

Indigenous 'Yarning Kidneys'

Report: Kalgoorlie Consultation

23 July 2019

Consultation meeting to inform the development of the new Guidelines for Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islander Peoples



Photo: Reproduced with permission. Participants of the Yarning Kidneys Consultation at Bega Gambirringu Health Services

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Please be aware that this report refers to feedback from and may contain the images and names of Aboriginal and Torres Strait Islander participants who may have since passed away.

1. Acknowledgement

1.1. Bega Garnbirringu Health Service

Kidney Health Australia acknowledge the valuable contribution of Bega Garnbirringu Health Services Aboriginal Corporation for organising, promoting and hosting the Kalgoorlie community consultation.

Special acknowledgement to Bega's team members: Ms Hilda Woolridge and Ms Carol Escudero for their assistance in the planning and implementation of the session, and Ms Irene Saunders for her guidance to ensure the consultation happened in a culturally safe way, and promoting the event with community members.

1.2. Clinical Champions and Local Leaders

The following clinical champions and local leaders are specially acknowledged for their leadership in helping facilitate the consultation, and contribution in the analysis and writing of this report (alphabetical order):

- Ms Fiona Norman
- Irene Saunders
- Ms Kerry Griffiths
- Ms Kim Tracey

1.3. 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
- Dr Janet Kelly, University of Adelaide
- Dr Jaquelyne Hughes, Menzies School of Health Research

- Ms Jess Styles, National Aboriginal Community Controlled Health Organisation (NACCHO)
- Dr Martin Howell, KHA-CARI Office
- Dr Odette Pearson, South Australian Health and Medical Research Institute (SAHMRI)
- Ms Rochelle Pitt, Metro South Health
- Professor Suetonia Palmer, KHA-CARI Office

1.4. Funding

Kidney Health Australia acknowledge the contribution from the Government of Australia for the generous funding provided to develop 16 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 Kalgoorlie 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

TIS – Tackling Indigenous Smoking

WAAHEC – Western Australian Aboriginal Health Ethics Committee

WDKH - Western Desert Kidney Health

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 Western Australian 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 guideline for the Management of CKD among 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.

As part of the consultation process, community consultations occurred in Adelaide, Port Augusta, Ceduna and Perth from December 2018 to June 2019.

Communities in Darwin, Alice Springs and Thursday Island were involved in similar community consultations through the Catching Some Air Project; and therefore, these sites won't be included in the Yarning Kidneys initiative.

4. Ethical Considerations

Kidney Health Australia made the necessary enquiries to the Western Australian Aboriginal Health Ethics Committee (WAAHEC) to ensure the consultations implemented in Western Australia comply with all ethical considerations.

Recognising that the 'Yarning Kidneys' consultation isn't a research project, the WAAHEC provided waiver of ethics for the consultations implemented in Perth, Kalgoorlie and Broome. As a result, a copy of this report will be submitted to the WAAHEC.

5. Community Engagement and Participants

Nine Aboriginal community members attended the consultation conducted on 23 July 2019, representing a mix of patients with CKD, diabetes and heart diseases. Family members, carers, Aboriginal health workers and community members with an interest in chronic diseases also attended the meeting.

Participants were invited by Bega Garnbirringu Health Service Aboriginal Corporation. Event flyers were visible in waiting rooms and clinics to encourage community members to attend the session.

Ms Irene Saunders, Tackling Indigenous Smoking (TIS) Project Officer, assisted with the promotion of the event by personally inviting TIS clients and community members who are experiencing chronic diseases. Aboriginal hostels were informed about the event and helped inviting their clients to attend the yarning session.

Participants

Patients, carers and community members (alphabetical order):

1. Mr Andrew Hughes
2. Mr Dale Graham
3. Mr Dwayne Morrison
4. Ms Donna McGuinness
5. Ms Jonelle Champion
6. Mr Seth Way
7. Mr Stephenson
8. Mr Tony Ugle
9. Michael McGuinness

Clinical champions, community leaders and organisers (alphabetical order):

1. Ms Carol Escudero
2. Ms Dora Oliva
3. Ms Fiona Norman
4. Ms Hilda Woolrich
5. Ms Kerry Griffith



6. Format

The yarning session initiated with an Acknowledgement of Country delivered by Mr David Humphries followed by an explanation of the purpose of the session by Ms Dora Oliva on behalf of Kidney Health Australia. Participants agreed that their feedback is presented to the Group that is writing the Guidelines for Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islander Peoples to help develop these new Guidelines.

The session was co-facilitated by Ms Irene Saunders, Ms Kelly Griffith, Ms Fiona Norman and Ms Dora Oliva, all who encouraged participants to discuss a set of pre-established questions validated in previous consultations. Lunch was provided after the consultation.

The session concluded with participants' approval of the use of the group photo for the consultation report.

7. Yarning Kidneys

7.1. Our experience with Kidney Disease

In addition to the multiple symptoms and discomfort experienced by renal patients, having to relocate to access treatment was the most significant challenge they experienced when they were diagnosed with kidney disease.

Relocation represents a massive challenge for rural and remote renal patients from Kalgoorlie, who relocated to Perth for an undefined time to have the fistula procedure, attend training and access treatment.

'Going to Perth to get the fistula done, then getting pumped up. Luckily I had family support in Perth' (Aboriginal patient).

Some people stay in hostel for several months. I had to travel from Joondalup (where I lived) to Fiona Stanley Hospital and good that I had taxi vouchers, because it is a long way and very expensive (Aboriginal patient).

Go to Perth for fistula and wait for a dialysis chair available in our communities. Get pumped and hopefully be back home one day (Aboriginal patient).

Disconnection from Country and family, financial stress, challenges associated with finding proper accommodation and transportation to get to appointments, the lack of understanding of the severity of the condition, and uncertainty about the future was particularly stressful for patients, who indicated these negatively affected their emotional and spiritual wellbeing.

Participants agreed that it is crucial to have family members travelling with them when they need to relocate to Perth for treatment.

Recommendation

1. Ensure culturally appropriate accommodation is provided in Perth for renal patients relocating from The Goldfields to access renal treatment.

7.2. Kidney Disease isn't a Death Sentence

Participants collectively agreed that kidney disease is not a 'death sentence', however, stated that community members in Kalgoorlie often think it is because of all the disruptions that kidney disease cause in patients' lifestyle, work and community commitments. Kidney patients can still work and do things that healthy people do if they receive proper and timely treatment and look after themselves.

In the view of the participants, culturally safe education in the first language is required to change the misconception that kidney disease is a 'death sentence' and to raise awareness about flexible treatment options that enable patients to continue with their life as close to normal as possible.

Participants agreed that some patients have never had the opportunity to have input in their treatment. While doctors and nurses often explain treatments, language barriers and medical jargon, difficult communication. Participants suggested to produce localised videos to explain different treatments, which will enable patients to make an informed decision about their care plan.

Recommendation

2. Develop videos about renal treatment options so that patients can decide what treatment is best and have input in their care plan.

7.3. Considerations about Peritoneal Dialysis

While peritoneal dialysis is a flexible treatment that allows patients to continue with their life as close to normal as possible, it is difficult for patients to attend training in Perth. Participants suggested that the one-week training should be conducted in Kalgoorlie.

While peritoneal dialysis is a flexible option, some participants commented that there is constant fear about this treatment as a result of community members in The Goldfields region who passed away due to infections.

There is a lot of fear about the bag – I have seen many Indigenous renal patients passing away because of infections (Aboriginal patient).

We realise hygiene is important and more education is needed to understand how to care for the bag and avoid infections and death. (Aboriginal community member).

The bag is a flexible option. The advantage of the bag is that it allows patients to be in the community and attend funerals, which is a big thing here in our communities' (Aboriginal community member).

Participants agreed that culturally safe education delivered by local Aboriginal health workers and Aboriginal educators to explain the flexibility of peritoneal dialysis and the hygiene required to avoid infections would help reduce concerns about this treatment and will increase use by patients in The Goldfields.

In the view of the participants, if patients using the bag share their stories, other patients will understand how to care for it and dispel fear.

Recommendations

1. Deliver culturally-safe and ongoing education by Aboriginal health workers and Aboriginal educators about peritoneal dialysis care to avoid infections.
2. Dispel fear about peritoneal dialysis and association with infections and death by sharing success stories of Aboriginal renal patients using this treatment.
3. Train and support local health professionals in Kalgoorlie to deliver one-week training on peritoneal dialysis, so that new patients can remain on Country.

7.4. Considerations about Haemodialysis:

Participants stated that renal patients are frequently concerned about having to relocate to Perth to access treatment due to limited haemodialysis services. Participants agreed that the health system must increase haemodialysis services in regional, remote and very remote communities in The Goldfields region.

Some communities in The Goldfields only have two haemodialysis machines, while others do not provide renal treatment at all.

The lack of renal services in rural and remote locations force patients to travel to Kalgoorlie; and in the worst cases, relocate indefinitely to Perth until a spot for haemodialysis treatment becomes available. Relocation, as well as the shock and uncertainty of being diagnosed with ESKD negatively impacts spiritual, emotional and social wellbeing because of disconnection from Country, community and family.

'Haemodialysis treatment should also be provided in Norseman, Laverton and Leonora' (Aboriginal patient).

'Get a truck for us in our own place – a dialysis truck' (Aboriginal participant).

The work of the Purple House is well known and praised by community members. Participants raised concerns about the Purple Truck not coming to their communities. Attendees suggested there should be mobile dialysis in The Goldfields to allow patients from regional and remote communities to return to their Country and spend time with family and community.

Recommendation

1. Increase the delivery of haemodialysis treatment in rural, remote and very remote communities of The Goldfields, so that renal patients can stay on Country.

7.5. Considerations about Transplantation

Attendees are aware that there are quite a few people in The Goldfields that have a transplant, but they do not share their experience with others. These patients prefer to focus their efforts on keeping healthy and looking after themselves.

In the view of the participants, people who have a kidney transplant may feel shy and do not want to speak about their journey with other patients because they may feel guilty that other people are not able to have a transplant.

It is a bit embarrassing to speak about your kidney transplant when other patients ask you – how come I never get it? (Aboriginal participant).
It is hard to explain to other patients that you have to be fit, young and healthy. People may get a bit angry and jealous and wonder how come I don't get a transplant? (Aboriginal participant).

Participants who have a kidney transplant stated that it is essential to be a non-drinker, non-smoker, eat healthy, attend appointments and take tablets regularly to get into the transplantation waiting list and suggested there should be additional support provided to the Aboriginal patients who want to have a transplant.

One of the participants mentioned his transplant journey and how important it was having his family with him while in Perth waiting to be transplanted.

'I had my mum and sisters ringing me – all family were supporting me, but some mob don't have the same support in Perth. It is difficult to get into the waiting list and more support should be provided' (Aboriginal participant).

Individual and culturally appropriate support should be given to help patients understand the criteria they need to meet and to achieve lifestyle changes to be eligible for a kidney transplant.

Participants acknowledged the critical support from family, community and patients who have gone through that journey to help new patients being in the right path and behaviours to get into the transplantation waiting list.

'Andrew could help new patients to understand treatment options and the journey to get a transplant' (Aboriginal participant).

Recommendations

1. Implement a peer support system to help renal patients to understand the steps they need to follow to meet all the criteria required to be eligible for a kidney transplant.
2. Develop culturally-safe videos about transplant featuring patients who have gone through the kidney transplantation journey.

7.6. Western Desert Kidney Health project (WDKH)

Participants mentioned the health promotion truck that travelled to remote communities in The Goldfields as part of the WDKH project, which implemented Aboriginal artwork to teach young kids about chronic diseases.

'Andrew was part of this campaign. They used art, visual kidneys to educate communities, and carried out health checks' (Aboriginal participant).

Community leaders with lived experience of chronic disease delivered education. One of the participants, who has a kidney transplant, mentioned his involvement in this initiative, delivering CKD education through art in ten communities of The Goldfields. The campaign aimed to prevent chronic diseases by raising awareness about healthy lifestyles, including healthy eating, physical activity and promoted health checks.

Attendees expressed their disappointment and frustration with the discontinuation of the funding and agreed that there is a greater need for culturally appropriate initiatives, such as the WDKH project to be continued and adequately funded in The Goldfields.

Reinstating the funding for the program implemented by Dr Christine Jeffries-Stokes was strongly recommended by participants.

Recommendations

1. Reinstatement and properly fund the WDKH project in The Goldfields to prevent chronic diseases, driven by community leaders with lived experience of chronic disease.
2. Utilise and promote the resources of the WDKH project to prevent CKD in Western Australia.

7.7. Education

Participants agreed that schools are crucial to raise awareness about health. Schools must deliver education about healthy lifestyles to prevent chronic diseases, including kidney

health. Education about kidney disease should consist of what is the function of the kidneys using visual organs representing good and bad kidneys, discuss what causes a kidney to fail and how to prevent kidney disease.

'In the WDKH, we used artists and art to paint good and bad kidneys and talk about how to care for kidneys' (Aboriginal participant).

Participants agreed that children and youth education would have a positive impact on Aboriginal families, as children usually share information with parents and siblings.

'Education about kidneys should start with the young ones, schools, start at primary school' (Aboriginal participant).

'Educating children will also impact adults – children are usually good teachers to their parents and other family members' (Aboriginal participant).

Participants agreed that education is better accepted if it comes from their community leaders; and therefore, localised campaign is more effective than a national campaign.

More Aboriginal educators in The Goldfields are needed to deliver culturally safe health education in first language, especially around chronic diseases and CKD. Renal patients are encouraged to take an active role and help to educate community members about how to care for their kidneys and how to slow progression of ESKD.

'Renal patients can be good educators – we would like to see Andrew doing this job again' (Aboriginal participant).

'There is need for educating community about lifestyles and the stages of CKD, so that we can understand that progression of kidney disease can be slowed' (Aboriginal participant).

'Our people should be talking 'facts' rather than what has been handed out' (Aboriginal participant).

In the view of the participants, videos are the best way to communicate health messages.

'Five minute videos about: where are your kidneys, risk factors, how to look after your kidneys with local people and patients would be good' (Aboriginal participant).

The media plays a vital role in raising awareness about healthy lifestyles to prevent chronic diseases, including chronic kidney disease.

'Podcast ABC has been a popular way to communicate health messages and is well received by community members' (Aboriginal participant).

Participants also mentioned the example of the Tackling Indigenous Smoking that implements both television and radio campaign, and localised interventions. One of the participants shared her experience in delivering tackling Indigenous smoking education to target children and prisoners, which has been hugely successful. Participants agreed that its success is associated with involving schools, positive role models and community leaders.

Education in prisons should include awareness about kidney disease. Unfortunately, the majority of prisoners are from Aboriginal background; and therefore, kidney education in this setting is essential, especially among pregnant women.

Recommendations

1. Learn from the Tackling Indigenous Smoking model that implements a comprehensive approach to reduce smoking, including community-driven interventions.
2. Implement localised CKD education in schools, prisons and other community settings, in partnership with local Aboriginal Medical Service, community leaders and positive role models.
3. Raise awareness about kidney health through videos and working with the media to raise awareness about healthy lifestyles.

7.8. Early Detection

Attendees discussed barriers experienced in rural and remote areas where there are not laboratories for the blood and urine tests to be processed promptly. Point of care was recommended to improve early detection of CKD in rural, remote and very remote communities of The Goldfields.

Health services in remote communities rely on a plane to transport blood and other samples, which occurs once a week. Therefore, more frequent visits from Aboriginal Medical Services are recommended to improve early detection in these communities.

Participants mentioned incentives as a way to encourage community members to conduct kidney checks. In remote and very remote communities, a voucher for the local shop to be drawn from the pool of entries who attended a health check can be an incentive.

In the views of the participants, this intervention isn't expensive, since a voucher of \$100 can be a good incentive, and can generate significant impact in increasing early detection of kidney disease.

Recommendations

1. Support Aboriginal Medical Services to increase early detection of kidney disease and implement point of care to process kidney checks in rural, remote and very remote communities.
2. Consider the use of incentives to increase early detection of CKD.

7.9. Closing the Gap Program

Participants stated that for programs to be effective in achieving change and positive impact, they should be consistently and adequately funded and community-driven.

Due to the loss of Closing the Gap funding, Aboriginal health workers and community leaders lost their jobs, which caused health organisations to lose key staff with essential knowledge and leadership.

'Good programs were discontinued due to the loss of funding' (Community leader).

'Closing the Gap Program should increase the funding in The Goldfields and must implement initiatives to prevent chronic kidney disease in this region' (Community leader).

7.10. Aboriginal Workforce

Participants suggested that community leaders who were employed by the Closing the Gap should be engaged to continue delivering local health campaigns.

There is also need to employ, train and support Aboriginal educators, as well as more Aboriginal Health workers and Liaison Officers specialised in renal health by the health system.

'There should be train the trainer on dialysis'. (Aboriginal participant).

Participants stated that Aboriginal Health Workers are often scared to work in renal health because they have seen family members passing away due to kidney disease. Representatives of the Renal Unit stated that there is a vacancy for a male Aboriginal Health Workers that hasn't been filled, which confirms that it is extremely difficult to engage Aboriginal workers to work in renal health.

'AHW don't last in the renal space because of fear' (Aboriginal participant).

Recommendation

1. Implement a strategy to recruit, support and retain Aboriginal workforce in renal health.

7.11. Cultural Awareness

Participants shared their personal experience dealing with racism in the health system. They stressed that ongoing cultural awareness should be routinely implemented in the health system.

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

'Some doctors speak to us like if we are 'dumb' (Aboriginal patient).

Recommendation

1. Implement ongoing cultural awareness training in the health system.

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 with:

- 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.

9. Appendix: Event flyer



In consultation with:



Indigenous Voices Yarning 'Kidney Health'

Tuesday, 23 July, from 10:00 am to 2:30 pm at

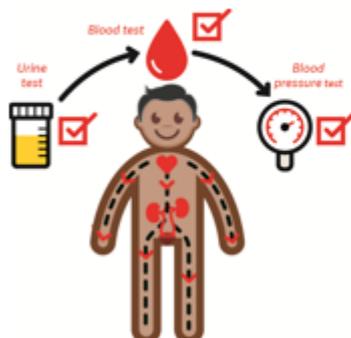
Clinical Board Room, Bega Garnbirringu Aboriginal Health Service,
16-18 MacDonald Street, Kalgoorlie.

Food, transportation and sitting fees will be provided.

Kidney Health Australia with support from Bega Garnbirringu Health Service invite you to attend the **Kalgoorlie '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, 18 July, 2019.** For more information call: Dora Oliva on 0406 809 712.

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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.