



'Yarning Kidneys'

Report: Dubbo

2nd, 7th & 8th April 2020

Consultations 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



'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.

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“The white circles in the centre represent all Aboriginal kidney clients 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 clients on dialysis to help cleaning their body to keep healthy. There are two footpaths that represent the journey of Aboriginal kidney clients. Wildflowers and grass are represented by purple, white, black, orange and green dots.”

1. Acknowledgements

1.1. Dubbo Health Service

Kidney Health Australia acknowledges the valuable contribution and support from Debbie Beahan and Craig Johnson of Dubbo Health Service.

We would like to acknowledge and thank local Elders and community leaders who supported this initiative and helped spread the word about the consultations.

Our greatest acknowledgement and thanks goes to all the clients, family members and carers who participated in the Yarning Kidney consultation process.

1.2. KHA 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

AH&MRC – Aboriginal Health and Medical Research Council

AHW – Aboriginal Health Worker

ALO – Aboriginal Liaison Officer

CKD – Chronic Kidney Disease

Clients – people living with kidney disease (patients)

ESKD – End Stage Kidney Disease

KHA – Kidney Health Australia

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

PD – Peritoneal dialysis

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.

Two participants that were interviewed during the consultations identified as Maori, First Nations people of New Zealand. They were both respectfully invited by the local Elders group to be a part of the community consultations.

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](#)¹ 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 Aboriginal Health and Medical Research Council (AH&MRC) provided waiver of ethics for the consultations implemented in Lismore, Dubbo and Mount Isa. A copy of this report will be submitted to the AH&MRC Ethics.

¹ 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

Clients, Carers and Family Members	Local Leaders, Clinical Staff and Organisers
Mrs Barbara Hill Mr Hill Mr Tony Peachy Mrs Sue Peachy Ms Valda Hampton Mr Ranera Taurau Mr George Stratton Ms Justine Lake Mr Larry Fox Ms Shirley Cubby Ms Barb Wilson Mr Percy Cubby Mrs Mary-Ann Hausia Mr Ray Jackson Mr Rodney Powell Mr Chris Hart Mrs Marg Walker Mr Guy Naden	Ms Kimberly Taylor Ms Debbie Beahan Mr Craig Johnson

6. Format

The Dubbo community consultations were conducted throughout the first week of April 2020. Due to the COVID-19 restriction the Yarnings were facilitated a little differently from the first few consultations. Usually Yarnings would be held in a community setting where everyone can meet face-to-face and talk together about their experiences and related concerns. To overcome the current restrictions the Yarnings were conducted through individual and group conversations over the phone. The Project Manager, Ms Kimberly Taylor facilitated these over three days and in total, 19 separate Yarnings were conducted with community members of Dubbo living with chronic kidney disease.

Debbie Beahan and Craig Johnson from Dubbo Health Service invited their clients to participate in the Yarnings. Information flyers about the community consultations were given to clients during the Elders group session that is held once a month in Dubbo and also during personal appointments (see Appendix 9.1). The clients were also encouraged to invite relatives and spouses to be involved in the phone Yarnings.

Throughout the phone conversations participants were guided by a set of pre-established questions regarding kidney care and other CKD related diseases, validated in previous consultations (see also Appendix 9.1).

7. Yarning Kidney's – Dubbo Community

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

Key Themes and Recommendations include:

<p>1.</p>	<p>Early detection</p> <ul style="list-style-type: none"> • Implement better health assessment programs and associated education and awareness raising resources associated with CKD. • Encourage and provide kidney checks to achieve early detection of kidney disease and allow clients (and family or carers) to participate in education programs and prepare for future treatment. • Involve respected and experienced community members for storing sharing.
<p>2.</p>	<p>Education, raising awareness and understanding</p> <ul style="list-style-type: none"> • Implement a localised campaign/program to prevent diabetes and kidney disease targeting children and youth. • Implement a “kidney or renal buddy” program using experienced kidney clients. • A Reference Group similar to the Elders group and meeting that are held monthly could be established to discuss ways of raising awareness and information sharing. • Information to be provided in clinics and community information days with relevant resources including posters, brochures, flipcharts, visual information, videos and associated collateral. • Incorporate Aboriginal health into studies at school. • Utilise forums such as Land council meetings or arrange special meetings for public health care to assist spread the message. • Address letters to parents/clients personally about issues, education, training, awareness etc. • Brochures to inform: <ul style="list-style-type: none"> ○ Seriousness of salt intake. ○ Information on traditional foods and ways to sources them –education around nutrition in food. • Implement community programs such as growing healthy vegetables in community gardens and sourcing other healthy indigenous bush-foods.

3.	<p>Health system issues and workforce</p> <ul style="list-style-type: none"> • Employ more permanent GPs and nurses with a preference for more targeted positions e.g. aboriginal health workers or community support workers. • Employ adequate numbers of male and female Aboriginal workers to address cultural sensitivities working with Aboriginal and Torres Strait Islander men and woman. • Revitalise renal units to provide a more engaging, welcoming and culturally safe environment. • Provide access to healthcare workers, patient navigators or preceptors to assist people in being able to better navigate social and health care systems, understand information and adapt to a changed lifestyle living with kidney disease.
4.	<p>Treatment options and transplantation</p> <ul style="list-style-type: none"> • Provide information and raise awareness about CKD treatment options and processes involved with dialysis and transplantation for both clients and potential donors. • Increase the opportunities for transplantation for Aboriginal and Torres Strait Islander people.
5.	<p>Impacts on lifestyle and quality of life</p> <ul style="list-style-type: none"> • Provide additional support to patient’s immediate family members to reduce family breakdowns and reduce stress and burden for the individual living with CKD. • Improve transport and access to dialysis services and assist with financial burden associated with moving or travelling away from home.
6.	<p>Impacts of being forced to leave community / country</p> <ul style="list-style-type: none"> • Treatment “closer to home” must be a priority for better health outcomes for clients and family impacted by end-stage kidney disease and dialysis treatment. • Increase the provision of renal services in rural and remote areas to avoid clients’ separation from family and disconnection from country and community. • Hospitals and Renal units should have access to in-house accommodation or partnerships with hostels or other organisations that can offer accommodation. • Provide information booklets/leaflets on the locations of secure and culturally safe accommodation where this may be required.
7.	<p>Engaging and communicating with health professionals</p> <ul style="list-style-type: none"> • Provide more relevant information without having to use the internet – health professionals need to explain this at appointments. Need for longer appointment times or more follow up sessions. • Use plain language during appointments and dialysis sessions and check for understanding back from the patient.

	<ul style="list-style-type: none"> • Provide information that is straight forward and easy to remember regarding caring for kidneys and CKD management. • Need to break the barrier that it is OK to go to the doctors and want to look after your health. Change the mindsets of both young and old.
8.	<p>Cultural awareness training</p> <ul style="list-style-type: none"> • Implement a comprehensive and ongoing cultural awareness training program within the healthcare system. • Cultural training should include local Indigenous history, customs, lore, language and the status of health and wellbeing at the grass-root level. • Increase access to culturally appropriate allied healthcare services including mental health support. • Create opportunities for community to interact and share stories with healthcare professionals.

7.1. Early detection

There were consistent reports by participants that they had little knowledge before diagnosis of what kidney disease was, the signs and symptoms and the risk factors to look for. There was a lot of awareness raising and education provided about other illnesses such as diabetes and heart health, but not about kidney health. A combination of more targeted, culturally appropriate education and health assessment / detection programs around kidney disease was suggested as ways in which to assist in the prevention and earlier detection of kidney disease. Participants talked about current successful ways of sharing stories and knowledge amongst the community which should be considered as a method of distributing information. This included the use of respected and experienced community members, gatherings of elders and community along with school and health-based programs.

“Didn’t know how important Kidneys were!!”

“There needs to be more Kidney resources and information the same as they do for heart health and diabetes”

“More family background checks with illnesses”

“Being Aboriginal I thought I would eventually get sick”

7.2. Education, raising awareness and understanding

In line with the above theme the provision of targeted information about kidney disease and an awareness raising campaign was consistently raised. More culturally appropriate CKD information and resources would assist increase the understanding of the community which may help with prevention or delaying the onset of kidney disease and encourage early detection and intervention of the disease. It would also assist with the general community having a better understanding of the impact of kidney disease on the person and on extended family and/or carers, along with treatment options and care required. It may also help the patient be less overwhelmed with a CKD diagnosis and associated treatment information.

The use of experienced clients (living with kidney disease) to assist with education and explaining the pathways associated with different stages of kidney disease and managing these was raised as being a good support to newly diagnosed clients. There are also different experiences and treatments so having a mix of people would be helpful.

There was also discussion about preventative education which included information about holistic healthcare, lifestyle changes and community programs that would assist in preventing or delay the onset of kidney disease. Diet and nutrition were key themes and understanding kidney healthy foods, how to source these and even implementing a community gardens program. Encouraging other lifestyle modifications or changes including reducing salt and sugar intake, the risks associated with smoking, drinking more water and exercising.

When there was interaction with the healthcare system there was usually good information provided, but this was not always easily understood and sometimes there was conflicting or inconsistent messaging. Communication was sometimes poor as things were not explained well or were pitched above a person's level of understanding and education which may vary between clients.

"It's always diabetes that's talked about and goes no further"

"There needs to be more information available about holistic care – diabetes, heart, feet, eyes, all that"

"Information needs to be consistent. It's always changing, never stays the same, every appointment something is different, diet and food information changes"

7.3. Health system issues and workforce

There was consistent messaging around the need for more specialist and fulltime doctors and nurses along with access to more dedicated aboriginal healthcare workers that can represent and support Aboriginal and Torres Strait Islander people.

There was feedback that the dialysis ward environment could be improved. The need for dedicated wards for specialist treatment and patient consultations was also raised.

Dialysis (Environmental factors) – comments included:

- Environment is not nice.
- Complain about the temperature but the renal staff don't listen.
- Nurses can be quite insensitive, they could be more understanding at times.
- Staff changing all the time.
- Food in renal unit is not nice. You can't choose what you like.
- Breakfast and food are premade, there isn't a lot of variety.

"Everything is cold! Cold chair, cold nurses but I get bad cramps in the cold and can only do 5 hours."

"I hate this place, all it is for me is misery"

There was also discussion about the health system, CKD treatment and other (invasive) procedures and how this was very difficult to deal with and understand.

- Not confident in receiving surgery – neck fistula operation.
- In the health system there needs to be more transparency about surgical procedures.
- Inserting needles gets easier over time, the blood vessels need to open up and it's a long process.
- Crying from the needle pain, we see it every day.
- Fear of needles – fistula procedure very scary.
- More training, awareness and understanding about dialysis, the fistula, needles and related procedures.
- Blood spurts out after dialysis if not careful.

"Concerns at the moment with COVID-19. Cautious about leaving the house but still attend my appointments."

"Because of personal experience, won't accept transplant. Want to learn home dialysis."

7.4. Treatment options and transplantation

The opportunity to have a chance at receiving a transplant was raised during consultation. It seemed to many that there was no choice and dialysis was the only option. There was not much information provided, or prior understanding about the treatment options, processes and what was involved.

"Didn't get a choice. I just did as I was told. When the PD equipment came I almost fell over. They didn't tell us about how much stuff was needed and space."

"My brother wants to donate his (kidney) moving forward when the current transplant goes - but is unsure how to go about it, whether he can or not."

"Did not expect a transplant but when I got it, I kept fit and did as I was told by the doctors."

7.5. Impacts on lifestyle and quality of life

There are many and varied impacts on not only the clients living with kidney disease but also the extended family which was raised consistently during consultations. It was discussed how kidney disease restricts many aspects of life, where everything is turned upside down as treatment options are quickly implemented and many of the normal things in life are modified, changed or just can't be done anymore. There are social, emotional, physical and financial issues associated with the isolation (mainly associated with dialysis) and being away from home, country and culture. Quality of life is compromised for all involved with CKD.

"It's life changing being on dialysis, you have no life, it takes over everything."

"Had a very active lifestyle before I was diagnosed. I try to keep up with sports and outdoor hunting but this has impacted that."

"Because of dialysis and kidney problems it has always made me feel left out/ bad by family."

"My sister has a terrible life. She has no life."

"Affects mum, sister, son, niece. They worry whether I'll come home from dialysis or from the hospital."

"After dialysis I always feel drained."

"It's been a tough journey."

"I hope there is a cure in the future."

"People alone don't have enough support. Some can't feel their own signs. It's dangerous when no one available to help."

7.6. Impact of being forced to leave community/country

This has been a consistent theme throughout the consultation and again was an important factor and major impact voiced by the community. The following dot points indicate a number of similar points raised.

- It took me away from family and friends.
- Lonely and afraid out of my comfort zone.
- Used to have strong support system back home but not now when having to travel
- Made depression worse and felt very isolated.
- Weren't aware of surroundings/ environment and how to get home or to accommodation.
- 300 miles from home.
- Still away from home. I miss my country.
- Pay for fuel and all other travel costs, go home every 6 months.
- Affects my life a lot.
- More mobile buses or more chairs in remote towns.

"Was once very independent which makes me sad because I depend on my daughters a lot in Dubbo. They have their lives and I don't want to be an inconvenience."

"20 years on dialysis – Orange 6 months, Forbes 11 years then transferred to Dubbo and been here ever since."

"I'm stuck here and I hate it! I would love to go home but there's no chairs back home."

7.7. Engaging and communicating with health professionals

Some clients indicated that they felt that they were not treated as a patient should be treated. That they were being talked down to and not asked for their thoughts or opinions. It was also difficult to be able to voice their opinion or provide feedback about the service and care being given and just refused to see some healthcare staff due the way they were treated.

A number of clients also commented on not fully understanding the information being given to them by healthcare workers and the need for the use of plain language, not jargon and to ensure they have understood the message being given. Also the issues of stereotyping Aboriginal and Torres Strait Islander peoples and being judgmental was raised.

"Talk down, don't explain."

"Treats cubby people like they have no brains."

"Didn't even explain, luckily my wife understands the medication."

"No information given about medication and treatments."

"Got given the wrong medication, almost died after having a stroke because of the medication?"

'Had a virus, it was unknown to doctors why I got sick'. They gave me a blanket excuse, oh your Aboriginal so you're vulnerable'. (*stereotyping*)

"During appointments and receiving care have been made to feel bad about me drinking in the past and my lifestyle habits. Some can be very judgmental and they don't need to be."

"Not much was explained – just get a pack of medication. No instructions."

Some other clients however also mentioned how helpful some of the renal units and healthcare staff had been.

"Really good team at the Dialysis unit in Dubbo."

"Doctor is very informative, has been there from the start."

"Yes, understood and when didn't understand asked to explain and medical staff were thorough when answering my questions and concerns."

7.8. Cultural Awareness Training

Many clients expressed how difficult it can be at times interacting, trusting and communicating with different doctors and nurses and participants recommended that the renal service staff undertake a formal induction process and cultural awareness training regularly. This would hopefully bridge the gap in understanding of the Aboriginal and Torres Strait Islander peoples culture and assist with communication, compassion and ultimately health outcomes.

- Main feature when working with Aboriginal people is we speak a different language.
- Annual cultural training – compassion training.
- There isn't enough cultural awareness training – more awareness in hospitals.
- New doctors are coming in all the time – there should be annual cultural training as well as reviews/updates every 6 months.
- Need to come down to our level and not talk over us.
- Elders don't understand, don't know how to ask the important questions.
- BBQs get together, sharing information.
- More visitors during dialysis.
- Keep drip feeding them all the time?
- Depends on community, need to feel comfortable with workers to discuss health issues.
- They never really answer questions of clients.

"They don't understand how we think about health."

"Took a while to gain confidence in talking about issues – lots of mob feel shame."

"Some doctors don't even look at you."

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 Aboriginal Health and Medical Research Council Ethics;
- The Dubbo Health Service, Renal Champions;
- Kidney Health Australia Website and
- Funding Agencies.

9. Appendix

9.1. KHA Yarning Kidney's Community Consultations Information Flyer



'Yarning Kidneys'

Kidney Health Australia's new 'Yarning Kidneys' sessions and consultation process will improve kidney care for Aboriginal and Torres Strait Islander Peoples. During these sessions, Aboriginal and Torres Strait Islander Peoples will share vital information on KHA-CARI guideline content and on how medical professionals can utilise this resource to improve Indigenous kidney care.



Funded by the Australian Government, the 'Yarning Kidneys' sessions are an opportunity for Aboriginal and Torres Strait Islander Peoples in metropolitan, regional and remote areas across Australia (with the exception of the Northern Territory as consultations have been conducted by the 'Catching Some Air Project'), to talk about what is most important to them and their kidney health.



Contact your doctor or Aboriginal medical service if you need more information.

Connect with us

www.kidney.org.au

Freecall 1800 454 363



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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11. Disclaimer

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