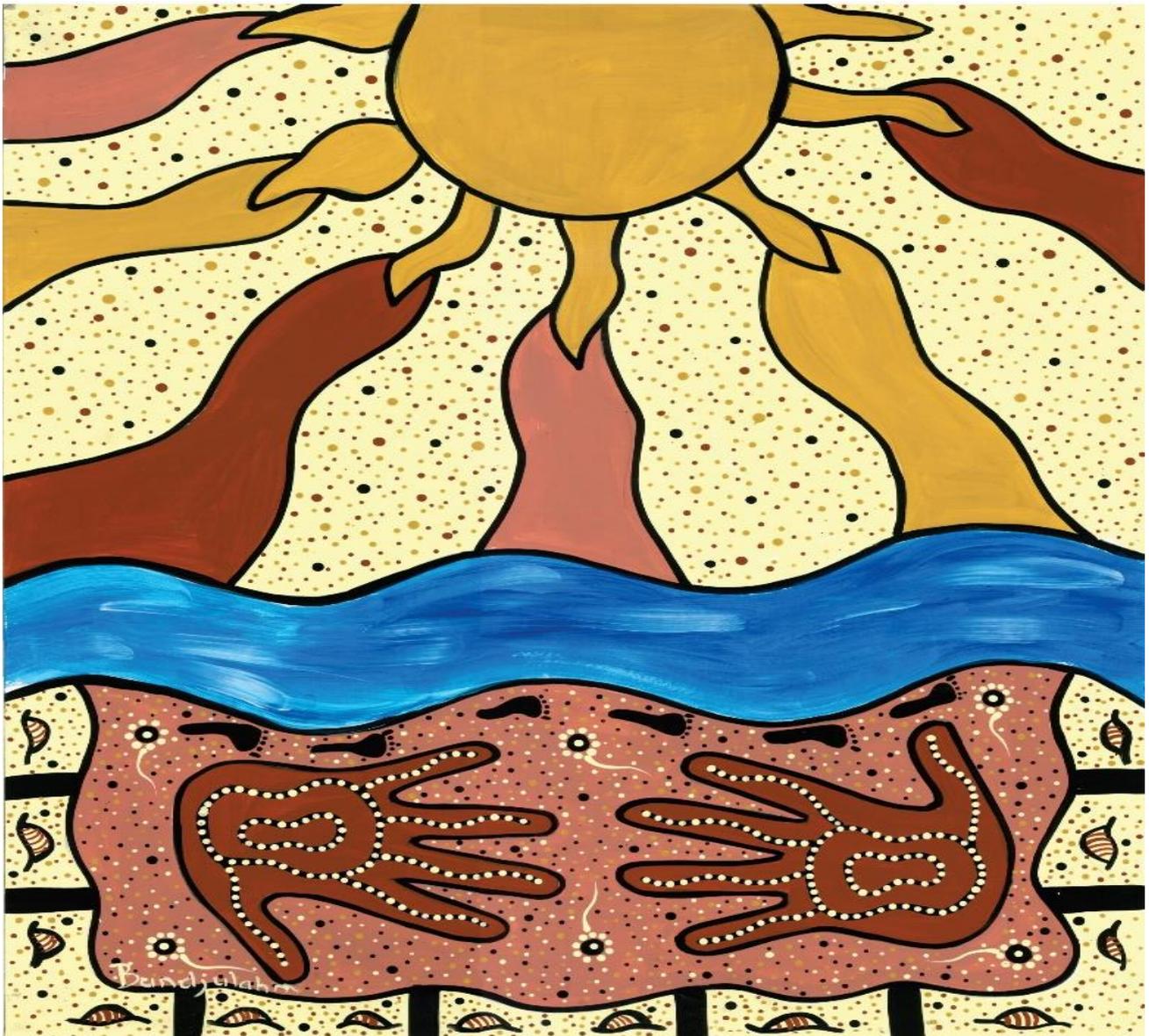


# 'Yarning Kidneys' Report

Lismore, Ballina & the Northern Rivers of NSW  
20th February 2020

Consultation meeting to inform the development of the Kidney Health Australia –  
Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines for  
Management of Chronic Kidney Disease for Aboriginal and Torres Strait Islanders



Artist: Patsy 'Bundjulahn' Nagus (Bundjalung Elder and renal patient: 1957-2014)

## Contents

|       |  |    |
|-------|--|----|
| 1.    | Acknowledgements .....   | 3  |
| 1.1.  | Bulgarr Ngaru Medical Aboriginal Corporation Richmond Valley .....               | 3  |
| 1.2.  | Kidney Health Australia Yarning Kidneys Advisory Group .....                     | 3  |
| 1.3.  | Funding .....  | 4  |
| 2.    | Abbreviations and Definitions .....  | 4  |
| 3.    | Background.....  | 5  |
| 4.    | Ethical Considerations.....  | 5  |
| 5.    | Community Engagement and Participants .....                                      | 6  |
| 6.    | Format.....  | 7  |
| 7.    | The Northern Rivers of NSW Aboriginal and Torres Strait Islander Community ..... | 8  |
| 8.    | KHA Yarning Kidneys – Outcomes, Key Themes and Recommendations .....             | 11 |
| 8.1.  | Re-addressing ongoing community recommendations .....                            | 12 |
| 8.2.  | Education, raising awareness and early detection.....                            | 12 |
| 8.3.  | Racism, discrimination and lack of understanding by clinicians .....             | 13 |
| 8.4.  | Health system issues and workforce .....   | 13 |
| 8.5.  | Communication / Miscommunication .....   | 14 |
| 8.6.  | Impacts on lifestyle and quality of life .....                                   | 14 |
| 8.7.  | Impact of being forced to leave community/country .....                          | 15 |
| 8.8.  | Impacts on social and emotional well-being (mental health).....                  | 15 |
| 9.    | Dissemination.....   | 16 |
| 10.   | Appendix.....  | 17 |
| 10.1. | KHA Yarning Kidneys Ballina & Northern Rivers Flyer .....                        | 17 |
| 10.2. | KHA Yarning Kidneys Community Consultation Questions .....                       | 18 |
| 10.3. | References .....   | 20 |
| 11.   | © Copyright.....   | 21 |
| 12.   | Disclaimer.....  | 21 |

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

# *1. Acknowledgements*

## *1.1. Bulgarr Ngaru Medical Aboriginal Corporation Richmond Valley*

Kidney Health Australia acknowledges and thanks Bundjalung Elders, and community members of who attended the Northern Rivers Kidney Yarn-up for their time and invaluable input into Kidney Health Australia's Community Consultation process.

Kidney Health Australia also thank Graeme Turner, Renal Nurse Practitioner with NSW Health and Dr Liz Rix for their enormous efforts in recruiting all the patients to the yarnings and getting the awareness out into the communities about the Kidney Yarnings consultation.

We would also like to again recognise and thank Dr Liz Rix who assisted in co-writing this report.

## *1.2. Kidney Health Australia 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*

**AHW** – Aboriginal Health Worker

**BNMACRV** – Bulgarr Ngaru Medical Aboriginal Corporation Richmond Valley

**CKD** – Chronic Kidney Disease

**ESKD** – End Stage Kidney Disease

**KHA** – Kidney Health Australia

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

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](#)<sup>1</sup> 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 Brisbane. A copy of this report will be submitted to the AH&MRC Ethics.

---

<sup>1</sup> 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*

Aboriginal and Torres Strait Islander community members attended the consultation conducted on February 20th, 2020 from Lismore, Ballina, Casino, Grafton and surrounding rural areas. Participants represented a mix of patients with CKD, diabetes and heart disease. Some of the CKD patients were receiving dialysis or had a kidney transplant. Family members, carers and community members with interest in chronic diseases also attended the meeting.

Several NSW health renal clinicians also attended. In addition, Ms Kelli Owen, Community Coordinator for the National Indigenous Kidney Transplantation Taskforce was invited to attend.

Participants were invited via NSW Health Renal Units and staff and Aboriginal Community Controlled Health Organisations. Event flyers were developed and placed visibly in waiting rooms and clinics to encourage community members to attend the session (see Appendix).

This project had the support of Bulgarr Ngaru Medical Aboriginal Corporation which is home to the Bulgarr Ngaru Medical Aboriginal Corporation Clarence Valley (BNMACCV) & the Bulgarr Ngaru Medical Aboriginal Corporation Richmond Valley (BNMACRV). These Aboriginal Medical Services (AMS) provide health services to the Aboriginal communities of Grafton & Casino areas as well as outreach clinics to Baryulgil, Malabugilmah, Yamba & Maclean, Coraki, Box Ridge, Tabulam & Muli Muli communities.

Transport was coordinated by local contact and KHA-CARI Guidelines Writing group member Dr Liz Rix to help assist patients in attending the yarning session along with being the main contact and local coordinator and facilitator.

### **Attendees of the Ballina and Northern Rivers NSW KHA Yarning Kidneys.**

| <b>Patients, Carers and Family Members</b> | <b>Local Leaders, Clinical Staff and Organisers</b> |
|--|---|
| Uncle Lewis Cook                           | Ms Kimberly Taylor                                  |
| Dwayne Fields                              | Ms Kelly Owen                                       |
| Earl Bostick                               | Dr Liz Rix  |
| Beverly Collins                            | Carl Daley  |
| Norah Caldwell                             | Mr Graeme Turner                                    |
| Sandra Williams                            | Kylie Wyndham                                       |
| Gail Turnbull                              | Ms Ro Stirling - Kelly                              |
|  | Erin Underhill                                      |

## *6. Format*

The yarning session was initiated with Welcome to Country delivered by local Elder Uncle Lewis Cook followed by a presentation about the purpose of the meeting by Dr Liz Rix and Kimberly Taylor.

The session was co-facilitated by Liz Rix and Kimberly Taylor. At the start of the session participants sat in a yarning circle and introduced themselves to one another. This gave community members the opportunity to become comfortable with the facilitators and the topic at hand to be discussed.

Participants were encouraged to base discussions around a set of pre-established questions (developed through previous Yarning consultations) regarding kidney care and other CKD related diseases (refer Appendix 10.2). This general discussion was not however limited to these questions and participants were encouraged to speak freely about these topics and the issues, challenges and impacts surrounding them. Notes were taken of participants responses during this session by the facilitators.

At the end of the Yarning kidneys session participants were informed that feedback from the session would be used to develop the consultation report and that this would contribute to and inform the broader national consultation process. All participants were thanked for their attendance and participation.



*Ballina and the Northern Rivers of New South Wales Yarning Kidneys*

## *7. The Northern Rivers of NSW Aboriginal and Torres Strait Islander Community*

In 2018 the Northern Rivers was selected as one of the sites for Consultation to inform the development of KHA-CARI for Aboriginal and Torres Strait Islander peoples. A number of family members of the original Community reference group established in 2010 by Dr Liz Rix attended the Yarning kidneys session in February 2020.

### *Discussion of outcomes from previous Yarnings held in the Northern Rivers Community*

Aboriginal and Torres Strait Islander Peoples make up only 3.2% of the population in the Northern Rivers of NSW. In 2011 however, 18% of patients with end stage renal disease requiring dialysis in the Northern Rivers region identified as Aboriginal and Torres Strait Islander Peoples. Around this time, local renal nurse Liz Rix began yarning with Aboriginal patients and Bundjalung Elders about the lack of culturally safe care and positive therapeutic relationships between renal staff and Aboriginal patients within mainstream renal services and dialysis units.

These yarns evolved into a formal doctoral research project aimed at improving renal service delivery and addressing institutional racism and lack of cultural safety within mainstream services for Aboriginal and Torres Strait Islander peoples. As part of that study a Community Reference Group was formed to guide Dr Rix culturally to ensure the voices of the Bundjalung Community were at the heart of her project. Members of that group included dialysis patients, family members, Bundjalung Elders and local Aboriginal health workers. Dr Rix gathered the perspectives of 18 Aboriginal and Torres Strait Islander dialysis recipients and 29 renal service providers.

The findings of this project centred on the urgent need to address institutional racism and increase the cultural competence of renal clinicians. There was found to be a lack of two way understanding and relationship building, with high levels of victim blaming of Aboriginal dialysis patients by some clinicians. A model of care where family, community and culture were placed at the centre of renal service delivery emerged from this study.

Five related publications described these findings in health and medical journals (refer Appendix 10.3) with the Community Reference Group reviewing and approving each paper prior to publication. Many of the findings, issues and associated recommendations

represented in these publications are still relevant a decade on from initial consultations and still require appropriate solutions and responses.

**These recommendations included:**

|    |   |
|----|---|
| 1. | <b>Screening for earlier detection and prevention</b>                           |
| 2. | <b>Flexible family focussed care</b>  |
| 3. | <b>An Aboriginal specific pre-dialysis pathway</b>                              |
| 4. | <b>Increased Home renal nurse support</b>                                       |
| 5. | <b>Cultural education of renal staff by patients, family members and Elders</b> |
| 6. | <b>Managing patient fear of mainstream services</b>                             |
| 7. | <b>Service provision shaped by culture</b>                                      |

**Screening for earlier detection and prevention:**

*"I didn't know I had kidney problems 'cause I was pretty active, fishin' huntin' golfin' ... until one day I felt a bit crook there ... so they rushed me to hospital and when I woke up I was in the intensive care ward ... and they said, 'Oh, you have to go down to dialysis and get blood into you. Your kidneys have had it". (Aboriginal man, 50s)*

*"Once they are on that machine the system has failed and the system will have had many opportunities for interventions. So the challenge for Aboriginal people is actually to get effective reasonable pre-dialysis, pre-end-stage care" (Senior renal manager)*

**Flexible family focussed care:**

*I just live day by day. I just thinkin' of my kids all the time. That's what keepin' me goin', seeing my boys, seeing the littlies. (Aboriginal woman, 30s)*

*"When this all happened I got them all together to have a family conference concerning my health and then my oldest boy put his hand up and said, "Mum, I'll give you my kidney," my other son jumped and said, "Well, Mum, I'll come and be your carer," and my baby son put his hand up and he said, "Mum, I'll learn the machine with you." So straight away the family was on to it, wanted to deal with it with me". (Aboriginal woman, 50s)*

**An Aboriginal specific pre-dialysis pathway**

*"Unfortunately most Aboriginal patients didn't come through the pathway. They usually crashed and burned ... and you know they wouldn't attend appointments with the nephrologist and things 'cause it's just like, "No, this is not happening." So that's denial. In saying that, though, it has to be earlier. It has to be at the AMS." (Dialysis nurse)*

### **Increased Home renal nurse support**

*"You cannot expect a lot of Aboriginal people to take on the dialysis responsibilities in their own homes. We need more support ... People have gotten used to being institutionalized. But if they had some encouragement they could do it ... Because what we're doing wrong is taking our people out of country and breaking their cultural spirit, and this is wrong"* (Aboriginal woman, 50s)

### **Cultural education of renal staff by patients, family members and Elders**

*"There be no good just any old black fella coming and talking to our staff about this because that fella don't have clue what a dialysis machine looks like. He wouldn't have clue what's going through that Aboriginal's mind ... so we need a dialysis patient to work at doing that with the staff ... partners or the mother to come in and talk about the cultural issues from the dialysis patient perspective".* (Aboriginal Man, 50s)

### **Managing patient fear of mainstream services**

*"I think there's is an element of lack of understanding of the past policies that were in place where Aboriginal people were taken away from hospitals, you know, removed, the stolen generation and the grief and loss that associates with that"* (Aboriginal Health worker, 40s)

*"I was born in the mortuary of the ... hospital, 'cause back in those days our mothers weren't allowed to birth in the maternity ward with all them white mothers"* (Aboriginal woman, 50s)

### **Service provision shaped by culture**

*'But the nurses that we have, we see 'em every day, they should be more sensitive about who they're talking to and how they do it. And that's an important thing'* (Aboriginal man, 50s)

## *8. KHA Yarning Kidneys – Outcomes, Key Themes and Recommendations*

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

### **Key Themes and Recommendations include:**

|           |   |
|-----------|---|
| <b>1.</b> | <p><b>Re-addressing ongoing community recommendations</b></p> <ul style="list-style-type: none"> <li>• That themes, feedback and recommendations from the previous Northern Rivers of NSW Aboriginal and Torres Strait Islander studies be reviewed and considered (refer documents at Appendix 10.3).</li> </ul>   |
| <b>2.</b> | <p><b>Education, raising awareness and early detection</b></p> <ul style="list-style-type: none"> <li>• Implement better health promotion tools/campaigns around CKD including culturally appropriate education around detection and treatment options.</li> <li>• Encourage and provide kidney checks to achieve early detection of kidney disease which will allow patients (and family or carers) to participate in education programs and prepare for future treatment.</li> <li>• Implement a localised campaign/program to prevent diabetes and kidney disease targeting children and youth.</li> <li>• Involve respected and experienced community members for storing sharing.</li> </ul> |
| <b>3.</b> | <p><b>Racism, discrimination and lack of understanding by clinicians</b></p> <ul style="list-style-type: none"> <li>• Implement a comprehensive and ongoing cultural awareness and/or safety training program within the healthcare system.</li> <li>• Cultural training should include local Indigenous history, customs, lore, language and the status of health and wellbeing at the grass-root level.</li> </ul>  |
| <b>4.</b> | <p><b>Health system issues and workforce</b></p> <ul style="list-style-type: none"> <li>• Revitalise renal units to provide a more engaging, welcoming and culturally safe environment.</li> <li>• Employ more permanent GPs and nurses with a preference for more targeted positions e.g. AHW's.</li> <li>• Employ adequate numbers of male and female AHW's to address cultural sensitivities working with Aboriginal and Torres Strait Islander men and woman (i.e. gender issues are an important inclusion to enable culturally safe service provision).</li> </ul>  |
| <b>5.</b> | <p><b>Communication / Miscommunication</b></p> <ul style="list-style-type: none"> <li>• Employ AHW's, navigators or preceptors to help renal patients understand their condition and treatments and improve communications with doctors.</li> <li>• Use plain language during appointments and dialysis sessions.</li> <li>• Provide information and straight forward, easy to remember messages on caring for kidneys and CKD management.</li> </ul>   |

|           |  |
|-----------|--|
| <b>6.</b> | <b>Impacts on lifestyle and quality of life</b> <ul style="list-style-type: none"> <li>• Provide 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.</li> <li>• Provide additional support to patient's family members to reduce family breakdowns and reduce stress and burden for the individual living with CKD.</li> <li>• Improve transport and access to dialysis services and assist with financial burden associated with moving or travelling away from home.</li> </ul> |
| <b>7.</b> | <b>Impacts of being forced to leave community / country</b> <ul style="list-style-type: none"> <li>• Treatment "closer to home" must be a priority for better health outcomes for patients and family impacted by end-stage kidney disease and dialysis treatment.</li> <li>• Increase the provision of renal services in rural and remote areas to avoid patients' separation from family and disconnection from country and community.</li> </ul>  |
| <b>8.</b> | <b>Impacts on social and emotional wellbeing (mental health)</b> <ul style="list-style-type: none"> <li>• Increase access to culturally appropriate allied healthcare services including mental health support.</li> </ul>   |

### ***8.1. Re-addressing ongoing community recommendations***

The themes and feedback from participants resonated strongly with the findings of the patient's stories collected almost a decade ago as part of the Northern Rivers of NSW Aboriginal and Torres Strait Islander study described above (refer Appendix 11.2).

Participants agreed kidney disease disrupted their life and caused major problems to their relationship with family and community, interfered with work commitments, community roles and responsibilities and caused substantial lifestyle changes.

Understanding the disease and trying to explain what kidney disease was to family and community members was a concern experienced by new patients. Attendees mentioned how useful it would be to gain support and advice from experienced patients sharing their learnings with patients who have just been diagnosed and are commencing dialysis.

### ***8.2. Education, raising awareness and early detection***

Targeted information about kidney disease and an awareness raising campaign was consistently raised which may help with prevention or delaying the onset of kidney disease and encourage early detection and intervention of the disease. More culturally appropriate

CKD information and resources would assist increase the understanding of the community. Increasing awareness within the general community will improve the understanding of the various impacts of kidney disease.

- Need for more awareness, health promotion about kidney health and CKD/ESKD
- There is a general lack of understanding (about kidney disease)
- A need for sharing stories and community representation
- Need to understand more about the signs and symptoms (i.e. foaming pee)
- More testing to detect early stages of kidney disease, like they do for cancer tests (prostate, bowel, breast, etc)

*"More awareness, health promotion needed."*

### *8.3. Racism, discrimination and lack of understanding by clinicians*

A number of 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.

- Daily experiences of racism were mentioned
- Victim blaming – patients made to feel it is their fault that they are sick
- Lack of respect for Indigenous patient's cultural concerns i.e. gender issues
- Feeling a larger impact than other racial groups
- Judgement (i.e. judgement of Aboriginal patient's reliance on his faith – feel like they are judged as being mad or crazy)
- Frustrated at lack of personal understanding

*"Made to feel shame and stupid for asking questions."*

### *8.4. Health system issues and workforce*

There was consistent discussion 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 them. There was also feedback that the dialysis ward environment could be improved.

- Difficulties in training for PD and HD - financial impact and transport issues
- Need for more home dialysis options
- Need for AHW support within renal units or home visits
- Lack of support for young patients
- Clinicians incorrect assumptions re depression when Indigenous patients have had enough of mainstream services

*"Would be better with an AHW or home visit to have a cuppa and a yarn."*

*"Environment to clinical, cold and claustrophobic."*

*"I've had enough, and now doctors think I'm depressed"*

### *8.5. Communication / Miscommunication*

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

- Lack of understanding (non-Indigenous views)
- Incorrect assumptions by health practitioners that when patients nod they understand what is being told to them
- Don't discuss with family and friends unless they ask
- Not being listened to or heard!

*"Doctors spoke too fast to understand, using big jargon words, need more plain language"*

*"Not many people supported, but the few that did really explained things to the patient – walk hand in hand"*

### *8.6. Impacts on lifestyle and quality of life*

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.

- Restricted within all aspects of life, everything is impacted
- Lifestyles are turned upside down
- Enduring constant hospitalisations
- Very grumpy, tired and confused
- Sore all over the body, aches and pains
- Away from home, country and culture
- Travel restrictions
- Financial impacts
- Social and physical isolation

- Feelings of loneliness
- Impacts the entire family

*“DOOMED, highly stressed, lack of understanding, shock, denial, apprehensive, uncertain, alone (even within family)” [participant describing emotions of being diagnosed with kidney disease]*

*“No income, isolated, can’t work”*

### *8.7. Impact of being forced to leave community/country*

This has been a consistent theme throughout the Yarnings and again was an important factor and major impact voiced by these patients. The following dot points indicate a number of similar points raised around leaving home due to kidney disease and associated treatment.

- Feeling alone – even within family
- Depressed from not being around family
- Need support from family
- Separated from family, even spouses
- Renal units in the communities

*“Not having what we had in the bush, miss the country lifestyle, miss the cultural stuff”*

### *8.8. Impacts on social and emotional well-being (mental health)*

Many of the participants commented on the varied mental health impacts living with kidney disease. It was discussed how from diagnosis there is the initial shock, confusion, fear and other emotions associated with a major upheaval in health and lifestyle. The varied emotions are highlighted below.

- Fear
- Depression and anxiety
- Loneliness
- Shock, confusion and denial
- Apprehension and uncertainty
- Frustration that is viewed as anger
- Suppression of emotions
- Sad and frightened, crying
- High levels of stress

*“Breaks the whole family down, breaks you down. Everything is impacted.”*

## *9. 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 Bulgarr Ngaru Medical Aboriginal Corporation Clarence Valley (BNMACCV) & the Bulgarr Ngaru Medical Aboriginal Corporation Richmond Valley (BNMACRV);
- Kidney Health Australia Website and
- Funding Agencies.



*Ballina and the Northern Rivers of New South Wales Yarning Kidneys*

## 10. Appendix

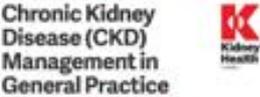
### 10.1. KHA Yarning Kidneys Ballina & Northern Rivers Flyer

 In consultation with:  

## Indigenous Voices Yarning 'Kidney Health'

In Australia and New Zealand there are Guidelines (instructions) that are used by doctors, nurses and other health professionals to know how best to treat kidney diseases. Currently these Guidelines do not include cultural aspects of care or specific needs or challenges that may occur for Aboriginal and Torres Strait Islander Peoples.

Kidney Health Australia is holding a community consultation in Ballina. We invite you to attend the consultation to tell us what should be in these guidelines, how we should use them, and give us ideas about improving kidney care locally and how to feed the information back to you.

   
Guidance and clinical tips to help identify, manage and refer patients with CKD in your practice

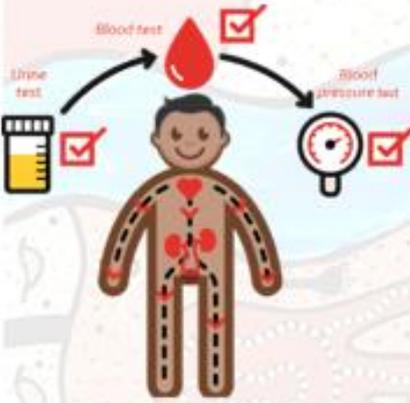


Aboriginal and Torres Strait Islander Peoples and their family members have the opportunity to discuss what is most important regarding their kidney health, kidney care and personal, family and community experiences with kidney education and treatments. The consultation will be recorded and written up, and then shared with all who attended, to get their feedback. Names of those attending will not be written on the consultation report unless permission is given.

Kidney Health Australia's Indigenous Yarning Day:  
Thursday 20<sup>th</sup> February from 10:30 am to 3:00 pm at Ballina Surf Club, Lighthouse Parade, East Ballina NSW 2478

**Food and transportation will be provided.**

Please RSVP by Monday the 17<sup>th</sup> of February to [Kimberly.taylor@kidney.org.au](mailto:Kimberly.taylor@kidney.org.au) or call Kimberly Taylor on, 0400 802 437 for more Information. To arrange free transport - call Liz Rix on 0401 577 659.



## 10.2. KHA Yarning Kidneys Community Consultation Questions

### **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?

### *10.3. References*

Rix, E. (2014). Avoiding the costly crisis: Informing renal services design and delivery for Aboriginal people in rural/regional New South Wales, Australia. (PhD), University of Sydney, Sydney.

Rix, E., Barclay, L., Wilson, S., Stirling, J., Tong, A. Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: a qualitative study. *BMJ Open* 2013 3: doi: 10.1136/bmjopen-2013-003581

Rix, E., Barclay, L., Stirling, J., Tong, A., & Wilson, S. (2014). Beats the alternative but it messes up your life: A qualitative study of Aboriginal people's experience of haemodialysis in rural Australia. *BMJ Open*, 4. doi:doi:10.1136/bmjopen-2014-005945

Rix, E., Barclay, L., Stirling, J., Tong, A., & Wilson, S. (2015). The perspectives of Aboriginal patients and their health care providers on improving the quality of hemodialysis services: A qualitative study. *Hemodialysis International*, 19(1), 80-89. doi:10.1111/hdi.12201

Rix, E., Barclay, L., & Wilson, S. (2014). Can a white nurse get it? 'Reflexive practice' and the non-Indigenous clinician/researcher working with Aboriginal people. *Journal of Rural and Remote Health*, 4: 2679.

Rix, E., Moran, C., Kapeen, R., & Wilson, S. (2016). Building cultural bridges and two-way understanding: working with Australian Aboriginal people within mainstream renal services. *Renal Society of Australasia Journal*, 12(12-17).

## *11. © Copyright*

This report is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced without written permission from Kidney Health Australia. Requests and enquiries concerning reproduction and rights should be directed to:

Kidney Health Australia

PO Box 9993

Melbourne VIC 3001

Kidney Helpline: 1800 454 363

[Kidney.Helpline@kidney.org.au](mailto:Kidney.Helpline@kidney.org.au)

ISBN: 978-0-6450022-1-8

Online ISBN: 978-0-6450022-5-6

## *12. 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.