

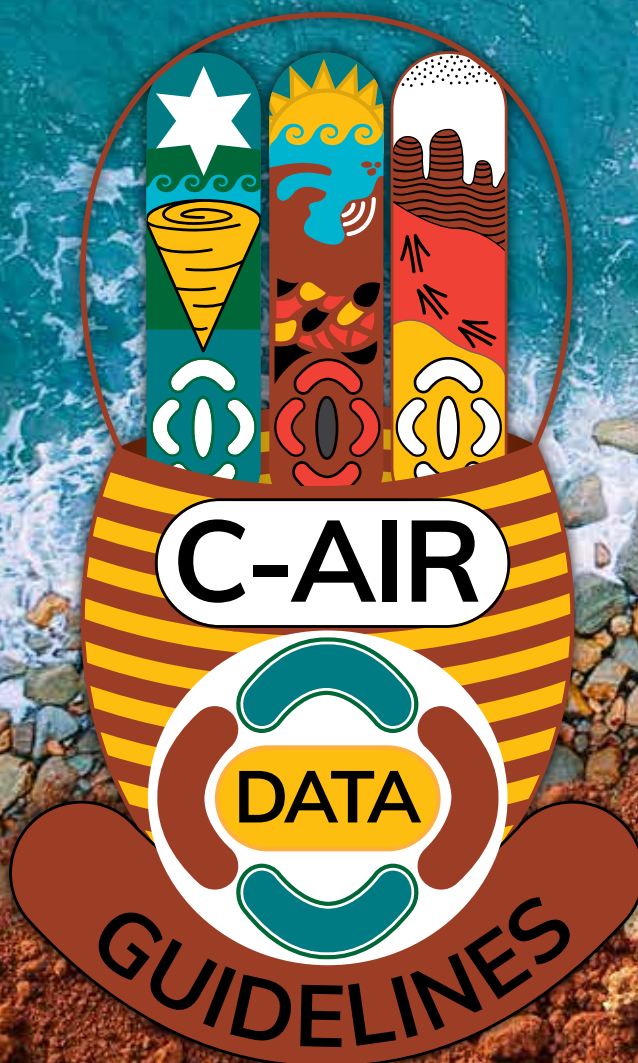


CATCHING SOME AIR

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





Summary Report 1 Darwin

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.

The Catching Some AIR - Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease Project engaged with the renal community and stakeholders to gather recommendations to inform best practise, clinical care and data use guidelines which advances health for Aboriginal and Torres Strait Islander people.



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)
© 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, Dr J Kelly, Ms L Ramsamy, Ms D Duff, A/Prof P Mills, Prof A Cass, Ms H Hall, Mr L Ross, Mr D Croker. Images supplied by Vicky Kerrigan and Melody Song (Menzies).

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>

Contents

| | |
|---|---|
| ACKNOWLEDGEMENTS..... | 4 |
| ABBREVIATIONS..... | 4 |
| CATCHING SOME AIR CONSULTATION PROCESS..... | 5 |
| CONSULTATION MEETING PARTICIPANTS..... | 6 |
| ABORIGINAL AND TORRES STRAIT ISLANDER PATIENT'S AND CARER'S CONSULTATION: A CLOSED SESSION..... | 7 |
| BRINGING DELEGATES TOGETHER: AN OPEN SESSION..... | 8 |
| KEY RECOMMENDATIONS..... | 8 |
| KEY DATES..... | 9 |
| STAYING CONNECTED..... | 9 |



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, Darwin. 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.

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

- The Top-End Renal Advisory and Advocacy Committee group members, Mr Lachlan Ross and Mr David Croker who were integral to the planning process

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)
- Dr Lisa Murphy, Interim Chief Executive Officer, Kidney Health Australia
- Administrative and media support:
 - Dr Janet Kelly, Evaluation Support
 - Ms Vicki Kerrigan, Video Producer



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, Darwin. 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); and*
2. *KHA-CARI Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples.*

The Catching Some AIR - Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease Project engaged with the renal community and stakeholders to gather recommendations to inform best practise, clinical care and data use guidelines which advances health for Aboriginal and Torres Strait Islander people. 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; refer Table 1.

Table 1 – Delegates

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

* Video support ** 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.

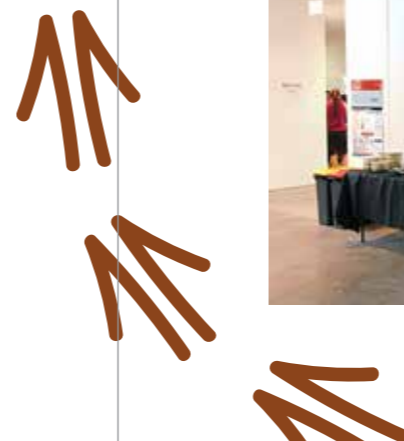
Existing guidelines in Indigenous kidney health were referred to, including:

- 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*
- 4. 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”

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.
- The first message (by video) was from Hon Minister for Indigenous Health, Hon Ken Wyatt AM.
- A presentation by Associate Professor Phillip Mills.
- 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)
 - 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 |

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



The Catching Some AIR message stick was 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.

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



Summary Report 2 Thursday Island

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

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.

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 | 14 |
| ABBREVIATIONS | 14 |
| CATCHING SOME AIR CONSULTATION PROCESS | 15 |
| CONSULTATION MEETING PARTICIPANTS | 16 |
| ABORIGINAL AND TORRES STRAIT ISLANDER PATIENT'S AND CARER'S CONSULTATION: A CLOSED SESSION..... | 17 |
| BRINGING DELEGATES TOGETHER: AN OPEN SESSION | 18 |
| KEY RECOMMENDATIONS | 18 |
| KEY ACTIVITIES AND OUTCOMES | 19 |
| KEY DATES | 20 |
| STAYING CONNECTED | 20 |



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, Darwin. 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 (community engagement lead consultant and consultation meeting facilitator)
 - Associate Professor Phillip Mills (community engagement lead consultant and consultation meeting facilitator)
- Administrative and media support:
 - Dr Janet Kelly, Evaluation Support
 - Ms Norma Benger 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 a project based at Menzies School of Health Research, Darwin. 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); and*
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. 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. The delegates are listed by name in Table 1. The stakeholders listed were those who provided direct feedback, and wished to stay connected with project development.

Table 1 – Delegates

| Patient & Community Delegates | Patient & Community Delegates | Stakeholder Delegates |
|--|--|------------------------------|
| Nazareth Adidi | Robert Sagigi | Salli-Anne Hart |
| Ina Apuita | Wally Shibusaki | Dr Murty Mantha** |
| May Assan | Walter Sailor | A/Prof Ashim Sinha** |
| Fr Dalton Bon | Nancy Sailor | Rochelle Pitt** |
| Ivy Chiney Bon | Wigness Seriat | C-AIR Support Team |
| Veda Bon | Seriako Stephen | Phillip Mills |
| Florence Dorante | Lucy Stephen | Mary Ward |
| Emma Gebadi | Rev Tom A Stephen | Jaqui Hughes |
| Abigail Harry | Enid Surha | Leeann Mick-Ramsamy |
| Diai Luffman | Betty Tekahika Mabo | Norma Bengier |
| Bua Mabo | Mary Ward | Janet Kelly |
| Syreeta Mills | Willie A Wigness | Will Tannapple |
| Patricia Nakata | Marsat Ketchell | |
| Cessa Nakata | Sam Mills | |
| Thomas Namoa | Yoko Nakata | |
| Bertha Natanielu | May Seriat | |
| Maleta Nona | | |

* Video support ** 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:

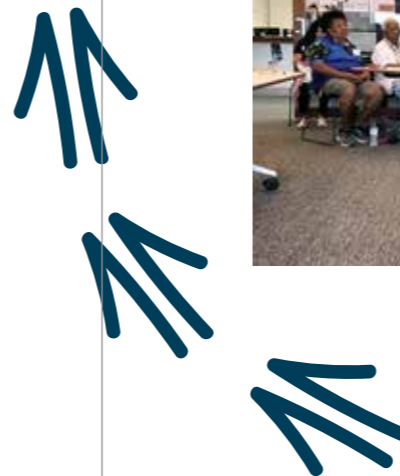
1. *Indigenous Patient Voices Symposium report (the most contemporary and published recommendation for Aboriginal and Torres Strait Islander kidney health advancement)*
2. *Central Australian Rural Practitioners Association (CARPA) Standard Treatment Manual for remote area health practitioners*
3. *KHA Guideline for the management of CKD in General Practice*
4. *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”

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 Hon 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 Mills
- 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 Jaqui Hughes 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 |

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.

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](https://twitter.com/CatchingSomeAIR)



Summary Report 3 Alice Springs

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

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: 978-1-922104-49-6 (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 Mick-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 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>



Contents

| | |
|--|----|
| ACKNOWLEDGEMENTS | 24 |
| ABBREVIATIONS | 24 |
| CATCHING SOME AIR CONSULTATION PROCESS | 25 |
| CONSULTATION MEETING PARTICIPANTS | 26 |
| ABORIGINAL AND TORRES STRAIT ISLANDER PATIENTS AND CARERS SESSION..... | 27 |
| KEY PRINCIPALS IDENTIFIED BY RENAL PATIENTS | 27 |
| BRINGING DELEGATES TOGETHER: AN OPEN SESSION | 28 |
| KEY RECOMMENDATIONS | 28 |
| KEY DATES | 29 |
| STAYING CONNECTED | 29 |



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, Darwin. 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
- 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)
- Administrative and media support:
 - Dr Janet Kelly, Evaluation Support
 - Ms Vicki Kerrigan, Video Producer
 - Ms Norma Bengier Artist in Residence



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 a project based at Menzies School of Health Research, Darwin. The project has been funded by the Lowitja 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); and*
2. *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.

Consultation Meeting Participants

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 – Delegates

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

* Video support

Aboriginal and Torres Strait Islander Patient's and Carer's Consultation: 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 presented. The desire for KHA-CARI and ANZDATA to have community informed best-practice guidelines was discussed.

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. *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*
4. *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.



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 carers.

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.

The afternoon session included:

- A summary of the morning's key discussion points was presented by several delegates.
- The first message (by video) was from Hon Minister for Indigenous Health, Hon Ken Wyatt AM.
- A presentation by Associate Professor Phillip Mills.
- 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

- 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 |

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 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.

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](https://twitter.com/CatchingSomeAIR)



the
Lowitja
Institute

