



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

Darwin, NT

23– 24 April 2018



the
Lowitja
Institute

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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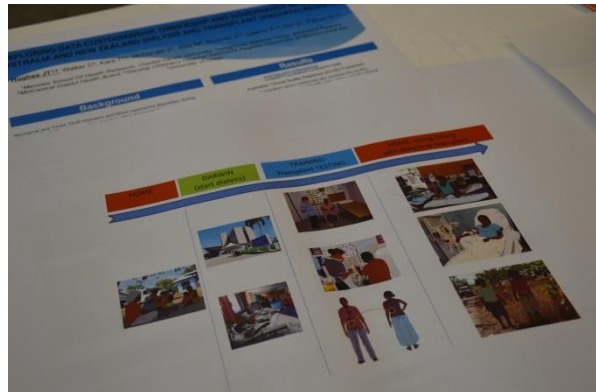
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The Darwin consultation meeting video report is found at <https://vimeo.com/267732848>

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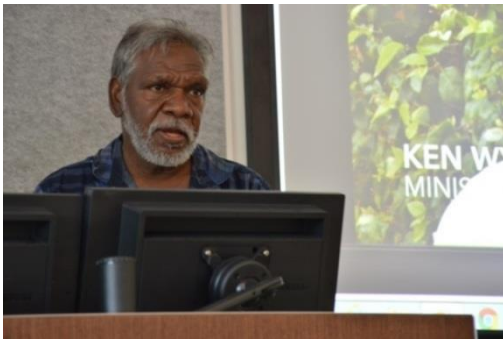
Acknowledgements

The Project team delivering the Catching Some Air -Asserting Indigenous 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 Lowijta Institute.

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

Special acknowledgement and our thanks are extended to:

- The Top-End Renal Advisory and Advocacy Committee group members, Mr Lachlan Ross and Mr David Croker who were integral to the planning process
- Expert technical advisors:
 - Mr Lachlan Ross, Walpirri leader, Kidney Transplant Patient, Cultural Leader, Kidney Advocate for Change
 - Dr Jaquelyne Hughes, NHMRC Early Career Research Fellow, Nephrologist Royal Darwin Hospital
 - Dr Lisa Murphy, Interim Chief Executive Officer, Kidney Health Australia
- Facilitators and logistic support



Mr Lachlan Ross



Dr Jaquelyne Hughes & Dr Lisa Murphy

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
RAAC	Top End Renal Patient Advisory and Advocacy Committee

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 carers, 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 a project based at Menzies School of Health Research. The project has been funded by the Lowijta Institute during 2017-2019. One key activity of the project is to gather recommendations from the Aboriginal and Torres Strait Islander kidney health community about the development of best practice and community-informed guidelines for an:

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

Consultation meetings in Darwin, Alice Springs and Thursday Island will form the main way of gathering these recommendations. There will be secondary consultation sites where we intend to demonstrate and test the consolidated recommendations learned from the three main sites.



Consultation Meeting Participants

A diverse range of delegates were invited to be involved in the meeting, and to identify future directions as a collective group.

Meeting participants included renal patient's, their carer's and family members; clinicians, policy makers, federal government, local government, housing and accommodation service providers, Northern Territory Department of Health, Aboriginal Community Controlled Health Organisations, Top-End Health Services, University training and research sector, community advocates for change, Transplant Society of Australia and New Zealand (Table 1).



Table 1 Delegates

Patient & Carer Delegates	Stakeholder Delegates	
Cedrina Algy	Amy Burrows	Sarah Robinson
Stanley Bara	Alan Cass	Selina Signal
Timothy Bidingal Butjala	Craig Castillon	Christina Spargo
Fed Bush	Leeane Caton	Tony Tapsell
Nancy Cooper	Swasti Chattervedi	Rachael Walker
Gloria Friday	Sinon Cooney	Christine West
Sian Graham	Beth Cooper	Justine Williams
Shana Harrison	Karrina Demasi	Anna Wood
Monica Haussin	Lenore Dembski	Ken Wyatt*
Peter Henwood	Kerry Dole	Catching Some Air project support team
Delma Holt	Karen Dwyer	Lydia Aguis
Doreen Long	Camilla Feeney	Paul Dale
Gundimulk Marrawilli	Helen Fejo-Frith	Jaqui Hughes
Cathie Nickels	Saehim Gamage	Janet Kelly
Kathleen Parry	Heather Hall	Vicki Kerrigan
Anne-Marie Puruntatameri	Willy Johnson	Vongayi Majoni
Myra Rory	Nadarajah Kangaharan	Phillip Mills
Cedric Stassi	William Majoni	Lisa Murphy
Cathy Stassi	Michelle Misener	Ada Parry
Richard Tasman	Sandra Nelson	Sylvannia Patrick
Josephine Timothy	Jessica Nikolwsky	Leeann Ramsamy
Gerarda Tipiloura	Irene O'Meara	Lachlan Ross
Melva Wanambi	Peter Perfremont**	Melody Song
	Josie Povey	Tabled video* or email** support

Aboriginal and Torres Strait Islander Patient's and Carer's consultation: a closed session

The morning session hosted patient and carer delegates, meeting facilitators and technical experts.

A summary of ANZDATA and Kidney Health Australia – Caring for Australasians with Renal Impairment guidelines group was presented.

The desire for KHA-CARI and ANZDATA to have community informed best-practice guidelines was discussed.

Existing guidelines in Indigenous kidney health were referred to, including:

1. Indigenous Patient Voices Symposium report (the most contemporary and published recommendation for Aboriginal and Torres Strait Islander kidney health advancement)
2. Central Australian Rural Practitioners Association (CARPA) Standard Treatment Manual for remote area health practitioners
3. KHA Guideline for the management of CKD in General Practice

There are no current Indigenous renal care guidelines available for use by kidney doctors and other health professionals.



Bringing Delegates Together: an open session

The delegates from the closed morning session met with stakeholder delegates over lunch.

The afternoon session included

- A summary of the morning's key discussion points was presented by several delegates
- A presentation by Associate Professor Phillip
- A shared discussion which gave stakeholders an opportunity to acknowledge and respond to the reflections and recommendations proposed by patient and carer delegates. Stakeholders were invited to respond, and further discussion occurred.



Key recommendations

The Darwin consultation meeting reflects a strong message that

- Kidney health and kidney disease is everyone's business - and this needs to be reflected in clinical care guidelines, data governance and holistic care that reflects patient's worldview. All stakeholders are valid and continuing partners in creating and sustaining community kidney health.
- The Darwin patient and carer delegation have confirmed the need to stay engaged in developing the key recommendations. The Catching Some Air project team have committed to continue working with:
 - Top-End Renal Advisory and Advocacy Committee (RAAC) and
 - Top-End Renal Service Indigenous Patient Reference Group



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/267732848>)
- Follow our activities on twitter #CatchingSomeAir

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Catching Some Air message stick designed by Ms Norma Benger. It represents Top-End Aboriginal 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.