



'Yarning Kidneys'

Final Report: Brisbane

July 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 patients coming together to have a yarn about kidney health with doctors and nurses, talking about the plans for the future and sharing what they want to see happening to improve kidney health for their people. The outside circles represent patients on dialysis to help cleaning their body to keep healthy. There are two footpaths that represent the journey of Aboriginal kidney patients. Wildflowers and grass are represented by purple, white, black, orange and green dots.”

1. Acknowledgements

1.1. Princess Alexandra Hospital

Kidney Health Australia acknowledges the valuable contribution and support from Breanna Solomon and Brett Mooney from the Princess Alexandra Hospital and Rochelle Pitt from Metro South Health, Queensland.

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 go to all the patients, family members and carers who participated in the Yarning Kidneys consultation process.

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), SA
- Ms Kimberly Taylor (Project Manager), SA

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

ATSI – Aboriginal and Torres Strait Islander

CKD – Chronic Kidney Disease

ESKD – End Stage Kidney Disease

KHA – Kidney Health Australia

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

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](#)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.

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

4. Ethical Considerations

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) provided waiver of ethics for the consultations implemented in Brisbane. A copy of this report will be submitted to the AIATSIS Ethics Committee.

5. Community Engagement and Participants

Patients, Carers and Family Members	Local Leaders, Clinical Staff and Organisers
Mr Cel Williams	Ms Kimberly Taylor
Ms Janelle Sands	Ms Breanna Solomon
Ms Katherine Widders	Mr Brett Mooney
Mr Robert Mitchell	Ms Rochelle Pitt
Mr George Steveson	
Family group of 3 (de-identified)	

6. Format

Breanna Solomon and Brett Mooney from the Haemodialysis Renal Ward, Princess Alexandra Hospital, Brisbane invited their patients to participate in the Yarning Kidneys community consultations. Information flyers about the consultations (see Appendix) were promoted to patients associated with this service and during personal appointments. Patients were also encouraged to invite relatives and spouses to be involved. Rochelle Pitt from Metro South Health, Queensland also assisted with promotion and sourcing participants.

The Brisbane community consultations were conducted throughout the entire month of July 2020. Due to the COVID-19 restrictions these Yarnings were not face to face and were conducted through 6 individual and group telephone conversations with Project Manager, Kimberly Taylor.

Throughout the phone conversations participants were guided by a set of pre-established questions regarding kidney care established in conjunction with community members in previous consultations (see Appendix). In addition, any new topics or issues were able to be freely raised.

7. Yarning Kidneys – Outcomes, Key Themes and Recommendations

There were five themes identified during the consultation which are discussed in more detail below.

Key Themes and Recommendations include:

1.	<p>Raising Awareness and providing Education for Prevention, Early Detection and Care of CKD</p> <ul style="list-style-type: none"> • Encourage early detection and interventions for CKD prevention – develop the environment for this to happen and don't limit just to kidney disease • Involve Community as part of the Awareness Campaign – community-led care will be essential to raising awareness • Food Security and Importance of Diet – needs specific targeting and education which should start early • Educational Resources - should be culturally appropriate and include story sharing and buddy systems
2.	<p>Cultural Awareness Training for Health Professionals</p> <ul style="list-style-type: none"> • Cultural Awareness and Safety Training – should be regular and compulsory for all health professionals
3.	<p>Health System Issues and Workforce</p> <ul style="list-style-type: none"> • Workforce - add more permanent staff and AHW's and navigators • Health Service Environment – improvements should make time spent in health services more efficient. There is an expectation that these Guidelines will lead to service improvements and change
4.	<p>Communication / Miscommunication</p> <ul style="list-style-type: none"> • Experiences of Poor Communication – a barrier to care, must be improved • Delivery of Information - should occur by the right people, with plenty of time and in simple and appropriate language to ensure messages are understood • Language Barriers – must always be considered. AHW's and patient preceptors are recommended
5.	<p>Multiple Impacts of living with CKD</p> <ul style="list-style-type: none"> • Being Away from Home - treatment closer to home is a top priority • Mental Health and Social Impacts – recommend additional and culturally appropriate resources to address, including Aboriginal Health Workers and patient preceptors • Family Burden and Family Support – recommend additional and culturally appropriate resources to address, including AHW's and patient preceptors

7.1. Raising Awareness and Providing Education for Prevention, Early Detection and Care of CKD

Encourage early detection and interventions for CKD prevention.

"It made me feel sad because I knew nothing about it."

- Targeted information about kidney disease and an awareness raising campaign was consistently raised by patients and family members to help with prevention or delaying the onset of kidney disease.
- Creating an environment in which to educate and encourage those at risk to have a kidney health check and modify their lifestyle and diet was seen to be of primary importance.
- Combine CKD information with other chronic disease information and community priorities around health, including diabetes, dementia, foot care, dental care.
- Adopt more holistic approaches to providing care in kidney disease – not just one person, one disease.

Involve Community as part of the Awareness Campaign

"Start community gardens – get the kids engaged - Isn't that what these convos are for?"

- Participants suggested involving the broader community in healthy lifestyle and diet programs, especially young people.
 - Encourage more visits to community, raising awareness about kidney issues, the impact of CKD and longer-term effects.
 - Hold family and community information sessions, especially in regional and remote areas. This could include family days at community venues and local places with respected elders so more people come to events.
 - Start addressing chronic disease and diet / lifestyle factors in schools via novel programs such as community gardens.
- Have local doctors and nurses come to community events so they can start relationship and trust building with communities.
- Co-facilitate training sessions with local aboriginal elders and leaders. These are people who the community will listen to and take seriously.

Food Security and Importance of Diet

"Talk to governments in rural and remote communities about lowering the prices (for healthy food). It is way too high!"

- Diet was seen as paramount. Food was the most important aspect for change and teaching the community the importance of healthy diet was a priority.
- Food pricing was a major issue as was access to healthy food options amongst the availability and mass promotion of fast foods without knowing the associated risks.
- Use schools, community events and social gatherings as a way of promoting information about healthy diet and active lifestyle

Educational Resources

"I didn't understand at first and the doctors had to repeat it several times, seeing my aunty go through the pain of needles and being stuck in a cold room. I felt helpless."

- More culturally appropriate CKD and dietary /lifestyle information and resources would assist to increase community understanding of early detection and kidney treatment options
- Consult with primary health services such as Aboriginal Medical Services and partner with "Deadly Choices" re CKD prevention and promotional T-shirts developed to raise personal and community awareness which can be given out after a 715 health check.
- Enable patients (and family or carers) to participate in education programs to help prepare for future treatment.
- Involve respected and experienced community members for story sharing.
- Access to a "renal buddies" system – education delivered by patients themselves.

7.2. Cultural Awareness Training for Health Professionals

Cultural Awareness and Safety Training

"More doctors and nurses just need to ask you, who are you and what you are about. Be friendly and talk, get to know us."

Patients commented on the issues of stereotyping Aboriginal and Torres Strait Islander peoples and experiences of racism, being judged and a lack of understanding of indigenous culture. Some participants stated they had not had the best experience with doctors and nurses. One stated he "was not treated like a person and was made to feel dumb, like they didn't matter". Others did not experience racism or discrimination and were complementary, particularly to their nurses and AHW's.

- The need for regular cultural awareness training was fully supported. This was felt to be especially important in areas that have a large percentage of Indigenous patients.
- Participants suggested training is needed urgently, should be mandatory every 6 months and facilitated by indigenous staff/ health staff.
- Participants suggested services bring in aboriginal cultural advisers who have more understanding and compassion (cultural training)
- Conduct a Kidney yarning workshop/in-service from ATSI CKD patients, elders and ATSI health professionals to provide renal non-indigenous health professionals education on their history, experience they have had in the system and how to be culturally safe. Staff may be more perceptive and be able to understand the systemic racism that exists within our society and hospital systems that prevents ATSI people from either coming to outpatient/inpatient services and discharging against medical advice.
- Staff could be cultural safety champions, wear ATSI style shirts (less corporate clothing) to appear friendly and most likely to advocate on their behalf.
- The ATSI map of tribes could be located somewhere within the unit for staff to be aware where each patient and ATSI health professional is from.

"New doctors, new training – All new healthcare staff should all be trained".

7.3. Health System Issues and Workforce

Workforce

“Understanding and patience – both the doctor and the patient need to be on the same page about everything, every step of the way through their journey.”

There was consistent discussion around the need for access to permanent clinical staff and more dedicated AHW's that can represent and support them.

- Permanent GPs are absolutely needed.
- Indigenous trainers first choice = relatability
- Non-indigenous staff need to take the time to get to know patients and community.
- AHW's really explained to me all the different options.
- PA (Princess Alexandra Hospital) staff are really good.
- Employ more permanent GPs and nurses with a preference for more targeted positions e.g. AHW's.
- Employ adequate numbers of male and female Aboriginal workers to address cultural sensitivities working with ATSI men and woman (i.e. gender issues are an important inclusion to enable culturally safe service provision).
- A suggested approach was to employ one male and one female AHW and one Indigenous nurse navigator to the outpatient/inpatient renal clinic, ideally with renal experience. This breaks down any communication barriers as they know the right people to discuss care with and what services are available.
- “Dialysis units within urban areas should also be using the model that works in Cairns, Tiwi islands, Kimberly, etc... there are ATSI health workers/practitioners who are capable of providing dialysis to ATSI and non-Indigenous patients. Multitude of evidence showing increased outcomes for ATSI patients and health professionals.”
- “By employing ATSI health professionals, they can create partnerships with the Institute of Urban Indigenous Health to assist patients with purchasing medical equipment, transport, medicines and how to have better outcomes when accessing services. Can also assist with facilitating transfer to other ATSI communities to visit family, attend cultural obligations, like sorry business.”
- One suggestion was to reintroduce the Indigenous cadetship program within the nursing and allied health workplace training system.

Health Service Environment

“I come in for the usual time and sometimes people are still in the chairs so you have to wait for them to finish and then get ready to have your needles put in. It can be very frustrating when I just want to get out of there on time.”

There was also feedback that the dialysis ward environment and use of appointment and/or treatment time could be improved or more efficient.

- Expectations of getting in and out of dialysis but it doesn't always work that way.
- Time can drag sometimes. They need to improve on their time efficiency.
- Hope the medical area improves.
- Revitalise renal units to provide an engaging, welcoming and culturally safe environment.

- Aboriginal medical services should also be funded and to provide dialysis as a satellite unit within urban areas such as Inala Indigenous Health.

“Really hope something happens with these guidelines – nothing has changed.”

7.4. Communication / Miscommunication

Experiences of Poor Communication

“Not (well explained) at first but the doctors took the time to explain things to us, well the aboriginal nurses and health workers.”

“Doctors saying this about food or nutritionist saying that about foods and it doesn’t always match up.”

A number of participants indicated that the information provided was not always easily understood and sometimes there was conflicting or inconsistent messaging.

- When attending the doctors there needs to be more straight forward language.
- They used all this language I didn’t understand and if it wasn’t for my wife being there too, and helping me understand things, I would be lost and confused.
- I felt like I wasn’t always given the correct information.
- As the family of the patient, they weren’t always treated well either.
 - Spoken down to and not listened to as well
 - AHW’s were very supportive in filling in the gaps

Delivery of Information

“When I haven’t understood things and asked the doctors to explain they use too many big words and they don’t always seem to have the time so appointments are rushed. My questions aren’t answered, and I leave more confused.”

“Small words, everyday talk.”

Communication was sometimes poor as things were not explained very well or used words that they were not familiar with. Participants asked for more plain language to be used to increase their understanding and also for more time in consultations.

There was also praise for some of the healthcare workers who did take the time to explain things and get to know the patients and build trust.

- Communication was a key issue especially in busy dialysis units.
- They were always supportive and understanding. Had a good way of explaining things.
- Speak at our level.
- Provide information and straight forward, easy to remember messages on caring for kidneys and CKD management.
- A suggested approach was to ensure patients are provided the option of having an AHW present to assist with two way communication, ensure there is enough time to process information and questions are answered, education provided in a culturally safe manner.

- This could be addressed within a workshop/in-service, to always use non-medical simple language to explain things, learn the importance of yarning. Take your time don't rush. Always ask a patient if they would like to have an aboriginal health worker to be present during their appointment, or to have education explained to them.

Language Barriers

"Tried my best (to understand the Doctors) but the Indigenous health workers were the ones that really supported me."

- Break the information down easy to understand language.
- Extend appointment times for peace of mind and being able to leave the doctors with adequate understanding.
- Use plain language during appointments and dialysis sessions.
- Employ AHW's, navigators or preceptors to help renal patients understand their condition and treatments and improve communications with doctors.

7.5. Multiple impacts of living with CKD

Being Away from Home

"Scared and sad when I had to leave Country but I had family support, they moved with me. Wife is a great support. She's been there through it all with me."

"Looking into the bag option or home dialysis so I can be with my family, spend more quality time with them."

This has been a consistent theme throughout the Yarnings and again was an important factor and major impact voiced by these patients. A number of points were raised around "leaving home due to kidney disease and associated treatment, particularly the impact on family.

- "From Cairns, 20 years living in Brisbane now. Scared and sad. Felt very alone."
- "Took me away from family and friends."
- "I talk to family a lot over the phone."
- "It has affected all the family."
- It was recommended by relevant patients that treatment "closer to home" must be a priority for better health outcomes for patients and family impacted by ESKD and dialysis treatment.
- This could include increased training for patients to dialyse at home.

Mental Health and Social Impacts

"When I do go out sometimes for a couple of hours afterwards, I feel very drained and can't move for the next 12 hours."

Many of the participants commented on the varied mental health and social impacts living with kidney disease.

- "Socially it has affected me a lot."
- "Attending social events is always draining. Energy levels are always low."
- "They have only ever known me as being sick. I think I am on the transplant list. I don't feel certain about getting one or I am too old for one."

- “It can be hard explaining to the rest of the family why I am not always at family gatherings. I get frustrated and tired when I have to justify my illness. Most of them understand, but not all do.”
- Patients recommended providing increased access to AHW’s, patient navigators or preceptors to assist better navigate social and health systems and adapt to a changed lifestyle living with kidney disease.
- Increase access to culturally appropriate allied healthcare services including mental health support.

“Since I moved here I started doing home training so I can dialyse at home. That way I get to spend more time with my son and have better quality of life.”

Family Burden and Family Support

“Don’t have the capacity to work anymore. My daughter helps me a lot. She keeps me company, but I also feel like a burden on her. She needs to live her own life and not worry about me. It makes me sad.”

Participants indicated that living with kidney disease restricts many aspects of life where everything is “turned upside down”. There are social, emotional, physical and financial impacts including the isolation and being away from home, country and culture. Quality of life is compromised for all involved including the family.

- “Time with the family is really affected.”
- “It was hard for everyone to accept at first, but we have just got on with life.”
- “Reduced capacity to work and financially impacted.”
- “Affect’s the whole family, especially when there are young children involved.”
- Participants recommended additional support for patient’s close family members to reduce family breakdowns and reduce associated stress and burden.

“I always feel drained and its hard explaining to family and getting them to understand why. They think just because I’m on dialysis I’m alright.”

8. Dissemination

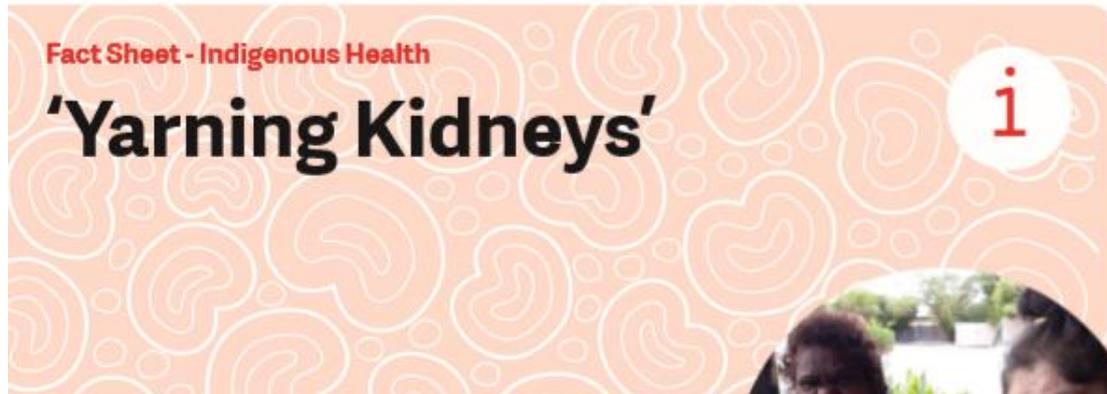
Key participants and AHW's who attended the consultation read the report and provided feedback.

This report was approved to be disseminated to:

- The Kidney Health Australia Yarning Kidneys Advisory Group
- The KHA-CARI Guidelines Writing Group
- The AIATSIS Ethics Committee
- Princess Alexandra Hospital Renal Ward, Renal Champions
- Kidney Health Australia Website
- 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 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.