



Summary Report

Catching Some AIR

Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease

A consultation meeting to inform

the development of clinical care and data guidelines for
Aboriginal & Torres Strait Islander kidney health

Alice Springs, NT

6- 7 September 2018



Australia's National Institute for Aboriginal and
Torres Strait Islander Health Research



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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Acknowledgements

The Project team delivering the Catching Some Air -Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease project (known as *Catching Some Air*) is based at Menzies School of Health Research. *Catching Some Air* acknowledges the support and funding provided by the Lowitja Institute.

We thank the patient, carer and stakeholder delegates who contributed to the Alice Springs consultation meeting, recognising the recommendations made to guide clinical care and data guideline would not have been possible without all these contributions.

A special acknowledgement and our thanks extend to the Alice Springs community engagement planning leaders

- Mr Lachlan Ross, Walpiri elder, member Top-End Renal Patient Advisory and Advocacy Committee, *Catching Some Air* project team
- Ms Irene Nangala member of the Central Australian Renal Voice (CARV)
- Mr Quintin Walker, Elder for Tennant Creek region
- Ms Leeann Mick-Ramsamy

We also thank the technical experts and facilitators as follows:

- Dr Jaquelyne Hughes, NHMRC Early Career Fellow, Nephrologist Royal Darwin Hospital (expert technical expert)
- Mr Lachlan Ross, Walpirri leader, Kidney Transplant Patient, Cultural Leader, Kidney Advocate for Change (expert technical expert and consultation meeting facilitator)
- Ms Leeann Mick-Ramsamy (community engagement lead consultant and consultation meeting facilitator)

Abbreviations

ANZDATA	Australia and New Zealand Dialysis and Transplantation Registry
CARPA	Central Australia Rural Practitioners Association
KHA	Kidney Health Australia
KHA-CARI	Kidney Health Australia – Caring for Australasians with Renal Impairment



Catching Some Air Consultation Process

Nationally endorsed clinical practice guidelines and data sovereignty processes are required to underpin best practice implementation, but require input from renal patients, their carer's, community and government stakeholders.

Whilst a resolve exists from both Indigenous communities and national health groups for partnerships to advance Indigenous kidney health, both parties are uncertain of ways to achieve this, and this joint uncertainty delays health benefits for communities most impacted by kidney disease.

Catching Some Air is based at Menzies School of Health Research and has been funded by the Lowitja Institute for 18 months. One aspect of the *Catching Some Air* project is to gather recommendations from the Aboriginal and Torres Strait Islander kidney health community about the design and development of best practice and community-informed guidelines for:

1. Indigenous Data Governance Framework for Aboriginal and Torres Strait Islander data within the Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA);
2. Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples.

Consultation meetings in Alice Springs, Darwin and Thursday Island have formed the main way of gathering these recommendations. Secondary consultation sites where we intend to demonstrate and test the consolidated recommendations learned from the three main sites are planned.

The *Catching Some Air* final report will be completed July 2019.

Delegates

The selection of participants for consultation was based on capturing all members of the wider kidney health community to meet and be informed by the patients and carers identifying future directions as a collective group, moving forward together.

Delegates represented a wide range of communities within Central Australian and Western Australian communities and those closely bordering Queensland, South Australia who have traditional kinship across borders.

Participants involved in consultation and meeting participants included: Renal patients, their carer's and family members; clinicians, policy makers, providers and other stakeholders. The delegates are listed by name in Table 1.

Table 1. Participants involved in Consultation

Patient & Carer Delegates	Rosie Pattesen	Kylie Dingwall	Leeann Ramsamy
Irene Nangala	Hettie Meneri	Sue Korner	Jaqui Hughes
Ronnie Rustie	Morris Jackson	Heather D'Antoine	Janet Kelly
Annie Ferbes	Ivy Nelsen Smith	Naomi Heinrich	Vicki Kerrigan
Sandra Wayne	Kerry Campbell	Alan Cass	Norma Benger
Trevor Couthard	Launa Graham	Bec Bromfield	
Marlene Wheeler	Lindsey Corby	Pauline Otieno	
Wendy Morgan	Larissa Granites	Megan Brown	
Preston Enalanca	Munatji Brumby	Kostas Kapellas	
Clarey Campbell	Nganana Tjungurringu	Lauren Caruana	
Tony Nelsen	Ivy Nelsen Smith	Michelle McGuirk	
William Sandy	Stakeholder Delegates	Sajiv Cherian	
Samuel Nelsen	Sue Crail	Ken Wyatt*	
Marilyn Nangala	Kiran Fernandes	Catching Some Air project support team	
Jimmy Langdon	Leisa McCarthy	Lachlan Ross	
Booby West	Basant Pawar	Irene Nangala	
Quinten Walker	Anna Holwell	Quinten Walker	

Aboriginal and Torres Strait Islander Patients and Carers Session

A Closed Session

The closed morning sessions hosted Aboriginal and Torres Strait Islander patient and carer delegates who met with the facilitator and technical expert team.

A summary of ANZDATA and Kidney Health Australia – Caring for Australasians with Renal Impairment guidelines was provided. We referenced the desire for KHA, KHA-CARI and ANZDATA to have community informed best-practice guidelines.

We referenced existing guidelines in Indigenous kidney health

1. Indigenous Patient Voices Symposium report (the most contemporary and published recommendation for Aboriginal and Torres Strait Islander kidney health advancement)
2. CARPA Manual for remote area health practitioners
3. KHA Guideline for the management of CKD in General Practice
 - Guidelines specifically for use by the nephrology clinical community were presently absent. These guidelines could be referenced to data and clinical care

Key questions included:

- “How ANZDATA is used- Do kidney patients want access to the data?”
- “What does your community want?”
- “KHA CARI Guidelines, what are key issues that need to be included”



Key principles identified by renal patients

- Our community health is important and we must educate our families and communities about kidney disease and how to prevent it.
- Kidney sickness is not our health story – never was part of our culture.
- Our right to live and have treatment in our community, and which does not impede the ability to live with culture.

Bringing Delegates Together

An Open Session

The closed discussion with kidney patients and carer's allowed and focussed the dialogue of the open discussions with stakeholders. This approach gave value to developing best practice guidelines for ANZDATA and KHA-CARI Guidelines, but value-added to inform current and future health service delivery and address gaps in services.

The Thursday and Friday afternoon stakeholder discussions addressed specific questions identified by renal patients and their carer's.

An action planning session followed, where a discussion of what type of commitment could be offered from various key stakeholders. These discussions will be further developed in the final Catching Some Air report.



Key Recommendations

- Kidney disease is everyone's business in Central Australia. Stakeholders need to strategically collaborate in moving the patient journey agenda forward.
- Renal patients, their carer's, families and communities cannot continue to work in isolation of renal health services in the wider community (government and non-government agencies) and vice versa.
- Moving forward requires a collective effort across the patient kidney community and levels of government and non-government agencies
- Systematic and comprehensive approaches are required.



Key Dates

- Consultation meeting dates:
 - Darwin April 23-24th 2018
 - Thursday Island June 5-7th 2018
 - Alice Springs September 6-7th 2018
- Overall project feedback July 2019

Staying Connected

- Catching Some Air project updates are featured here:
https://www.menzies.edu.au/page/Research/Projects/Kidney/Catching_Some_Air-Asserting_Indigenous_Information_Rights_in_Renal_Disease/
- The webpage also features our newsletters and videos
(<https://vimeo.com/277034735>)
- Follow our activities on twitter #CatchingSomeAir

Catching Some Air Project lead

Dr Jaqui Hughes

Senior Research Fellow

Menzies School of Health Research

www.menzies.edu.au

jaqui.hughes@menzies.edu.au

Phone: 08 8946 8518



Catching Some Air message stick designed

by Ms Norma Benger. It represents

Central Australian health care user's
authority to guide recommendation
standards for data and clinical care for

kidney health. The artwork and
photographs are not to be reproduced.