

October 2020

Executive Summary 'Yarning Kidneys' Community Consultations

Community Consultations to Inform the Development of the CARI (Caring for Australian and New Zealanders with Kidney Impairment) Guidelines for Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islander Peoples



Front Cover Artwork

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

This artwork was created specifically for the community consultations and research project and has been used across a number of Yarning Kidneys consultation reports with her permission.

'My Kidney Journey' - Inawinytji Williamson

"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."

The Honourable Ken Wyatt AM, MP, former Minister for Aged Care and Indigenous Health and Mr Chris Forbes, Chief Executive Officer Kidney Health Australia receiving the first Yarning Kidneys Adelaide Report before attending the Perth community consultation event.



Background

In 2018, the Honourable Ken Wyatt AM, MP, former Minister for Aged Care and Indigenous Health, awarded a grant to Kidney Health Australia (KHA), as the peak consumer organisation for people living with kidney disease, to conduct consultation with Aboriginal health experts, consumers, community members, service providers and peak bodies around Australia to ensure the planned CARI Guidelines for Management of Chronic Kidney Disease (CKD) for Aboriginal and Torres Strait Islander peoples.

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

- the focus and content of the proposed CARI clinical guidelines and ensure they are aligned with community needs and preferences
- the opportunities for translation of the new clinical guidelines into culturally-appropriate and useful community information, clinical tools and education materials.

These consultation findings were designed to acknowledge and complement decades of activities by many others across Australia in the area of Indigenous Kidney Health research and community engagement and the “Catching some AIR” Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease consultation project conducted in the Northern Territory by Menzies School of Health Research and the Lowitja Institute.¹

The over-arching principles and methodology for these consultations “A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease.”² was 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.

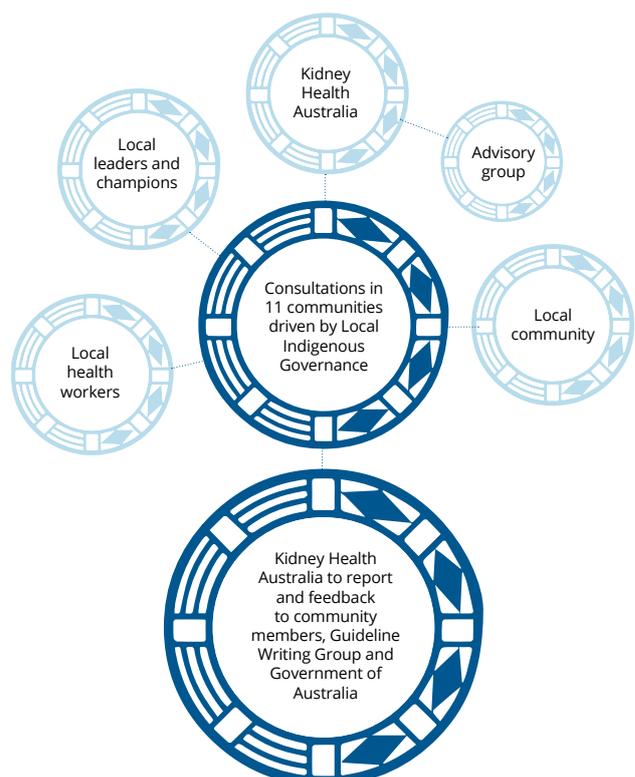
In March 2019, Kidney Health Australia delivered the “Expert Clinician Panel Consultation Report”³ which is a companion document to this report. It outlines the results of consultation with health care professionals across Australia from a broad range of disciplines, and recommendations for Guidelines scope, content and barriers / facilitators to implementation.

Yarning Kidneys Methodology

The approach was one in which Kidney Health Australia worked with local Aboriginal leaders and kidney health champions to co-facilitate each Yarning. This included explain the purpose of the project, determine a culturally safe and inclusive approach, develop the format and select a preferred venue, identify local preferences for participant invitation, and conduct the “Yarning Kidneys” community consultations in accordance with community wishes. Approvals from the relevant Aboriginal Ethics Committees in each jurisdiction were obtained.

A report was written for each of the 11 yarning kidneys sites containing key statements, themes and recommendations by community members along with a full representation of each of the Yarning Kidneys community consultation process. These were finalised with involvement of local contacts/co-facilitators and feedback from participants and authorised for distribution and use.

To access the Yarning Kidneys Community Consultation Reports and the Expert Clinician Panel Consultation Report please visit <https://kidney.org.au/get-involved/advocacy/aboriginal-and-torres-strait-islander-peoples-1>



Impact of Bushfires December 2019 and the Coronavirus Pandemic March 2020

Consultations were originally planned to include perspectives from 16-18 metropolitan and regional sites in all states and territories (other than NT where consultations were led by the Catching Some Air Project team). However, the impact of bushfires and the coronavirus pandemic significantly delayed and restricted the ability of communities to participate and for face-to-face Yarning Kidneys consultations to occur safely. Ultimately eleven jurisdictions were consulted in the time frame of the project grant. Dubbo and Brisbane consultations were conducted entirely by telephone. Proposed additional sites for consultation included Hobart, Melbourne, Canberra, Orange, Broken Hill and Western Sydney. Ongoing consultation will continue with communities in the next stage of the Guidelines development project.

Yarning Kidneys Information Sharing and Promotion

An essential component of this community consultation and engagement process was the involvement of peak and local indigenous, community and renal care health organisations.

Consultations have been guided by local Indigenous Reference Groups along with local Renal Clinics and Health Services providing leadership in each step of the process, from the community consultation organisation to the writing, review and authorisation for distribution and use of the reports.

The Yarning Kidneys community consultations and CARI Guidelines were also promoted and information shared in various key stakeholder meetings, forums and conferences and media including the following examples:

- Internationally within a [World Kidney Day article](#)
- Nationally within the [Australian Indigenous Kidney Health Bulletin](#)
- Local media about the consultations included the ABC Kimberly, [Broome](#), West Coast Sentinel, [Ceduna](#) and The Transcontinental, [Port Augusta](#).

Click here for further information on these activities
<https://kidney.org.au/get-involved/advocacy/aboriginal-and-torres-strait-islander-peoples-1>



Note: Consent to use photographs was obtained from each participant.

Acknowledgements

Participants:

Our greatest acknowledgement and thanks goes to all the patients, family members and carers who participated in the Yarning Kidneys community consultations. We thank them for their considered and honest input and commentary throughout this process including permission to utilise some film footage, pictures, artwork and personal comments within the final reports and outcomes.

Local Leaders, Organisations and Reference Groups:

We also acknowledge and thank the main organisations, local Aboriginal reference groups, elders and community leaders, and health professional champions who supported this initiative, helped with promotion and recruiting participants along with coordinating the consultations. The main organisations and reference groups for each site are highlighted below.

South Australian sites including Adelaide, Port Augusta and Ceduna:

aKction Research Group and Aboriginal Reference Group, South Australian Health – Central Adelaide Local Health Network and Country Health, Central and Northern Adelaide Renal and Transplantation Service, Royal Adelaide Hospital, South Australian Health and Medical Research Institute, Aboriginal Chronic Disease Consortium, University of Adelaide, Kanggawodli Aboriginal Hostel, Nunkuwarrin Yunti of South Australia, Wonggangga Turtpondi Aboriginal Primary Health Care, Pika Wiya Health Service, Port Augusta Dialysis Unit, Ceduna District Health Service and Koonibba Health Service.

Western Australian sites including Perth, Kalgoorlie and Broome:

Aboriginal Health Council of Western Australia, Derbarl Yerrigan Health Service Aboriginal Corporation, Minister Ken Wyatt, former Minister for Indigenous Health, Bega Garbiringu Health Services, Kalgoorlie Renal Unit, Kimberley Renal Services and Kimberley Aboriginal Medical Services Ltd.

Queensland sites including Mount Isa, Cairns – Yarrabah and Brisbane:

North West Hospital and Health Service, North Queensland Primary Health Network, Apunipima Cape York Health Council, Northern Queensland Primary Health Network, Princess Alexandra Hospital and Metro South Health, Queensland.

New South Wales sites including Lismore and Dubbo:

Bulgarr Ngaru Medical Aboriginal Corporation Richmond Valley and Clarence Valley, National Indigenous Kidney Transplantation Taskforce and Dubbo Health Service.

KHA Yarning Kidneys Advisory Group and Project Team:

A Project Team was engaged by Kidney Health Australia and an Advisory Group 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.

The Project Team included:

- Associate Professor Shilpa Jesudason, Kidney Health Australia Clinical Director, SA
- Dr Lisa Murphy, Kidney Health Australia General Manager Prevention and Advocacy, VIC
- Ms Dora Oliva (Oct 2018 – Oct 2019), Ms Kimberly Taylor (Nov 2019 – June 2020), Mr Stephen Cornish (July 2020 – Sept 2020), Kidney Health Australia Project Managers, SA

Advisory Group members included:

- Professor Alan Cass, Menzies School of Health Research, NT
- Dr Janet Kelly, University of Adelaide, SA
- Associate Professor Jaquelyne Hughes, Menzies School of Health Research, NT
- Ms Jess Styles, National Aboriginal Community Controlled Health Organisation (NACCHO), ACT
- Dr Martin Howell, CARI Guidelines, NSW
- Dr Odette Pearson, South Australian Health and Medical Research Institute (SAHMRI), SA
- Ms Rochelle Pitt, Metro South Health, QLD
- Professor Suetonia Palmer, Chair CARI Guidelines Group, NZ
- Associate Professor Shilpa Jesudason, Advisory Group Chairperson, SA

Ethical considerations and approvals

Kidney Health Australia sought and received ethical consideration and approval for all sites from the:

- Aboriginal Health Research Ethics Committee of South Australia;
- Western Australian Aboriginal Health Ethics Committee;
- Aboriginal Health and Medical Research Council Ethics Committee;
- Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee.

Funding:

Kidney Health Australia acknowledges the contribution from the Government of Australia Department of Health for the generous funding provided to develop these community consultations (Grant Number: 4-8HOGOW8).

Common Themes, Priorities and Recommendations

Each community had specific comments and recommendations relevant to their services and location. The following list does not encompass all recommendations or community feedback. Further details can be found in the full reports that have been approved for public release and contain a wealth of important commentary from community members.

Involve and Engage Community in Key Activities



- Guidelines development, dissemination and implementation
- Education and awareness raising programs
- Peer support networks and Patient Navigator Programs
- Workforce planning and delivery
- Cultural awareness activities
- Empower and strengthen community to facilitate participation

*"We have to stop this dependence on other people to solve problems. People need to be empowered."
(Aboriginal participant)*

Promote Prevention and Education Strategies for Better Health



- Innovative and community-driven education
- Engage Elders and local kidney champions
- Educate children, youth and pregnant women
- Communicate through videos, storytelling, music, arts
- Empower communities to make decisions about healthy lifestyles
- Educate about healthy diet and accessing food on budget

*"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."
(Aboriginal participant)*

Promote and Focus on Early Detection of Kidney Disease



- Kidney patients to encourage family and communities to kidney check
- Provide incentives to encourage kidney checks
- Implement strategies to inform that kidney disease can be prevented
- Develop strategies to dispel the fear of kidney disease

*"There needs to be more Kidney resources and information the same as they do for heart health and diabetes"
(Aboriginal participant)*

Address the Burden of Kidney Failure Treatment



- Strategies to assist patients avoid relocation from Country
- Kidney care in rural and remote communities
- Training for home-dialysis on Country
- Better coordination to reduce multiple appointments
- Include kidney disease management as part of other chronic disease care
- Improve kidney clinic facilities to be engaging, welcoming and culturally-safe

*"It's difficult to keep our spirits up without spending time on country and with our family and loved ones"
(Aboriginal participant)*

Focus on Support for Patients and Families



- Provide affordable and culturally-safe accommodation
- Provide reliable transport services to help people access care
- Reduce associated financial burdens
- Provide social, emotional and spiritual support for kidney patients and carers
- Encourage patient group activities and sharing experiences

*"It's life changing being on dialysis, you have no life, it takes over everything."
(Aboriginal participant)*

Support Patients to Access Transplantation



- Increase kidney transplantation access for Aboriginal and Torres Strait Islander peoples
- Deliver culturally appropriate education on pre and post-transplantation care.
- Involve family and carers in the work-up process

*"It needs to go further than education – advocacy from the people caring for us is so important. Not just from the visiting nephrologists, but from local GP's 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)*

Develop a Sustainable and Appropriate Workforce



- Employ Aboriginal and Torres Strait Islander peoples who are experienced kidney patients as navigators, mentors or preceptors to assist with educating and providing support to others.
- Increase the number of Aboriginal Health Workers delivering haemodialysis.
- Employ adequate numbers of male and female Aboriginal Health Workers to address cultural sensitivities working with Aboriginal and Torres Strait Islander men and women.
- Ensure continuity of care and stable workforce for Aboriginal and Torres Strait Islander kidney patients

"The chopping and changing of health care providers is really problematic, because when they start in community it takes them a long time to establish trust and familiarise themselves with the problems." (Aboriginal participant)

There is need for specialised Aboriginal Health Worker workforce in kidney disease." (Aboriginal participant)

Improve Cultural Awareness within Health Services and Staff



- Implement a comprehensive and ongoing cultural awareness training program within the healthcare system.
- Cultural training should include local Indigenous history, customs, connections with land and family, lore, language and the status of health and wellbeing at the grass-roots level.
- Create opportunities for community to interact and share stories with healthcare professionals.
- Understand community roles and responsibilities and adjust care based on needs

There should be cultural awareness training in hospitals – not once, but constant training at the workplace, on an ongoing basis." (Aboriginal participant)

Promote Strategies to Minimise Communication Barriers



- Improve use of interpreters to help kidney patients understand their condition and treatments
- Use plain language during appointments and dialysis sessions
- Provide information and straight forward, easy to remember messages on caring for kidneys and CKD management.
- Use visual resources in appropriate languages to aid information delivery

"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." (Aboriginal participant)

Advocate for Better Government Support for Kidney Patients



- Increase funding for kidney health
- Implement a funding scheme to support kidney patients who perform home dialysis
- Support financially family members caring for kidney patients
- Coordinate further opportunities to provide input and feedback

"Primary health services should be doing a lot more home visits and being aggressive to slow kidney failure progression down and be doing more kidney health early prevention programs as Indigenous people are at risk." (Aboriginal participant)

Ensure Completion and Implementation of Meaningful Guidelines



- Involve patients in the writing process
- Share draft guidelines for feedback from community
- Guidelines should be completed and be designed to achieve change
- Ensure Guidelines are holistic and address chronic diseases together

"Really hope something happens with these guidelines. Nothing has changed." (Aboriginal participant)

The Next Steps

In June 2020 Kidney Health Australia was awarded further Federal funding investment to support the writing and dissemination of the CARI Guidelines (Grant Number: GO3133).

"Since 2018, we have conducted consultations with Aboriginal and Torres Strait Islander communities around Australia to develop a framework for evidence-based guidelines that are specific to the management of kidney disease within their communities, and will deliver better health outcomes.

The Federal Government funding enables us to deliver what the community has clearly told us is long-overdue - meaningful and appropriate clinical guidelines that are aligned with First Nations' community preferences and needs."
Chris Forbes CEO Kidney Health Australia

The CARI Guidelines writing group will conduct this process. Community engagement and Indigenous leadership will be embedded at all stages of Guidelines development.

Future steps over the next two years include:

Scientific processes for synthesis of evidence and guidelines writing

- 1 Production of 8-10 new evidence-based Guidelines
- 2 Review and feedback on Draft guidelines
- 3 Development of Consumer versions of Guidelines in collaboration with community
- 4 Delivery of final Consumer and Health Professional Guidelines

Production of final guidelines and supporting content

- 5 Translation of Guidelines into selected languages
- 6 Development of Consumer Guidelines into appropriate formats (written, video, digital, other) to facilitate use
- 7 Development of Health Professional guidelines in user-friendly formats (written, video, digital, other) to facilitate use

Implementation of Guidelines across community and health services

- 8 Dissemination of Guidelines and Resources to Community organisations
- 9 Dissemination of Guidelines and Resources via NACCHO, Health Services, Professional Societies, Peak Bodies and other professional channels
- 10 Dissemination of Guidelines to State and Local Hospital Clinical Pathways
- 11 Promotion of Health practitioner awareness and education by local community clinical leads and champions, AIDA, CATSINaM, ANZSN, RSA, RACGP, PHNs, Kidney Health Australia, and other educational organizations
- 12 Incorporation of Guidelines content into all Kidney Health Australia Primary Care Education modules, fact-sheets, digital content and other resources

| Further information about this project please contact careteam@kidney.org.au

Abbreviations

AIDA	Australian Indigenous Doctors Association
ALO	Aboriginal Liaison Officer
AMSANT	Aboriginal Medical Services Alliance Northern Territory
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
ANZSN	Australian and New Zealand Society of Nephrology
ATSI	Australian and Torres Strait Islander
CARI	Caring for Australians and New Zealanders with Renal Impairment
CATSINaM	Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
CKD	Chronic kidney disease
DNT	Dialysis, Transplantation and Nephrology
ESKD	End stage kidney disease
KHA	Kidney Health Australia
NACCHO	National Aboriginal Community Controlled Health Organisation
NIKTT	National Indigenous Kidney Transplantation Taskforce
PHN	Primary Health Network
RACGP	Royal Australian College of General Practitioners
RSA	Renal Society of Australasia

References

- 1 <https://www.lowitja.org.au/page/research/research-categories/science-and-health-conditions/health-conditions/projects/catching-some-air>
- 2 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
- 3 Jesudason S, Oliva D, Barfoot K, Stoic J. (2019). Expert Clinician Panel Report for the KHA-CARI Guidelines for the Management of Chronic Kidney Disease among Aboriginal and Torres Strait Islander Peoples. <https://kidney.org.au/uploads/resources/expert-clinician-panel-consultation-report.pdf>

Disclaimer

The recommendations contained in this report were formed from feedback obtained through consultation with expert, community-based health practitioners from metropolitan, rural and remote regions, who were actively involved in clinical care delivery for kidney disease, and primary health care professionals. 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.

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