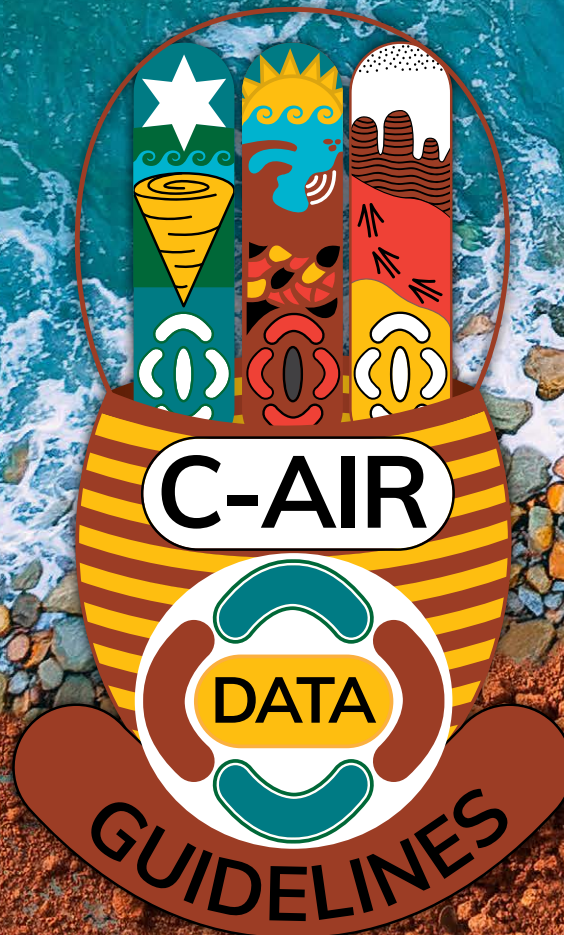


# CATCHING SOME AIR

ASSERTING ABORIGINAL AND TORRES  
STRAIT ISLANDER INFORMATION RIGHTS  
IN RENAL DISEASE



# THE FINAL REPORT



In the spirit of respect, Menzies School of Health Research acknowledges the people and elders of the Aboriginal and Torres Strait Islander nations who are the traditional owners of the land and seas of Australia.

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<https://www.menzies.edu.au/CatchingSomeAir/FinalReport>

**The Catching Some AIR project consultation meetings focused on gathering recommendations to inform the development of kidney health guidelines for best practice clinical care and data use which advances health for Aboriginal and Torres Strait Islander people.**



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# Recommended use of this report

This report will be useful for a wide group of stakeholders, with particular relevance to the renal health care community, and has the potential for translation to and impact across other health sectors.

Stakeholders who may particularly benefit from the methodology, outcomes, policy, recommendations and principles developed from the Catching Some AIR project will include:

- Aboriginal and Torres Strait Islander Communities
- Policy and Public Health Planners
- Health Services
- Aboriginal and Torres Strait Islander Health Workforce
- Data Repositories and Clinical Quality Registries
- Students in health care studies and health care educators
- Office of the Department of Prime Minister and Cabinet
- Office of the Minister for Indigenous Australians
- Departments of Health and of Treasury and Finance at State, Territory and Commonwealth levels

## Abbreviations

ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
KHA	Kidney Health Australia
KHA-CARI	Kidney Health Australia- Caring for Australasians with Renal Impairment Guidelines
NHMRC	Australian National Health and Medical Research Council
RAAC	Top End Renal Patient Advisory and Advocacy Committee

## Catching Some AIR Artwork

Local Darwin Aboriginal woman, Ms Norma Chidanpee Benger, born to stolen generation parents Marathiel/Keytej, specializes in creating images in her unique personal style, which enables the translation of information and transfer of biomedical knowledge into stories and cultural messages. Ms Benger explains her role in the Catching Some AIR project below.

*As the Catching Some AIR project Artist in Residence, I immersed myself in the issues identified by patient and family members at the consultation meetings in Thursday Island and Alice Springs. I also immersed myself in the culture and meeting dynamics within the consultation spaces, which enabled me to develop a vision, and create the Catching Some AIR project artwork.*

*My observations were that clients were very engaged in their personal responsibilities for their treatment. They were also prepared for the consultation meetings and focused on creating dialogue for moving forward. I also observed the Catching Some AIR project team was also ready to do business.*

*The message sticks represent the consultation meeting sites in Darwin, Thursday Island and Alice Springs. Message sticks were, and are, a form of communication which carry messages from place to place for Aboriginal and Torres Strait Islander peoples.*

*The pandanus basket appropriately holds the message sticks. Sun mats woven from pandanus fibers are places to sit upon, and meet with people.*

*The pandanus fibers are dyed from ochre which comes from the earth. Ochre colours represent the people and lands of these meeting places.*

*I really enjoyed working with the Catching Some AIR project team and am grateful to the team for providing me this experience. I have produced artwork for many projects, but this experience was different.*

*I am forever changed and grateful. I remain in-awe of our nations and our people's ability to face challenges while they are not well, and who fight, as a collective society, for a better way of life in the future for themselves and future generations.*

*From me, a Marathiel artist, I wish my countryman and the Catching Some AIR project team, "Musuri Guti," Good Inner Health and Wellbeing.*



Artist Norma Chidanpee Benger



## Our Team: C-AIR Investigators



### **Dr Jaquelyne Hughes**

is a Torres Strait Islander woman, living on Larrakia country in Darwin with her husband and two sons. Dr Hughes' Torres Strait Islander family come from Mabuiag Island in the near west Torres Strait. Dr Hughes is a nephrologist at Royal Darwin Hospital, and the clinical leader for the Top End Renal Services Consumer Engagement, New Start Dialysis Transition Program and Research Translation. Dr Hughes is also a Senior Research Fellow, supported by a National Health and Medical Research Council (NHMRC) Early Career Research Fellowship. Dr Hughes holds appointments with national leadership positions, including the convener of the ANZDATA Aboriginal and Torres Strait Islander Health Working group (2015- ), and the Australian co-convener of the KHA-CARI technical guideline writing group for the 'KHA-CARI Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander Peoples and Māori' (2016- ). In the Catching Some AIR project, Dr Hughes was the project leader overseeing all aspects of the project, was the technical expert in renal health care and ANZDATA at all consultation sites, and led the workforce priority focus, strategic stakeholder engagement and peer review publication outputs and completed and approved the Final Report.



### **Ms Leeann Mick-Ramsamy**

is an Aboriginal woman with traditional kinship to Kutatj (Gulf of Carpentaria), Kokoberra and Kungen (Western Cape York), and Kuku Yalanji (Palmer River/Maytown). Ms Mick-Ramsamy has extensive networks throughout Australia and has worked in Aboriginal and Torres Strait Islander health, focusing on social justice, health advocacy, policy and planning, and leadership in health planning. Her key focus includes Aboriginal and Torres Strait Islander rural and remote community health planning, health policy and planning, health promotion, community development and training. In the Catching Some AIR project, Ms Mick-Ramsamy led the design of the community consultation meetings in Darwin, Thursday Island and Alice Springs, led the development of the site reports, and policy development, and strategic stakeholder engagement. Ms Mick-Ramsamy also advised on Aboriginal and Torres Strait Islander intellectual property, project management strategy, and community engagement. Ms Mick-Ramsamy wrote the first draft of the Final Report.



### **Ms Donisha Duff**

is an Aboriginal and Torres Strait Islander woman from Thursday Island in the Torres Strait, with family links with Moa and Badu Islands, and is a Wuthathi Aboriginal traditional owner of Cape York. Ms Duff is the General Manager, Preventative Health- Deadly Choices at The Institute for Urban Aboriginal and Torres Strait Islander Health. Ms Duff is a member of the ANZDATA Aboriginal and Torres Strait Islander Health Working group, who initiated the ANZDATA Indigenous Data Sovereignty project. In the Catching Some AIR project, Ms Duff had key leadership in renal health policy development and developed the ANZDATA First Nations Data Governance Framework. Ms Duff contributed to, and approved the Final Report.



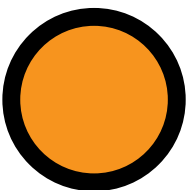
### **Dr Janet Kelly**

is a nurse researcher and lecturer at the University of Adelaide and works with Aboriginal patients, families and health care professionals to map journeys and improve health care experiences and outcomes. Dr Kelly grew up on Kangaroo Island and is of German/English descent. Dr Kelly is a member of the technical guideline writing group for the 'KHA-CARI Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander Peoples and Māori.' In the Catching Some AIR project, Dr Kelly led the documentation of all discussions at all three consultation meetings and evaluated the site consultation process, and immediate outcomes and impacts. Dr Kelly contributed to, and approved the Final Report.



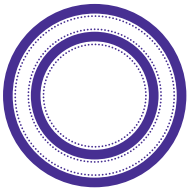
### **Mr Lachlan Ross**

is a senior Warlpiri man from the Tanami Desert community of Lajamanu. Mr Ross has a strong passion and drive to improve the quality of life for his family, community and renal patient group. Mr Ross' own personal renal journey has provided him with skill, knowledge and leadership as a Patient Expert. In 2012, Mr Ross was a foundation member of the Top-End Renal Patient Advisory and Advocacy Committee (RAAC). Mr Ross works as a Purple House Preceptor team leader, cultural advisor and link to the community. In the Catching Some AIR project, Mr Ross co-designed the consultation processes in Darwin and Alice Springs and was a clinical-community-cultural technical expert in Darwin and Alice Springs, and co-facilitated the Alice Springs consultation meeting. Mr Ross contributed to, and approved the Final Report.



### **Mr David Croker**

is an Anmatjere, Warlpiri, Jingili man. In 2012, Mr Croker was a foundation member of Top-End Renal Patient Advisory and Advocacy Committee (RAAC). Mr Croker is a Purple House Preceptor and strong advocate for people living with kidney disease. Mr Croker has worked on several research projects at Menzies. Becoming a patient educator/preceptor has been a long-term goal. Mr Croker had a renal transplant 12 years ago, after many years self-caring with home haemodialysis. In the Catching Some AIR project, Mr Croker led the information exchange between the Catching Some AIR project team and the Top-End Renal Patient Advisory and Advocacy Committee. In 2018-19, Mr Croker designed and delivered regular RAAC meetings. Mr Croker contributed to, and approved the Final Report.



### **Ms Heather Hall**

is a registered nurse, who has worked in the Top End of the Northern Territory for more than 20 years. Ms Hall's clinical experience in the acute health care and community sector covers renal nursing and Aboriginal and Torres Strait Islander Health. In the research setting, Ms Hall was a research officer and clinical facilitator with Menzies School of Health Research. Ms Hall is the Top End Manager of Panuku, the Darwin based support centre for Purple House. Ms Hall has supported RAAC since its inception in 2012, and promotes the importance of partnering with patients and facilitates consumers to raise priority concerns with decision makers and service providers. In the Catching Some AIR project, Ms Hall supported and attended the Darwin consultation meeting, and facilitated knowledge exchange between the project team and RAAC. Ms Hall contributed to, and approved the Final Report.



### **Professor Phillip Mills**

is a senior Kalkulgal elder of the Torres Strait. Professor Mills is an adjunct professor with the Australian Institute of Tropical Health Medicine, James Cook University, and an expert in cultural knowledge, policy, governance, self-determination, and a professional facilitator. He has previously led the Torres Strait Health strategy. In the Catching Some AIR project, Professor Mills supported the project leader with cultural mentorship, led all aspects of the planning and delivery of the Thursday Island consultation meeting, and facilitated the Thursday Island consultation meeting, and co-facilitated the consultation meeting in Darwin. Professor Mills supported the Thursday Island Diabetes and Kidney Health Community Committee submission to the QLD Statewide Renal Health Review. Professor Mills contributed to, and approved the Final Report.



### **Professor Alan Cass**

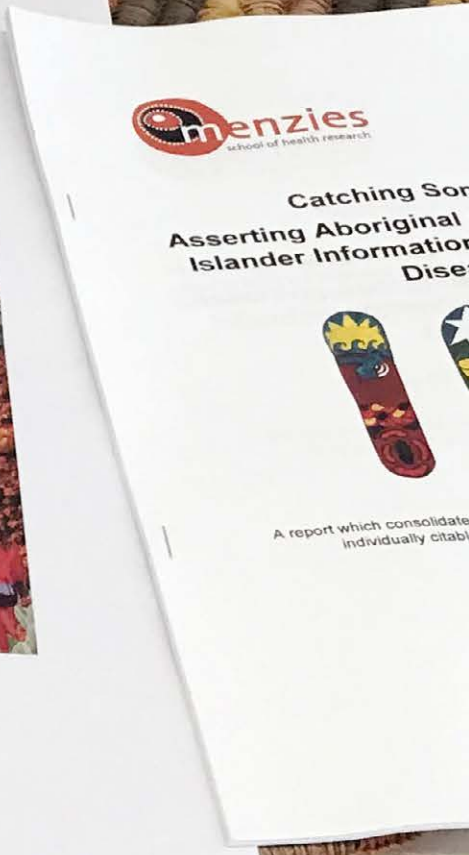
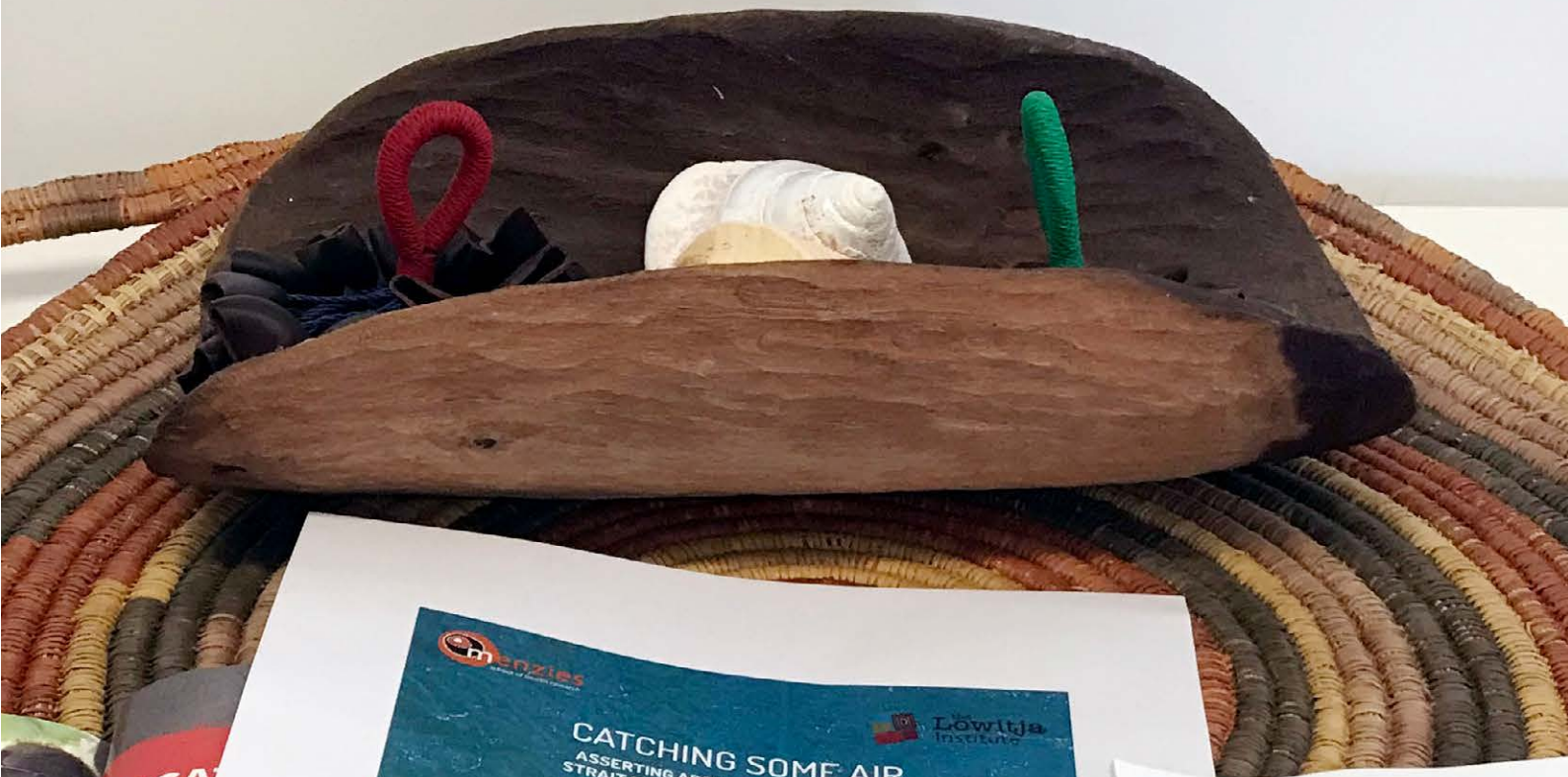
is a nephrologist by training, and the Director of Menzies School of Health Research in Darwin. Professor Cass is an internationally esteemed renal health researcher and for more than 25 years has led Australian renal policy development which has directly impacted the Northern Territory. In the Catching Some AIR project, Professor Cass supported the consultation meetings in Darwin and Alice Springs, supported key policy development, and assisted the project leader with strategic engagement of key stakeholders. Professor Cass contributed to, and approved the Final Report.

The Catching Some AIR project investigator team was responsible for the conduct and delivery of the project. Catching Some AIR project investigators acknowledge and thank many people who supported Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease.

Supporters who assisted in the delivery of the consultation meeting sites have been acknowledged within each individual site report.

We thank colleagues within Menzies and external businesses who were contracted for aspects of the project including with research administration, ethics administration, legal support, operations and logistical support, event management and catering, accounts and business management, photography, video documentation and production, transcription, evaluation, report preparation, and communications.





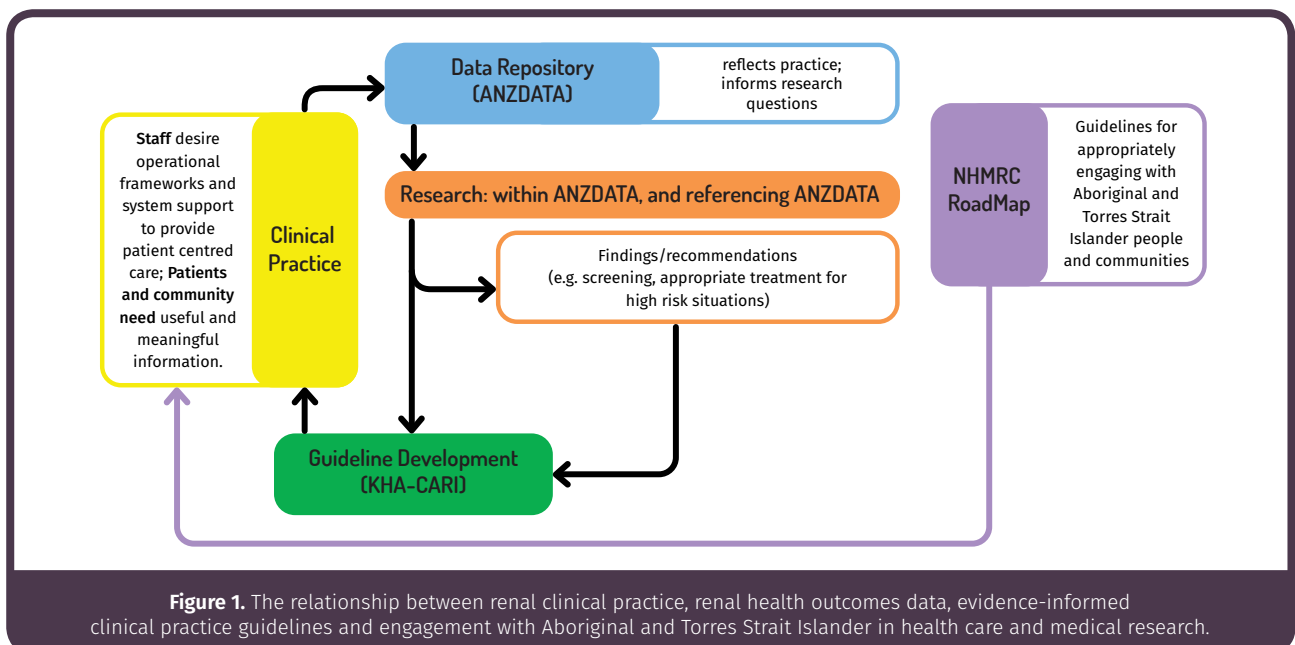
# Introduction

There is a heavy burden of chronic kidney disease (CKD), progressive CKD and dialysis requiring end stage kidney disease (ESKD) among Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander people are also reported to have low access to kidney failure treatment care close to their homes [1].

Optimal renal health care outcomes for Aboriginal and Torres Strait Islander peoples across Australia can be strategically supported through the development and use of nationally endorsed clinical practice guidelines (Figure 1). Health care users benefit from endorsed best practice guidelines, when they are implemented in the health care setting. Australia lacks nationally-relevant community-informed best practice renal clinical care guidelines for the management of CKD in Aboriginal and Torres Strait Islander peoples [2].

In 2016, Kidney Health Australia Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines committed to creating the inaugural 'KHA-CARI Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples and Māori'. The KHA-CARI Guidelines technical writing team was appointed in 2016, and await community-informed recommendations for care, which will contribute to existing published evidence for this guideline [2].

Australian Clinical Quality Registry's collate, store and report data about specific health conditions and are an important oversight mechanism of the Australian health care system. The Australia and New Zealand and Dialysis and Transplant Registry (ANZDATA) reports health care outcomes for kidney failure treatments (dialysis and kidney transplantation) [3]. Australian Clinical Quality Registry's lack guidelines for First Nations Data Sovereignty which specifically address data practices for Aboriginal and Torres Strait Islander peoples data. Therefore, ANZDATA lacks a First Nations-informed best practice guideline for data use and processes [4].



# The Catching Some AIR Project

The Catching Some AIR project (Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease) was authorized and endorsed by ANZDATA and KHA-CARI Guidelines to seek community-informed recommendations for these guidelines for best practice from Darwin, Thursday Island and Alice Springs.

The Catching Some AIR project was funded by the Lowitja Institute for Aboriginal and Torres Strait Islander Health CRC, under the priority research theme of First Nations Data Sovereignty. The project commenced in December 2017, and concluded in May 2019.

## Funder and Collaborators

### Funder



### Partners

- ANZDATA
- KHA-CARI Guidelines
- Top End Renal Patient Advisory & Advocacy Committee (RAAC)
- Menzies School of Health Research

### Collaborators

- Panuku
- Top End Health Services
- Thursday Island Diabetes and Kidney Health Community Committee
- Kaurareg Aboriginal Land Trust
- Kidney Health Australia

## Aims

To collate recommendations from Aboriginal and Torres Strait Islander patients and carers living in Darwin, Thursday Island and Alice Springs which would inform the evidence base for creation of:

1. The inaugural KHA-CARI Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples and Māori.
2. An Inaugural Indigenous Data Governance Framework within a binational kidney disease clinical quality registry (ANZDATA).

# Processes

Aboriginal and Torres Strait Islander peoples who live with chronic and end stage kidney disease were invited to participate in consultation meetings and advise recommendations for guidelines for 1) Best Practice Renal Clinical Care and 2) Best Practice Renal Health Data.

## Consultation Resource development

In order to discuss the intended outcomes of the consultation meetings, we developed Figure 1 to conceptualize the relationship between clinical practice, health outcomes data, research, and evidence-informed guidelines for best clinical practice. Figure 1 also references Australian National Health and Medical Research Council (NHMRC) best practice guidelines for engaging with Aboriginal and Torres Strait Islander communities in health and medical research.

Two technical booklets were prepared to aid the consultation goals.

Booklet 1 summarised key information about the ANZDATA organisation and included the ANZDATA information graphic representing key information about kidney failure treatments received by Aboriginal and Torres Strait Islander peoples.

Booklet 2 focused on the definition of clinical care guidelines, and referenced existing clinical care guidelines, and a report which presented patients views about renal health and the care they receive:

1. The Indigenous Patient Voices: Gathering Perspectives Finding Solutions to Chronic and End Stage Kidney Disease Symposium Report [5].
2. The Central Australian Rural Practitioners Association (CARPA) Standard Treatment Manual for remote area health practitioners [6].
3. The KHA Guideline for the Management of CKD in General Practice [7].


## Community engagement

The community development principle of 'valuing the local' was used to engage renal patients as experts. The cultural strengths of the facilitator team included both Aboriginal and Torres Strait Islander facilitators, including both a male and female facilitator, who had strengths in community development principles and practices. In the Catching Some AIR project, the consultations were structured around the values and strengths of the consulted community. The Catching Some AIR project consultation team referenced the following best practice methods in the design of consultation meetings [2]:

1. Consultations should be informed by Aboriginal and Torres Strait Islander peoples who are expert in their own communities, renal health care service delivery, and have a lived experience of chronic and end stage kidney disease.
2. Transparent and inclusive community consultations which would ensure relevance of guidelines to the local context.

Prior to each consultation meeting, technical experts at each site (Darwin, Thursday Island and Alice Springs) partnered with the expert-facilitator over a two-week period, to co-design the optimal participation of Aboriginal and Torres Strait Islander delegates (Box 1). Local community members and renal patients played an integral role as cultural brokers which ensured culturally appropriate bidirectional knowledge was exchanged between the community delegates and the Catching Some AIR project team.

Expert professional facilitators brokered culturally safe consultation meetings in "closed morning meetings" for patients and carer delegates and technical experts. The facilitators anticipated the desire for patients and carer delegates to immediately present regionally-specific key recommendations, which could be further addressed by participation of external



stakeholders. Therefore, the closed meetings were followed by an “open afternoon meeting”, which brought together stakeholder delegates with patients and their carers. A summary of the key discussion points was presented by Aboriginal and Torres Strait Islander renal patient delegates, followed by an interactive discussion which enabled stakeholders to acknowledge and respond to the reflections and recommendations proposed by patient and carer delegates.

Following the consultation meetings, and over the next nine months, where possible, the Catching Some AIR project aided and advocated for key policy and strategic outcomes on behalf of recommendations identified at the consultation site meetings.

Individual written site reports and an individual video summary report for each consultation site was also developed and delivered locally.

Three additional validations of consultation-methodology sites were engaged. The Catching Some AIR project team were hosted by The Institute for Urban Indigenous Health (March 2019), Local Government Association of the Northern Territory (LGANT) (April 2019), and Katherine Dialysis Clinic, Fresenius Medical Care Australia Pty Ltd (May 2019).

An integrated planning approach was used which worked interchangeably between the community, Territory/ State governments, local government, and Federal government. Advocacy which followed the site consultations was undertaken with full knowledge and consent of patient and carer delegates (see strategic outcomes).

### **Pre-Meeting Planning and Consultation**

- Identifying cultural brokers/ facilitators/ renal patients
- Selection and engagement of participants: renal patient, carers and stakeholders

### **Meeting Facilitation and Consultation**

- Cultural brokers/ facilitators/ renal patients
- Closed session (alternate days) with renal patients and carers
- Open session with stakeholders

### **Post Meeting Feedback**

- An in-person presentation by the Catching Some AIR project leader of the site report and site video before public release.

### **Project Reporting**

- The Catching Some AIR final project report was presented in a Final project video
- A Talking Report Symposium involving 56 patient’s, carer’s, community members and stakeholders was delivered on the 17th June 2019. A presentation of project activities, findings and recommendations was delivered. A list of delegates is provided in the appendix.
- This Final Project Report was completed and informed by dialogue at the Catching Some AIR project Talking Report Symposium.

# Reporting and Outputs

Reporting the Catching Some AIR project activities and outcomes throughout the project was important to participating communities, and valued and emphasised by the project funder, the Lowitja Institute. Renal clinical-academic stakeholders and intended health care users of guidelines value peer reviewed publication. The Catching Some Air project team included investigators with skills in community based reporting and academic dissemination. The Catching Some AIR project outputs are described below.

<b>Reports</b>	Site Reports	<a href="https://menzies.edu.au/icms_docs/306883_Combined_Summary_Report_Catching_Some_Air.pdf">menzies.edu.au/icms_docs/306883_Combined_Summary_Report_Catching_Some_Air.pdf</a>
	Final Report	<a href="https://menzies.edu.au/CatchingSomeAir/FinalReport">menzies.edu.au/CatchingSomeAir/FinalReport</a>
<b>Policy</b>	A Targeted Policy Brief	<a href="https://menzies.edu.au/icms_docs/306882_Targeted_Policy_Brief_Catching_Some_Air.pdf">menzies.edu.au/icms_docs/306882_Targeted_Policy_Brief_Catching_Some_Air.pdf</a>
<b>Video</b>	Site Videos	<a href="https://vimeo.com/album/5831154">vimeo.com/album/5831154</a>
	Project Summary Video	<a href="https://vimeo.com/343341838">vimeo.com/343341838</a>
<b>Media</b>	Print Media	<a href="https://menzies.edu.au/icms_docs/284626_NT_News_Meetings_for_Health_School.JPG">menzies.edu.au/icms_docs/284626_NT_News_Meetings_for_Health_School.JPG</a>
		<a href="https://menzies.edu.au/icms_docs/284584_Creating_better_guidelines_for_kidney_health_management.pdf">menzies.edu.au/icms_docs/284584_Creating_better_guidelines_for_kidney_health_management.pdf</a>
	Social Media	<a href="https://youtube.com/watch?v=g8HL0-nlfr4">youtube.com/watch?v=g8HL0-nlfr4</a>
	Twitter	<a href="https://twitter.com/CatchingSomeAir">#CatchingSomeAir</a>

**Box 2.** Resources and publications developed in the Catching Some AIR project which assert Aboriginal and Torres Strait Islander information rights in renal disease.

# Recommendations

The Catching Some AIR project team recorded recommendations for best practice guidelines from each consultation site. Some key recommendations were consistent in each site as evidenced by the site reports and videos. A peer reviewed publication which describes clinical care guidelines recommendations is planned. The identified key themes were expressed as “Principles for optimal renal health”:

## Principles for optimal renal health

- *Aboriginal and Torres Strait Islander peoples assert their right to live with optimal renal health*
- *A coordinated and economically sustainable strategy across all levels of government is required to achieve Aboriginal and Torres Strait Islander renal health*
- *Renal Prevention Centres in rural and remote Aboriginal and Torres Strait Islander communities should be developed and supported*
- *Aboriginal and Torres Strait Islander cultural leadership in renal health prevention, diagnosis, treatment, management, and data governance should be supported*
- *Renal health data which can support and promote Aboriginal and Torres Strait Islander renal health should be used to monitor renal health, report renal health advancement, and inform Aboriginal and Torres Strait Islander people of activities and outcomes directed toward closing the gap in renal health and renal disease*
- *Allocation of existing funding and policy efforts should be re-focused to improve Aboriginal and Torres Strait Islander renal health.*

The principles for optimal renal health guided activities of the Catching Some AIR project team, and resulted in the following strategic outcomes.



# Strategic Outcomes

## 1. Recommendations for Guidelines

- Best Practice Renal Clinical Care: is foundationally based on the Principles for Optimal Renal Health, which are informed by the individual site reports, site videos and Policy brief (Strategic Outcome 3).
- Best Practice Renal Health Data: A presentation outlining the recommendations for an Indigenous Data Governance Framework for ANZDATA was presented at the Catching Some Air Talking Report Symposium, and will be detailed in a manuscript prepared for peer reviewed publication.

## 2. Top End Renal Advisory and Advocacy Committee (RAAC)

- Were supported financially to partner with the Catching Some AIR project, which enabled their self-determination to design and define stakeholder engagement on behalf of members, who also developed a business profile.

## 3. A Targeted Policy Brief

- Dr Hughes engaged directly with the Minister for Indigenous Health and Shadow Minister for Indigenous Health on 29th November 2018, who invited the Catching Some AIR project to submit a targeted policy brief.
- The Targeted Policy Brief addressed four areas and was submitted on December 18th 2018:
  1. Coordinated and economically sustainable strategies to address renal health across all levels of government
  2. Meaningful knowledge sharing for the Aboriginal and Torres Strait Islander Renal Patient Community
  3. Preventative Health care
  4. Sustainable Workforce, including Aboriginal and Torres Strait Islander people in diverse roles and leadership across the entire renal health care workforce

## 4. Community Voices Directly Influencing National Policy

- April 2018: KHA Interim Chief Executive Officer, Dr Lisa Murphy, participated as a technical expert at the Catching Some AIR project consultation meeting in Darwin.
- April 2019: The Catching Some AIR Targeted Policy Brief was submitted to the Federal Department of Health as a parallel and unedited document sitting alongside the National Strategic Action Plan for Kidney Disease which was led by Kidney Health Australia, and commissioned by the Federal Department of Health.

## 5. Renal Health Workforce

- The Northern Australia Aboriginal and Torres Strait Islander Kidney Health Workforce Taskforce was developed from a meeting hosted on August 3rd 2018, in response to a request from Aboriginal and Torres Strait Islander workforce delegates who participated in the Catching Some AIR consultation meetings.
- Dr Hughes participated in the 'Aboriginal and Torres Strait Islander Health Workforce Round Table' on January 23rd 2019. The Round Table was convened by the Minister for Indigenous Health, the Hon Ken Wyatt AM MP. Minister Wyatt presented the Roundtable recommendations on the 8th March 2019 to State and Territory Health Ministers at the Council of Australian Governments Health Council Meeting.



# Moving Forward

The Catching Some AIR project team, renal patients, carers and stakeholders endorsed the following statements:

We will

- 1. Support Aboriginal and Torres Strait Islander people's human rights to live with optimal renal health**
- 2. Advocate for the creation of coordinated and economically sustainable strategies across all levels of government to achieve Aboriginal and Torres Strait Islander renal health**
- 3. Advocate for the development and support of Renal Disease Prevention Centres in rural and remote Aboriginal and Torres Strait Islander communities**
- 4. Advocate for and support Aboriginal and Torres Strait Islander cultural leadership in renal health prevention, diagnosis, treatment and clinical management and data management and custodianship**
- 5. Use Renal health data to support and promote Aboriginal and Torres Strait Islander renal health, by monitoring renal health, reporting renal health advancement, and informing Aboriginal and Torres Strait Islander people of activities and outcomes directed toward closing the gap in renal disease**
- 6. Advocate for and support the allocation of existing funding and policy efforts to improve Aboriginal and Torres Strait Islander renal health.**

## Catching Some AIR Project Evaluation

Independent evaluators were contracted to deliver findings related to key strengths, weaknesses, opportunities and threats associated within the Catching Some AIR project. The evaluation included two parts. Part 1 included an observation of the site visit consultation meetings (Darwin, Thursday Island and Alice Springs), with reference to the Aboriginal and Torres Strait Islander leadership roles in facilitation and community engagement. The Part 2 evaluation reported feedback from structured interviews with key patient experts, and key government and non-government stakeholders.

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6. Remote Primary Health Care Manuals. (2017). CARPA Standard Treatment Manual (7th edition). Alice Springs, NT: Centre for Remote Health. *Chronic Diseases, Chapter 4, Chronic Kidney Disease*; 244-245. Accessed from: <https://docs.remotephcmanuals.com.au/review/g/manuals2017-manuals/d/20315.html?page=16> Access date: 26/4/2019.
7. Chronic Kidney Disease (CKD) Management in General Practice, in Guidance and clinical tips to help identify, manage and refer patients with CKD in your practice. 2015, *The Australian Kidney Foundation: Melbourne*.

# Appendix

A final project report was presented in The Catching Some AIR Talking Report Symposium on June 17th 2019 in Darwin, in conjunction with video conferencing live sites hosted in Thursday Island and Alice Springs. Fifty six delegates attended, including 26% of delegates who were representing the patient, carer and community sector and 74% of delegates representing other stakeholders.

## *Delegates in attendance*

Ms Lydia Agius  
Mr Willie Baira  
Ms Barbara Beaton  
Dr Shayne Bellingham  
Fr. Dalton Bon  
Dr Stephen Brady  
Dr Megan Brown  
Mr Craig Castillon  
Dr Swasti Chaturvedi  
Dr Sajiv Cherian  
Ms Belinda Davis  
Ms Vanessa Drotini  
Professor Karen Dwyer  
Ms Jodie Ellis  
Ms Amanda Elzini  
Ms Eleanor Garrard  
Dr Nick Georges  
Ms Gill Gorham  
Ms Launa Graham  
Ms Abigail Harry  
Ms Caroline Hombarume  
Ms Dell Hunter  
Associate Professor Shilpa  
Jesudason  
Ms Yomei Jones  
Professor Matthew Jose  
Ms Katarina Keeler  
Ms Vicki Kerrigan  
Dr Renae Kirkham

Ms Gwen Lowah  
Ms Gundimulk Marawilli  
Ms Solanima Mareko  
Ms Kelly McIntosh  
Ms Shona Medley  
Mr Sam Mills  
Ms Michelle Misener  
Ms Cessa Nakata  
Ms Patty Nakata  
Ms Yoko Nakata  
Mr Samuel Nelsen  
Dr Odette Pearson  
Ms Sarah Robinson  
Mr Robert Sagigi  
Mr Seriako Stephen  
Ms Mandy Troung  
Mr Quentin Walker Jurrah  
Ms Rachel Walker  
Ms Diane Walker  
Mrs Mary Ward  
Mr Bobby West  
Ms Christine West  
Mr John Whop  
Mr Willie Wigness  
Mr Daniel Williamson  
Ms Sharon Wilson  
Ms Pamela Wood  
Ms Keesha Yamashita

## *The Talking Report Symposium Catching Some AIR Project Team*

Mrs Norlisha Bartlett  
Professor Alan Cass  
Ms Paris Caton-Graham  
Ms Donisha Duff  
Ms Julie Green  
Ms Heather Hall  
Dr Jaquelyne Hughes  
Dr Janet Kelly  
Ms Dorothy Morrison  
Dr Perry Morrison  
Ms Leeann Mick-Ramsamy  
Mr Lachlan Ross

