



Catching Some AIR

Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease



A report which consolidates the initial consultation site summary reports which are individually citable for Darwin, Thursday Island and Alice Springs



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

The Catching Some Air project consultation meetings focussed on the development of kidney health guidelines for best practice clinical care and data use which advances health for Aboriginal and Torres Strait Islander people



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



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: 978-1-922104-46-5 (online).

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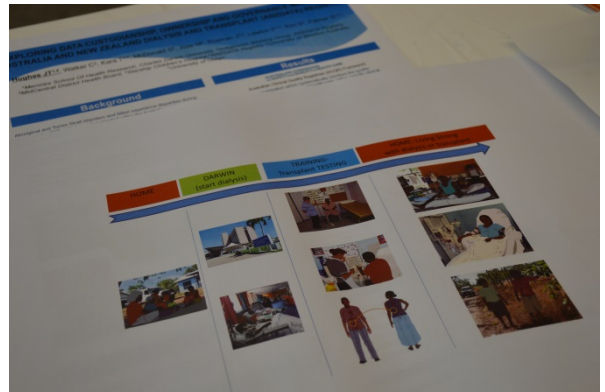
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Suggested citation: Hughes JT, Mick-Ramsamy L, Mills P, Ross L, Kelly J. (2018) Summary Report, Darwin, Catching Some Air- Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease. [online] Darwin: Menzies School of Health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

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

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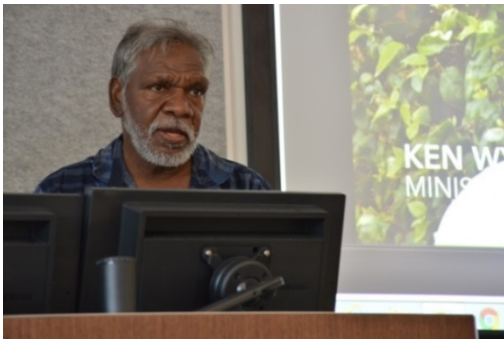
Acknowledgements

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 Chatervedi	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

Catching Some Air Project lead
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Phone: 08 8946 8518



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.



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

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

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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>

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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.

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

Mr 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.

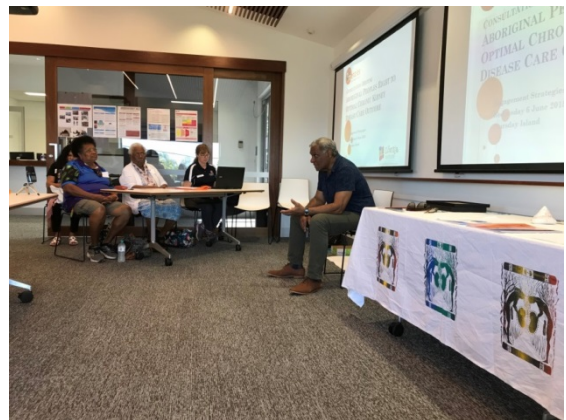
The desire for KHA-CARI and ANZDATA to have community informed best-practice guidelines was discussed.

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

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- Overall project feedback July 2019

Staying Connected

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- The webpage also features our newsletters and videos (<https://vimeo.com/277034735>)
- Follow our activities on twitter #CatchingSomeAir

Catching Some Air Project lead

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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



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ISBN: 978-1-922104-49-6 (online).

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Photos and images by Vicki Kerrigan.

Suggested citation: L Mick-Ramsamy, L Ross, J Kelly, JT Hughes (2018) Summary Report, Alice Springs, 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/2qULr4S>

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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)

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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
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Staying Connected

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