Workers and Aboriginal Care Coordinators assisted to co-facilitate this section. Each sub-group designated a note-taker to write down recommendations. Key themes and suggestions were presented at the end of the session. The event concluded with participants’ approval to use the feedback from the session to develop the consultation report and the group photo for the report front cover.
7. Yarning Kidney’s – Outcomes and Themes

7.1. The Impact of Kidney Disease

Participants agreed kidney disease disrupted their life and caused major problems to their relationship with family and community, interfered with work commitments, community roles and responsibilities and caused substantial lifestyle changes. Understanding the disease and trying to explain what kidney disease was to family and community members was a concern experienced by new patients. Attendees mentioned how useful it would be the support from experienced patients sharing their learnings with patients who have just been diagnosed and are commencing dialysis.

‘Had to tell family, i.e. sad and worried for them. What is the meaning of kidney disease? They asked’ (Aboriginal participant).

‘Trying to understand and translate to family. Learn and then let the family know’ (Aboriginal participant).

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 Kimberley communities with rural and remote renal treatment and conduct training on their country to avoid separation from family and disconnection from their land.

‘The worst thing is the separation – there is no-one for you. Biggest treat when a family member passes away, you need to attend the funeral’ (Aboriginal participant).

The discussion centred on the need to provide emotional and social support to renal patients, and particularly, to those who have been recently diagnosed and relocated to Perth. Attendees also agreed that experienced renal patients could play a crucial role in assisting new patients in understanding the disease and treatment options. In their opinion, the peer support will reduce the anxiety and fear caused by lack of understanding experienced by new patients and their families.

‘It took me a while to understand why I was in Perth for six months. I cried at night away from my kids and grandkids. That was very hard for me. After associating with other patients in Perth, made me feel a lot better about my situation because I found other people that have been through the same and helped me understand things better’ (Aboriginal participant).
Recommendations:

- Employ experienced renal patients to mentor new patients, provide peer support and help understand the disease and treatment options.
- Provide renal patients with social and emotional support, and particularly, to those who relocated to Perth to commence treatment.
- Increase the provision of renal services in rural and remote areas of the Kimberley region to avoid patients’ separation from family and disconnection from country and community.

7.2. Treatment Options

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, treatment was imposed. Participants agreed that being able to decide on their care and treatment plan could result in better health outcomes and increased compliance.

‘Need to be given more choices for dialysis. Some of us never had a choice’ (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.

Recommendations:

- Provide culturally appropriate education around renal treatment options through videos.
- 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 compliance.

7.3. Support from KAMS/KRS

Participants are thankful for the renal services and support that KAMS/KRS provide to them.

‘The service that KAMS Provides is OK. I get picked up and taken home. I am staying with family. I am waiting for a house. My husband is in Halls Creek’ (Aboriginal participant).

Patients are aware that there is additional funding to expand haemodialysis treatment in the Kimberley region; however, indicated that having more haemodialysis machines in Broome,
Derby and Fitzroy Crossing doesn’t mean patients will be able to return to their country, as these towns are still several kilometres away from their communities.

‘I am not bad, because I have family here, but it is not my home’ (Aboriginal participant).

Attendees suggested KAMS/KRS discuss with the Government to implement haemodialysis machines in remote communities of the Kimberley to help patients return to country.

**Recommendation:**

- KAMS and KRS to discuss with the State Government the implementation of haemodialysis machines in remote communities of the Kimberley region to help patients to return to their country.

### 7.4. Home Haemodialysis and Peritoneal Dialysis

Attendees who are doing home haemodialysis and peritoneal dialysis highlighted the need to have clinical support available in their communities and stressed the need for KAMS/KRS or Fresenius to employ a renal nurse or care support that can help out when there is emergency. They also suggested the delivery of culturally safe education around night food, fluid intake and emergency signs for renal patients on home haemodialysis and peritoneal dialysis.

‘We need 24-hour support when on home haemodialysis and peritoneal dialysis. When a problem occurs, a nurse needs to be on the ground in our communities to assist due to not getting through Fresenius in Perth on the renal hostels. We need to be trained on night foods/drinks, signs of renal patients when we are fluid overloaded, etc.’ (Aboriginal participant).

**Recommendations:**

- KAMS/KRS and Fresenius to employ a renal nurse to support patients on home haemodialysis and peritoneal dialysis, and particularly, during emergency episodes.
- Provide culturally safe education to patients on home haemodialysis and peritoneal dialysis to identify emergency signs.

### 7.5. Transplantation

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 is diagnosed with 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).

‘Education in hospitals is all well and good, but it means it’s only reaching the people who are already sick. The focus should be on the next generation, so that they know what transplant is. If they keep drinking coke and eating junk food that’s what they’re going to need one day’ (Aboriginal Participant).

Participants who had travelled to Perth for transplant-related assessments indicated that the Patient Assistance Transport Scheme (PATS) worked well in terms of getting them from the Kimberley to Perth, but that transport upon arrival in Perth was much more difficult to arrange, particularly airport pick-ups/drop-offs.

‘There’s no pick-up from the airport and transport in Perth is a massive problem. You have to ask doctors for a taxi voucher – it’s never volunteered, YOU have to ASK’ (Aboriginal Participant).

Several participants outlined issues with the accommodation provider in Perth (the Autumn Centre) relating to culturally inappropriate practices and the provision of meals that are not suitable for renal patients.

‘The people at the Autumn Centre have no idea what it’s like to be a renal patient, and what they offer just isn’t culturally appropriate for us Kimberley fellas’ (Aboriginal Participant).

‘I was once served a roast chook that had been drenched in a bottle of Kikkoman soy sauce. No veggies, nothing healthy. I explained that I couldn’t eat that, but I wasn’t given anything else’ (Aboriginal Participant).

Participants also acknowledged the scarcity of renal resources in the Kimberley, particularly concerning the appropriate staffing of renal services. Participants suggested that staffing shortages meant that local GPs, nurses and Aboriginal Health Workers were extremely time poor, and while they still manage to deliver excellent health care to their patients, their ability to promote and advocate for transplantation is limited.

‘It needs to go further than education – advocacy from the people caring for us is so important. Not just from the visiting nephrologists, but local GPs right through to ALO’s and social workers. These people who we know and trust need to encourage and support us – we need those people to fight for us to get on the wait list’ (Aboriginal Participant).

Recommendations:

• Deliver culturally appropriate education on pre and post-transplantation.
• Provide appropriate accommodation and culturally safe and nutritious meals to Kimberley renal patients travelling to Perth.
• Provide Kimberley renal patients travelling to Perth with reliable transportation services, particularly for airport pickups and drop-offs.
7.6. **Education and Prevention**

Attendees agreed that there should be a campaign to prevent diabetes and kidney disease among Indigenous Australians in the Kimberley.

> There should be tackling diabetes and kidney awareness campaign in the Kimberley. (Aboriginal participant).

When asked if the suggestion provided by previous consultations to engage Elders to deliver education was appropriate for the Kimberley region, participants stated that many Aboriginal children lack respect for Elders, so having Elders deliver education about kidney disease to kids in the community won’t be effective.

In the view of the participants, education is much more likely to be effective if a person that the Aboriginal children look up to delivers it. Suggestions provided included Indigenous AFL players, such as Cyril Rioli or Buddy Franklin.

**Recommendations:**
- Implement a localised campaign to prevent diabetes and kidney disease targeting children and youth using role models.

7.7. **Communication Barriers**

Participants indicated that non-compliance is usually associated with a lack of understanding due to communication barriers and the use of medical jargon. One example mentioned by attendees was a patient who had a kidney transplant and ended the treatment after completing the first course of medication thinking that the treatment was completed. It was evident the lack of understanding of care post-transplant and the misconception that having a transplant is the cure for kidney disease. Participants agreed that interpreters should be available in the health system at all times to help overcome language barriers.

> ‘The work of the interpreters is important to break down the language barriers from a medical term to Indigenous people, I.e. Kriol language’ (Aboriginal participant).

**Recommendation:**
- Employ interpreters to help renal patients understand their condition and treatments.
7.8. **Food Access**

Some participants mentioned that it is difficult to access fresh vegetables locally, and when available, prices are extremely high. Also, water isn’t often available, and the quality isn’t appropriate for consumption, which forces community members to find unhealthy alternatives.

‘When you see lettuce sold for $6.50, you prefer to buy a pack of chips and a coke instead’ (Aboriginal participant).

Participants agreed that access to vegetables and other nutritious foods and water are necessary to keep healthy. Participants agreed that the Yarning Kidneys Consultation was a good platform to raise these issues and suggested this report be submitted to the Government in the hope that health and local government representatives can take actions to improve access to nutritious foods and good-quality water in rural and remote Kimberly communities.

‘If they are serious about addressing health issues, they should look into access to good food and other challenges we are facing.’ (Aboriginal participant).

**Recommendation:**
- Federal, State and Local Government to identify mechanisms to improve access to nutritious food and good-quality water in rural and remote communities of the Kimberley region.

7.9. **Cultural Awareness Training**

Assisting health professionals to gain an understanding of Aboriginal culture and maintain an effective way to communicate with appropriate language is crucial to engage with and provide effective patient-centred care to Aboriginal and Torres Strait Islander peoples. Participants agreed that health professionals should gain an understanding of the key family groups within the Kimberley communities, and understand cultural lore, female and male position, eye contact, and verbal and non-verbal communication.

‘Lore disallows men from eye contact with women, non-verbal communication can be misinterpreted and can often be observed as being uninterested or avoidance’ (Aboriginal participant).

Some participants mentioned racial discrimination as the cause of the low access to kidney transplantation rates among Aboriginal and Torres Strait Islander communities, which should be addressed by the health system.
We are aware of transplant and how much is involved to getting a transplant, because of racial biased, a lot of restrictions have been imposed in place in renal patients getting transplants in the Kimberley region (Aboriginal participant).

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

**Recommendation:**

- Implement a comprehensive and ongoing cultural awareness training in the health system.
- Conduct research to identify (racial biased) restrictions imposed for Indigenous Australians to access kidney transplantation and improve access and outcomes.

### 7.10. Aboriginal Workforce: Male and Female Case Management

As in previous community consultations, participants recommended the health system to employ Aboriginal and Torres Strait Islander communities to deliver renal services. Participants are pleased that there KAMS and KRS employ Aboriginal Health Workers to deliver haemodialysis and Aboriginal Care Coordinators to support renal patients; however, suggested more Aboriginal health workers should be employed in renal health. Additionally, participants suggested it is crucial to create a protective environment of dual case management due to cultural sensitivities around male workers caring for male patients and female workers looking after female patients.

**Recommendations:**

- Increase the number of Aboriginal Health Workers delivering haemodialysis.
- Employ male and female Aboriginal workers to address cultural sensitivities around dual case management.

### 7.11. Closing the Gap Initiative

Some participants expressed disappointment that health outcomes for Indigenous Australians in the Kimberley is going backwards, despite the Closing the Gap strategy and related initiatives and funding. When asked whether they thought overall outcomes (i.e. health, education, employment, housing, child protection, etc.) for Indigenous Australians was improving, declining or staying the same, participants agreed unanimously that it was
getting worse. Participants noted that tipping money into these issues without adequate consultation and Indigenous empowerment is ineffective.

**Recommendation:**
- The Closing the Gap Initiative should conduct proper community consultation and engagement in the Kimberley region to achieve better outcomes.

### 7.12. Follow up

The need for Indigenous kidney community support groups was discussed. Participants acknowledged that KHA’s community consultation provided a great opportunity to meet people who are experiencing the same treatment and associated challenges who otherwise they would not have come into contact with. Participants emphasised the importance of having regular opportunities to engage with other members of the kidney community as well as peak bodies such as KHA and TSANZ; one-off consultations are not enough. Some attendees suggested KAMS and KRS organise periodical consultations locally. The group agreed there should be a similar meeting by the end of the year to follow-up and discuss the priorities and recommendations from this meeting.

**Recommendation:**
- KAMS/KRS to organise local community consultations in Broome, Derby, Fitzroy Crossing and Bidyadanga to follow-up and discuss the feedback from this meeting.

### 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 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 (Appendix).
9. Appendix

9.1. KHA Yarning Kidney’s Broome Flyer

Indigenous Voices Yarning ‘Kidney Health’

Thursday, 15 August, from 10:00 am to 3:00 pm
at Nyemba Buru Yawuru Ltd on
55 Reid Rd, Cable Beach Broome

Food, transportation and sitting fees will be provided.

Kidney Health Australia with support from the Kimberley Aboriginal Medical Services and Kimberley Renal Services invite you to attend the Broome Yarning Kidneys’ Morning tea and lunch.

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 Kalgoorlie 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 and book your transport with Dora Oliva on 0406 809 712 by Thursday, 10 August 2019. For more information call: Dora Oliva on 0406 809 712.


9.2. **Summary – Broome Report**

The yarning session initiated with an Acknowledgement of Country delivered by Dianne Appleby followed by a presentation about the purpose of the meeting by Ms Ronie Lee. A video regarding the Perth community consultation showcasing renal patient stories was played to explain how they will inform the new Guidelines.

The session was co-facilitated by Ms Veronica Lee and Ms Dora Oliva. An art session took place during the morning to allow participants to paint their kidney story. After this session, participants presented the art and shared their journey with kidney disease.

Mr Chris Forbes, Chief Executive Officer, Kidney Health Australia, welcomed attendees and highlighted the purpose of the consultation. Ms Eleanor Garrard, TSANZ Executive Officer, highlighted that their feedback concerning access to kidney translation will support the work and initiatives of the NIKTT.

The discussions included:

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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.