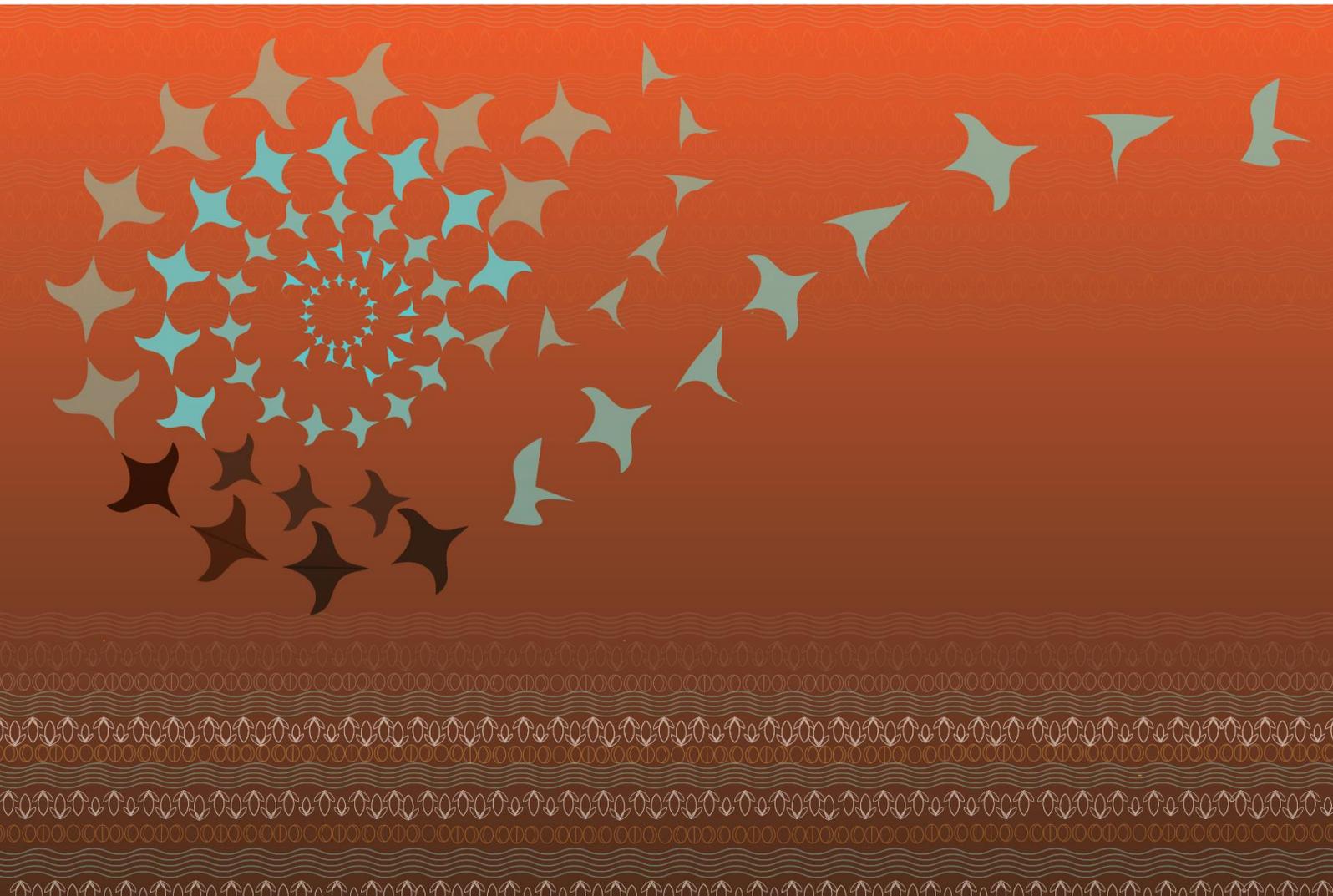


“Indigenous Voices Yarning Kidney Health”
Report: Cairns and Yarrabah 31st October 2019
Authors Cilla Preece and Katherine Mairu

Community Yarning to inform the development of the new KHA-CARI Guidelines
for Management of Chronic Kidney Disease for Aboriginal and Torres Strait
Islander Peoples



Artwork by Sheree Jacobs

“Collaborate” represents the importance of coming together as part of the yarning circle to talk about health and wellbeing. The birds represent the participants and together their journey is strengthened through sharing.

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1) List of acronyms and abbreviations

ACCCHS	Aboriginal Community Controlled Health Service
ACYHC	Apunipima Cape York Health Council
APD	Automated Peritoneal Dialysis
CAPD	Continuous Ambulatory Peritoneal Dialysis
CNC	Clinical Nurse Consultant
CRD	Chronic Renal Disease
CHHHS	Cairns and Hinterland Hospital and Health Service
ED	Emergency Department
ESRD	End Stage Renal Disease
ESRF	End Stage Renal Failure
GP	General Practitioner
GYHSAC	Gurriny Yealamucka Health Service Aboriginal Corporation
HD	Haemodialysis
HHD	Home Haemodialysis
ILO	Indigenous Liaison Officer (Renal)
KHA	Kidney Health Australia
KHA-CARI	Kidney Health Australia Caring for Australasians with Renal Impairment
PAH	Princess Alexander Hospital
PD	Peritoneal dialysis
PTS	Patient Travel Scheme
RN	Registered Nurse
NIKTT	National Indigenous Kidney Transplant Taskforce
NQPHN	North Queensland Primary Health Network
TL	Team Leader
WHS	Wuchopperen Health Service

The authors Cilla Preece and Katherine Mairu acknowledge the term Aboriginal and Torres Strait Islander people is used throughout this Far North Queensland report. In the Indigenous Voices Yarning Renal Health introduction, the participants identified as either Aboriginal or Torres Strait Islander or both. The term Indigenous has been used throughout this report as the patients have described.

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.

2) Welcome to Country

Uncle Bernie Singleton (senior) “welcomed all the patients and their carers and guests to Country”. Uncle Bernie is a traditional land owner and elder from the ‘Gunggandji’ people from Yarrabah. Uncle Bernie has worked in many positions including health and was Chairperson for Apunipima Cape York Health Council (ACYHC) for 11years. He also welcomed other traditional land owners from ‘Darumbal’ people from Central Queensland, ‘Yidinji’ traditional owners make up of 8 clans including South of Cairns to the Russell River and west to parts of the Atherton Tablelands’. ‘Djabugay’ traditional land owners from Kuranda the Rainforest people. ‘Kuka Yalanji’ (Eastern and Western) traditional land owners around the Mossman Gorge and North. From Chillagoe west of Cairns the ‘Wakaman’ traditional owners. Uncle Bernie acknowledged the ‘Thubi Warra’ people from Hopevale and from Lockhart River the ‘Kuukuya’u traditional land owners.

From the Torres Straits the ‘Kaurareg’ traditional owners from Horn Island also ‘Badugal’ traditional owners from Badu Island and ‘Koebyuway and Moegibuway Saibai Island traditional land owners. Uncle Bernie was invited to stay and listen to the patient’s journeys and for morning tea. After the ‘Welcome to Country’ and part of our agenda all of the renal patients and their carers introduced themselves and were given the opportunity to say where they are from and tell us a bit about themselves.

Photo 1: Uncle Bernie signing KHA consent form before “Welcome to Country.”



3) Acknowledgments

It is difficult to imagine how the Indigenous Voices Yarning Kidney Health for Cairns and Yarrabah would have taken place on the 31st October 2019 without the support from Kidney Health Australia and ACYHC. ACYHC is a member based community controlled health organisation responsible for delivering high quality, culturally appropriate and comprehensive primary health care to 11 Cape York communities.

The co-facilitators for the Indigenous Voices Yarning Kidney Health Cilla Preece and Katherine Mairu are sincerely grateful to Paul Stephenson, Chief Executive Officer for ACYHC for his support and commitment to renal patients having a voice amongst the complicated tertiary hospital health system.

We would also like to thank his Executive Officer Larnie Prosper for her efficiency and support to set up the use of the training room's at no cost to Kidney Health Australia. On the day of the Indigenous Voices Yarning Kidney Health we are thankful to Elaine Corrie for her support in helping with the renal patients' arrival and their carers for showing them to where the Indigenous Voices Yarning Kidney Health was taking place and for assisting Cilla with some administration matters.

We extend our heartfelt gratitude to the patients and their carers because without them the day would not have turned out so successful. We did not extend an invitation to any clinical staff from the Cairns and Hinterland Hospital and Health Service as it's the patients' we want to hear from, their perspective and experiences having End Stage Renal Failure (ESRF) and all the associated medical, social, financial and stress factors having renal failure. We also did not invite any politicians for the same reason. **Patients always come first.**

We also would like to thank Dora Oliver, (National Program Manager), for her work completed with the co-facilitators before she left Kidney Health Australia. We also welcomed the assistance and support from Kimberly Taylor, (National Project Officer) who had only been in her new position for three days. We acknowledge Eleanor Garrard, (Executive Officer) from the National Indigenous Kidney Transplant Taskforce (NIKTT). We also valued input and support from Valerie Nancarrow who is the Indigenous Liaison Officer working in the renal unit.

We would also like to thank Vivan Mook (Area Manager) and Dawn Kraft (Senior Program Officer) for the Northern Queensland Primary Health Network. We also thank Gail from Stratford Deli in providing healthy choices morning tea and Jaimee Boneham for her time in delivering healthy wraps and rolls. Thanks to Sheree Jacobs a Torres Strait Islander for her artwork design, expertise in communication and IT skills.

Wuchopperen Health Service were approached initially, but no rooms were available to conduct the Indigenous Voices Yarning Kidney Health.

4) Background

Cilla gave an explanation as to why the Indigenous Voices Yarning Kidney Health were being conducted.

In June 2018, KHA received Government funding to consult with 16 Aboriginal and Torres Strait Islander communities with renal issues across Australia in particular metropolitan, regional and remote areas. So far, six communities have been completed with the Cairns and Yarrabah being the seventh communities to participate. In Queensland, Mt Isa and Brisbane are yet to complete their Health Indigenous Voices Yarning Kidney with renal patients, carers and their families (KHA flyer 2019).

The Indigenous Voices Yarning Kidney Health are an important opportunity for Aboriginal and Torres Strait Islander renal patients, carers and families to yarn about their experiences with kidney disease and to help inform the new Kidney Health Australia Caring for Australasians with Renal Impairment KHA-CARI guidelines. Once collated after all the communities have participated in the Yarning Circles these guidelines will provide instructions for doctors and nurses about the best care for Aboriginal and Torres Strait Islander peoples with kidney disease and best ways to improve kidney care (KHA flyer 2019).

At present these Guidelines **do not include cultural issues of care** and **do not consider the needs and challenges that Aboriginal and Torres Strait Islander renal patients usually face.** (KHA flyer2019)

5) Community Engagement

The facilitators worked closely with GYHSAC from Yarrabah and WHS in Cairns. Bronwyn Hayes the Transplant CNC supported the Yarning Circle and gave one of the facilitators a list of names but unfortunately most of those clients were on the Tuesday, Thursday and Saturday shifts.

Cilla Preece, co-facilitator, recruited the majority of the kidney patients with the plain language flyer which was explained to each of the patients. The actual recruitment list was large (37) but when ringing patients to remind them of the Yarning Circle they could not make the Yarning Circle due to other medical appointments or just felt unable to attend.

Two patients were recruited from the Yarrabah satellite unit, and the remaining patients were recruited from the CHHHS and Cairns Private satellite unit. The flyer was described as a chance for only 'Indigenous renal voices' to be heard. All of the patients expressed this was a great idea and more yarning circles should take place.

Most of the patients knew one of the facilitators as she keeps in touch with them regularly and gives them moral support and helps guide the patients to the right person to get an answer or if requested will act as an advocate on their behalf with their consent. Recruitment of patients took about a week and a half. ACYHC was instrumental in accepting the Indigenous Voices Yarning Kidney Health take place within their organisation within a short timeframe.

6) Participants

From a total of 37 recruited patients, 23 people attended the Indigenous Voices Yarning Kidney Health with 11 kidney patients in total consisting of 7 females and 4 males. Carers consisted of 4 female carers and 3 male carers. Ages of the kidney patients varied from 31 years of age through to 69 years of age.

Other guests including the co facilitators accounted for 7. All the renal patients, their carers and other guests signed in the ACYHC sign in sheet upon arrival as part of their health and safety procedures.

Far North Queensland Aboriginal and Torres Strait Islander Advisory Group

At present the Cairns, Yarrabah, Far North Queensland, Cape York and the Torres Straits renal patients have not allocated members to sit on a Local Renal Community Reference Group. With so many renal patients who have a lot to say about their journey and about their renal treatment (good and bad) who were not present being unavailable due to their dialysis treatment this Reference Group would be easy to establish. An Expression of Interest will be sent to all renal patients with either assistance from the Cairns Hospital Renal Department or through the Primary Health Care Networks.

7) Indigenous Voices Yarning Kidney Health – Question and Themes

Cilla Preece (renal health qualitative researcher) and Katherine Mairu (CNC) from the Yarrabah satellite dialysis unit were co-facilitators for the Yarning Circle. Cilla explained that a photo/tape recorder and video consent and release form from KHA was being handed out, all consented except for one of the carers who didn't like her photo taken.

The Indigenous Voices Yarning Kidney Health then broke into two groups that were facilitated by Cilla Group 1 and Katherine Group 2. Both of the facilitators went through the agenda and wrote notes on butcher's paper. Kimberly Taylor assisted Katherine and Eleanor Garrard took notes which was greatly appreciated. There is a summary at the end of each of the questions from the patients Indigenous Voices yarning Kidney Health. All of the dot points are quotes from the patients and carers.

The following questions and themes were discussed.

Q1. When did they know their kidneys were not working?

- Patients had swollen faces and feet.
- Patients felt puffy.
- Patients felt frustrated by lack of information.
- A patient "found out through her GP in 2012 up at one of the Islands in Torres Strait then came down here to Cairns and was told her kidneys were not working."

- One of the patients said “I was sick at home in my community and was medivac-ed to Cairns Hospital as I had double pneumonia. From there I found out my kidney function was poor and I had to start dialysis, I had a permacath placed in my chest until my fistula was made.” “I was in ICU for a little while.”
- Another patient described her experience as “My kidneys were not working because I have diabetes and other medical problems”. She also stated that “stress plays a big part in all your health problems.”
- A patient described “as being on a return flight from Brisbane with Dr Mantha and he noticed I did not look well and asked me to go to ED. From there they did all the tests and I went to the Renal and Respiratory ward at the Cairns Hospital. From there the renal team said “my kidneys are not working.”
- Another patient described her journey “as she found through her specialists when she was young she had an autoimmune disease that would require dialysis treatment.”
- Another patient described that “through her GP she was referred to the renal specialists, then my visits became regular and then I was told I needed dialysis.”
- Another patient described their experience as “being from a small town out west from Cairns and after many hospital visits he was diagnosed with diabetes in 1991, then he decided to move to a larger town west of Cairns where he fainted and had a puffy face.” When he found out he was in renal failure he then moved to Cairns.
- Another patient described her experience as “I saw my Doctor as I felt unwell and had nausea then he referred me to the Renal Specialist I was in ICU then the renal team placed a permacath in my chest, I only do one day at the moment I don’t understand why as I have no family history of diabetes or kidney disease.”
- A patient described as “having a stroke then found out about the kidney failure.”
- A patient found out at Christmas in 2015 she experienced “short wind and had cellulitis in her leg”. She also said “I felt sick as I came from a remote Island in the Torres Strait to Thursday Island and then flown to Cairns.”
- Another patient spoke about her “swelling in her leg and face.”
- Another patient spoke about “feeling sleepy all the time and very tired.”
- Patients also mentioned they experienced “back and gout pain.”
- Another patient also discussed their journey from two Cape York communities to a community close to Cairns and then found out he had kidney problems.
- A patient described her experience as “they were not answering my questions.”
- A patient said there is “no patient friendly information or resources in our remote communities on kidney health which would include diet changes and fluid limits.”
- A majority of the patients also described that “no explanation as to why their kidneys weren’t working and also wanted a straight answer” from the kidney team.”
- A majority of the patients also described their experiences during hospital stays as “that there weren’t enough consultations, if so they felt rushed and not being respected as a human being.”
- Patients also asked the kidney doctors “what are the long term effects on their body and this was not explained properly.”
- Patients said “there is no communication between the health sectors within the hospital and they were not included in their own health decisions.”

In summary:

- Physical effects such as swollen feet, face, puffy, stroke, short wind, tiredness, cellulitis, feeling sleepy, back/gout pain, nausea, pneumonia and stress.
- Frustration, lack of information, no patient friendly information and lack of resources.
- Renal team discuss your health in front of you but you're not part of your own health decisions.
- Questions about long term effects on your body not given a straight answer.
- Renal consultations were short and rushed, no time to answer any questions
- Kidney disease not being explained properly.
- No understanding of what the renal team are explaining.
- Lack of communication between specialists areas.
- Other medical conditions diabetes and autoimmune diseases.
- Going through your GP and being referred to renal specialist then onto the dialysis journey.
- Going to ED with from advice from renal specialist.
- Patients with ESRF being transferred to Cairns then to start dialysis via permacath.
- No respect shown to the patients.

Q2. When you got told your kidneys were not working how did this information make you feel?

- A majority of the patients felt sad, upset, unhappy, scared then turned to being angry.
- A patient just said "she cried."
- A patients said "she was in shock and dealing with ESRD and being homesick very badly."
- Patients felt the psychosocial factors (depression, anxiety, lower social support)
- Patients also described to "being in shock nothing the doctors or nurses were telling me made no sense I just shut off."
- One of the patients asked "why me."
- A patient asked "what's going to happen and how is it going to happen". So the patient was anxious about the future and loss of income.
- A patient described that "there is lack of follow-up in my community in the primary care sector."
- A patient described "you learn to enjoy it."
- A patient said "you have to get on with it, don't let it pull you back."
- A patient described "she has needle phobia and the needles are painful."

In summary:

- Patients described a number of natural human emotions when they were told they have kidney failure anxious about the future, sad, shock, upset, scared, angry, just cried, and 'why me'
- Loss of income.
- One patient described that being on dialysis 'you learn to enjoy it'.
- A patient has "needle phobia." No options were explained about any numbing gel to overcome the pain or fear.
- A patient described "you have to just get on with it don't let it pull you back."
- Lack of follow and early awareness in the community by the primary care sector.
- Nothing the renal team said 'I just shut off'.

Q3. Did they have to leave their community?

- A patient from an Eastern Cape York described how "upset she is as she misses her family and community and the lifestyle at home." This patient currently stays in a nursing home and spoke about "the nursing home takes a big amount of my pension and she only has \$20 to \$30 spare each fortnight." She described how "she would like to stay with her sister and daughter but accommodation in Cairns is very expensive and they all cannot afford it." This patient also "would like her grandchildren down in Cairns and how much she worried for her family back home." She also asked "why can't they give us cheaper accommodation so that can help us bring family to Cairns." This patient also wanted to know "why can't they set up dialysis chairs in her community."
- Two patients described they were 'homesick, Cairns not home, miss family members, miss traditional lands, way of life in community, miss activities like fishing, hunting, family gathering.
- Moving to Cairns some (Cape & Torres patients get told they have to live in Cairns permanently).
- Another patient described "the Red Cross as not appropriate accommodation, the kitchen is downstairs and you buy food and label it but other people steal it". "Catching taxis to town to buy food is expensive and very draining."
- A patient described "waiting times to get public housing is about 5 years."
- Patients talked about "communities need to drive change through community-controlled health organisations."
- Another patient who was living in a Western Cape community described "being in Cairns for 26 years as they did not have the kidney machines or staff up there to help me."
- Another patient described it's been 7 years since they left their community and they "miss eating turtle and dugong." One patient identified "she was from Cairns and had no issues"
- Other patients described they need "more dialysis chairs in remote health care centres."
- One patient said "he mainly missed his traditional country."

- A majority of the patients described they had to leave their communities as they were sick.
- A couple of patients live close to Cairns were able to go home to a satellite unit but “in other places like in Thursday Island you have to either wait for someone to pass away or wait for a patient to come down for a medical procedure in Cairns and you can go up there for a break. The only thing is we are not from Thursday Island and accommodation is really expensive.”
- A patient described leaving Central Queensland community and has been up here for years, I have family up here so I feel comfortable.”

In summary:

- A number of patients did have to leave their communities.
- Very sick had to leave.
- Missing home and families a big issue.
- Miss the lifestyle, way of life and traditional country.
- Eating traditional foods.
- Inappropriate accommodation in Cairns. Some accommodation kitchen is downstairs and other people steal your food.
- Can't bring family/grandchildren and great grandchildren down to stay with you.
- Expensive accommodation in Cairns.
- Expensive accommodation in Thursday Island.
- Expensive to catch taxis to buy food. Feel drained.
- Waiting time for public housing is about 5 years.
- Aboriginal Community Controlled organisations need to drive the change.
- Feel comfortable and settled in Cairns.
- Happy doing in hospital dialysis and private hospital staff friendly.
- No dialysis chairs in our communities and no renal RN's.
- From Cairns, no issues.

Q4. Did they understand all the information the medical/renal team explained to them?

- A patient “did not understand all the jargon what the medical/renal teams were talking about as English was her third language.”
- A majority of the patients “felt they were still in shock and sick then the medical/renal team were explaining to them what was happening with their kidneys but they didn't listen to any questions we had”. Patients talked about “not understanding what dialysis was until I started.” Patients also talked about “blood tests results were not explained to them, no pictures were drawn to help explain kidney disease.”
- One patient was told “your kidneys are failing and you're going on dialysis”. Another patient “never had an opportunity to ask any questions.”
- Another patient described seeing an ILO early upon arrival would have helped just for comfort and someone to talk to.” This service was not offered to this patient.

- A patient described she “wanted information about diet from the doctors, and got told you have to see a dietician to get that.” “Our diet back home is very different more traditional foods.” This patient has not seen the renal dietician as yet but has requested a visit.
- Two patients described when “they got on dialysis they had no idea about all the complications.” Another patient described she “didn’t know what questions she should be asking.”
- A patient said she asked “lots of questions about medications and her treatment. The renal pharmacist gave me a long list on medications but it made no sense.”
- A patient talked about “in remote communities we don’t get that early pre education maybe in the diabetes area, blood pressure area but the health centres have so many sick people to look after and if patients are headed down the renal failure pathway they should pay more attention to us.” The same patient “talked about having the ‘fly in fly out’ service and the CHHS staff, they seem not to be working together for the best interests of our people or our future generations.”
- A patient talked about “having expert patients being involved in pre dialysis education.”
- A patient described if he “had the more knowledge about his dialysis issues like blood pressure, no salt or foods high in potassium he could manage his own health better.”

In summary:

- Not understanding all the medical jargon. Maybe pictures would help me understand.
- English third language.
- Not listening still sick and in shock.
- Not understanding dialysis, blood tests and what was being explained to me.
- No opportunity to ask questions. Didn’t know what to ask.
- No idea about all the complications from kidney failure.
- Renal dietician missing in action.
- Seeing an ILO would have helped comfort me.
- Renal pharmacist gave me a list on medications but made no sense.
- No pre education about renal failure in remote communities.
- Fly in fly out model with ACHYC and CHHS doesn’t seem to be working, not working together for our community people or future generations.
- Patient expert model being involved in pre dialysis education.
- Knowledge required to monitor own health like blood pressure, reduced salt intake, fatty foods and about foods high in potassium.

Q5) How did they decide on which dialysis treatment suited them?

- A patient described that “in remote communities there is not enough information from the Primary Care Health Centre’s and what our options are - either have dialysis or not.” “When the kidney team arrive they should have the Renal Nurse

Educator who can educate us about dialysis, medications, fluid restrictions and what diet changes need to happen. The renal diet is hard to follow and it's very restrictive."

- Another patient described "when you start to get used to dialysis in hospital and the staff you end up not wanting to leave even if home dialysis is an option". "I don't think I have the confidence to do home dialysis."
- Patients described "being sick and the renal team make the decisions about what dialysis treatment to go. Once in Cairns after you feel better the Renal Nurse Educator has a couple of sessions to talk about all the treatment options and which treatment would suit you. I decided to do PD at home as I didn't want to be stuck in the hospital but got an infection in my belly and now I'm on hospital HD."
- A patient described "the kidney team do talk to you about what dialysis would suit you and you're given the opportunity to make that choice."
- A patient decided to "do home dialysis then was worked up for a transplant."
- A patient decided to "do PD at home then recently received a kidney transplant in Brisbane."
- Patients felt aware of kidney transplant as a treatment option and Eleanor described patients are assessed case by case and the risk of the operation on the patient's life.
- A couple of patients described "trying PD first but now are on HD in a satellite unit in Cairns."
- A patient described "how hard Bronwyn Hayes the CNC Transplant Nurse for Cairns Hospital works". Up until June 2019 all transplants were either Aboriginal or Torres Strait Islanders patients.
- Another patient described "that there should be more awareness in our communities about all the dialysis treatments including kidney transplants. She said the kidney team should stay longer in communities if they want to make a difference."
- A patient talked "about the kidney transplant nurse gave me a short yarn but not in detail and she hasn't followed me at all and I've on dialysis for 5 years. If I don't qualify she should just tell me straight."
- After you finish the pre work up preparation for a transplant you have to travel to Brisbane for one day. It's hectic. You meet the kidney surgeon, nephrologist, renal ward RN's, social worker and pharmacist.
- A patient started "HD in hospital then decided to go home with a machine and get worked up for a transplant, when you get the phone call to get a transplant in Brisbane you are away for 3 months approximately from home then go home to Cairns for follow up as immunosuppressed drugs have to be monitored by renal team."
- Some issues "faced by transplants patients include large city living, all the traffic, navigation, being close to the Princess Alexander Hospital, cost of accommodation and out of pocket expenses that PTS do not cover." "Taxis are expensive as well."
- PTS Queensland Department of Health for renal patients is insufficient.
- Some patients may not be suitable for a transplant.

- A patient “told the group that a traditional elder made the difficult decision **not to receive** dialysis treatment and return home to pass away.” “Family were involved in the process although very sad, emotional and sensitive time for this patient to decide, the family respected his decision and he died back on his traditional lands.”

In summary:

- Patients from remote communities spoke about not enough information from the Primary Health Care Centres and there should be more awareness about all the treatment options if you’re headed down the ESRF pathway.
- Patients spoke about being too sick and coming to Cairns, getting better and then explained about the dialysis treatments.
- Patients decide that PD was a good option as they didn’t want to be stuck at the hospital. Then received a transplant.
- No follow up from the transplant CNC. If not suitable just tell me straight.
- Renal Outreach teams should stay in the communities longer if they want to make a difference. Renal Nurse Educator should also visit and do pre education, diet, fluid restrictions.
- A patient was on home HD then received a transplant.
- Renal team do discuss with you the options and you make your own decisions.
- Patients tried PD first but now are in a satellite unit receiving hospital HD.
- Patient was trained for home dialysis then got worked up for a transplant.
- Patient decided to do PD but got an infection in her belly now based at hospital HD.
- Renal diet restrictive.
- Patients not wanting dialysis but go home to pass away.

Q6) How does kidney issues affect you and your family?

- A patient who moved from an Island in Torres Strait talked about how “she brought all her family down to Cairns after she fell ill.” She has families still at her home Island but is content in Cairns as her medical needs are high so missing family not a problem.”
- A patient described “missing country and family in particular her grandchildren. My accommodation from the hospital is very strict on the number of people staying me with.”
- Another patient described “her family are a huge support, I sit back and relax while my son will cook my meals and my daughter will do my laundry.”
- Another patient described “her family came together when I got the news about kidney problems and they sit with me when I’m on the machine.”
- A patient described “being young, transplant was spoken about a lot. But couldn’t get on the list right away, and if I got a virus they’d take me off the list and it had to be completely resolved before they put me back on the list”. “She also spoke about

the travel time being a big factor for a transplant, especially coming from Far North Queensland and the need to get to Brisbane in a short period of time.”

- Another patient explained her experience about “the possibility of receiving a kidney from her brother but because of her family history of diabetes in the family this was not an option. I am on HD in a satellite unit.”
- A patient from the Torres Strait living in Cairns permanently said “getting onto NDIS has helped so her life so much as she has a hoist to lift her up and out of bed for showering, a shower chair, a new wheel chair and a 2nd hand hospital bed and other organisations like Blue Care, St Johns and Life Without Barriers do my cleaning or washing.”
- A patient expressed “she got very depressed by recurrent infections which pushed me off the wait list and when I was better back on the list.”
- Another patient was informed about a kidney transplant but decided not to pursue it as he got used to HD and was happy with his treatment.
- Another patient described “missing out on family events, even in Cairns as that day might be my dialysis day and I don’t like missing treatment.”
- Another patient described “she tries to spend as much time with her family as possible.”
- A patient talked about “being strong in their spirit” “ Being strong after so many ups and downs of kidney treatment, you have to be positive to get your mind back into believing you’re going to feel well again soon.”
- Another patient also described “that accommodation like El Dorado, Koala Court and Red cross provided by the PTS is bad especially if you want family members to come down for more support, they don’t allow it.”
- A patient said “it would be good to have our own renal accommodation just for us and our family.”
- Patients described “feeling so tired, can’t sleep and not being able to do anything after dialysis treatment.”
- Another patient also described the renal team have you coming in for appointments on non-dialysis days, I am there 3 days a week surely they can make a time before dialysis treatment.”
- A patient talked “about the monthly blood tests, they do not tell you the results what’s high or low, they just stick in in our folder.”
- Patients talked about “trying to educate their families, grandchildren about their diet but they love fast food and soft drinks.”
- A patient described “she only has a couple of experienced RN’s that can needle her fistula.”
- A patient was “working full time and that loss of income was difficult to secure a job around dialysis schedule.” Centrelink didn’t understand as I was trying to apply for a disability pension.”
- Patients “described loss of future and could not see what enjoyment they could have in life while on dialysis.”
- Filling in all the paperwork to go a Disability pension, Newstart pension for younger patients is very difficult “Centrelink kept telling me to look for a job.”

- Staying in accommodation near the hospital – you have to buy your own food & cook.
- Patients still “have financial responsibilities back home.”
- Patients spoke about no transport if you wanted to go fishing or day outings on free dialysis days. No transport on weekends to do activities.

In summary:

- Patient brought all her family down to Cairns after she fell ill up in a Torres Strait Island close to Thursday Island and as her medical needs are high.
- Missing country and family especially grandchildren.
- Missing out on family events back in community.
- Accommodation patient travel strict on family member staying with me.
- Only certain RN’s can needle my fistula.
- Patients have strong family support at home her son cooks her meals and her daughter does her washing. After dialysis you just want to rest.
- Being young transplant was spoken about often to me but if I had an infection I’d be taken off the list then got better than on the list. It was like that for a little while waiting for a transplant. I got depressed.
- Travel time to Brisbane short. Time in Brisbane too long. Financial burden on me and my hubby and finding the right accommodation that is not expensive. Patient travel gives you a number of options but are expensive.
- Could not get a live donor as family history of diabetes. On HD in a satellite unit.
- Not being told about monthly blood tests, the RN’s just stick our results in our folders.
- Having own kidney accommodation and transport in Cairns just for kidney patients and families.
- Feeling tired and not sleeping well.
- Having responsibilities back in community.
- Appointments made on non-dialysis days. Would like appointments made before they begin their treatment.
- Patients trying to educate their own family members about eating fresh food and vegetables and not eating fast food and no soft drinks.
- Patient talked about being strong in spirit. There are many ups and downs but staying positive helps.
- Spending as much time with her family.
- Got told about a transplant but happy on HD in satellite unit.
- Don’t like missing my dialysis treatments.
- NDIS and other organisations that support Aboriginal and Torres Strait Islanders at home like bathing, cleaning, shopping and help with equipment like a hoist, a shower chair, new wheel chair and a 2nd hand hospital bed.
- Having transport to do activities on non-dialysis days would help patients mentally.

Q7) Have you ever experienced any issues that made them feel uncomfortable whilst receiving dialysis treatment?

- A patient described “her 1st treatment with an RN and ultrasound went really smooth although he was very anxious he didn’t even feel the needle go in but the 2nd treatment the RN said she didn’t need the ultrasound even though the patient requested the ultrasound the RN just ignored him and she blew my fistula it was all blue and purple.” “I expressed my disgust and he said to her you are never to needle me again.”
- Patients described a couple of the “RN’s at the CHHS talk down to us and are rude.”
- Other patients described “whilst in a hospital the kidney team talk about you like you’re not there and they don’t include you in the conversation.”
- Patients described “a couple of the RN’s in the unit are supposed to be good at needling given it’s their expertise field but sometimes they have a few goes even with the guidance of the ultrasound and they still miss. It’s not a nice feeling being a pin cushion plus it hurts.”
- A majority of the patients said “they’re “not being listened to.”
- A patient described “issues with racism and staff have no cultural knowledge of Aboriginal and Torres Strait Islanders people.” “It’s all about getting people on and off dialysis so the next lot of patients can have their treatment and the RN’s can all go home.”
- A patient described “just sitting there watching TV, it would be good if all the TV’s work properly and have some interaction with the RN’s.” “I got told that we (the patients) aren’t supposed to talk to the renal RN’s.”
- Another patient described that “her kidney family are important to her as social contacts and someone to talk to.”
- A patient got told “not to play Island music as her two other kidney friends sitting beside her were singing and we were happy until the team leader (TL) came in and told us off - you’re not supposed to sing and be happy its times like these that your spirit gets you down just because of a (TL) with no cultural knowledge and does not care for us proper. The volume wasn’t loud either just enough for us to listen to”.
- Patients described “they did not know how to make a complaint if a RN or renal team member was rude they feared they might get treated differently.” They also spoke about “their gammon yearly renal patient survey they hand out, it’s not something I would complete but I would just tell the renal staff verbally.”
- A patient said “the staff at Cairns Private are very good.”
- Patients talked about “the RN’s in the (RRW) talk too much medical jargon and I asked them to break down what they said.”
- Another patient was told she “would only have dialysis for 1 to 2 weeks and here I am 14 months later. The renal team didn’t explain what was happening properly. And I’ve had no follow up.” “A renal physiologist would be a good resource to talk with.”
- A patient talked about the “renal consultations you’re with a different specialist each time and I leave feeling I am all over the place. There is no consistency. I think

they don't read the notes or have multi-teams discussions, its usually one specialist talking to another specialist."

- Another patient "only requests Dr Mantha for their consultations as he felt they had a good rapport. He treats me 100% like a human being."
- A patient would like to see "the renal specialist look at me in a holistic way."
- The GP's approach is holistic. Why can't the renal specialist do the same, they work in their own renal world it's like tunnel vision and not seeing the bigger picture."
- An Island patient described "the RN's at CHHS avoid me if I need a pad change, so I am laying there all soiled and my husband has to do it at home." "If a few of the experienced RN's are on they will change my pad."
- A majority of patients described "having to take up 5 or more medications as they have more than 3 to 4 other chronic medical conditions to deal with."
- "Finding a community pharmacist once out of hospital is hard as you have to think about where your GP is plus where the pharmacy is."

In summary:

- A majority of the patients were not being listened to.
- A couple of RN's at Cairns Hospital talk down to us and are rude.
- Renal doctors talk about like you're not there.
- Dialysis specialised area but some RN's not good at needling even using the ultrasound. Don't like being used as a pin cushion.
- A patient described he could feel underlying racism in the unit, no cultural knowledge.
- RN's in a rush to get people on and off treatment.
- Most of the TV's don't work properly.
- RN's are not to talk to renal patients only if it concerns their treatment.
- Going to dialysis is like my second family.
- Can't play music and enjoy yourself. That particular RN does not care for us.
- Cairns Private staff are very good.
- Patients feared to make a complaint as they did not know how, if so would they be treated differently. Patients do a verbal complaint but nothing gets done.
- Yearly generic patient surveys are rubbish.
- RN's in the (RRW) talk too much medical jargon.
- No consistency with renal specialist when your appointments come around. Each one of them tell you something different to the previous visit.
- A patient said he gets the same Dr each visit they have a good rapport.
- Engagement of a renal psychologist for the patients.
- Patient was told she would be in Cairns for 1-2 weeks and 14 months later still here. Renal team have told me what's happening - but there is no follow up.
- Patient would like the renal specialist's to view them in a holistic way. It's like tunnel vision for the renal team – just interested in the kidney health.
- Patient avoided by some RN's if pad change is required. I have to wait until I get home where my husband does it. If the experience RN's are on they will change me.
- Finding a good GP and local pharmacy is important.

Q8) How do you think we can find kidney issues early in our community?

- Patients spoke about “early prevention in primary and high schools and parents being good role models and doing exercise with their kids and eating a good diet. Also using some local North Queensland sporting models like Johnathan Thurston.”
- A patient described “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 to all patients as Indigenous people are at risk.”
- A patient talked about having “better educational resources, patient friendly information ones that are easy to follow.”
- Patients spoke about having “a renal support person or buddy” the ILO’s are good as they help with accommodation and Centrelink forms. A support person that knows us and what we are going through.”
- Patients liked the idea of having “our own local Indigenous renal network and a patient who shows leadership.”
- A patient described having “a renal psychologist like they do in the Brisbane transplant unit would help a lot.”
- A patient described “the nurse navigators in Cairns are a waste of time and money and very rude to me because I can’t understand her.”

In summary:

- Early prevention programs in primary and high schools.
- Parents being ‘role models’. Making the right choices with their diet and include exercise.
- Local or national role models promoting awareness of the renal problem Aboriginal and Torres Strait Islander people are facing.
- Primary health care centres with help from the Indigenous Health Workers taking on the chronic patients with renal disease more aggressively.
- The need to slow progression of ESRD.
- Better educational resources, patient friendly information.
- Renal support worker, or renal buddy.
- Patients support idea of having local reference group.
- Patients who have leadership skills.
- Having a renal psychologist.
- Patients described nurse navigators are a waste of time, money and are rude.

Q9) How important do they think health professionals should complete cultural awareness training?

- All of the patients agreed it was very important that all health professionals working at hospitals should complete cultural awareness training, especially in the renal units as a large percentage identify as Aboriginal or Torres Strait Islander or both.

- This training should be made mandatory.
- A patient described “we have a lot of agency RN’s at the moment who we don’t know – they don’t us and if they have had any cultural training, they are on really higher wages then the local RN’s. The shift I am on isn’t as busy as the Tuesday, Thursday or Saturday shifts which I used to be on”. “They have a middle shift and patients that come on after 4pm are usually in patients and they get back to the ward about 9pm.” “You call feel the extreme pressure the RN’s are under at the moment and you can feel the tension.”

In summary:

- All of the patients agreed that Dr’s, RN’s and all hospital staff complete mandatory cultural awareness training.
- In CHHS and a number of satellite units a majority of patients identify as Aboriginal or Torres Strait Islander or both.
- When there is a high influx of sick renal dialysis patients the units have 3 shifts, RN’s extremely busy and patients can feel the tension.
- This compulsory Aboriginal and Torres Strait Islander cultural training and awareness should come from as a directive from the CHHS Board of Directors as a must complete task before working in all areas of the CHHS.

Q10) What are the best ways to engage our community?

- A patient described “that through her Aboriginal and Islander Health Service they have days during the year where a large number of clients and community members attend events such as Elders Week, Youth and Adolescent, Diabetes events but there are no events for Kidney Week.” “The service could work together with CHHS and have a promotion day at the community level.”
- Patients like reading any promotional leaflets/flyers and looking at posters while waiting for the Renal Dr to call their name out.
- The “Aboriginal and Islander Health Service where I go have a Renal Practitioner visit every 3 months to keep a close eye on Stages 3 and 4 of patients I think he should be looking at Stage 5 downwards and working very closely with the primary health care Doctors and health workers to slow the progression down.”
- A patient said “all of our qualified Indigenous health workers should be more informed about kidneys and educating our patients who are not on dialysis about their diet, less salt, obesity issues and less fatty foods.”
- “At my local health service they have Wednesday afternoon from 3-5pm to do training but I think it would be better to get all our health team to some education about kidneys health.”
- “Where I came from in a remote community there are not enough options like for our store to sell healthy foods like fresh fruit and vegetables, all they sell is food in fried batter and all the take-away food you can imagine.”
- One of the patients in Kidney week has organised a walk for “Autoimmune Diseases” which was the cause of their kidney problems.

- Patients also discussed “having health workers as role models, educating young children about kidney disease, have more community consultations and having community gardens in the schools and health service managed by the schools and health services.”

In summary:

- Target community events through local Aboriginal and Islander Health services. Lots of community members attend the events.
- Educating the younger generations about kidney disease.
- Local Indigenous role models that work at the Aboriginal and Islander Health services.
- Promotional flyers and leaflets in waiting rooms.
- Qualified health workers should know more about kidney disease.
- Education for staff when their scheduled training afternoon is on a Wednesday afternoon.
- Stores in remote communities sell a lot of unhealthy food, no fresh fruit or vegetables.
- More support and awareness for autoimmune diseases.
- More local consultations or yarning circles, community gardens in schools and health services.
- Renal Practitioner visits the Aboriginal and Islander Health services consulting patients at the stages 3-2 but should be looking at stage 5 and working with the GP’s and Indigenous workforce to work collaboratively to slow the progression down.

Q11) How can we do kidney care better for you and our community?

- A patient said “having a good GP that understands what you’re going through. My GP her father has been on HD then he had a transplant.” “She worries for her father and mother living in another country.”
- Patients spoke about “kidney health promotion days at all community events, during NADOC week having stalls there to promote looking after your kidneys.”
- A patient described linking in better with your local primary care team even through you’re in the tertiary area with kidney problems but for any infections or other medical conditions its good to have that support.”
- Patients said “it would be good to have our own networking amongst the patients to share our stories and journeys and how we can help each other. Maybe meet every 3 months.”
- Patients also liked the idea of having a “renal buddy or support worker to talk to.”
- Maybe “KHA can set up a health message for kidney health awareness like the diabetes radio skit funded by Diabetes Queensland. It’s very effective on the Murri radio station 98.7 BBM a lot of community people listen to that station and have some TV adverting on SBS or NITV that run all year.”
- Patients also spoke about “having stalls at All Black Carnivals which attract a lot of people.”
- A patient said “more Indigenous staff in the units would be good as they put me at ease.”

- Patients also spoke about “targeting schools and setting up career pathways for Indigenous people interested in health.”
- A patient spoke about “young ones giving up the smokes and grog would be good for our community.”
- Other patients talked about early awareness in the community, knowing the signs and the information.

In Summary:

- Having a GP that understands what you’re going through.
- Big events during like NAIDOC week and having kidney stalls, All Blacks’ rugby league tournaments up in the Torres Straits, in Cairns. They come from everywhere to compete.
- Diabetes Queensland funded an audio skit on local Murri radio station advertising diabetes and is popular in Cairns and in some remote communities can pick up the station.
- SBS or NITV promoting kidney health awareness all year.
- More Indigenous staff working in the renal units would help ease Indigenous patients.
- Career pathway for Indigenous people interested in health.
- Promotion for the young ones giving up the grog and smokes.
- Having renal buddy or support worker to talk to.
- Networking amongst renal patients to share stories and our journeys.
- More early awareness and what signs and symptoms to look out for in our community.

8) Outcomes and Discussion

End stage renal disease is epidemic locally and nationally especially in remote, regional and metropolitan areas. ESRD is a complex condition and managing it is not easy. In Cairns approximately around September 2019 there had been a 15% increase in the numbers of Aboriginal and Torres Strait Islander patients commencing dialysis treatment compared to other areas a 3% rise in Queensland. This puts an enormous strain on the renal health system having extra patients and dialysis machines available to perform treatment. Having extra shifts not only at the Hospital but other satellite units around Cairns.

Briefly the patients have discussed those issues which are important to them: In brief these are:

- Own kidney knowledge (no understanding of what's going on)
- Family issues (missing family, traditional country and gathering, other financial commitments back in home community)
- Not understanding all the medical jargon (medical language complicated)
- Not being treated in the discussions about your health (not being involved in the discussion about your health)
- Health Professional/Patient interaction (not happening)
- Continuity of care (not happening, different opinions from specialists causing confusion)
- A majority of the RN's are fantastic, it's just a couple of have stopped being a health professional
- Accommodation (not appropriate, not selected by patients and expensive)
- Patient Transport Service (limited number of flights and limited appropriate accommodation)
- Transport (no transport to GP's and shopping if you're in hospital accommodation)
- Financial issues (not use to Cairns, everything expensive, still paying off rent in their community)
- English not 1st language (patients speak English as 3rd or 4th language)
- Quality of life (poor QoL, if no family members are here in Cairns)
- Medication (too many medications to take even through a renal pharmacist on hand)
- Pathology (no understanding of what the tests mean)
- Renal Support Worker or Patient Expert (has to have good communications skills and have renal knowledge)

Similarly it is important to raise early awareness and prevention of ESRD and slowing progression down. For that contribution all PHCC are responsible and have in collaboration for this to occur. Patients spoke about life on dialysis in essence but staying positive does help.

It is vital that the Indigenous Voices Yarning Kidney Health Yarning Circles deliver important feedback from the grassroots patients from around Australia which will lead to reviews and changes to the KHA-CARI guidelines. Not only for present patients but for future patients. A

key challenge is getting the Renal Dr's and RN's and other health professionals to respect the work that has been conducted with Aboriginal and Torres Strait Islander renal patients, carers and their family members.

Having a local Renal Advisory Body or Expert Renal Patient are great ideas, as Aboriginal and Torres Strait Islander patients like talking to other patients as we have travelled down similar paths to where we are now.

9) Conclusion

As clearly indicated by the Cairns and Yarrabah Indigenous Voices Yarning Circle Aboriginal and Torres Strait Islander patients face an uphill battle trying to cope with their routine dialysis treatment including all the other issues that come associated with this dreadful disease. Aboriginal and Torres Strait Islander patients have higher number of Emergency Department hospital admissions and longer stays in hospitals with their compromised immune levels, less chances of getting a kidney transplant and don't understand how complicated dialysis treatment is.

Patients who had to leave their community and loved ones for dialysis treatment emphasized missing their home environment and family members both of which play a positive role for the patient in the healing process.

Other issues include, not understanding what's going on, getting appropriate accommodation where family members can stay for support, other medical conditions, lack of understanding about medications and pathology, diet and fluid restrictions, financial burdens here in Cairns but also back in their community and carer burn-out. Transport was also a major issues for some of the patients. Finding a good GP to connect with for 'Closing the Gap' incentives and a pharmacy for scripts.

Overall most of the patients indicated communication problems with renal staff and specialist's. This undoubtedly has an enormous impact on the environment and causes disharmony within the renal unit and ward.

In conclusion, whilst the Yarning Circle was a success it does provide an insight into the gaps within the complex tertiary health and renal systems and where immediate actions need to take place. Patients have been discussing the same issues for a very long time but seems to fall on deaf ears. Research conducted by one of the facilitators named "Indigenous Perceptions of Renal Transplants in the Cairns Community" at the Cairns Base Hospital (as it was known) over 22 years ago the same issues are present in 2019. Renal patients in Far North Queensland live in hope that the new KHA-CARI guidelines will make that difference.

10) Recommendations

1. We would recommend giving those renal patients living in remote areas who missed out on the Indigenous Voices Yarning Kidney Health an opportunity to participate with a one on one interview with an Indigenous person to obtain their experiences with renal dialysis back in their communities where they have more hardships and less or no access to medical services.
2. We also recommend that **validation themes** from previous “Yarning Circles” should not be used as we found it would bias the renal patient’s views. As nine communities are left to consult some of the questions the patients’ responses would reach full saturation.
3. We recommended a question around “carer burnout”. This occurs frequently with all patients especially the patients with high renal, medical, social and home assistance needs. Some of the carers had their own health issues to deal with plus be support for their loved ones on dialysis.
4. We recommend a question around finances “how does being on dialysis affect your finances”.
5. We recommend Aboriginal and Torres Strait Island cultural awareness training be mandatory for all hospital staff but in particular the Dr’s and RN’s of the renal units.
6. We recommend *patients always come first* and be treated in a culturally sensitive and respectful environment.
7. We recommend further research on dialysis treatments especially on calcium removal as patients have indicted not suitable for a kidney transplant therefore higher risk of heart problems.
8. We recommend a renal psychologist be engaged in the renal unit of CHHS and for satellite units. Also be available to videoconference to outer satellite units for remote communities like Bamaga.
9. We recommend better communication between the renal health unit and the patient’s GP. Often pathology results are not shared from the renal health unit, patients have to request a copy of their monthly pathology to take to their GP.
10. We recommend Aboriginal and Torres Strait Islander people need visual resources to help them understand their renal problem but some don’t have access to the internet. Renal Nurse Educator could make print outs from the KHA websites and explain to the patients where English is not first language.
11. We recommend that renal patients ask as many questions as they can as that knowledge will help better inform themselves about their renal problems.

11) Appendices

(Flyer for Indigenous Voices Yarning Kidney Health)



In consultation with:



Indigenous Voices Yarning 'Kidney Health'

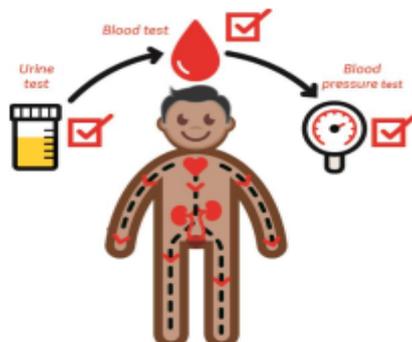
Thursday, 31 October 2019, from 10:00 am to 2:00 pm at
Apunipima Cape York Health Council, 186 Mccoombe St, Bungalow QLD.

Food and sitting fees will be provided.

Kidney Health Australia with support from Apunipima Cape York Health Council and Gurriny Yealamuka Aboriginal Health Service invite you to attend the **'Yarning Kidneys' morning tea and lunch.**

Aboriginal and Torres Strait Islander kidney patients, carers, family and community members with interest in Kidney Health are invited to attend this event to:

- 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.



During the yarning session, community members in Yarrabah and Cairns will 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 your attendance with Cilla Preece on 0415817298 or Katherine Mairu on (07) 42264209 **by Monday, 28 October, 2019.**

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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.