



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

Thursday Island, QLD

5-8 June 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.

ISBN: 978-1-922104-47-2 (online).

© Menzies School of Health Research 2018

The material contained in this document is the subject of copyright and / or privileges information. Any use, disclosure (written or verbal), copying or dissemination of this document is prohibited without written consent from the Menzies School of Health Research. Catching Some Air investigators are Dr JT Hughes, Ms L Ramsamy, Ms D Duff, A/Prof P Mills, Prof A Cass, Dr J Kelly, Ms H Hall, Mr L Ross, Mr D Croker. Photos and images by Will Tinnapple, Formation Studios.

Suggested citation: Hughes JT, Kelly J, Mick-Ramsamy L, Mills P (2018) Summary Report, Thursday Island, Catching Some Air- Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease. [online]: Menzies School of Health Research. Available at: <https://bit.ly/2AQz1Td>

Contents

Acknowledgements	4
Abbreviations	5
Catching Some AIR Consultation Process.....	6
Consultation Meeting Participants.....	7
Aboriginal and Torres Strait Islander Patient's and Carer's consultation: a closed session.....	8
Bringing Delegates Together: an open session.....	9
Key Recommendations	10
Key Activities and Outcomes.....	11
Key Dates.....	12
Staying Connected	12



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.

The Catching Some Air project team have a delegated role to consult with the Aboriginal and Torres Strait Islander kidney community to obtain guidance on

1. The development of an Indigenous data governance framework and implementation processes within a binational kidney disease clinical quality registry (ANZDATA)
2. How to create effective, safe, culturally appropriate health systems for patients and communities most impacted by kidney disease. These recommendations will feed into the KHA-CARI Guidelines for Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples and Māori.

We thank the patient, carer and stakeholder delegates who contributed to the Thursday Island 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:

- Expert technical advisors:
 - Dr Jaquelyne Hughes, NHMRC Early Career Fellow, Nephrologist Royal Darwin Hospital
 - Mrs Mary Ward, Torres Strait Islander expert cultural mediator and community development research advisor
- Facilitators:
 - Ms Leeann Mick-Ramsamy
 - Associate Professor Phillip Mills
- Administrative and media support
 - Dr Janet Kelly, Evaluation Support
 - Ms Norma Bengier Artist in Residence
 - Mr Will Tinapple, Video Producer

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 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 based at Menzies School of Health Research and has been funded by the Lowijta 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 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. The project has a waiver of ethics (negligible risk) to undertake consultations, and approval for the community members and elders in Thursday Island. Image use was approved by delegates.

Key stakeholders within the community of Thursday Island invited the *Catching Some Air* project team to extend a series of consultation meetings over four days (5th-8th June 2018). Engagement with key stakeholders in Cairns also occurred on the 4th June 2018.

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 (Table 1). The stakeholders listed were those who provided direct feedback, and wished to stay connected with project development.

Patient & Community Delegates

Ms Nazareth Adidi

Ms Ina Aputa

Ms May Assan

Fr Dalton Bon

Mrs Ivy Chiney Bon

Mrs Veda Bon

Ms Florence Dorante

Ms Emma Gebadi

Ms Abigail Harry

Ms Diai Luffman

Ms Bua Mabo

Ms Syreeta Mills

Ms Patricia Nakata

Ms Cessa Nakata

Mr Thomas Namoa

Ms Bertha Natanielu

Ms Maleta Nona

Mr Robert Sagigi

Mr Walter Sailor

Mrs Nancy Sailor

Mr Wigness Seriat

Mr Seriako Stephen

Mrs Lucy Stephen

Rev Tom A Stephen

Ms Enid Surha

Mrs Betty Tekahika Mabo

Mrs Mary Ward

Mr Willie A Wigness

Mr Marsat Ketchell

Mr Sam Mills

Ms Yoko Nakata

Ms May Seriat

Mr Wally Shibasaki

Stakeholder Delegates

Ms Salli-Anne Hart

Dr Murty Mantha*

A/Prof Ashim Sinha*

Ms Rochelle Pitt*

* Cairns consultation

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

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.

Recommendations from the community were developed during five sessions over the study visit.



Bringing Delegates Together: an open session

We hosted an open session on Thursday 7th June where other members of the community and stakeholders were able to contribute.

- Messages of support for the Catching Some Air consultation process were presented
 - a. The first message (by video) was from Minister for Indigenous Health, Hon Ken Wyatt AM.
 - b. A verbal message of support for the Catching Some Air project from Dr Mantha, Nephrologist and Director of Renal Services Cairns, Cairns District and dialysis units in Thursday Island and Cape York was also shared by Dr Hughes.
- A summary of the 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 key recommendations are referenced to the community view of health, recognising delegates as patients, carers, parents or children or siblings of those living with diabetes and kidney disease, including recognising members of families who have since passed from kidney disease. These delegates provided strong evidence for change. The delegates shared their personal experiences and acknowledged that kidney disease in the Torres Strait is an important area that must be discussed with various different stakeholders.

The Torres Strait Islands health services cover eighteen rural and remote communities that are separated by ocean, to the north Papua New Guinea to the south Cape York Peninsula. Delegates recognised the importance of current clinical services, and emphasised the need for preventative health care and health promotion, referenced to culture and the Torres Strait way, to prevent kidney disease and chronic disease throughout the Torres Strait Islands.

Delegates asked for an urgent need for health reform in the Torres Strait Islands, with emphasis on local Indigenous leadership. Local Indigenous leadership was identified as the essential strategy to ensure sustainable, effective, efficient and culturally appropriate health reform in kidney and chronic disease health.

Discussions about data related to health, healthcare access, equity, equality and health workforce and leadership by Indigenous peoples in the Torres Strait Islands. There were recommendations for data within ANZDATA. The local community are seeking to remain engaged with Catching Some Air team to develop the ANZDATA Indigenous Data Governance framework.

Key Activities and Outcomes

- 6th June 2018
 - The 'Thursday Island community action group for diabetes and kidney health committee' was formed during the Catching Some Air consultation meetings.
- 25th June 2018
 - Associate Professor Phillip Mills and Dr Hughes have joined a Global Alliance in Chronic Disease Grant (led by Associate Professor Louise Maple-Brown) to develop community worker health coaches for diabetes in sites in Northern Territory, Torres Strait & Apunapima. Mills and Hughes have been advocating for cultural leaders as health-coaches.
- 24-25th July 2018
 - Members of the 'Thursday Island community action group for diabetes and kidney health committee' participated in the Hot North meeting in Thursday Island. Committee members advocated for new research about health advancement in the Torres Strait region should be driven by the community, in-line with the recent Catching Some Air meetings.
- 26th July 2018
 - Dr Hughes was invited to join the planning group for the Torres and Cape Renal Strategy as an expert technical adviser.
- 31st July- August 3rd 2018
 - Dr Hughes sponsored Mr Sam Mills, renal nurse from the Torres Strait to visit Darwin to participate
 - 1) As a Renal clinical observer with Top-End Renal Services
 - 2) In the eGFR Study Stakeholders meeting
 - 3) And present at the inaugural Aboriginal and Torres Strait Islander Renal Workforce networking meeting
- 1st August 2018
 - Recommendations and priorities identified by the consultation meeting were submitted to the Queensland Statewide Renal Services Plan, who met on August 2-3rd 2018. The submission letter was endorsed by Kaurareg Aboriginal Land Trust and leaders of the Thursday Island community action group for diabetes and kidney health committee

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 Torres Strait Islander 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.