the Lowitja Institute

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

Changing the Narrative in Aboriginal and Torres Strait Islander Health Research

Four Cooperative Research Centres and the Lowitja Institute: The story so far

Prepared by
Australian Institute of Aboriginal and Torres Strait Islander Studies &
The Lowitja Institute

1997–2003

Cooperative Research Centre for Aboriginal and Tropical Health

Cooperative Research Centre for
ABORIGINAL & TROPICAL HEALTH

2003–2009

Cooperative Research Centre for Aboriginal Health

Cooperative Research Centre for
Aboriginal Health

2010 →

The Lowitja Institute

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

1997 **2003** **2010** **2014** **2019**

2010–2014

Cooperative Research Centre for Aboriginal and Torres Strait Islander Health

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

Incorporating the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health

2014–2019

The Lowitja Institute Aboriginal and Torres Strait Islander Health CRC

the Lowitja Institute
Aboriginal and Torres Strait Islander Health CRC

Cover
The Lowitja Institute office opening, October 2014

Peter Casamento Photography

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Aboriginal and Torres Strait Islander people are advised that this brief history contains the names and images of individuals who have passed away.

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A companion e-book has been published separately. Printed copies and a PDF version of this publication, and access to the e-book, may be obtained from:

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Australian Government
Department of Industry, Innovation and Science

Business
Cooperative Research
Centres Programme

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Foreword

It has been 20 years since I was asked to be the inaugural Chairperson of the Cooperative Research Centre for Aboriginal and Tropical Health.

One of my fundamental objectives as a Chairperson was to work towards reconciliation between Aboriginal and Torres Strait Islander and Western perspectives of health and wellbeing and encourage a different way of doing research.

That meant bringing the academics and the researchers together with those who are qualified to know what's needed on the ground. I wanted practical people to investigate the changes that need to be made in Aboriginal and Torres Strait Islander communities to bring about the change we all want to see for our peoples.

We also needed to train our people sufficiently for the communities to manage their own programs, for the non-Aboriginal and Torres Strait Islander people to hand over and the communities to act on their own behalf.

That was the line of sight, if you like, that I saw as the Chairperson.

As a Patron, when I agreed in 2010 to have the Lowitja Institute named after me, I entrusted in the Institute my spirit and energy, my values and priorities.

I told them that I wanted them to be a courageous organisation committed to social justice and equity for Aboriginal and Torres Strait Islander people, to match words to action, to achieve real, tangible outcomes.

Also, to be known throughout Australia as a strong and sustainable organisation.

Looking at the work that it has done to date, I can say that I am very proud of the organisation, its leaders, researchers, partners and participants, members and supporters, staff, our champions and friends.

I thank you for all your hard work.

Not that that is any reason for you to relax.

The future is in your hands, and we still have a big job to do.

Your job is to work ceaselessly, with confidence in who we are, with our knowledge timeless and modern, our endless strength and resilience, our capacity for hard work, our wise heads, our wonderful talented young.

We have outstanding Aboriginal and Torres Strait Islander leadership and organisations in this country. They are more than capable to guide the decisions that need to be made in a way that is true to our cultures and that will therefore have the right outcomes.

In order to empower our capabilities, Aboriginal and Torres Strait Islander people must be at the centre of the decisions and properly resourced.

We must work with government to get the job done; we want our non-Aboriginal and Torres Strait Islander friends and colleagues to work with us. But it is important that we know when to step up and they know when to step aside.

I entrust you all to deliver on this agenda.

Dr Lowitja O'Donoghue AC CBE DSG
August 2017

Thank You

This brief history outlines the journey and the success of four Cooperative Research Centres and the Lowitja Institute since 1997. Over this 20-year period there has been enormous support, commitment and goodwill by many individuals and organisations to get us to this point in our journey.

We acknowledge and thank everyone who has worked with us including researchers (institutions and individuals) and government departments, agencies and ministers. We acknowledge, in particular, our CRC Partners and Participants who have played an integral role in the delivery of our work. It has not been possible to include everyone who has been part of our story in this publication, but we gratefully acknowledge their contribution.

We especially acknowledge the investment of the Australian Government, through the Cooperative Research Centres Programme of the Department of Industry, Innovation and Science, to change the paradigm of health research for better results in Aboriginal and Torres Strait Islander health and wellbeing, and its investment in our capacity to make a significant contribution to this important work.

Many individuals have worked as staff, Link people and consultants for the CRCs and the Lowitja Institute over the period covered by this brief history. Their contribution has been invaluable and is gratefully acknowledged.

Finally, we thank our reason for being: the Aboriginal and Torres Strait Islander communities, organisations and individuals, who have shared their expertise, wisdom and guidance to improve the health and wellbeing of Australia's First Peoples.

Acknowledgments

In May 2014, the Lowitja Institute commissioned the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) to write a brief history of the Institute, including an oral history component highlighting the vision of influential individuals. While the Lowitja Institute is a separate organisation, four Cooperative Research Centres are central to this publication, particularly their contribution since 1997 to changing how research is conducted in Aboriginal and Torres Strait Islander health and wellbeing.

The oral history and surrounding research and writing undertaken by AIATSIS form an integral part of this work, together with the contribution of the Lowitja Institute editorial team. This publication is one of two, with the second being an e-book that includes, instead of photographs, edited video and audio files. The e-book is available from the Lowitja Institute website at www.lowitja.org.au.

A number of individuals contributed to this publication. Firstly, we thank the interviewees for their time and contribution to the project and regret that we were not able to connect with others who, nevertheless, were very important to this story. Interviewees are listed below with their relevant roles in the CRC organisations and/or the Lowitja Institute.

Professor Ian Anderson AO (CRCATH Board Member and Research Leader, CRCAH/CRCATSIH Research Director, CRCATSIH Interim Board Member)

Ms Pat Anderson AO (CRCATH Director, CRCAH/CRCATSIH/The Lowitja Institute Board Member and Chairperson)

Ms Stephanie Bell (CRCAH/CRCATSIH Board Member)

Ms Jenny Brands (CRCAH Research and Development Manager)

Ms Lyn Brodie (The Lowitja Institute CEO)

Dr Jeannie Devitt (CRCATH Research Fellow)

Associate Professor Terry Dunbar (CRCATH Research Leader)

Professor Judith Dwyer (CRCAH/CRCATSIH Research Program Leader)

Professor Michael Good AO (CRCATH Board Member)

Mr Mick Gooda (CRCAH CEO)

Professor Shane Houston (CRCATH/CRCAH/CRCATSIH Interim Board Member)

Professor Marcia Langton AM (CRCATH Researcher)

Professor John Mathews AO (Inaugural Director and CRCATH Board Member)

Mr Romlie Mokak (The Lowitja Institute CEO)

Dr Lowitja O'Donoghue AC CBE DSG (CRCATH Chairperson, The Lowitja Institute Patron)

Professor Komla Tsey (CRCAH/CRCATSIH Research Program Leader)

Detail from the weavers circle at the Lowitja Institute International Indigenous Health and Wellbeing Conference 2016

James Henry Photography

The project was overseen by the Lowitja Institute Steering Group comprising Pat Anderson AO, Mary Guthrie and Cristina Lochert.

The AIATSIS research team was led by Dr Mary Anne Jebb, with AIATSIS Research Associate Dr Blake Singley and Research Fellow Dr Lawrence Bamblett. The AIATSIS team provided oral history interviews, transcripts and edited audio-visual segments from the interviews to support this publication and the e-book. This team acknowledges the help and support of former and current staff at the Institute including Mr Russell Taylor AM, Dr Jaky Troy, Dr Mick Adams, Dr Lisa Strelein and Mr Dylan Daniel-Marsh, and the research support provided by Ms Marie McInerney. They would also like to thank AIATSIS staff members Mr Andrew Turner, Mr Lachlan Russell and Mr Tom Eccles for their assistance in producing the audio-visual material for the project. The recorded interviews with key people will be archived at AIATSIS where they will be available to future generations of researchers.

AIATSIS
AUSTRALIAN INSTITUTE OF ABORIGINAL
AND TORRES STRAIT ISLANDER STUDIES

The Lowitja Institute editorial team that reviewed and expanded the work consisted of Mary Guthrie, Cristina Lochert, Leila Smith and Jane Yule from Brevity Comms and we thank them for their commitment to this project, as well as other Lowitja Institute staff who supported the endeavour.

Production of this publication and the e-book was in the talented hands of Stuart Pettigrew Design, in particular Svetlana Andrienko. We are also grateful to Jane Yule for overseeing the design and layout process.

The Lowitja Institute gratefully acknowledges the contribution of the photographers, professional and not, whose work is included in these pages. Where possible we have acknowledged photographers by name, and apologise where this has not been possible.

About this Brief History: Voices for Change

The Lowitja Institute, Australia's national institute for Aboriginal and Torres Strait Islander health research, commissioned the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS) to describe its evolution and its contribution to Aboriginal and Torres Strait Islander health research.

The Institute, which was established in January 2010, hosts the Lowitja Institute Aboriginal and Torres Strait Islander Health CRC (Lowitja Institute CRC) whose history dates to 1997 when the first of four consecutive CRCs was established. The evolution, focus and contribution of the CRCs are integral to this narrative.

To accompany the text, audio-visual segments were commissioned to help highlight the vision of influential individuals whose vision has and will influence the Institute's work, including some of the significant contributors to the establishment of the first CRC in 1997.

This work has been published in two formats, an e-book that contains these audio-visual segments, and a printed book where the recorded voice is replaced by a photo and/or a brief quotation.

The recorded voices and words are an important element of this brief history and are used to gather significant information that often gets left out of formal written records. This method of research follows the Aboriginal and Torres Strait Islander principle of yarning in health research to broaden the base of information exchanged, and to leave a record of spoken voice.[1]

Extended oral history interviews created for this publication, stored at AIATSIS, provide information about the aims and development of the Lowitja Institute and the CRCs, and capture in sound and vision the character, voices and ideas of some of the people who led to its establishment and continue to champion its causes. Interviewees were selected by the project steering group, with a few others identified for interview but unfortunately unavailable. Their contributions, however, have often been mentioned by others or described within published and unpublished documents.

Terminology

This brief history uses the term **Aboriginal and Torres Strait Islander people** to refer to individuals, and **Aboriginal and Torres Strait Islander peoples** to refer to groups. It also uses the term **Australia's First Peoples**. The term **Indigenous** is used in an international context or in direct quotes and titles of programs, services and initiatives. The term **non-Indigenous** is used to describe people and organisations who do not identify as members of First Nations.

Naming convention: When an individual's name first appears in the text, his or her title at the time of writing is given but not in subsequent mentions.

CRC Programme terminology

Core Partners are the research, government and industry organisations that partnered with the CRCATH and the CRCAH.

Participant Organisations are those institutions that have signed an agreement to be a Participant of the Lowitja Institute CRC.

- **Essential Participants** are those institutions that partnered with both the CRCATSIH and the Lowitja Institute CRC, as listed in Schedule 5 of the Commonwealth Agreement and at: www.lowitja.org.au/partners.
- **Other Participants** are those institutions that are not Essential Participants, but which have signed an agreement that is consistent with Part 3 of the Participant Agreement.

Partner Organisations are those institutions that are named in the Research Activity Funding Agreement.

Program Leader Each of the three CRCATSIH research programs was overseen by two Program Leaders, who were appointed by the Board to provide advice on sound research practice.

Project Leader (or Chief Investigator) is that person who has the primary responsibility for the funded research activity.

In-kind contribution or support is a non-cash contribution by Essential and Other Participants to the activities of Lowitja Institute CRC.

In-kind projects are those carried out by Essential and Other Participants under the umbrella of the Lowitja Institute CRC.

Commonwealth Agreement is the contractual agreement between the Australian Government and the CRCs.

Timeline of Key Events that Influenced this Brief History

For information about the many roundtables and workshops held by CRCs and the Lowitja Institute, please visit www.lowitja.org.au.

1967

The 27 May referendum sees more than 90% of Australian voters choose to alter the Constitution by voting ‘Yes’ to count Aboriginal and Torres Strait Islander peoples in the Census and to give the Australian Government power to make laws for them

1971

The first Aboriginal Medical Service established in Redfern, Sydney

1973

Central Australian Aboriginal Congress (CAAC) established in Alice Springs

Victorian Aboriginal Health Service established in Fitzroy, Melbourne

1976

National Aboriginal and Islander Health Organisation established (closed in 1989)

1979

Aboriginal Health, a report by House of Representatives Standing Committee on Aboriginal Affairs, which notes ‘little progress had been made in raising [Aborigines’ standard of health]’

1980

The *Program Effectiveness Review*, an internal Commonwealth report, considers Aboriginal and Torres Strait Islander involvement in health policy, introducing specific health initiatives and existing arrangements for funding and administration

1981

Commonwealth initiates a $50 million five-year Aboriginal Public Health Improvement Program focusing on unsatisfactory environmental conditions associated with inadequate water, sewerage and power systems

1984

Responsibility for all Commonwealth Aboriginal health programs consolidated within Department of Aboriginal Affairs

Menzies School of Health Research (MSHR) established in Darwin

1986

National Conference on Research Priorities into Aboriginal Health convened by the National Health and Medical Research Council (NHMRC) and the Menzies Foundation in Alice Springs

1987

Prime Minister Hawke announces Royal Commission into Aboriginal Deaths in Custody

Formation of Joint Ministerial Forum on Indigenous Health and appointment of National Aboriginal Health Strategy (NAHS) Working Party

1988

Ian Anderson’s *Koorie Health in Koorie Hands* published by Victorian Government

1989

Release of NAHS Working Party final report, *National Aboriginal Health Strategy*

1990

First (unsuccessful) bid to establish a Cooperative Research Centre (CRC) for Communicable Disease Control in Aboriginal Communities

Aboriginal and Torres Strait Islander Commission (ATSIC) established, replacing Department of Aboriginal Affairs and Aboriginal Development Commission, and assumes national responsibility for Aboriginal and Torres Strait Islander health

Lowitja O’Donoghue appointed as Chairperson of ATSIC (1990–96)

1991

Danila Dilba Health Service established in Darwin

1992

The High Court of Australia hands down landmark decision in *Mabo v. Queensland (No. 2)*, which inserts the legal doctrine of Native Title into Australian law

1993

National Aboriginal Community Controlled Health Organisation (NACCHO) established

Australian Parliament passes *Native Title Act* enabling Aboriginal and Torres Strait Islander peoples to claim traditional rights to unalienated land

1994

Negotiations commence to establish a CRC for Aboriginal and Tropical Health (CRCATH)

Aboriginal Medical Services Alliance Northern Territory (AMSANT) established

1995

Responsibility for Aboriginal and Torres Strait Islander health transferred from ATSIC to Department of Human Services and Health, specifically the newly established Office for Aboriginal and Torres Strait Islander Health Services (OATSIHS)

1997

Human Rights and Equal Opportunity Commission releases *Bringing them Home: National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families*

1997 (cont.)

Cooperative Research Centre for Aboriginal and Tropical Health established on 1 July, with Lowitja O’Donoghue as inaugural Chairperson of CRCATH Board and John Mathews as inaugural Director

Inaugural Board meeting of CRCATH, July

Commonwealth funding transferred to CRCATH

1998

First National Sorry Day on 26 May

CRCATH official opening in Darwin, July

1999

First internal review of CRCATH operations

John Mathews resigns and Tony Barnes appointed CRCATH Director

2nd-year Commonwealth review of CRCATH

2000

More than 250,000 Australians walk across Sydney Harbour Bridge in May in support of reconciliation, with a million more participating in walks across Australia

Australian Government’s *Health Is Life: Report on the Inquiry into Indigenous Health* praises CRCATH efforts in improving Aboriginal and Torres Strait Islander health

Links Action Project initiated to undertake internal evaluation of CRCATH

2001

Research Partnerships: Yarning about Research with Indigenous People workshop findings inform positioning of Links research team

2002

CRCATH publishes first Links Reports outlining Indigenous Research Reform Agenda

5th-year Commonwealth review of CRCATH

Pat Anderson appointed Deputy Chairperson of CRCATH Board in September

2002–03

Pat Anderson serves as Chairperson of NACCHO

2003

Mini-Convocation held to bring together CRCATH Core Partners with those of planned new CRC for Aboriginal Health (CRCAH)

Final CRCATH Board meeting at Nguiu, Bathurst Island, 30 April

CRCATH is wound up on 30 June

CRCAH commences operations on 1 July, and Pat Anderson appointed as Chairperson of CRCAH Board

Official launch of CRCAH at Flinders University, Adelaide in August

CRCAH Inaugural Board meeting held in August

Tony Barnes resigns as Director of CRCAH in December, and Tony Grivell appointed Interim Director

2004

CRCAH Board endorses new Programmatic Approach to research under leadership of Research Director, Ian Anderson

Social Determinants of Aboriginal Health Workshop, Adelaide

Mick Gooda appointed CEO of CRCAH in November

2005

The Facilitated Development Approach introduced in the CRCAH

ATSIC formally abolished

Canberra CRCAH Showcase: 'Listening to Aboriginal voices and valuing Aboriginal solutions to Aboriginal health'

Aboriginal Health Research Expo, hosted by Flinders University and CRCAH, in Adelaide

2006

Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse established (Pat Anderson co-Chair)

CRCAH Showcase, Melbourne Town Hall

2006 (cont.)

CRCAH PhD scholarship holder Yin Paradies is awarded NAIDOC Scholar of the Year

Work begins on future funding strategy for CRCAH

CRCAH Annual Symposium, Adelaide

2007

Productivity Commission releases *Public Support for Science and Innovation* that recommends 'public good' objectives of CRC program be reinstated

CRCAH hosts WHO International Symposium on Social Determinants of Health in Adelaide

Close the Gap Campaign formally launched in April

Ampe Akelyernemane Meke Mekarle 'Little Children are Sacred' report by Pat Anderson and Rex Wild released in June

Australian Government's suspension of *Racial Discrimination Act* leads to Northern Territory National Emergency Response legislation

2008

Australian Parliament Apology to Australia's Indigenous Peoples on 13 February

Prime Minister Rudd and Opposition Leader sign Close the Gap Statement of Intent at the Close the Gap Campaign's National Indigenous Health Equality Summit

Australian Government commits $1.6 billion to National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes

CRCAH Showcase, Parliament House, Canberra

CRCAH Board and Research Director participate in the Rudd Labor Government 2020 Summit

National Indigenous Health Equality Council established with Ian Anderson as Chair

CRCAH pilots a quality assurance process for researchers preparing NHMRC funding applications for Aboriginal and Torres Strait Islander health research

CRCAH co-hosts Fulbright Symposium 2008 – Healthy People, Prosperous Country in Adelaide

2009

One21seventy, National Centre for Quality Improvement in Indigenous Primary Health Care launched in Brisbane

First Interim Board meeting of National Institute for Aboriginal and Torres Strait Islander Health Research Ltd operating as the Lowitja Institute held in Brisbane, August

Final CRCAH Board meeting, November

2010

The Lowitja Institute established on 1 January

Mick Gooda takes up role as Aboriginal and Torres Strait Islander Social Justice Commissioner

CRC for Aboriginal and Torres Strait Islander Health (CRCATSIH) commences

Official launch of the Lowitja Institute at Parliament House, Canberra, February

1st Congress Lowitja, Sydney

Kerry Arabena appointed CEO of the Lowitja Institute

The Lowitja Institute permanent Board of Directors appointed with first Board meeting, November

2011

Launch of the Lowitja Institute headquarters in Grattan Street, Carlton, Melbourne, March

The Lowitja Institute becomes one of 12 Aboriginal and Torres Strait Islander foundation members of the National Health Leadership Forum

2012

Lyn Brodie appointed CEO of the Lowitja Institute

Successful mid-term review of CRCATSIH

2nd Congress Lowitja, Melbourne

2013

National Indigenous Cancer Network and DISCOVER-TT, Centre for Research Excellence (CRE) for Aboriginal and Torres Strait Islander cancer research launched, March

Australian Government commits further $777 million to National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes

2013 (cont.)

Australian Government announces the Lowitja Institute will be funded $25 million from a new CRC Public Good Fund

Australian Government releases National Aboriginal and Torres Strait Islander Health Plan (NATSIHP) 2013–2023

2014

The Lowitja Institute Aboriginal and Torres Strait Islander Health CRC (Lowitja CRC) commences operations on 1 July

Romlie Mokak appointed CEO, and new Drummond Street, Carlton office opened

3rd Congress Lowitja, Melbourne

2015

More than 130 non-government health organisations sign up to Recognise Health; launch in Parliament House, Canberra

Australian Government releases Implementation Plan for the NATSIHP 2013–2023

2016

Pat Anderson AO appointed co-Chair of the Referendum Council

Launch of *The Lancet–Lowitja Institute Global Collaboration* report

Redfern Statement, a call for government to take a 'more just approach to Aboriginal and Torres Strait Islander affairs'

The Lowitja Institute International Indigenous Health and Wellbeing Conference, Melbourne

Co-hosted Canada–Australia Roundtable on Indigenous Health and Wellbeing

2017

First Nations National Constitutional Convention, Uluru, NT

50th Anniversary of 1967 Referendum

25th Anniversary of High Court Decision *Mabo v. Queensland*

20th Anniversary of *Bringing Them Home* report

Detail from Congress Lowitja 2014 venue

James Henry Photography

Patron Lowitja O'Donoghue addresses guests at launch of the Lowitja Institute, Parliament House, Canberra, 24 February 2010

T8 Photography

The Lowitja Institute Journey

This brief history tells the story of four Cooperative Research Centres (CRCs) and the Lowitja Institute and maps the evolution of a new model of Aboriginal and Torres Strait Islander health research that was developed by the CRCs and is embodied in the Institute.

In doing so, it describes the work and contribution of the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) (1997–2003), the CRC for Aboriginal Health (CRCAH) (2003–09), the CRC for Aboriginal and Torres Strait Islander Health (CRCATSIH) (2010–14), and the Lowitja Institute for Aboriginal and Torres Strait Islander Health Research CRC (Lowitja Institute CRC) (2014–19). All have been funded through the Australian Government's Cooperative Research Centres Programme as 'public good' CRCs.[2]

The Lowitja Institute was launched in January 2010 as an organisation separate from the CRC structure, with the aim of establishing an ongoing national institute for Aboriginal and Torres Strait Islander health research. Its work, however, is intimately connected to the CRCs and what has happened over the past 20 years. The Institute hosted the CRCATSIH until 2014 and, at the time of writing, hosts the Lowitja Institute CRC.

The Lowitja Institute journey began long before the first CRC was established in Darwin in 1997. Its roots lay in calls by Aboriginal and Torres Strait Islander people over many decades for real change in health status and health delivery for their communities. Paramount to that was the need for a new research paradigm, amid a growing sense and concern that research into the alarming evidence of health disparity for Aboriginal and Torres Strait Islander peoples was descriptive and too often serving the priorities of researchers and non-Indigenous people. In other words, for too long research had been done *on* Aboriginal communities not *by or with* Aboriginal communities. At the time, Aboriginal and Torres Strait Islander people argued they had been 'researched to death' with little benefit.

Each of the subsequent CRCs has built on the legacy of the preceding organisation; gathering supporters, partners and a wider network of researchers committed to its mission, values and methodologies. This has been underpinned by the philosophy that effective health research requires a process that reflects community priorities and earns trust and community engagement. Each CRC also owes much of its success to the energy and determination of key individuals who came together, regardless of differences and gaps in their background and experiences, to build something they knew could be important.

Foremost among these is Dr Lowitja O'Donoghue, inaugural Chairperson of the CRCATH who gave her name to the Institute, with strict conditions that it stay true to its Aboriginal and Torres Strait Islander foundations and the rigour of its work.

The vision of Lowitja O'Donoghue and others has now been realised at the Lowitja Institute, with Aboriginal and Torres Strait Islander people:

- setting the research priorities
- leading the development of the research process
- forging viable partnerships with, and between, key stakeholders
- building the health research workforce
- strengthening relationships with and between Aboriginal and Torres Strait Islander health researchers and their non-Indigenous counterparts
- providing cultural authority for non-Indigenous researchers
- benefitting from the research findings.

However, in the early history of the CRCs bringing university-based researchers and Aboriginal and Torres Strait Islander community controlled health organisations together was not an easy task and took both time and inspiration to break through attitudinal and structural barriers. Relationships framed by a history of disengagement with non-Indigenous experts and researchers defined Australian health research in the 1980s and had to be challenged in the early years of the CRCATH.

The first application to the CRC Programme, although strongly linked to the Menzies School of Health Research in Darwin and to its Director, epidemiologist Professor John Mathews, would not have succeeded without the support of Aboriginal leaders in the Northern Territory (NT) like Pat Anderson, Stephanie Bell and, later, Johnny Liddle. They were joined over the next 20 years by other Aboriginal and Torres Strait Islander researchers, and leaders in organisations, policy and research who understood that the old paradigm was unlikely to result in the changes to Aboriginal and Torres Strait Islander health research and policy that were desperately needed.

Changing the health research paradigm

Since its inception, the Lowitja Institute has built a national presence in health research with particular recognition for its contribution to creating networks and dialogues that support and encourage Aboriginal and Torres Strait Islander-led research. Key to that has been the development of a new way of working, which became formalised under the CRCAH as the Facilitated Development Approach (FDA) and adopted as the driving research methodology.

The approach was a marked departure from the 'traditional' way that research into Aboriginal and Torres Strait Islander health had been carried out. Instead of researchers putting forward proposals that may or may not align with community need, the CRCs brought together the Aboriginal and Torres Strait Islander health sector and communities, researchers and practitioners to identify areas where research may be able to make a real, measurable and positive difference, to conduct the research, and to disseminate the results or findings. Research impact and collaboration, rather than competition, along with Aboriginal and Torres Strait Islander knowledge, leadership and ethics, were to be at the heart of its ethos.

Such an approach did not have an easy transition, and this brief history details some of the difficulties that arose, particularly in the early years, as mainstream research practices were challenged. However, doubts and suspicions gradually gave way to respectful working relationships across Australia and changed the direction of research prioritisation from investigator driven to community based within a strategic framework and directed by a majority Aboriginal and Torres Strait Islander Board during the CRCATH and the CRCAH.

The CRCs also recognised that capacity strengthening was a crucial factor in developing a new research paradigm and have made health research workforce development a priority, providing scholarships and other support for postgraduate research training and coursework degrees, as well as undergraduate and vocational training. They built skills, knowledge and capability in a wide range of areas and personnel – including within the community and among researchers – and published popular and effective guides to assist both Aboriginal and Torres Strait Islander and non-Indigenous people to improve their approach to research (see p. 107). CRC researchers have gone on to make a significant contribution to Aboriginal and Torres Strait Islander health research and policy. CRC scholarship holders have, for example, led international research on the impact of racism on health, examined the broader social and cultural determinants associated with trauma recovery in urban Aboriginal communities, and undertaken population-based studies of cervical screening for Aboriginal and Torres Strait Islander women in Queensland (see pp. 99–100).

Through each CRC, significant research projects were identified and developed. Some have broadened and continued through subsequent CRCs, garnering funding and interest from other research and policy areas. With each new successful funding round, more long-term relationships between researchers, policymakers and community organisations have been forged and nurtured.

Impact on policy and practice

The work of the Lowitja Institute and the CRCs has influenced and created opportunities for change in how research into Aboriginal and Torres Strait Islander health is done in universities, communities and health organisations. It has provided structures and forums for changing language and attitudes, and has shown many measurable impacts in the development of policy and practice, including being singled out in a 2008 review as an 'exemplar' of a 'public good' CRC (see p. 57).[3] A 2006 submission to the Productivity Commission study on science and innovation promoted the CRCAH as a 'Cooperative Research Centre that symbolises the gains increasingly within our reach by dent of public support'.[4] It was in the context of this high regard that the third application for CRC funding was successful, which was exceptional, as few CRCs had succeeded through three rounds of funding let alone extending into a fourth iteration and a 20-year life span.

Birrarung Marr and Melbourne CBD

James Henry Photography

This brief history looks at many examples of the influence of the Lowitja Institute on national policy and in health outcomes in individual communities. For instance, the CRCAH's early support of the Centre for Excellence in Indigenous Tobacco Control (CEITC, now defunded) in targeting tobacco control as a high priority for Aboriginal and Torres Strait Islander communities influenced the Council of Australian Governments' (COAG) National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes in 2008 (see p. 85),[5] and made a significant contribution to attracting research funding from the then Health Minister, the Hon. Nicola Roxon MP.[6]

Another initiative, the Audit and Best Practice for Chronic Disease Project (ABCD), pioneered best practice and quality improvement practices that changed the way governments and the Aboriginal and Torres Strait Islander community controlled sector worked together. It is credited, for example, with significantly improving the quality of care and outcomes for diabetes and led to the establishment of One21seventy, the National Centre for Quality Improvement in Indigenous Primary Health Care (see p. 81).

A CRC investigation into the burden imposed on Aboriginal and Torres Strait Islander health services by a complex and fragmented set of funding sources was hailed as 'significant' by the Auditor-General (see p. 89).[7] Research on the legal barriers to improved Aboriginal and Torres Strait Islander health was submitted to the Expert Panel on Recognising Aboriginal and Torres Strait Islander Peoples in the Constitution, which reported to the Prime Minister, and led to the Lowitja Institute's Recognise Health initiative in which more than 130 health organisations, including the Australian Medical Association, endorsed constitutional recognition (see p. 91).

Other impacts have been felt more directly in Aboriginal and Torres Strait Islander communities. For example, the Healthy Skin program led to a coordinated and integrated effort – using biomedical and clinical methods, public health and service delivery strategies, and targetted research transfer and education – to tackle the incidence of childhood skin infections linked to chronic kidney disease and rheumatic heart disease in adults. One program halved the prevalence of skin sores in an East Arnhem community over 18 months (see p. 87).

The Lowitja Institute has also been a strong voice in drawing attention to the relationship between racism and health. For example, the CRCATSIH 2012 report, *Mental Health Impacts of Racism Discrimination in Victorian Aboriginal Communities*,[8] provides clear evidence for the link between racism and ill-health; the Lowitja Institute has presented this evidence in a number of ways to bring awareness of this issue and to influence the discussion around racism.[9]

Importantly, the Lowitja Institute journey has placed culture at the centre of its work, with its leaders, such as Romlie Mokak, CEO since 2014, describing the Institute as a 'black organisation', emphasising the capacity of its Aboriginal and Torres Strait Islander membership and leadership to improve the lives of Australia's First Peoples. As a result, the growth and expanding reach of the Lowitja Institute and the legacy of quality research outputs from the CRCs has led to a demand for research to operate within a cultural framework.

Lowitja O'Donoghue

> **I was accepted by the academics and the Aboriginal Board members, though I know they were pretty frightened at times about how I would react to certain things! But on the other hand, we got there. I wasn't going to give in.**

Interview, 11 March 2015

Click to play video

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'We got there'

Dr Lowitja O'Donoghue was the inaugural Chairperson of the Cooperative Research Centre for Aboriginal and Tropical Health and became Patron of the Lowitja Institute in 2010. Her role has been crucial to the success of the CRCs and the Institute.

Lowitja O'Donoghue spoke with current Institute Chairperson Pat Anderson AO and Romlie Mokak, in her interview for this brief history, about her background and the CRCATH experience. Removed from her Aboriginal family as a two-year-old, becoming part of the Stolen Generations, she described both her career as a nurse and the struggle that she, like many Aboriginal and Torres Strait Islander people, experienced in order to succeed.

Lowitja O'Donoghue's experiences of prejudice as a young nurse, her deep knowledge of the situation for Aboriginal and Torres Strait Islander peoples, and her capacity for leadership underpinned her style as first Chairperson of the CRCATH.

A key issue she identified for the early CRCATH was ensuring unity between 'the Aboriginal and non-Aboriginal people on the Board' by getting 'them to sit around the table' and talk about 'what was needed to improve the health of our people', and 'not where their next dollar was coming from'. Working effectively and practically to benefit Aboriginal and Torres Strait Islander peoples were her main aims, which she managed to do by being 'a practical operator'.

I've never been afraid to work with academics and doctors who are much more qualified than I am… as they're not qualified to chair meetings like I did and bring them together… I was accepted by the academics and the Aboriginal Board members, though I know they were pretty frightened at times about how I would react to certain things! But on the other hand, we got there. I wasn't going to give in.
(Lowitja O'Donoghue Interview, 11 March 2015)

Dr Lowitja O'Donoghue AC, CBE, DSG

Lowitja O'Donoghue was born in 1932 at Indulkana, in the remote north-west corner of South Australia, to a Pitjantjatjara mother and an Irish father. When only two years old, she and two of her sisters were taken away from their mother by missionaries on behalf of South Australia's Aborigines Protection Board.

Renamed 'Lois' by the missionaries, she and her sisters grew up at the Colebrook Home for Aboriginal Children and did not see their mother again for more than 30 years. They weren't allowed to speak their own language or to ask questions about their origins or even about their parents.

Lowitja O'Donoghue attended Unley General Technical High School in Adelaide and set her sights on becoming a nurse. After initial training, she had to fight to be able to continue her studies, thus beginning her lifelong advocacy for Aboriginal rights. In 1954 she became the first Aboriginal trainee nurse at the Royal Adelaide Hospital, where she became Charge Sister after graduation, staying for 10 years.

After spending time in the mid-1960s at the Baptist Overseas Mission in Assam, India, Lowitja O'Donoghue returned to Australia and joined the South Australian Department of Aboriginal Affairs. She accepted a position in the remote South Australian town of Coober Pedy, where an aunt and uncle, noticing the family resemblance, recognised her in a local supermarket. Through this chance meeting she was finally reunited with her mother, Lily, who by this time was living in the nearby town of Oodnadatta.

From 1970–72, Lowitja O'Donoghue was a member of the Aboriginal Legal Rights Movement, and later became Regional Director of the Australian Department of Aboriginal Affairs. In 1976, she became the first Aboriginal woman to be awarded an Order of Australia, and a year later was appointed the foundation Chair of the National Aboriginal Conference and Chair of the Aboriginal Development Commission.

In March 1990, Lowitja O'Donoghue was appointed the founding Chairperson of the Aboriginal and Torres Strait Islander Commission, and played a key role in drafting the Native Title legislation that arose from the High Court's historic Mabo decision.

When she stepped down from this role, Lowitja O'Donoghue became the inaugural Chairperson of the CRCATH, and Patron of the Lowitja Institute – Australia's National Institute for Aboriginal and Torres Strait Islander Health Research.

Lowitja O'Donoghue was made a Commander of the Order of the British Empire in 1983 and Australian of the Year in 1984, during which time she became the first Aboriginal person to address the United Nations General Assembly. She won the Advance Australia Award in 1982, was named a National Living Treasure in 1998, was awarded the Companion of the Order of Australia in 1999, and became a Dame of the Order of St Gregory the Great, a Papal Award, in 2005.

An Honorary Fellow of both the Royal Australasian College of Physicians and the Royal College of Nursing, Lowitja O'Donoghue also holds an Honorary Doctorate of Law from the Australian National University and Notre Dame University, and and Honorary Doctorates from Flinders University, ANU, University of South Australia and Queensland University of Technology. She has been a Professorial Fellow at Flinders University since 2000.

Fiona Hamilton Photography

Detail from venue design by Jirra Lulla Harvey (Kalinya Communications) for the Lowitja Institute International Indigenous Health and Wellbeing Conference 2016

James Henry Photography

Time for Change: Cooperative Research Centre for Aboriginal and Tropical Health

Pat Anderson

> **I was part of the group that would say, 'we're the most researched people in the world'. And we spent a lot of decades sort of chucking stones, if you like, metaphorically, at researchers… A lot of Aboriginal and Torres Strait Islander people are, to this very day, very much opposed to research.**

Interview 2, 24 October 2014

Pat Anderson AO referred to her childhood in the 1950s at Parap camp in Darwin as a time when she was surrounded by an extended family of strong working men and women who critiqued and occasionally actively resisted constraints imposed by the various state, territory and federal administrative structures pertaining to Aboriginal affairs.

I grew up in this household where people really had a strong sense of, probably [not what I] would… describe as human rights, but a sense of justice and right and wrong, irrespective of one's circumstances…
(Pat Anderson Interview 1, 23 October 2014)

She left school at 15, worked with government as a secretarial assistant, travelled overseas and was one of the first Aboriginal graduates of the University of Western Australia. She remarked how fortunate she was in having a strong and positive sense of her mother's and grandmother's connection to land and family. However, there was an overriding sense of inequality that framed her life and continues to affect Aboriginal and Torres Strait Islander people and organisations:

… to be any good as an Aboriginal person you, in fact, had to be better, better than most, and there's elements of that still sticking, still part of this fabric of Australian society today… [T]hat's been my personal experience and it was told to me when I was very young: 'Listen, if you wanna be good in what you're doing, you have to be better than (most) to be even thought of'.
(Pat Anderson Interview 1, 23 October 2014)

Pat Anderson reflected back to the 1960s and 1970s when she and many other Aboriginal leaders were teenagers and young adults were energised by global movements for change and equal rights. It was a time of demonstrations, strikes, moratoriums and anti-war marches set against a backdrop of revolutionary Bob Dylan songs and Black Power literature.[10]

So there was a whole lot of energy for change in the world and we were caught up in that…
(Pat Anderson Interview 1, 23 October 2014)

While this sense of outrage at inequality was being expressed at the universities and in the big cities, little change was occurring in the rural and remote areas of Australia where services for Aboriginal and Torres Strait Islander people were limited. Those that did exist were segregated and hidden in Aboriginal and Torres Strait Islander welfare departments, missions, reserves and pastoral stations.

In the 1970s, however, there was a significant increase in Aboriginal and Torres Strait Islander health research.[11] The results of much of this research confirmed that Aboriginal and Torres Strait Islander life expectancy was lower, and morbidity higher, than for other Australians. In the Northern Territory, these statistics were worse than they had been for non-Indigenous Australians at the turn of the twentieth century.[12] Other indicators – such as living conditions, maternal and infant health and chronic disease – highlighted a huge gap in health outcomes between Aboriginal and Torres Strait Islander and non-Indigenous Australians.

This crucial time of activism followed the 1967 referendum to allow amendments to the Australian Constitution that would give the Commonwealth Government the right to make laws affecting Aboriginal affairs and to include Aboriginal peoples in the national Census.[13] It was a movement that was 'most symbolically expressed through the land rights campaigns, but first gained concrete organisational form through the establishment of the Aboriginal legal aid and health services'.[14]

Change would not happen until the 1970s. The first Aboriginal Community Controlled Health Service (ACCHS) was established in Sydney's Redfern in 1971, with the Victorian Aboriginal Health Service in Melbourne's Fitzroy and the Central Australian Aboriginal Congress (CAAC) in Alice Springs two years later.[15] The CAAC prides itself today as 'the voice of Aboriginal health', from its beginnings in the early 1970s and on its foundation objective that 'Aboriginal health must be in Aboriginal hands'.[16] However, it was not until 1991 that Darwin's Danila Dilba Biluru Butji Binnilutlum[17] and smaller services like[18] Miwatj in East Arnhem Land the following year.[19] A noticeable exception was Utopia's Urapuntja Health Service, which opened in 1977.[20]

When these services are set up, it was very clear that the mainstream system was failing us. So we decided we had to set up our own services… those original AMSs, Redfern and Congress and all the others that followed… were… hotbeds of political activism as well. We were flexing our muscles in terms of, not only self-management, but self-determination.
(Pat Anderson Interview 3, 14 November 2014)

Pat Anderson drew attention to the sense of 'struggle' against inefficient government control and past polices and the desperately poor health situation for Aboriginal and Torres Strait Islander peoples that framed their thinking in setting up these Northern Territory community controlled health services.

There was a whole range of Aboriginal national bodies that was set up around that time, but in particular with the health services, that was a very conscious decision to be able to be part of the struggle. We used to sign letters in those days, 'Yours in the Struggle', with a capital 'S'.
(Pat Anderson Interview 1, 23 October 2014)

The independence of the ACCHSs was enabled by a wide range of people from within the medical profession in Alice Springs and Darwin:

… When we decided that we were going to set up our own organisation, not a government initiative, doctors and nurses and a whole lot of people, as well as Aboriginal people… worked for nothing in those days. They would donate some of their time. The doctors, for instance, when they finished their shifts, they would come to the AMS and they did that for quite a while… NACCHO remains because it came out of the Aboriginal and Torres Strait Islander local communities.
(Pat Anderson interview 3, 14 November 2014)

National Aboriginal Health Strategy

The other thread that provides crucial background to the establishment of the CRCATH and changes to the Aboriginal and Torres Strait Islander health research landscape that began to emerge at this time was the 1989 National Aboriginal Health Strategy (NAHS).[21] It aimed at developing mechanisms to achieve improvements in Aboriginal and Torres Strait Islander health; in particular it focused on taking into account 'specific health issues, health service provisions, Aboriginal and Torres Strait Islander participation, research and data collection and ongoing monitoring'. It also aimed at maximising the involvement of Aboriginal and Torres Strait Islander people in their own health care.[22]

A Working Party was established in 1987, which included stakeholders from across a number of sectors involved in Aboriginal and Torres Strait Islander health, including government, communities and the Aboriginal controlled health sector. Its Chairperson was Dr Naomi Mayers, Director of the Redfern Aboriginal Medical Service. Other members of the group included Associate Professor Ted Wilkes and Professor Shane Houston, both of whom would go on to serve on the Board of the CRCAH. The Working Party carried out consultations with interested parties from across all Australian jurisdictions and received approximately 120 submissions for its consideration.[23]

The Working Party's report highlighted many of the Aboriginal and Torres Strait Islander community's concerns regarding the nature of health research. It noted that research was too often imposed on communities, with the communities having little control or redress, and seldom of actual benefit to them. The report also acknowledged that the pervasive nature of the existing Western-centric approach to research needed to be questioned and re-examined.[24] The Working Party called for reform of the research processes in Aboriginal and Torres Strait Islander health and, in particular, for more involvement by Aboriginal and Torres Strait Islander people:

… The community should be involved in framing the questions so that the research is relevant to their needs. The Aboriginal community must actively participate in the research process, be kept fully informed, and have some say in how research findings are publicised and used. Only when research projects are subject to Aboriginal community influence, will they be both relevant and of benefit to the community.[25]

Shane Houston described the Working Party as 'visionary' to 'embrace this notion that good data and good research could be the bedrock or the springboard on which we built really quite an innovative model and approach to Aboriginal health and research'. This was in spite of the fact that, up to that point, 'appalling relationships [existed] between Aboriginal communities and researchers' resulting from 'countless examples' of research failing to engage in ethical and effective ways with Aboriginal and Torres Strait Islander communities (Shane Houston interview, 1 December 2014).

Shane Houston was critical of what he saw as the dilution of the recommendations of the Working Party in the final report.[26] Nevertheless, he later also recognised that it helped reshape the discussions around some of the most important issues regarding Aboriginal and Torres Strait Islander health and continued to be influential 25 years later. He pointed out that the NAHS was a breakthrough for policymakers and for Aboriginal and Torres Strait Islander community controlled health services, as it carried the debates beyond blaming researchers for their self-interest, and grasped the idea of influencing good and ethical research to create better data.

The report talked about intersectoral collaboration before people were talking in this country about the social determinants of health. It argued the case that housing affected health, that education affected health, that education affected housing. And it did so in a really coherent [way] that both government and communities agreed with. It argued for a reform to the style of service delivery in communities. It argued for more collaborative planning – ongoing planning, joint planning by state, territory and Aboriginal communities in the Aboriginal health arena…

And I think, looking back on it, it was one of those key turning points in the Aboriginal health movement across the country that just flipped the debate, that created a new way of talking about, a new way of engaging [with] and a new way of solving the challenges that we confronted. It was never going to be a panacea that would solve every problem. But it gave us the experience and the tools to approach problems in a new way.
(Shane Houston Interview, 1 December 2014)

Shane Houston

> **And I think, looking back on it, [the National Aboriginal Health Strategy] was one of those key turning points in the Aboriginal health movement across the country that just flipped the debate, that created a new way of talking about, a new way of engaging [with] and a new way of solving the challenges that we confronted. It was never going to be a panacea that would solve every problem. But it gave us the experience and the tools to approach problems in a new way.**

Interview, 1 December 2014

Click to play audio **Play online** (browsers and mobile devices)

Shane Houston, CRCATH/CRCAH/CRCATSIH Interim Board Member, interview 1 December 2014 (p. 188)

Professor Ian Anderson also regarded the NAHS as an important milestone in that, for the first time, there was extensive consultation with Aboriginal and Torres Strait Islander communities, and all stakeholders 'seemed to share some consensus about strategic directions in Aboriginal health'.[27]

The debate informing the development of culturally appropriate research involving Aboriginal and Torres Strait Islander people continued throughout the early 1990s, and involved government, non-government organisations and private enterprise as well as research institutions. An editorial in the *Aboriginal and Islander Health Worker Journal*, for example, noted the continuing bitterness with which many Aboriginal and Torres Strait Islander people regarded existing research practices, arguing that 'a lot of money is being spent funding research on Aborigines but Aborigines are not seeing any of it'.[28] This particular issue of the journal contained articles focusing on reforming research practices in the field of Aboriginal and Torres Strait Islander health, including one by Ken Wyatt,[29] who would later become Australia's first Aboriginal member of the House of Representatives, Minister for Indigenous Health and Minister for Aged Care. Echoing the NAHS Working Party, Ken Wyatt called for research priorities to be determined and established by communities, arguing that they were best placed to identify particular areas of research that could result in beneficial health outcomes for Aboriginal and Torres Strait Islander peoples.[30]

It became evident that real reform would require more than a reliance on procedural guidelines and changes to the existing institutional culture of research management and practice in Aboriginal and Torres Strait Islander health. The focus was now shifting towards implementing more profound forms of institutional change.

Taking control

One of the most significant changes in the landscape of Aboriginal and Torres Strait Islander health was the transfer of responsibilities for funding health services from the Aboriginal and Torres Strait Islander Commission (ATSIC) to the Commonwealth Department of Human Services and Health in 1995. The Hawke Labor Government had established ATSIC, with Lowitja O'Donoghue as Chairperson, in 1990 to replace the Department of Aboriginal Affairs and Aboriginal Development Commission, and assume national responsibility for Aboriginal and Torres Strait Islander health.

However, many Aboriginal Medical Services (AMSs), like the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT), campaigned for better primary health care funding for Aboriginal communities across Australia. This was a strategy to access the much larger, $17 billion budget of the Department of Human Services and Health, 20 times larger than ATSIC's, and to direct funding more effectively to Aboriginal Community Controlled Health Services.[31]

The AMSs, many of which are currently referred to as ACCHSs, and the National Aboriginal Community Controlled Health Organisation (NACCHO) regarded the transfer back to the federal department as a means to create a more mainstream and fairer distribution of funds and access to services.[32] The CAAC and other Northern Territory Aboriginal Community Controlled Health Services commissioned research to provide evidence for their campaign. Stephanie Bell was part of the senior administration of Congress when the challenges were made to ATSIC's role in overseeing Aboriginal and Torres Strait Islander health funding. She reflected on this time and as a part of the beginning of the CRCATH and Lowitja Institute journey:

> *… When we began this journey, we had already begun the challenge of getting Aboriginal health out of ATSIC. So that era kind of highlighted the importance [of this]. Congress led the transfer of Aboriginal health out of ATSIC in 1994–95, [and] commissioned a paper at the ANU [Australian National University] called Beyond the Maze … We used the Beyond the Maze document to advocate the importance of why Aboriginal health needed to stop being ghettoed and to have a rightful place in the Parliament, [and] that we wanted a frontbench minister and we needed to be treated equally [with] access to good quality health.*
> *(Stephanie Bell Interview, 12 March 2015)*

The authors of the report *Beyond the Maze: Proposals for more effective administration for Aboriginal health programs* called for Commonwealth funds for Aboriginal and Torres Strait Islander health to be transferred from ATSIC to the Commonwealth Department of Human Services and Health.[33] In addition, they recommended a number of initiatives to support organisations providing health services to Aboriginal and Torres Strait Islander people. These included training, organisational support and research capabilities. There was also clear recognition that there had been little funding directed to support community controlled health organisations across a number of essential functions including an Aboriginal and Torres Strait Islander community controlled research capacity.[34]

Stephanie Bell remembered a gradual shift in attitudes within the community controlled health organisations to become involved in research:

> *I think, for us, the next natural step was to get into the research world 'cause there were millions of dollars being expended and being handsomely given to many research institutes. And we wanted to stop being the subjects of research. We wanted to be in control; we wanted to drive it. And we could see the importance of working in partnership.*
> *(Stephanie Bell Interview, 12 March 2015)*

Stephanie Bell

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Interview, 12 March 2015

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Stephanie Bell, CRCAH/CRCATSIH Board Member, interview 12 March 2015 (p. 188)

Finding a 'cooperative structure'

The early 1990s were a time of growing advocacy and independence for local Aboriginal organisations that saw health research as a rights issue; they wanted better research and to stop being treated like a poor relation. Stephanie Bell admitted that they were also 'in the right frame for a fight', with Congress having already stood firm for land and governance issues for many years, and social welfare and health organisations also becoming stronger.

By late 1995 there was awareness that the experiment of placing Aboriginal and Torres Strait Islander health within the control of ATSIC had not been successful. Efforts to advocate for change were encouraged by the establishment in 1994 of the Aboriginal Medical Services Alliance of the Northern Territory known as AMSANT.

Pat Anderson and others, believed that AMSANT's practice of bringing members together for regular 'forums' was particularly successful in developing a 'degree of trust and respect' between the ACCHS organisations to work collaboratively. It provided a space for what had previously been independent organisations to meet and 'talk of bigger terms' and advocate for funding and services to the Commonwealth and Northern Territory governments (Pat Anderson Interview 2, 24 October 2014)

At a conference in September 1995, AMSANT and Danila Dilba, the Darwin Aboriginal Community Controlled Health Service, noted:

> *Handing over [I]ndigenous health to ATSIC was disastrous precisely because it was another centralised organisation which had no expertise in the area and no resources to attack the problem.*[35]

At the same conference Stephanie Bell acknowledged that ATSIC had been unfairly expected to be an expert on everything concerning Aboriginal and Torres Strait Islander peoples:

> *Roads and reconciliation, land and language, health and housing: the response of the mainstream has been to dump all these issues in the too hard basket, and then to give that basket to ATSIC.*[36]

Pat Anderson, Stephanie Bell, Marion Scrymgour and other Aboriginal and Torres Strait Islander health leaders called for a paradigm shift. This would see community controlled health organisations as the bedrock of future health services for Aboriginal and Torres Strait Islander people in the Northern Territory and across the nation. They were also beginning to view research as necessary for improving the health outcomes for Australia's First Peoples. However, the climate of mistrust and criticism against research continued to overshadow relationships between researchers and the Aboriginal and Torres Strait Islander health sector leadership. For many Aboriginal and Torres Strait Islander people, research was often tainted as knowledge for knowledge's sake that would only benefit a minority, with no clear application or benefit for Aboriginal and Torres Strait Islander communities.

The meeting that started it all

A meeting in 1996 attended by Pat Anderson, John Mathews and Marcia Langton was consistently mentioned in our interviews as a crucial turning point. At the time, Pat Anderson was Director of Danila Dilba Health Service and Chairperson of AMSANT. She worked closely with Stephanie Bell, who was Acting CEO of the Central Australian Aboriginal Congress, and John Liddle, CEO of Congress but seconded to ATSIC at the time, advocating for radical change in the delivery of health services for Aboriginal and Torres Strait Islander people nationally. They were all working in leadership positions in community organisations in the 1990s and were key to the establishment of the CRCATH, as Pat Anderson recalls:

> *I think reluctantly we agreed that maybe we needed to have a look at this question of research, and maybe that would supply us with the ammunition – or as it is called now, evidence base. But at the time, our thinking wasn't that sophisticated; we just knew that it might be a better way because they weren't going away, nor were we.*
> *(Pat Anderson Interview 2, 24 October 2014)*

'They' in this quote refers to researchers generally and more specifically to medical researchers at Menzies led by its Director John Mathews. 'Us' refers to the ACCHSs, Congress, AMSANT and more generally to Aboriginal and Torres Strait Islander peoples. Marcia Langton at the time was Ranger Professor of Aboriginal and Torres Strait Islander Studies at Northern Territory University (now Charles Darwin University). As an Aboriginal researcher, she straddled both worlds.

For the most part, non-Indigenous researchers undertaking Aboriginal and Torres Strait Islander health research at this time were viewed with suspicion. The majority of health research was funded through biomedical or medical organisations like the National Health and Medical Research Council (NHMRC), hospitals and universities. There were few Aboriginal and Torres Strait Islander people involved at the level of developing research, carrying it out or reporting and evaluating it.

Research results about the alarming evidence of health disparity for Aboriginal and Torres Strait Islander peoples were often seen as descriptive and serving the priorities of researchers and non-Indigenous people. According to Pat Anderson, there was open resistance from the ACCHOs towards this kind of research, and a lack of trust about the value of research for improving the lives of Aboriginal and Torres Strait Islander people. As Pat Anderson, Terry Dunbar, Stephanie Bell and others stated, research was viewed by Aboriginal and Torres Strait Islander communities as being done *on* them not *with* them. The gradual shift in attitudes by individuals from doubts and suspicions to a working and respectful relationship over the terms of the CRCATH and CRCAH underpinned more extensive shifts in collaborative processes in research and changed the direction of research prioritisation from investigator driven to community based.

Individuals like John Mathews were also central to the development of the first CRC and to the change in the health research landscape. John Mathews came to Darwin in 1985 as a medical researcher and first Director of the Menzies School of Health Research, which had been established in 1984. He graduated in science in 1961 and in medicine in 1964 and concentrated on epidemiology and public health. Before joining Menzies he worked in New Guinea and with epidemiological research units in the United Kingdom and in Melbourne.

Asked in his interview why he came to the Northern Territory to research, John Mathews answered that he was ‘naïve’ enough to think he could bring biological, social and genetic research together without too much difficulty. The mid-1980s publicity around poor Aboriginal and Torres Strait Islander health statistics and programs like the National Trachoma and Eye Health Program caught his interest in the potential for effective health research in a northern Australian region with a large Aboriginal population (John Mathews Interview, 27 November 2014).

From the beginning of the CRCATH John Mathews took cooperation with community seriously, writing in 1998 that partnerships between individuals, disciplines, Aboriginal and Torres Strait Islander stakeholders, health services and government were the ‘secret of success’ for Menzies to develop a cooperative research paradigm.[37] A central principle for change related to resolving conflicting approaches to prioritising research needs; one competitive for short-term results, the other interactive processes, and to ‘balance competition with cooperation… to achieve a balance between short term returns (efficiency) and longer term strategic outcomes’.[38]

John Mathews AM, inaugural Director and CRCATH Board Member, interview 27 November 2014 (p. 188)

Finding the funding

As a researcher and the Director of Menzies, John Mathews had long seen the potential of the Commonwealth’s Cooperative Research Centre Programme to fund a new approach to Aboriginal and Torres Strait Islander health research. Established in 1990 to build Australia’s scientific research capacity and to encourage and stimulate collaboration between publicly funded researchers and the private sector, Mathews believed that funding through the CRC Programme would provide a structure for linking the biomedical and behavioural aspects of health research with greater Aboriginal and Torres Strait Islander involvement than had previously existed at Menzies.

> *I was convinced pretty early on that we had to try and find a vehicle that could be seen as more Aboriginal owned… Even though we had Aboriginal people on the Board, and we had an Aboriginal unit in Menzies, it was always seen as primarily being driven by white people. Even though, in order to look at the renal disease and the ear problems and so forth you also had to look at the social and environmental issues, there was still suspicion of the attitude that you wanted to explain what was going on in terms of scientific cause and effect, even if most of the causes that you could intervene on early were social and environmental.*
> *(John Mathews Interview, 27 November 2014)*

John Mathews

> **I was convinced pretty early on that we had to try and find a vehicle that could be seen as more Aboriginal owned… Even though we had Aboriginal people on the Board, and we had an Aboriginal unit in Menzies, it was always seen as primarily being driven by white people.**

Interview, 27 November 2014

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John Mathews, inaugural Director of CRCATH

To John Mathews, the CRC approach seemed a good way of building this ‘cooperative structure’ in conjunction with Aboriginal and Torres Strait Islander people. Under the guidelines, each CRC had to include at least one Australian end-user and one higher education institution, and could also involve other parties, such as federal, state and local government, commercial organisations and industry bodies. Emphasis was placed on enhancing ‘research cooperation through concentrating research activities in one location, or through effective methods of networking; strengthening research training; and on the economic and social benefits of research’.[39]

The CRC structure also supported in-kind collaborations between industry and community within a governing structure led by Aboriginal and Torres Strait Islander people and community organisations. Partner organisations, in consultation with the CRC Board, had the ability to earmark research as ‘in-kind’ projects. This meant that the research was carried out by the Core Partner organisation within the CRC framework. This process allowed the partner organisation to utilise the CRC’s broader support and collaboration network to enhance its research projects and to take advantage of the organisation’s research dissemination programs. These projects then became identified as CRC projects and recorded as ‘in-kind’ contributions in annual reports and financial statements.

Thus, in 1994 Menzies had made its first, unsuccessful, bid for CRC funding for a Cooperative Research Centre in Aboriginal and Tropical Health.[40] John Henry from Deakin University, and one of the key architects of the bid, suggested it had failed because it did not have Core Partners signed up from relevant Aboriginal health organisations.[41]

However, John Mathews was not put off by the 1994 failure and led negotiations in 1995 and 1996 to create a new submission for a CRC with Danila Dilba and Congress as Core Partners. He felt that a CRC for Aboriginal and Torres Strait Islander health was a way of getting ‘new money’ for research but, more importantly, it was a structure intended to facilitate cooperation between partners both from a science research background as well as an Aboriginal and Torres Strait Islander community and health service background.

John Mathews was aware from the outset that the success of the CRC idea depended on bridging the gap between partners from what he termed a ‘cultural environment’ and a ‘research environment’. He believed that Aboriginal and Torres Strait Islander people:

> ***… always felt disempowered that they weren’t setting the priorities and so the CRC opportunity provided a way of getting some new money and the cooperative structure, if it worked, would help to deliver a research product that was following priorities that Indigenous people have decided on, through the Board.***
> *(John Mathews Interview, 27 November 2014)*

He recalled that there was disappointment among some of his colleagues working through Menzies that the proposed structure for the CRCATH would be unusual in that it would give biomedical researchers less direct influence over the direction of research and distribution of research grants. Some were resistant to an ‘organisation where the priorities would be decided by Indigenous people’ (John Mathews Interview, 27 November 2014).

Pat Anderson remembered this time:

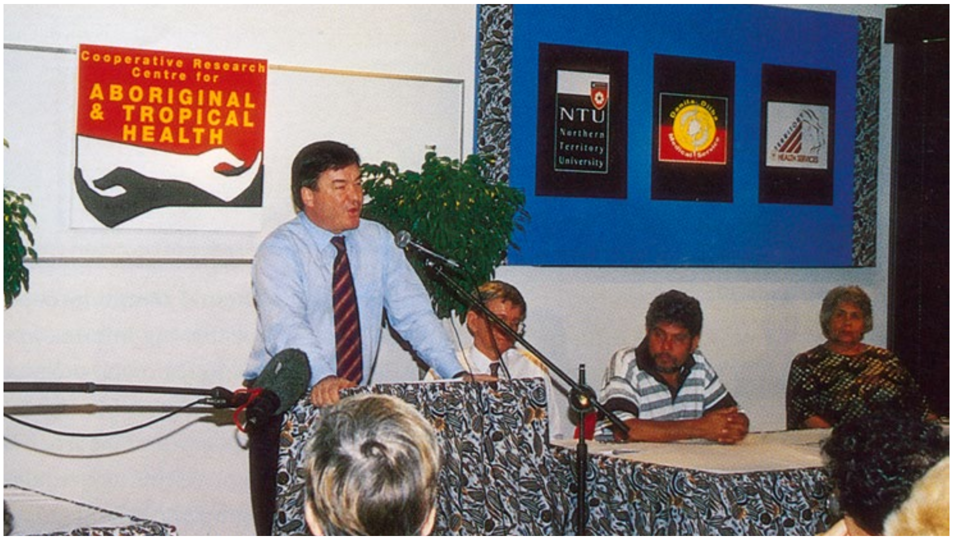
> *We were at a bit of a checkmate kind of situation… John [Mathews] with his consistency kept approaching us and we kept saying 'no'… I even went to one public meeting and I was the only one that stood up and said, 'I'm not gonna do this. We're not going to go down this road'. We had several meetings, and I would sort of go and be the lone objector often. To his credit, though, he persevered and he was able to get a few people on board, like Marcia [Langton].*
> (Pat Anderson Interview 2, 24 October 2014)

Marcia Langton's role in encouraging Pat Anderson to meet with John Mathews and discuss the idea for a CRC of Aboriginal and Tropical Health was mentioned often in our interviews. For her part, Marcia Langton reflected on what a 'very different world' it was in the Northern Territory in the mid-1990s when she took what at worst could be seen as 'an old white doctor' to meet with Pat Anderson at Danila Dilba. She believed in research to create evidence and that quality health research would make a difference. She also believed that setting up a CRC for Aboriginal and Tropical Health was 'a fabulous idea'. So taking John Mathews to meet with Pat Anderson was not a particularly difficult decision for her, as he was 'a great intellectual… who had the smarts… and the experience to make this happen' (Marcia Langton Interview, 14 January 2015).

During the meeting with John Mathews, Pat Anderson was reluctant to commit the organisations to any research collaboration. There was, however, a possible way to break the impasse if the Board overseeing the proposed CRCATH had both a majority of members and an independent Chairperson who were Aboriginal and Torres Strait Islander. She put this proposal to John Mathews and he accepted and submitted the application to the CRC Programme.

A 'public good' Cooperative Research Centre

A few months after this meeting with John Mathews and Marcia Langton, Pat Anderson along with Stephanie Bell decided that they should perhaps pull out of the proposal – but they were too late as the bid for the CRCATH had been successful. Once committed, however, 'there was no better person to take the stirrups and the halter and drive the horse in the right direction' than Pat Anderson (Marcia Langton Interview, 14 January 2015). According to Dr Jeannie Devitt, the first Aboriginal Medical Services Research Fellow with the CRCATH, there would not have been any CRCs without Pat Anderson 'staying with the original vision' and seeing it 'through several transformations, but still seeing the value that she'd originally thought it had to offer' (Jeannie Devitt Interview, 13 March 2015).



The Hon Michael Wooldridge officially opens the CRCATH, July 1998

Seated: John Mathews, Larrakia Elder Billy Risk and Lowitja O'Donoghue

***Pat Anderson, CRCATH Director, CRCAH/CRCATSIH/
The Lowitja Institute Board Member and Chairperson,
interview 2 24 October 2014 (p. 188)***

Stefan Postles Photography

In 1997, shortly before the opening of the Cooperative Research Centre for Aboriginal Tropical Health in July, the Minister for Health and Family Services Dr Michael Wooldridge informed the House of Representatives that:

> *We are not going to have success without research. Research has to underpin any endeavour in health, and particularly in Aboriginal health. We have a very exciting venture happening in Darwin with the Menzies School of Health Research. We have $50 million – $14 million direct from the Commonwealth and $35 million matched mainly by Commonwealth and state agencies – to spend to look at just the health needs of Aboriginal people. This is a Cooperative Research Centre of the Department of Science and Technology that is looking at Aboriginal wellbeing.*[42]

The CRCATH and the subsequent CRCs were part of the category known as a 'public good' CRC involving research in the public interest and for the good of the community. The first CRCATH annual report noted that:

> *This CRC is a public good CRC, and it is unlikely that any of the research programs will result in commercial products. The public benefit, and the benefit to Aboriginal people, will come through the identification and implementation of more effective education, training, health services and intervention strategies, through the cooperative partnerships between the research and health service partners.*[43]

'Public good' CRCs sat a little awkwardly within the broader structure of the CRC Programme, which encouraged the commercialisation of research through CRC linkages. Pat Anderson remembered times when the aims and emphasis of the CRCATH, and subsequent CRCs, seemed at odds with issues like the commercialisation of intellectual property or patent outputs. She described the CRCATH as occasionally seeming like a 'square peg in a round hole', with its Second Year Review portraying it as being 'intrinsically different to other CRCs elsewhere in Australia'.[44]

An independent Chairperson

All of the interviewees recorded for this story paid tribute to the decision to ask Lowitja O'Donoghue to be the first Aboriginal and Torres Strait Islander independent Chairperson of the CRC for Aboriginal and Tropical Health – and to her role in making it work:

Lowitja O'Donoghue was our first Chairperson... we decided that for [the CRCATH] to get any wings at all, we needed a Chair who had some status and some authority, a lot of both... We looked at each other – me, Stephanie and Johnny Liddle – and we delegated Johnny to have the initial conversation with [Lowitja] to see if she was interested or not. And to her credit she said yes, and the rest is history.
(Pat Anderson Interview 2, 24 October 2014)

Lowitja O'Donoghue was highly respected both within the Aboriginal and Torres Strait Islander community and outside the immediate circle of the CRCATH Board and health research organisations. Her name was well known across Australia as Chairperson of ATSIC and for her public advocacy of reconciliation (see Biography, p. 6). Jeannie Devitt regarded the decision to invite Lowitja O'Donoghue to be the first independent Chairperson of the Board as a strategic 'masterstroke'.

She just carried that job so convincingly and confidently that everybody fell in behind... She was of the stature that people wanted to support. And of course, she had a professional health background. She had so much experience at the most senior levels of management and government... there was so much skill that Lowitja brought to that table, and so much authority... I can't think of a single other person who could have done that job at that time as well... Watching her operate in a room of all these people and professors... gave everybody confidence that – yes – we'd be able to work these things out with people of that skill.
(Jeannie Devitt Interview: Part 1, 13 March 2015)

Marcia Langton saw Lowitja O'Donoghue as a true innovator who brought her personal experience as a nurse and her willingness to contend with uncomfortable issues to the role of Chairperson of the first and second CRCs. She believed that Lowitja O'Donoghue's constant resetting of discussions from a local to a grander scale set her apart and made her such an important part of the success of the early CRCATH.

Lowitja was highly disciplined and hard working and wanted the best for herself and her people... She was a problem solver, she gave things labels, she identified problems, she solved the problems, she dealt with it... She contended with the most uncomfortable issues. You had to be brave to take on the lack of our civil rights back then, very brave. So she's the kind of leader who put her name to the CRC, she backed it all the way, she lent her reputation and credence to it and opened doors for people.
(Marcia Langton Interview, 14 January 2015)

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Marcia Langton

“Lowitja was highly disciplined and hard working and wanted the best for herself and her people... She contended with the most uncomfortable issues. You had to be brave to take on the lack of our civil rights back then, very brave. So she's the kind of leader who put her name to the CRC, she backed it all the way, she lent her reputation and credence to it and opened doors for people.”

Interview, 14 January 2015

Professor Marcia Langton AM, CRCATH Researcher, interview 14 January 2015 (p. 188)

A majority Aboriginal and Torres Strait Islander Board

From the outset, one of the most distinctive 'intrinsically different' features of the CRCATH was its unique Board structure, which had a majority of Aboriginal and Torres Strait Islander members – a requirement of the Commonwealth Agreement. This particular structure was regarded as a mechanism through which to ensure that the profile of the CRCATH developed 'in accordance with the priorities of Aboriginal Australians themselves'.[45]

The initial Board membership consisted of representatives from the six Core Partners of the CRCATH:

- Menzies School of Health Research
- Flinders University
- Northern Territory University (which became Charles Darwin University in 2004 following its merger with Alice Springs Centralian College)
- Danila Dilba Biluru Butji Binnilutlum Health Service Aboriginal Corporation
- Central Australian Aboriginal Congress
- Territory Health Services (which became Department of Health and Community Services in 2002).

In addition, four Board members were collectively appointed by the Core Partners based on their expertise in health, education or community affairs, while membership was for a period of two years with the possibility of re-appointment. The Board was obliged to meet at least twice a year, but no more than four times a year, with six Board members needing to be present for a quorum.

Members of the Board included the following Core Partner representatives:

- Pat Anderson, Danila Dilba
- Michael Good, Menzies School of Health Research
- Trish Angus, Territory Health Services
- Charles Webb, Northern Territory University
- Paul Hughes, Flinders University
- John Liddle, Central Australian Aboriginal Congress.

Ordinary Members of the CRCATH Board were:

- Edna Barolits, Miwatj Health Services
- Donna Ah Chee, Institute of Aboriginal Development
- Charles Tipungwuti, Tiwi Health Board
- Ian Anderson, The University of Melbourne.

The unique Board structure of the CRCATH is regarded as one of the key factors to the organisation's success and ongoing impact in the field of Aboriginal and Torres Strait Islander research. As Ian Anderson has noted:

> *... it was also important to have a signal to the broader practice world in Indigenous communities that this is an agenda which we're having some control over... I think in some ways it was also very healthy because it actually made Indigenous Australians in leadership positions take leadership on this issue rather than allowing for other people to get in the decision-making role. So it was useful. It provoked us into actually taking control and it... helped build capabilities in those very important initial 10 years.*
> *(Ian Anderson Interview, 17 December 2014)*

Marcia Langton also acknowledged the significance of having an Aboriginal and Torres Strait Islander controlled Board:

> *[It was] tremendously important because you had to get the confidence of the Aboriginal community to get involved with the medical research community and that was the deal, those were the conditions, and so it was very important at that time.*
> *(Marcia Langton Interview, 14 January 2015)*

An executive committee was instituted as part of the management structure of the CRCATH to support the Board in its operations. Members of the committee included the Director John Mathews, the Deputy Director Dr Peter d'Abbs, the Business Manager, and the Program Leaders responsible for overseeing the research programs. The committee also included the Education and Training Coordinator Dr Dorothy Mackerras and Jeannie Devitt. The role of the committee was to facilitate communication between the various research programs and to act as a point of contact between the researchers in the CRCATH and the Board.

Ian Anderson

> **… it was also important to have a signal to the broader practice world in Indigenous communities that this is an agenda which we're having some control over… I think in some ways it was also very healthy because it actually made Indigenous Australians in leadership positions take leadership on this issue rather than allowing for other people to get in the decision-making role. So it was useful. It provoked us into actually taking control and it… helped build capabilities in those very important initial 10 years.**

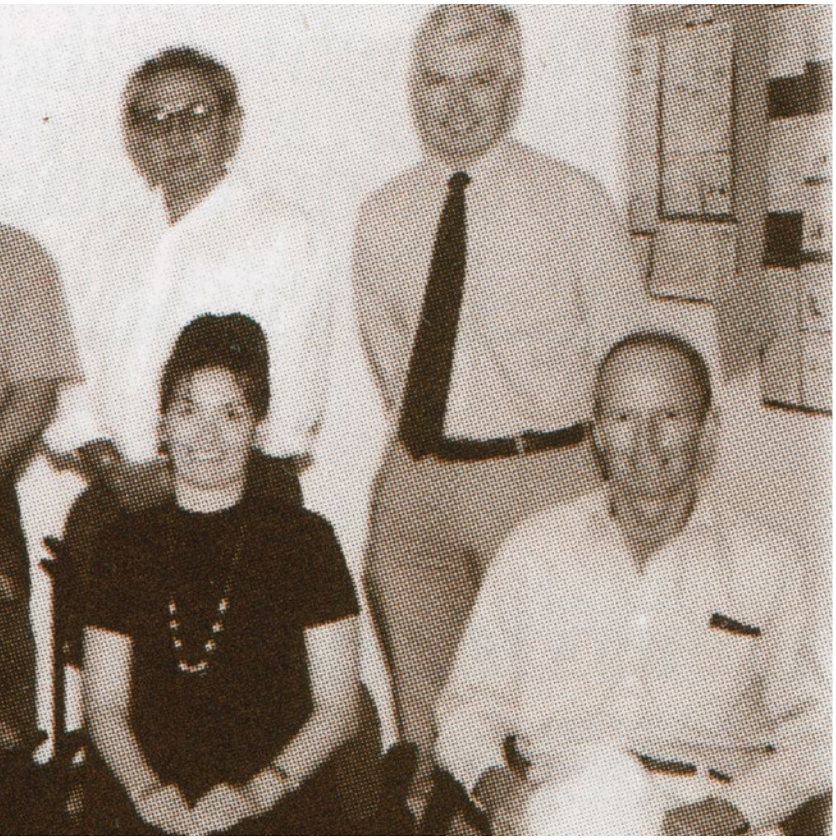
Interview, 17 December 2014

The other area that needed organisation and expertise was the setting up of the new CRC's business and administrative processes, systems and policies.

> *Once we got the Board established, and we worked through a whole lot of processes within Menzies, it was Terry Dunbar who worked with John [Mathews] at that time, a young Aboriginal woman… [who] was responsible for organising all the administration around the work of the new CRC… It hadn't been done before by us, so it was a whole new area that she went into, and I was really impressed.*
> *(Pat Anderson Interview 2, 24 October 2014)*

Terry Dunbar had come into the CRCATH development process in 1996 when she applied for a position at Menzies, where she met with a number of people who were key to the establishment of the CRCATH, including Marcia Langton and Stephanie Bell. For Terry Dunbar, who worked on the application and, from 1997, was Business Manager, two main issues emerged as they developed the structures and administrative processes of the CRCATH:

> *One was that issue around the research agenda and the processes that then follow on from that. But it was also to do with making sure that in the Northern Territory, because that's where [the organisation] was going to be focused to start off with, the two AMSs did get a decent say about shaping that agenda, and the financial flow-back to those organisations who wanted to do more research as well.*
> *(Terry Dunbar Interview Part 1, 11 March 2015)*



Inaugural Board of the CRCATH

Standing L–R:
Ian Anderson, Charles Webb, Paul Hughes, Charles Tipungwuti, John Liddle, Sutti Ahmat Michael Good (absent: Pat Anderson)

Sitting L–R:
John Mathews, Edna Barolits, Trish Angus, Chairperson Lowitja O'Donoghue, Donna Ah Chee, Peter d'Abbs[46]

Ms Pat Anderson AO (CRCATH Director, CRCAH/CRCATSIH/The Lowitja Institute Board Member and Chairperson), interview 2 24 October 2014 (p. 188)

Pat Anderson

> **Once we got the Board established, and we worked through a whole lot of processes within Menzies, it was Terry Dunbar who worked with John [Mathews] at that time, a young Aboriginal woman… [who] was responsible for organising all the administration around the work of the new CRC… It hadn't been done before by us, so it was a whole new area that she went into, and I was really impressed.**

Interview 2, 24 October 2014

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Associate Professor Terry Dunbar (CRCATH Research Leader), interview 11 March 2015 (p. 188)

Ensuring change through research

It took time to establish a research program but the Board and staff carved out five program areas in that first year of operation: Indigenous Education; Health Resources and Service Delivery; Public Health; Communication and Information; and Biomedical. The program structure was designed to 'lead not only to better health outcomes, but also better-informed debate about health issues'.[47]

A source of conflict in the early stages of the Board was the view from Aboriginal community controlled health services that researchers and research institutions saw the CRCATH as 'just another funding source' for non-Aboriginal, non-community investigator led projects (Jeannie Devitt Interview 1, 13 March 2015). Their commitment to real change in recognising Aboriginal and Torres Strait Islander community authority and their role in research prioritisation remained in doubt, as Ian Anderson explained.

> *First of all it was probably true to say that the community partners and the research partners were not very trustful of each other. In talking with my colleagues from the community controlled sector, they certainly talk about coming into this research enterprise with a degree of anxiety of not really knowing what it was about, not wanting to be not included but also not being completely convinced in the value of the exercise, and I think that's a reasonably fair assessment of the dynamics in the period. I do remember that a lot of the Board meetings reflected that tension. I have to say that the relationships, by and large, were very collegial and, the fact is, quite enjoyable for the whole of that first period of time. But there were obvious issues that were reflected in the dynamics of the organisation.*
> *(Ian Anderson Interview, 17 December 2014)*

Ian Anderson was a member of the CRCATH Board from 1997 to 2003. As the first Aboriginal medical graduate of the University of Melbourne in 1988 and Medical Adviser to the Commonwealth's Office for Aboriginal and Torres Strait Islander Health Services (OATSIHS) from 1996 to 1998, his background and experience as an Aboriginal health researcher contributed to his effectiveness on the Board.

As the CRCATH developed, Ian Anderson led the process of research prioritisation and publishing in the health research area. He identified the transfer of Aboriginal and Torres Strait Islander health out of ATSIC as the beginning of change in the broader policy landscape that began to emphasise the strategic importance of having research priorities identified by service users and the Aboriginal and Torres Strait Islander community as well as researchers.

Ian Anderson was aware of the NHMRC's interest in developing a long-term research agenda that considered processes for building Aboriginal and Torres Strait Islander community involvement in health research.

> *I became involved in doing some of that work in my role as a Commonwealth medical officer. It really started me thinking about how you build processes and mechanisms to actually help and work with researchers to shape the direction of their research in the first instance, and secondly, and probably more significantly, ensure that the outcomes of the research impact on policy and practice.*
> *(Ian Anderson Interview, 17 December 2014)*

Jeannie Devitt, who had worked previously with Congress on health research projects and was trusted to promote their interests, had been employed by the CRCATH as a contact point to provide information to Danila Dilba and Congress. She remembered the first two-day planning workshop organised by the CRCATH at which representatives from all the stakeholder groups – including Congress, Danila Dilba, the Commonwealth Department of Human Services and Health, and the Flinders and Melbourne universities – met to develop the seven-year plan and priority research areas for the CRCATH. The application for funding had outlined priority areas but the Aboriginal and Torres Strait Islander health representatives did not feel they had been adequately consulted and identified a different program of research for the CRCATH.

We kind of overturned the program that had been written up in the... agreement documents... We chucked all that out and people got down to put down the kind of priorities that they wanted to look at.
(Jeannie Devitt Interview 1, 13 March 2015)

Planning workshops with all stakeholders were important for establishing collaborative processes and effective working relationships. In the second year, again at a stakeholder, staff and researchers' planning workshop in Darwin that he was facilitating, Ian Anderson remembered the continuing suspicion of researchers and research that he worked to overcome.

We had two corners and the researchers were clustered in one corner, the community sector was clustered in the other corner and I spent a lot of time kind of running messages between the two of them. Now that might be a bit of an over-exaggeration but I think it's probably fair to say that one of the major things that impacted – one of the major consequences actually, the good consequences of that process – was that over time that dynamic began to shift. People began to see that the research enterprise had value in the Indigenous health service delivery enterprise, and people actually came to form warm relationships. And that kind of shifted the nature [of] ... institutional practices around Indigenous health research.
(Ian Anderson Interview, 17 December 2014)

These meetings in the early years of the CRCATH are well remembered as times of change when Aboriginal and Torres Strait Islander people stood firm on their principles of real inclusion. As a result, some researchers withdrew from the planning process, unable to accept the situation. Pat Anderson recalls a meeting held with key researchers in Darwin where the Board stated, in no uncertain terms, that it wanted to reshape the manner in which research into Aboriginal and Torres Strait islander health was carried out:

There was a meeting held in Darwin, in a hotel, of the researchers and the Board, and we pretty much said that we didn't want to do research that way, that we wanted to do it this way. Now, that was a huge meeting... [in which] people were polarised. There was us, the Aboriginal people, and a lot of the researchers on opposing sides. They resented being told by Aboriginal people that there's a new sheriff in town and this is how we're going to do business – that we wanted to change the whole way that research was done. But we weren't even talking in those terms either at that meeting, we were just saying we wanted to have more say about research. We hadn't quite got to the stage yet of saying, very definitely, 'we will set the research agenda', but we were on that path if you like.
(Pat Anderson Interview 3, 14 November 2014)

Professor Michael Good was an inaugural member of the CRCATH Board from 1997 as the representative for Menzies, and continued as a Board member on behalf of the Queensland Institute of Medical Research (QIMR) from 2000 to 2003 and again from 2006 to 2010.[48] As Director of the CRC for Vaccine Technology, he was a scientist with little experience of working with an Aboriginal and Torres Strait Islander majority committee or of working directly with Aboriginal and Torres Strait Islander communities.

Ian Anderson, Pat Anderson, Jeannie Devitt and others spoke of the importance of Michael Good's persistent questioning at a Board level about the rationale behind cultural protocols and processes that added layers to consultation and could delay decisions about research. His questions broke down some of the language barriers between scientific and community research, helped to build a level of understanding between the different members of the Board, and freed up discussions about topics that would otherwise remain hidden but were important to improving health outcomes. Ian Anderson recalled that Michael Good

... would ask questions about 'Why can't we talk about genetics research? Why can't we talk about sex? Why can't we talk about x, y, z?' Of which there would always be, kind of, a little bit of a chuckle and they would then go on and talk about something else and say to him, 'Michael, we can't talk about this'. But that really, I think, laid the ground open for us to actually start questions about why [not]. If we can't research difficult topics in an environment in which Aboriginal people are the majority of the Institute at a Board level, in an environment which is building close collaborations with service providers, where is it going to happen?
(Ian Anderson Interview, 17 December 2014)

These early meetings and Board discussions were spaces where non-researchers began to question openly research methods, aims and practices in a genuine effort to understand why things had been done in a particular way. This constant questioning for increased understanding became a two-way thing – from both experienced biomedical researchers and less experienced researchers – that, as Ian Anderson states, 'hurried up practice in a way'.

Click to play audio | **Play online** (browsers and mobile devices)

Dr Jeannie Devitt (CRCATH Research Fellow), interview 13 March 2015 (p. 188)

Pat Anderson

> **There was us, the Aboriginal people, and a lot of the researchers on opposing sides. They resented being told by Aboriginal people that there's a new sheriff in town and this is how we're going to do business – that we wanted to change the whole way that research was done.**

Interview 3, 14 November 2014

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Ms Pat Anderson AO (CRCATH Director, CRCAH/ CRCATSIH/The Lowitja Institute Board Member and Chairperson), interview 3 14 November 2014 (p. 188)

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Professor Ian Anderson AO (CRCATH Board Member and Research Leader, CRCAH/ CRCATSIH Research Director, CRCATSIH Interim Board Member), interview 17 December 2014 (p. 188)

James Henry Photography

CRCATH trainee Melita McKinnon inspects samples for the otitis media project

The CRCATH was responsible for many significant research projects. Staff included Komla Tsey who had worked as health educator for the Anyinginyi Health Aboriginal Corporation in Tennant Creek and with the CAAC. He headed up the Central Australian Unit of Menzies in Alice Springs between 1995 and 1997, and became one of the inaugural Program Leaders with the CRCATH in charge of the Indigenous Education Research Program. After leaving his role as Program Leader in 1999, Komla Tsey continued with the CRCAH and the Lowitja Institute CRC as a researcher and Project Leader, and, in 2012 as Program Leader, Healthy Communities and Settings.

Komla Tsey discussed how his childhood experiences in Ghana underpinned his approaches to conducting research and working collaboratively with Aboriginal and Torres Strait Islander people. He highlighted the role of the CRCATH in making research relevant to Aboriginal and Torres Strait Islander people and in involving them in the process of research. This process began with a series of workshops in Alice Springs, Katherine and Tennant Creek that posed an open question to workshop participants: what did they want from the CRC?

And people made a number of suggestions. Again, the idea that Indigenous people should be involved in doing the research was a recurring theme. So, in the end, the steering group decided that we should focus on research capacity enhancement. How do we enhance Indigenous people's capacity to identify their own research? And in fact, what people said was, 'If non-Indigenous people really want to be relevant to us, then they should collaborate with us, help us to do our own research'. (Komla Tsey Interview, 25 March 2015)

And collaborate they did on a range of strategic research programs that achieved some positive outcomes, including:

- 'Sharing the True Stories', an analysis of cross-cultural communication within a Darwin dialysis unit
- Cost-benefit analyses of fluoridation and of the provision of renal units in the Barkly region
- *Atlas of Health-Related Infrastructure* and its related publications, which informed the health zones created under the Commonwealth Government's Primary Health Care Access Plan
- Evaluation of the Central Australian Rural Practitioners Association's *Standard Treatment Manual*.

Other research, longitudinal in focus, offered health outcomes for the future including:

- Several trials of antibiotics and vaccines aimed at chronic and infectious diseases, such as otitis media and chronic obstructive pulmonary disease
- Breakthroughs in skin health through the identification, isolation and taxonomic description of several *Sarcoptes* (scabies) species
- Research into the melioidosis-causing bacteria *Burkholderia pseudomallei*, the most common cause of fatal community-acquired bacteriaemic pneumonia at Royal Darwin Hospital.[49]

The great strength of the CRCATH approach to research was its focus on bringing together researchers and Aboriginal and Torres Strait Islander community, developing research capacity, improving ethical processes in Aboriginal and Torres Strait Islander health, transferring research outputs, and developing the Indigenous Research Reform Agenda or IRRA, which was further developed by the CRCAH in its Facilitated Development Approach.

Changing the research culture

The 'foundation of the [CRCs'] collaborative philosophy', the Indigenous Research Reform Agenda (IRRA), had as its aim 'to redress traditional research methodology (which often objectifies and relegates Indigenous people)... [and to guide] a process of organisational reflection on research practice and processes'.[50] However, the structure of the organisation placed some obstacles in the way of this new research paradigm that sought to make significant changes to the way research was developed, in particular by increasing the influence of Aboriginal and Torres Strait Islander communities in the process, and a research culture that was slow to change.

These issues became evident in the IRRA, which was developed as part of the Links Action Project. Initiated in 2002 under the CRCATH, the project aimed to investigate the effectiveness of the organisation's research procedures, the manner in which research was managed and the manner in which research was disseminated.[51] Part of the project's focus was to formalise an approach to research that sought to decolonise the Western research traditions that had long held sway in mainstream research institutions.[52]

Ian Anderson points out that at the time the CRCAH was developing internal policies and structures to support Aboriginal and Torres Strait Islander-led research, the wider environment was beginning to change with the IRRA placing key issues at the forefront of discussions.

Komla Tsey, CRCAH/CRCATSIH Research Program Leader, interview 25 March 2015 (p. 188)

Komla Tsey

> **... the idea that Indigenous people should be involved in doing the research was a recurring theme. So, in the end, the steering group decided that we should focus on research capacity enhancement. How do we enhance Indigenous people's capacity to identify their own research? And in fact, what people said was, 'If non-Indigenous people really want to be relevant to us, then they should collaborate with us, help us to do our own research'.**

Interview, 25 March 2015

Click to play video

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Two key mechanisms that emerged to shape research were the 'ethical regulation of research practice' and the 'development of an Indigenous health research capability; in other words, the building of an Indigenous research workforce' (see next page) (Ian Anderson Interview, 17 December 2014).

Ian Anderson noted the gradual increase over the period of the CRCATH and the early part of the CRCAH in the number of Aboriginal and Torres Strait Islander researchers that influenced the shape and flexibility of the priority-setting process in the organisation. It broke down the 'unhelpful' and simplistic division that there was 'a bunch of users or service providers who are Aboriginal and the bunch of researchers who are not Aboriginal' (Ian Anderson Interview, 17 December 2014).

With Aboriginal and Torres Strait Islander researchers 'leading and developing and building their own research agendas', Ian Anderson believes a 'critically important transition in the Indigenous research agenda' occurred.

> *The CRC itself began to show leadership in this space and CRC researchers began to look at issues around how do you, for example, practically build research capabilities so that community organisations and the Aboriginal community controlled health sector can actually develop their own research agendas or work in collaboration with the research partners from other organisations.*
> *(Ian Anderson Interview, 17 December 2014)*

It was not seamless and, for Ian Anderson, needs to be seen within the bigger picture of changing opportunities and ideas about Aboriginal and Torres Strait Islander-led health research and the questions that Aboriginal and Torres Strait Islander researchers posed about research.

Terry Dunbar, who by this time was the CRC's Deputy Director (2002–05), reflected on the challenges she found in trying to resolve tensions between some of the stakeholders in the Aboriginal and Torres Strait Islander health research area who could not understand the role of non-research trained Aboriginal and Torres Strait Islander people being involved in research priority setting or defining a research topic (Terry Dunbar Interview Part 1, 11 March 2015). She pointed out that the deeper tensions between qualitative and quantitative research methodologies also needed to be tackled to overcome old prejudices within the biomedical research sphere that qualitative research methods are 'soft' and 'not actually going to prove anything'. A key component for bringing about change came with 'having Indigenous people on the project as researchers in their own right' to work out how to make research effective for those providing services and for the recipient of the services as well (Terry Dunbar Interview Part 1, 11 March 2015).

Terry Dunbar found that even in discussing ethical approaches to research, there was a divide between researchers who struggled with the notion that their research topic might be challenged or altered when it was considered in the context of community understanding or involvement. She recalled conversations with senior biomedical researchers during the early phase of the CRCATH that were aimed at convincing them that research ethics included taking into account the level of understanding of the people being researched (see pp. 53–4 for more on ethics). Rethinking a project's design to be inclusive meant understanding that Aboriginal and Torres Strait Islander people 'need to be able to speak' (Terry Dunbar Interview Part 1, 11 March 2015).

The key findings of the project identified many of the concerns people had in the way that research was carried out. It recognised a responsibility on the part of organisations working in Aboriginal and Torres Strait Islander health research to support reform initiatives to ensure better outcomes for Australia's First Peoples. It identified the need to prioritise the needs and interests of Aboriginal and Torres Strait Islander peoples in setting research agendas and the importance of their involvement in framing research questions. It acknowledged the need to create closer collaboration between Aboriginal and Torres Strait Islander and non-Indigenous researchers in order to promote the exchange of skill and knowledge, and the crucial role played by ongoing institutional support in facilitating this process.[53] At the heart of the Links Project and the IRRA was an attempt to bring about a degree of critical reflection to the development of research practices.

The IRRA was to become the core foundational mechanism by which research was identified, developed, carried out and disseminated under the new CRCAH's Facilitated Development Approach to research (see pp. 40–1). As part of this, improving Aboriginal and Torres Strait Islander control of ethical issues and understanding the ways in which Aboriginal and Torres Strait Islander people might gain constructive input in the health research agenda also became fundamental to the CRCs' work (see pp. 53–6).[54]

In the CRCAH this work was expanded in the FDA and crystallised into the five key research principles that guide the work of the Lowitja Institute CRC and the Lowitja Institute (see p. 56).

Indigenous Research Reform Agenda

The IRRA, developed by the CRCATH and the CRCAH, encompassed a broad platform of activity that included Aboriginal and Torres Strait Islander health reform as well as greater integrity in relation to research.

Some of the critical issues included:

- involving Aboriginal and Torres Strait Islander communities in the design, execution and evaluation of research
- defining the coordinating role of Aboriginal and Torres Strait Islander community-controlled organisations
- consultation and negotiation defined in practice as ongoing and open to scrutiny
- mechanisms for Aboriginal and Torres Strait Islander control and transformation of research
- mechanisms for ongoing surveillance of research projects
- processes to determine research priorities and benefits
- determination of ethical processes for the conduct of research in terms of consultation and negotiation
- transformation of research practices from 'investigator-driven' to a re-assertion of control by Aboriginal community controlled organisations over the research project and an adoption of the needs-based approach to research
- linkage between research and community development and social change
- the training of Aboriginal and Torres Strait Islander researchers
- the adoption of effective mechanisms for the dissemination and transfer of research findings
- ownership and control of research findings by Aboriginal and Torres Strait Islander communities.

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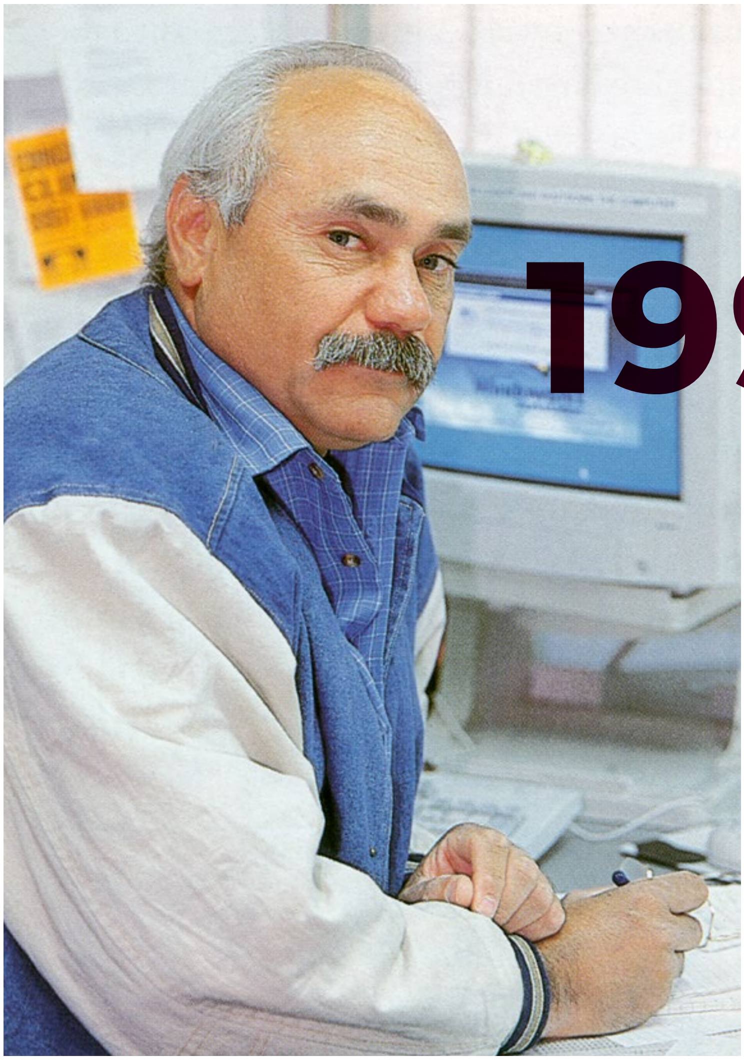
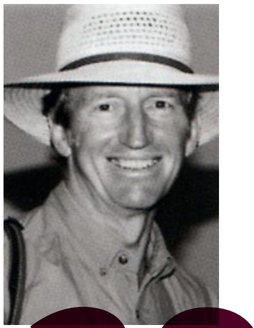




–2003

Clockwise from top left

Johnny Liddle, CRCATH Board member and CEO, Central Australian Aboriginal Congress

Mark Mayo at work in the lab researching melioidosis

CRCATH Board, 2001–2002 (L–R): Pat Anderson, Charles Webb, Kez Hall, Tony Barnes, Chairperson Lowitja O'Donoghue, Terry Dunbar, Charles Tipungwuti, David Ashbridge, Veronica Arbon and Kerin O'Dea

From L–R:
Peter d'Abbs, CRCATH Deputy Director;
John Mathews, CRCATH inaugural Director;
Terry Dunbar, CRCATH Deputy Director

Jeannie Devitt, CRCATH Research Fellow with John Robinson from Danila Dilba Medical Service

Director Tony Barnes, Maria Scarlett, Steve Yunupingu (artist), Lawurrpa Maypilama, Sally Matthews and Terry Dunbar with the painting 'Yalu' marŋgithinyaraw – The Yalu Story' presented to the CRCATH by clan representatives from Galiwin'ku (see http://yalu.cdu.edu.au/)

CRCATH trainee Erin Lew Fatt

Delegates at CRCAH Convocation, Adelaide, November 2006

Bridging the Research Divide: Cooperative Research Centre for Aboriginal Health

With strong and effective Aboriginal input and control, we will conduct high quality strategic Aboriginal health research, and we will engage in effective development activities with Aboriginal communities, service providers, policy formulators and decision makers.

CRCAH Annual Report 2003–2004

The success of the CRCATH led to Commonwealth funding for a second CRC, the Cooperative Research Centre for Aboriginal Health. In his 2003 report on the CRCs for Aboriginal Health 1997–2003 undertaken for the Department of Education, Science and Training, John Henry highlighted the success of the 'public good' model that had been inherent in the CRCATH and had led to its refunding. He argued that:

> *… over the period since 1997, when the core industry and research organisations came together in what was to be a shaky marriage given the prior histories of relationships amongst some of the key Northern Territory players, the CRC model has been shown to be flexible and robust enough to enable shared accommodation of different perceptions on ways to build a viable research culture in Indigenous health and services delivery, and then create a set of new understandings on these very same matters.*[55]

The vision of the new CRCAH was simple – 'Sustained improvements in Aboriginal health through strategic research and development':

> *With strong and effective Aboriginal input and control, we will conduct high quality strategic Aboriginal health research, and we will engage in effective development activities with Aboriginal communities, service providers, policy formulators and decision makers.*[56]

Launched at Adelaide's Flinders University in August 2003, the CRCAH made it clear from the start that it would expand the CRCATH research 'towards a greater emphasis on national Aboriginal health concerns'.[57] The new Chairperson, Pat Anderson who had taken over from Lowitja O'Donoghue, was also determined that the Aboriginal and Torres Strait islander community be 'an equal partner throughout the research process, from priority-setting through research practice to dissemination of results'.[58]

CRCAH Chairperson Pat Anderson, Chris Marlin, Patron Lowitja O'Donoghue, Wendy Edmondson, Director Tony Barnes and Anne Edwards at official launch of the CRCAH, Adelaide, August 2003

To help achieve these aims, six more Core Partners were sought, in addition to the existing partners, to ensure 'greater research capacity and increased representation from small- to medium-sized enterprises and from industry'. Board membership was expanded to 12 to include the following new Core Partners:

- Commonwealth Department of Health and Ageing (DoHA)
- La Trobe University
- Queensland Institute of Medical Research
- The University of Melbourne
- University of Queensland
- Australian Institute of Aboriginal and Torres Strait Islander Studies.

The new Board had an independent Aboriginal chair, two independent Aboriginal members, a representative from Menzies School of Health Research, a representative each from AIATSIS and the four industry partners, and three members representing the six academic partners. Board members included Stephanie Bell representing CAAC, Shane Houston representing the NT Department of Health and Community Services (DHCS), Steve Larkin representing AIATSIS and Ted Wilkes as an Independent member.

The new management structure also saw the appointment of former Board member Ian Anderson as Research Director, whose role was to work with the Research Development Group to set a research agenda for the new organisation. The role of the Centre Director, ably filled from 1999 until 2003 by Professor Tony Barnes, was changed to that of Chief Executive Officer; however, the position maintained similar responsibilities. After an initial period of 18 months without a full-time CEO, during which time Tony Grivell acted as interim Director, Mick Gooda was appointed to the position in November 2004.

From the outset, as a virtual organisation with a significant geographical footprint, it was essential for all Core Partners to maintain close working relationships. To foster these, each organisation appointed an identified Link person who was able to act as a contact point for their stakeholders, and report on CRC activities, programs, policies and projects to their respective host institutions. The importance of providing the right level of support for individuals in this position was acknowledged, and in 2005, the CRCAH created the position of Link Coordinator in recognition of both the complex nature of their roles and, at times, the high turnover of Link people in the various partner organisations.

Another mechanism for creating linkages, as well as for discussing research priorities, communication and management processes, was the annual convocation.

Convocations: A space for changing the conversation

From the beginning, the annual CRC meetings had provided a space for people to come together and discuss the broader nature and shape of the Aboriginal and Torres Strait Islander health research agenda. The purpose of these convocations – which would later evolve into Congress Lowitja (see p. 110) – was to provide both a forum for potential research partners to develop relationships both within and across program areas,[59] and a place for researchers, community stakeholders and policymakers to come together to identify priorities in Aboriginal and Torres Strait Islander health research.

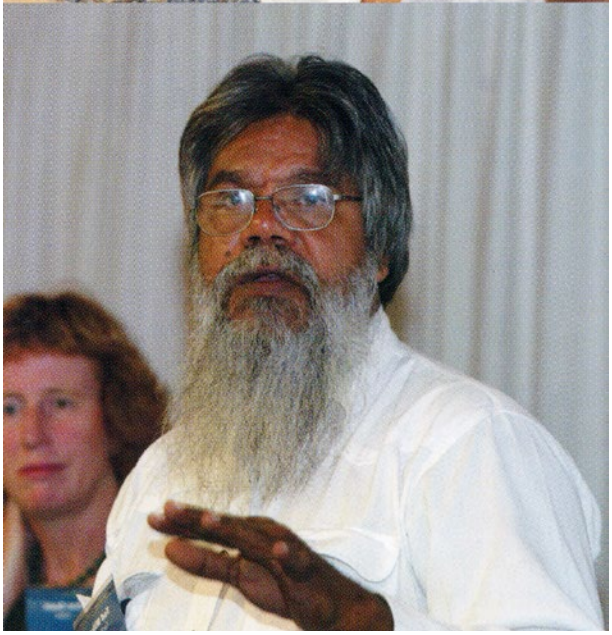
These meetings, initially termed research learning conferences, developed from an internal retreat held in 1999. According to Pat Anderson:

> *We started having these discussions, getting people together… we started talking to Aboriginal people who didn't really have a lot to do with the CRC. So we started to scoop up… Aboriginal people who… might be interested in research or, like in Congress and Danila Dilba's case, working actually at the coalface. And it was very clear to them what sort of research might work [and what] needed doing that would help them.*
> *(Pat Anderson Interview 3, 14 November 2014)*

In her opening address at the first conference held in Darwin in August 2000, CRCATH Chairperson Lowitja O'Donoghue highlighted the changes that were needed to create real impact in resolving many of the issues regarding Aboriginal and Torres Strait Islander health:

> *Over time, it has become abundantly clear… that the simple action of placing health outcomes at the centre of research implies a major cultural shift in the way we think about and manage health research generally…*[60]

Getting researchers and stakeholders together in the same room to discuss issues of concern was one of these cultural shifts. Lowitja O'Donoghue noted that the 2000 conference demonstrated willingness by participants to have open and frank discussions regarding the strengths, weaknesses and challenges facing the CRCATH:



April 2003 Mini Convocation:

Stephanie Bell, Donna Ah Chee, Rebecca Kidney

Fran Baum, Ted Wilkes

> *Many of our Core Partners had not always seen eye to eye in the past. And this conference, in which all Core Partners took part, proved to be an excellent opportunity to address differences of opinion and build trust… Researchers were challenged to question the cultural and political circumstances that have shaped their worldview, and the way they do research. To bridge the chasm between researchers and Aboriginal communities.*[61]

These annual meetings, or convocations, were to become central to the CRCAH's research priority pathway as the place where commissioned research briefs would be identified.[62] However, while the contribution of the annual convocation to the CRCAH's research priorities was recognised, there also was an acknowledgment that further refinement of priorities was difficult with the large groups attending these meetings.

Terry Dunbar, who took on a number of roles at the CRCs, including Deputy Director, sees the convocations as places where people could come together and have discussions about:

> *'What are we doing?'; 'What did we do last year?'; 'Did that work?'; 'Where do we go now?'. So it's like an evaluation with everybody in the room [able] to move forward and critique what this new presentation's looking like… And so people then have ownership of it, as well. So it's bringing the virtual organisation together in one place at one time…*
> *(Terry Dunbar Interview Part 3, 11 March 2015)*

Long-time Board member Stephanie Bell commented on the positive and beneficial nature of convocations becoming

> *… an environment of everyone coming together, community research talking about the projects and what the future is. I think they've been really positive structures. It has given space for that conversation to take place.*
> *(Stephanie Bell Interview, 12 March 2015)*

CRCAH CEO Mick Gooda also acknowledged the importance of these convocations in shaping the new research agenda that was instituted with the advent of the CRCAH:

Mick Gooda

… these events were perfectly timed to provide input into this new approach of proper and appropriate engagement with the Aboriginal health sector and health industry.[63]

CRCAH Annual Report 2004–2005

Stephanie Bell

> **… [Convocations created] an environment of everyone coming together, community research talking about the projects and what the future is. I think they've been really positive structures. It has given space for that conversation to take place.**

Interview, 12 March 2015

Lowitja O'Donoghue at the Smoking Ceremony,
CRCAH Convocation, Adelaide, November 2006

Facilitated Development Approach: Putting community in the driver's seat

In the first years of the CRCATH, the Board had faced criticism as to its often-long approval processes for research projects. According to Ian Anderson, this 'reflected the anxiety that people had' about the decision-making process of the early CRCATH. There were concerns, too, that some of the projects being supported and funded were still driven by a biomedical researcher focus, and that significant efforts were needed within the organisation to reshape the nature of research prioritisation and practice.

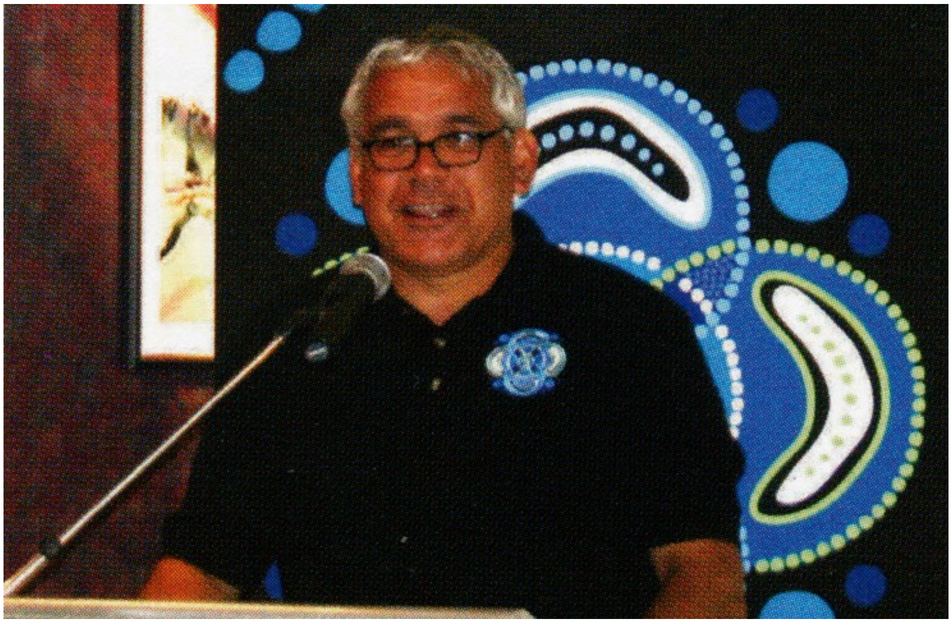
These issues were tackled head on in the CRCAH under the management of Mick Gooda, who with Ian Anderson and the newly appointed Research and Development Manager Jenny Brands led the development of the Facilitated Development Approach to research. According to Jenny Brands, Mick Gooda brought experience and confidence with government bureaucracies to the organisation.

Mick quite openly stood up against some of the senior scientists who had been very influential in the CRC up to that point, who've done great work, but would say things like, 'We don't know about knowledge translation. That's not our business. Our business is the science.' And that's fair enough, but it didn't mean that the CRC for Aboriginal Health needed to fund the science if it wasn't clear how that was going to be directly related to change on the ground in Aboriginal health.
(Jenny Brands Interview, 2 March 2015)

There had been a clear recognition that research into Aboriginal and Torres Strait Islander health, and in particular the development of research projects, often failed to take into account the needs and interests of Aboriginal and Torres Strait Islander peoples. Having an Aboriginal and Torres Strait Islander Chairperson and majority Board had resulted in some big and positive changes, but now it was time to broaden the base further both for deciding on research direction and for making it more effectively Aboriginal and Torres Strait Islander driven rather than researcher led.

Or, as Pat Anderson put it:

We wanted to actually set the research agenda. So it did take us some time to sort of turn that whole thing around, to go away from the investigator driven and make it so as Aboriginal people were in charge of the research agenda and set the agenda.
(Pat Anderson Interview 3, 14 November 2014)



CRCAH CEO Mick Gooda

Facilitated Development Approach

Developed by the CRCAH to extend and operationalise the framework provided by the CRCATH's Indigenous Research Reform Agenda (see p. 31), the FDA mediates relationships between researchers, the Aboriginal and Torres Strait Islander health sector and government agencies to set research priorities and develop research projects.

Experience has shown that this approach has led to higher quality and more strategic research that:

- is community driven and reflects the priorities of Aboriginal and Torres Strait Islander peoples
- is based on collaboration, not competition
- provides mutual benefits to Aboriginal and Torres Strait Islander communities and to researchers.

Broadly speaking, the FDA methodology allows for:

- **Priorities identified by Aboriginal and Torres Strait Islander people** – by bringing together community, researcher and industry partners, such as the Aboriginal community controlled health sector and health organisations, as well as governments and others with an interest in Aboriginal and Torres Strait Islander health.
- **Research transfer focusing on getting knowledge and information out and in use in the community** – by ensuring the research is done in a way that makes it most likely to be relevant and of use to inform and bring about positive change.
- **Project design to have early input from those most likely to use the research outcomes** – so that the research findings are useful and credible to the Aboriginal and Torres Strait Islander health sector.
- **Capacity development** – to build the skills of Aboriginal and Torres Strait Islander people, communities and organisations to conduct and use health research, and the capacity of non-Indigenous researchers to work successfully in the sector.

Roslyn Dhurrkhay (2nd from right) with CRCAH Program Leader Ross Andrews and colleagues

***Video:** Pat Anderson, CRCATH Director, CRCAH/CRCATSIH/ The Lowitja Institute Board Member and Chairperson, interview 3 14 November 2014 (p. 188)*

An inclusive approach to research

Pat Anderson noted that, even in the 'early days' of the CRC for Aboriginal and Tropical Health, the research agenda included the core principles that later, and much more explicitly, formed the basis of the Facilitated Development Approach:

> *… it had to be useful, it had to be relevant, and people are able to use it… the research had to be translated back to the community or the group or the organisation on which the research was done. So, once again, we started talking and talking… We've always done research where we had some kind of consultation, discussion, or organised a formal meeting where we can discuss [things]. So it's from that, building up from that… the facilitated development of the process [came to the surface], meaning that Aboriginal people were involved from day one in the design, the selection of the research question, which is quite difficult as you know, and to get that right in the first place.*
> (Pat Anderson Interview 3, 14 November 2014)

The FDA, which came to be formally adopted as the driving methodology of the CRCAH approach to research, sought to broaden both the scope and engagement of the Indigenous Research Reform Agenda into Aboriginal and Torres Strait Islander health. It became an important framework for the ideal of 'working from the community level up', which lies at the heart of all the CRCs (Pat Anderson Interview 3, 14 November 2014).

The FDA emerged gradually over the first few years of the CRCs, and was then clearly articulated in 2006 by Jenny Brands and Mick Gooda in their *Australian Aboriginal Studies* article 'Putting the Users of Research in the Driver's Seat: The Cooperative Research Centre for Aboriginal Health's new approach to research development'.[64] Here, they argued for the development of a culture in which research could be seen as a 'useful – and usable – tool for improving health service planning, delivery and evaluation'.[65]

The overarching goal of the FDA was to put Aboriginal and Torres Strait Islander people in the driver's seat in all aspects of health research. This was to be done by changing the relationships within the system for developing research projects, and ensuring their effectiveness and involvement by those delivering the services and those affected by the services. In her interview, Jenny Brands emphasised the two aspects, 'development' and 'facilitation':

> *[I]t was about developing research projects that were about the right topic, that were what people really wanted to see researched and that would make a difference, that were priorities where research could actually make a difference. So, there's a lot of things where research really isn't helpful, but these projects were. And the facilitated part of it was about trying to even out the balance of power between researchers, community members, practitioners, governments and give particularly Aboriginal and Torres Strait Islander people a much stronger voice in that process.*
> *(Jenny Brands Interview, 2 March 2015)*

An integrated programmatic approach

Paramount in the CRCAH's conception of a new research paradigm was Aboriginal and Torres Strait Islander people setting the research priorities, engaging end-users in the development of the research process, forging viable partnerships between the key stakeholders, building Aboriginal and Torres Strait Islander capacity to direct and manage research, strengthening the relationships between Aboriginal and Torres Strait Islander and non-Indigenous health researchers, and ensuring the adequate transfer of the research findings.

The first step in this change to the FDA was the implementation of an integrated programmatic approach to narrow and sharpen the organisation's research focus. At the first CRCAH Convocation held in Darwin in November 2003, participants had identified nine priority research areas for the new CRCAH.[66] After an internal review by the Research Development Group

Jenny Brands, CRCAH Research and Development Manager, interview 2 March 2015 (p. 188)

Jenny Brands

… the idea that Indigenous people should be involved in doing the research was a recurring theme. So, in the end, the steering group decided that we should focus on research capacity enhancement. How do we enhance Indigenous people's capacity to identify their own research? And in fact, what people said was, 'If non-Indigenous people really want to be relevant to us, then they should collaborate with us, help us to do our own research'.

Interview, 2 March 2015

Click to play video | **Play online** (browsers and mobile devices) led by Ian Anderson, these were refined and five main research priorities identified:

- Comprehensive Primary Health Care, Health Systems and Workforce
- Chronic Conditions
- Social and Emotional Wellbeing
- Social Determinants of Health
- Healthy Skin.

These research programs consisted of a number of interrelated projects that formed a cohesive approach to addressing particular areas of interest to the organisation, and allowed it to 'gain value beyond the simple sum of the component projects'.[67]

Two key operational roles were identified in the running of this programmatic approach, that of Program Leaders and of Program Managers. The Program Leaders role was shared by a leader in research and by a leader in the corresponding industry. Their role was to provide the required leadership in the proposal and implementation of the individual programs. The Program Managers were entrusted with the operational development and implementation of the research process. In both cases, the roles involved the practical application of research transfer and capacity development in the research projects under their control. In keeping with the organisation's commitment to the capacity development of an Aboriginal and Torres Strait Islander research workforce the CRCAH placed a strong emphasis on the recruitment of Aboriginal and Torres Strait Islander people to the role of Program Leader and Program Manager.[68]

In 2005 and 2006, shortly after the programmatic approach was introduced, the CRCAH engaged five Aboriginal and Torres Strait Islander Program Leaders and two Program Managers across its five programs.[69] Ian Anderson felt that this shift from approving individual research proposals to a process for building research proposals was partly influenced by his experience with the NHMRC. It was intended to develop pathways of research through a more rigorous process of discussion that included the Program Managers and the Board. Ian Anderson explained:

> *The first part of that framework was to develop a much more programmatic agenda that started to articulate one of the key deliverables in terms of strategic knowledge gained from pursuing a particular path of research. This was a little bit more sophisticated than saying, 'What are the key research questions?'. What we're trying to do is say, 'Let's build a particular program of research and let's – at the beginning, at the programmatic level – be clear about what the destination is in terms of the sort of strategic knowledge that we can build that might impact on policy and practice'.*
> *(Ian Anderson Interview, 17 December 2014)*

People from communities and Aboriginal and Torres Strait Islander controlled health services, state and territory government health services, and policymakers contributed to facilitated discussions within a particular program area like Chronic Conditions Management, or Social and Emotional Wellbeing that produced from five to 10 issues that people felt were important (Jenny Brands Interview, 2 March 2015).

Program Managers then facilitated the process of developing the research project, and made sure that community representatives and/or health service representatives contributed to that process. Jenny Brands reflected that this extended process of research development represented an important shift in research strategy. It was particularly significant as a research commissioning process that brought parties together with the end-users in mind (Jenny Brands Interview, 2 March 2015).

> *Having the program managers involved in the negotiation about the project design kept it on track a bit more, and kept the voices of community members or health service people stronger in that process. It didn't always work perfectly, and sometimes it worked brilliantly, but I think that the shift was quite significant.*
> *(Jenny Brands Interview, 2 March 2015)*

The FDA, having shifted the competitive process into a more collaborative one, had the advantage of being able to develop the commissioning of research with community and other stakeholder involvement. Ian Anderson noted that this was 'not rocket science', but that up until this point it had not been done in the Aboriginal and Torres Strait Islander health research context. Such an important innovation meant that the CRCAH could

> *… actually build into the processes for project development input by the end-users of research, in particular the service providers and other community agencies and other community members that actually might usefully have input into the whole project design, implementation and then uptake cycle of research.*
> *(Ian Anderson Interview, 17 December 2014)*

Another identified barrier was the competitive nature of the traditional peer-reviewed approach to grant assessment, which did not always serve the best interests of the end-users of the research. As a result, much of the research undertaken by the CRCAH was, at times, deemed to be incompatible with the strictures laid out in the traditional peer-review process. 'In a competitive national research environment', one researcher noted, community-driven projects 'just don't fit in'.[70] The new approaches instituted by the CRCAH stressed the cooperative and collaborative nature of research that lay at the heart of the CRCs' ethos. The scientific rigour of the grant assessment process was ensured through a quality assurance mechanism in which research 'peers', such as community members, health practitioners and policymakers measured the proposals against an agreed criteria established by the CRCAH and which was compatible with its broader aims.[71]

Roundtables

The commissioning of new projects for the CRCAH began with the arrangement of Industry (later Research) Roundtables, which involved individuals from Aboriginal and Torres Strait Islander health organisations, relevant government bodies and the CRCAH Program Leaders and Managers. The aim of these roundtables was to discuss and identify the most pressing needs of Aboriginal and Torres Strait Islander health organisations so as to provide better services to communities. According to Pat Anderson, they were also places at which difficult and sensitive conversations could be held (Pat Anderson Interview 3, 14 November 2014).

Ian Anderson also emphasised the importance of creating spaces for conversations that not only included Aboriginal and Torres Strait Islander people, but allowed people to 'actually participate in the conversation without fear of humiliation or being knocked about' (Ian Anderson Interview, 17 December 2014). By putting time, effort and thought into the discussions about what research might be needed, 'dangerous topics' like genomics (see p. 96) could be discussed.

However, according to Ian Anderson, these discussions between organisational partners, researchers, policymakers and service providers required a degree of 'curation' and so were not always 'straightforward':

> *We were all keen to make sure we got a good representation of Indigenous Australians who we brought together through our networks – the key researchers – and that we created the ground rules or the rules of engagement… It wasn't particularly just the community space or particularly just the research space but it was a meeting place where people could actually begin to build relationships and exchange ideas… People were conscious about the need to create some degree of safety for all participants and manage that conversation fairly carefully in order to deal with a much more liberated discourse around some of these issues.*
> *(Ian Anderson Interview, 17 December 2014)*

Mick Gooda also spoke of the importance of roundtables that were run by each program area to ensure a collaborative process that pushed people beyond their particular areas of concern and facilitated solutions to shared problems. He recalled one particular roundtable in Melbourne at which health research users, clinicians and Aboriginal and Torres Strait Islander health workers came together and stimulated discussions about issues from a community perspective and broke through into the area of patient understanding of their condition. Health workers from Katherine were comfortable enough in this communication forum to express their views on issues of concern at a community level – issues around chronic diseases like diabetes, patient agency and why people were not seeking medical assistance or recognising they could do something to manage illness. In the roundtable environment the discussion could be initiated and led by community health workers and translated into a research framework.

The Overburden research project, which examined the practices and policies of health authorities and, in particular, their funding relationships with primary health care providers, was one of the first major pieces of research to go through the new FDA. For Jenny Brands this was an example of health research that could bring about change because it dealt with the 'system and the way that funding is delivered and the requirements across many health services' (Jenny Brands Interview, 2 March 2015).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CRCAH roundtables and workshops

Clockwise from top left
Leisa McCarthy and Kevin Rowley at CRCAH Convocation, Alice Springs, 2005

Dancers at Far North Queensland Health Forum, Cairns, October 2006

Mark Wenitong addresses Far North Queensland Health Forum, Cairns, October 2006

Participants at Healthy Skin Roundtable, March 2007

CRCAH staff Jodie Lew Fatt, Lindy Quall, [name missing, with apologies] and Leah Ahmat at Northern Territory Showcase

CRCAH Research Development Group meeting, Melbourne, February 2009

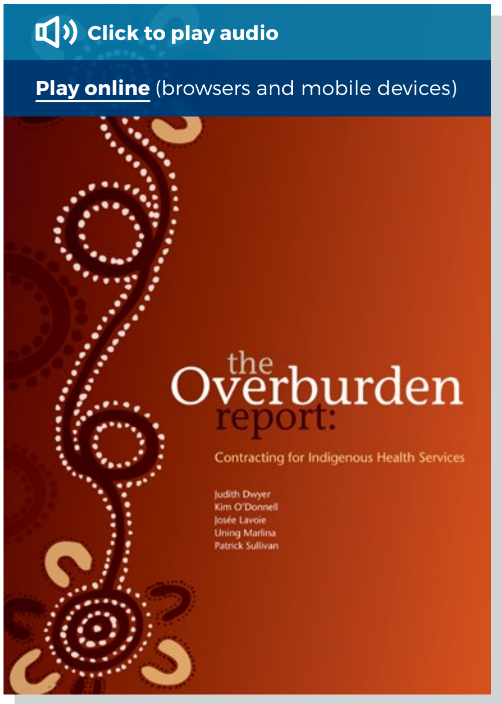
The report's author, Professor Judith Dwyer, who served as Program Leader and Project Leader for the CRCAH and the Lowitja Institute CRC, described her initial experience of the FDA as a rather bruising and difficult one. She produced what she felt was a rather 'rough and scrappy' response to a research question and found in the roundtable discussion that she had not understood what had been wanted.

> *Even though I found it tough, it did help me get to a question that the sector wanted answered.*
> *(Judith Dwyer Interview, 5 March 2015)*

Ultimately, the FDA for setting research priorities and designing research projects empowered researchers like Judith Dwyer, as it created safeguards within an authorising environment that was 'determined by Aboriginal people – at least largely, if not entirely – as what needs to be done' resulting in an agenda 'based on what people want done' (Judith Dwyer Interview, 5 March 2015).

The Overburden Report, one of the first major pieces of research to go through the FDA

***Audio:** Judith Dwyer, CRCAH/CRCATSIH Research Program Leader, interview 5 March 2015 (p.188)*



Making research relevant

Mick Gooda was keen to emphasise the way in which the FDA streamlined the development and prioritisation of research projects by the CRCs, and connected different areas of the broader health research area. From one discussion

> *… we developed three projects: self-management of chronic diseases, health promotion (how come these messages aren't getting through to our mob) and finally a men's project because this is really affecting men. So out of all the projects we got out of there, we wrote about half a page on each of them and took it to the Board, right at the beginning before we did any more work, to prioritise them, and those three got up. That's when we went away and instead of having a competitive round, we just went to all of our partners and said, 'Who wants to develop the research proposal?'.*
> *(Mick Gooda Interview, 30 October 2014)*

Ian Anderson explained how the involvement and engagement of a wide range of parties, including those from the research and the community implementation spheres, influenced project design and especially opened up space for community voices and direction.

Mick Gooda

… we developed three projects: self-management of chronic diseases, health promotion (how come these messages aren't getting through to our mob) and finally a men's project because this is really affecting men… we [then] went to all of our partners and said, 'Who wants to develop the research proposal?'

Interview, 30 October 2014

Click to play video **Play online** (browsers and mobile devices)

Participants at the Prison Health Roundtable, Alice Springs, 2007

Video: *Ian Anderson AO, CRCATH Board Member and Research Leader, CRCAH/CRCATSIH Research Director, CRCATSIH Interim Board Member, interview 17 December 2014 (p. 188)*

In a sense, some of the parameters were fixed and they were fixed by the program structure or by the program objective. But, in some ways, it actually brought people in to the whole process of project design, implementation and development of findings and knowledge transfer at the end of the process... That model has been used right through most of the second CRC and into the third CRC. [It was] probably one of the most useful ways of actually building a research practice that, in a sense I think, has changed the landscape in Indigenous health research.
(Ian Anderson Interview, 17 December 2014)

The priorities identified by the roundtable were then taken to the CRCAH Board, which then considered and ranked them according to how the expertise of the CRCAH could provide the most impact for the end-users of the research.[72] As Jenny Brands has noted:

One of the things we did that was quite different at that point was to start to require research proposals to be assessed in terms of their capacity to make a difference. So they weren't just being assessed in terms of how good was the science. They were being assessed on whether they had the potential to actually make a difference on the ground, and what was built into the research project to do that. So generally, projects that were involving communities or health services or the people who would use the research in the project itself were more likely to be able to make a difference.
(Jenny Brands Interview, 2 March 2015)

The research priorities identified by the Board were then developed and fine-tuned into relevant research questions by the appropriate Program Leaders. Judith Dwyer commented on some of the limitations and constraints of the roundtable and collaborative process and the role of Program Leaders in developing research projects:

Eventually, you'd come to some articulation of something that needed to be researched and using a roundtable as part of the development. But my experience with the roundtables is that you get a sense of priorities, but you do not get to the kind of thought-through approach to a research project that you need to get to. And it would be unreasonable to think you would out of a roundtable. So there's a lot of work to be done after a roundtable, and often that fell to the program leaders.
(Judith Dwyer Interview, 5 March 2015)

However, they were also a novel and welcome means for researchers, especially those with less experience, to meet with policymakers and discuss the policy possibilities of their research.

Capacity development

Capacity development was regarded as one of the crucial factors in successfully developing a new research paradigm. Essential to this process was the building of skills, knowledge and capability in a wide range of areas and personnel – among community members, as well as Aboriginal and Torres Strait Islander and non-Indigenous researchers – and at different levels of the organisation including the Board.[73]

The key components of capacity development were:

- To promote and involve Aboriginal and Torres Strait Islander contribution and leadership throughout each stage of the research process
- To ensure that Aboriginal and Torres Strait Islander individuals and industry representatives are effectively engaged in the research process
- To provide opportunities such as scholarships, traineeships and professional development for Aboriginal and Torres Strait Islander people.

An important element for changing the research prioritisation process was actually assessing research projects on whether they 'would help build capacity in the community or with Indigenous people' and then working with researchers to design their projects to include capacity building. Many researchers had 'thought about making the science good, but they hadn't necessarily thought about how to make sure that it would be workable out in the real world' (Jenny Brands Interview, 2 March 2015). However, for those who were willing to make adjustments to their research plans the CRCAH provided the right environment in which to do so.

Jenny Brands also emphasised that while funding scholarships and traineeships for Aboriginal and Torres Strait Islander health researchers were important for capacity development, the other side of capacity building is to create a health research and delivery system that does not 'get knocked around when there's a change of government'. She felt that one of the hidden impacts of the CRC was to 'build the capacity of communities and organisations and particularly of governments to be able to work together' to 'bring about change' (Jenny Brands Interview, 2 March 2015).

An independent report conducted into the CRCAH in 2010 identified capacity building as a series of mechanisms to support the skill development of Aboriginal and Torres Strait Islander people, and those working in ACCHSs, to conduct and participate in the research process. In addition, capacity building aimed to support non-Indigenous researchers to develop their skills in order to work more collaboratively with Aboriginal and Torres Strait Islander peoples.[74] The report noted, however, that not all projects undertaken or supported by the CRCAH had been able to implement capacity development fully into the project structure, with the main obstacles being a lack of time and available financial resources to engage in developing the capacity of staff.[75] However, while acknowledging some of the limitations encountered in capacity building, the report also recognised it as an integral aspect in growing an Aboriginal and Torres Strait Islander health research workforce and in improving the quality of health research and recommended its continued implementation in the future.[76]

Judith Dwyer spoke of the limitations of capacity building considerations in research priority setting and development, and how it demanded roles and skills of both Aboriginal and Torres Strait Islander and non-Indigenous researchers that were not always available. As she recalls, the system was 'not foolproof' (Judith Dwyer Interview, 5 March 2015). The Board and research facilitators also realised that research which met the priorities for being Aboriginal and Torres Strait Islander driven, relevant and useful could not always include Aboriginal and Torres Strait Islander researchers. Judith Dwyer observed:

> *I can think of one project… which resulted in the Legally Invisible report, and that was done by a single, non-Aboriginal public health lawyer. It was a small project… we weren't doing capacity development for the people on the advisory team. We were just making sure that an Aboriginal perspective was brought to bear in that case. But we felt that that was a technical question worth getting a good technical answer to, even though doing it on a small scale and quickly – it was done over six months – there wasn't going to be any capacity building in that. So there were exceptions…*
>
> *(Judith Dwyer Interview, 5 March 2015)*

Knowledge exchange and research translation

Central to the research agenda was recognising Aboriginal and Torres Strait Islander peoples as key knowledge holders and ensuring the research was accessible to end-users through research translation or knowledge exchange. While traditional research practices often confined the results to a specialised audience within the pages of peer-reviewed journals, the CRCAH sought a broader audience for its research findings – end-users who would then have the capability to ensure the research would be put into practice.

> *What we realised was that often that means it's about doing different research. The research that just sits on the shelf is generally not stuff that someone wants to be using. Knowledge brokerage is about making sure that the knowledge that is in existence, or is around, is actually accessible for people, and helping people to access it.*
> *(Jenny Brands Interview, 2 March 2015)*

As Ian Anderson explains, this serious consideration of research translation and knowledge exchange at the beginning of the research prioritisation process also had implications for policy and practice.

> *So rather than wait to the very end of the project and then go and talk to health services and policymakers and say, 'Look, this is what we've uncovered; how's it going to impact on your policy and or your practice?', [we] would involve those users from the very beginning… It was important to make sure that the project was crafted in a way that actually addresses some of the key issues but, strategically, what it built was coalitions of interest around particular projects. [This meant everyone was]… engaged from the very beginning and therefore much more interested in the outcomes and much more amenable to the conversation about the implications for policy and practice.*
> *(Ian Anderson Interview, 17 December 2014)*

Jenny Brands recognised the progress that the CRCAH made in communicating research findings to multiple audiences, but believed this was an area where there was still more work to do.

> *Certainly, I feel like while that was what got me into the area of research translation, I don't feel that we really took that far enough. We've spent a lot of time looking at the front end of the research project and getting that right – and that was very important. You can't translate bad research or research that's not useful. But we didn't spend enough time looking at the end product.*
> *(Jenny Brands Interview, 2 March 2015)*

The importance of planned research translation and knowledge exchange in research is reflected in the Lowitja Institute CRC's funding commitment for this type of activity in all its research, This work facilitates workforce development, scholarly debate, public engagement, and increasing end-user and community understanding. (Lowitja Institute Publishing and other networks of knowledge and communication are discussed further on pp. 105–21.)

Click to play video

Play online (browsers and mobile devices)

CRCAH staff members Candice Fordham and Jodie Lew Fatt at Larrakia Women's Day Gathering, 2005

Video: *Jenny Brands (CRCAH Research and Development Manager), interview 2 March 2015 (p.188)*

Legacy of the Facilitated Development Approach

The CRCAH envisaged the new approach to research into Aboriginal and Torres Strait Islander health to have an impact across the broader landscape of research into Aboriginal and Torres Strait Islander issues. As Chairperson Pat Anderson noted in the CRCAH's *2005–2006 Annual Report*:

> *Through the CRCAH's approach to research we have created a process for ensuring greater Aboriginal control of the research agenda and, although designed for health research, this approach may prove to be a model for reform of research processes throughout the various disciplines engaged in Aboriginal research.*[77]

A 2008 review of the entire CRC Program commissioned by the then Minister for Innovation, Industry, Science and Research, Senator Kim Carr, highlighted the achievements of the CRCAH. In particular, it focused on some of the key research innovations implemented through the FDA.[78] The review also noted the important role played by the CRCAH in addressing issues of social inequity through a research agenda that was driven by the needs and priorities of Aboriginal and Torres Strait Islander people themselves.[79]

In her summing up of the gradual development of the FDA, Pat Anderson emphasised that the process enabled researchers to be more confident that their research had been carefully designed to be useful, to fill gaps in existing research and

> *a much easier way than going, as they used to… 'I'm going to do this research', and then go the community and say, 'I'm Pat Anderson. I'm a researcher and I'm going to talk to you for the next week or two.' That's how it was done, very crudely. It was pretty much done like that in the past.*

Healthy Skin curriculum writer and educator Loyla Leysley (3rd from left) working with mothers at Galiwin'ku Pre-school, Arnhem Land, 2009

‘Authenticity and power’: Ensuring an ethical approach

The way of doing research being carved out by the CRCs had, according to Pat Anderson, a ‘kind of authenticity and power’, which focused on improving Aboriginal and Torres Strait Islander communities’ control of ethical issues and constructive input into the health research agenda.[80] This approach was in stark contrast to the way things had been done in the past, which led to many Aboriginal and Torres Strait Islander communities being suspicious of research and researchers. This distrust grew out of conventional research processes that had treated them as passive subjects rather than active participants of research, and all too often failed to translate findings into meaningful changes in health policy or practice.

There had long been deep concerns within Aboriginal and Torres Strait Islander communities about many of the ethical issues surrounding health research. A workshop on ‘Research priorities to improve Aboriginal health’ in Alice Springs in 1986, organised by the NHMRC and the Menzies School of Health Research in consultation with Aboriginal community controlled health organisations, set in motion a process to develop ethical guidelines for research in Aboriginal and Torres Strait Islander health.[81] The following year a ‘National Workshop on Ethics of Research in Aboriginal Health’ was convened in Camden, NSW, the key goals of which were to develop a set of ethical guidelines for research into Aboriginal and Torres Strait Islander health and to establish a close connection between ethical guidelines and the funding of research. In addition, the workshop also identified mechanisms that recognised and responded to the ‘pivotal role of Aboriginal communities in the design, execution and evaluation of research into Aboriginal health’.[82]

Among the participants at the Camden workshop were two future Board members of the CRCAH, Ted Wilkes and Shane Houston. The latter recalls that the issue of funding Aboriginal and Torres Strait Islander health research was one of the items discussed at the workshop:

> *Control over funding was one way of ensuring people did it right and was one of the important issues that came up… The community-controlled sector strongly believed at the time, and still does, that if you control the purse you actually control the policy and control what happens.* [83]

A report of the workshop submitted to the (now defunct) National Aboriginal and Islander Health Organisation also noted that:

> *Funding of research was the most effective way of maintaining control over the ethical behaviour of researchers and their initiatives… The relationship between locally determined ethical standards and the administration of project funding would, in this way, be a most effective monitoring mechanism.*[84]

From the outset in 1997, the CRCATH focused on mechanisms to improve the ethical guidelines for conducting research into Aboriginal and Torres Strait Islander health. The process of developing appropriate ethics guidelines, however, was never an easy one and often reflected the tensions that existed between the CRCs and the scientific community undertaking the research. Terry Dunbar recalls an example of this when she questioned a researcher about his methods:

> *…’Tell me what you learn about people that you want to organise treatment for. Tell me about how you think they feel about what you’re doing. Tell me about the circumstances where they live or the histories that they live with.’ So he sort of looked at me and was really puzzled… And I said, ‘Well, why do you think it’s ethical if you just quote a methodology and painstakingly follow each step as per how a non-Indigenous person has written it? Why do you think that that’s ethical when you go out in the field and you speak to people or you take fluids or sample tissues and you don’t understand how these people feel about you doing that ’cause they’re really worried about what you’re going to do with these samples? …Why do you think that’s ethical?’*
> *(Terry Dunbar Interview Part 1, 11 March 2015)*

During the CRCATH, all projects undertaken by the organisation were required to gain ethics approval either from the Top End Human Research Ethics Committee, the Central Australian Human Research Ethics Committee or the Northern Territory University Research Ethics Committee.

After a workshop held in March 2000, Jeannie Devitt led a project entitled ‘Promoting ethical research with Indigenous communities’ that sought to develop sustainable ethical processes for research, including a review of ethics committees and to involve Aboriginal and Torres Strait Islander communities in the process of research.[85] The project was taken over in 2004 by Ian Anderson and Terry Dunbar among others.

Terry Dunbar

‘Well, why do you think it’s ethical if you just quote a methodology and painstakingly follow each step as per how a non-Indigenous person has written it? Why do you think that that’s ethical when you go out in the field and you speak to people or you take fluids or sample tissues and you don’t understand how these people feel about you doing that ’cause they’re really worried about what you’re going to do with these samples? ...Why do you think that’s ethical?’

Interview Part 1, 11 March 2015

Terry Dunbar played an influential role in shaping the development of ethics in Aboriginal and Torres Strait Islander health. She served on a number of committees and working groups for the NHMRC, including the Aboriginal and Torres Strait Islander Research Advisory Working Group, which developed the national ‘road map’ to establish Aboriginal and Torres Strait Islander research priority setting, and the working party for the Australian Human Ethics Council’s review of the 1991 Interim Ethics Guidelines for Health Research with Indigenous Peoples. She was also a member of the NHMRC’s scholarship assessment panel and the Deputy Chair of the Indigenous Health Research Panel.[86]

Terry Dunbar spoke of her role on ethics committees:

It was not about always taking people on. It was more about an education process because that’s how I saw the ethics role. It’s not to say I put blocks in the road. It’s about talking to people where we consider there’s a process in play that possibly will cause harm and it’s about saying, ‘Well, okay, this is what we feel about this approach that you’re taking. Is there another way to consider this or reconfigure that because we find that that’s an unethical approach?’ And they’d sit and listen and then we talk it through and give examples of – and then they’d get an idea of then how to actually attend to that.
(Terry Dunbar Interview Part 1, 11 March 2015)

As Jeannie Devitt recalls:

.... a couple of key people got on NHMRC’s committees and Terry was one of them and they were keen that they manage and control these processes that were to do with ethics for Aboriginal... But looking back now, I’d say what was missing was it became very focused on the institutional process of ethical review because, of course, it was about projects and ethical review. What there wasn’t, really, was a kind of more wide ranging consideration of ethics as Aboriginal people may have understood that term and what it might mean...
(Jeannie Devitt Interview Part 2, 13 March 2015)

There was concern that even when ethical guidelines were put in place and formalised they did not necessarily ensure the rights and interests of Aboriginal and Torres Strait Islander participants and that there were few mechanisms to monitor the activities of researchers once ethical approval had been granted.[87]

Developing ethical guidelines, networks and evaluations

With the commencement of the CRCAH, projects began to seek ethics approval from committees with high levels, or majority membership, of Aboriginal and Torres Strait Islander involvement. This involvement was difficult to assess due to the large number of different ethics committees involved.[88] A set of guidelines for Project Leaders developing projects through the FDA highlighted the importance of conducting ethical research, and recommended researchers consult the NHMRC's *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*.[89]

The CRCAH played an active role in shaping the discourse surrounding ethical research in health and for effective research to improve the wellbeing of Aboriginal and Torres Strait islander communities. In 2003, the CRCAH convened a workshop that gathered together Aboriginal and Torres Strait Islander people involved in Human Research Ethics Committees. Its aim was to discuss common issues among committee members, to identify resources to support them in the process of ethics assessment and to provide a forum for the discussion of relevant issues regarding the ethics of Aboriginal and Torres Strait Islander research. Participants at the workshop recommended community consultation and better communication between researchers, ethics committees and Aboriginal and Torres Strait Islander communities. Furthermore, they recognised ongoing issues regarding consent and called for better tools to inform research participants.[90]

In 2007–08, the CRCAH commenced the development of an online Indigenous Ethics Network to build both peer support and the research capacity of Aboriginal and Torres Strait Islander researchers. Ian Anderson emphasised the importance of establishing strong ethical guidelines for research projects:

> *The National Health and Medical Research Council and other research agencies really had significant problems in their research productivity in the Indigenous research space… Probably up to 50 per cent of projects would fall into some difficulty – in some cases actually stop – … for three major reasons. One is that the collaboration would fail, the second one is that there were disagreements around the ethics and the management of ethics in the project, and the third is that there was a naive application of methodologies that just didn't work in the Indigenous context. So an organisation that actually builds research capacity, that builds collaborations, that builds partnerships, that has established practices around collaboration and ethics and so on, is actually providing for a much more efficient research system.*
> *(Ian Anderson Interview, 17 December 2014)*

The Lowitja Institute continues to focus on driving a stronger ethical approach to research into Aboriginal and Torres Strait Islander health. In 2013, the Institute partnered with AIATSIS, and was selected to undertake an evaluation of two key NHMRC ethics guidelines, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research* (2003) and *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander Peoples about Health Research Ethics* (2005).[91]

The four-month evaluation included extensive consumer engagement via consultation and workshops held in all states and territories around Australia. It recommended 'revision of the two guideline documents, training and orientation for stakeholders,

Tarrn doon nonin Aboriginal and Torres Strait Islander health research ethics award 2015 winners Janet Stajic (SAHMRI and formerly AHCSA), John Singer and Rosie King (AHCSA), with Pat Anderson and Romlie Mokak (The Lowitja Institute) (see p. 56)

increased assessment and monitoring, and targeting key stakeholders to increase uptake of the revised guidelines'.[92] It also highlighted the anxiety felt within the Aboriginal and Torres Strait Islander community regarding new health research technologies not covered in the guidelines, such as genetic/genomic science, epigenetics, stem cell research, psych testing, and data linkage and identification issues.

Lowitja Institute CEO Romlie Mokak was subsequently appointed a member of the NHMRC Indigenous Research Ethics Guidelines Review Working Committee to undertake its revision of the two guidelines in response to the evaluation. As he has noted:

> *The Lowitja Institute believes there is no point in doing research into Aboriginal and Torres Strait Islander health unless it involves our people at every step along the way, and that we have a voice throughout the process. At the heart of health research ethics is listening. This 'ground-up' approach has been the underlying philosophy that has driven us from the very start.*[93]

In 2015, the Lowitja Institute developed EthicsHub, an online clearinghouse to guide users, as much as possible, around specific ethics processes and provide information and guidance on health research ethics to potential researchers (see p. 108). It also established the *Tarrn doon nonin* award, meaning 'trust' in Woiwurrung language, to promote, recognise, uphold and reward excellence in Aboriginal and Torres Strait Islander health research ethics. The award is assessed against a set of criteria that reflects the Lowitja Institute's research principles and values, and is assessed by an independent evaluation panel.

The Lowitja Institute key research principles

Since its inception, the Lowitja Institute has worked to expand, consolidate and incorporate in all its processes the key criteria developed, implicitly or explicitly, by the IRRA and FDA, identifying, in 2014, the key principles that would guide our research effort.

Current Lowitja Institute CEO Romlie Mokak pointed to the ongoing 'primacy' of the FDA, at a University of Canberra seminar in 2015, where he outlined the five guiding principles for the Institute's work, against which all research funding is assessed.

The Lowitja Institute key research principles

- Beneficence – to act for the benefit of Aboriginal and Torres Strait Islander peoples in the conduct of our research
- Leadership by Aboriginal and Torres Strait Islander people
- Engagement of research end users (Aboriginal and Torres Strait Islander organisations and communities, policymakers, other potential research users)
- Development of the Aboriginal and Torres Strait Islander research workforce
- Measurement of impact in improving the health of Aboriginal and Torres Strait Islander peoples.

While conceding that the term 'Facilitated Development Approach' sounds 'jargonistic and technical', he said it represented a methodology that 'operationalises' these five principles in all Lowitja Institute research activities. In this way, it ensures consistent and appropriate high-quality input from stakeholders in the priority-setting process, mediates relationships between researchers, communities, organisations and policymakers to set research priorities and develop projects, and provides a strong foundation for translating research findings into effective practice.[94]

Romlie Mokak told the seminar, 'We're in the business of benefiting our people', so

> *when we think about research and policy… the question of benefit has to be fundamental. It's not good enough just to complete the project… [we need to ask] what does that mean, what does traction look like, how have Aboriginal and Torres Strait Islander communities benefitted from that?*
> *(Romlie Mokak Interview, 11 December 2015)*

Building on experience

Ian Anderson noted that, during negotiations in 2009 for the third iteration of the Aboriginal and Torres Strait Islander Health CRC, there remained a level of 'uncertainty about the value of public good CRCs', and 'not everyone was convinced, particularly in the policy environment, that the sort of CRC that we were, was actually the sort of CRC that they wanted to see' (Ian Anderson Interview, 17 December 2014). There were also tensions between 'public good' CRCs and those more actively geared towards commercialising the output of their research. The Board was of the opinion that if it was obliged to commercialise its research it would not seek further funding from the CRC program believing that 'if people had to pay to use our research, it was just another barrier for them using it' (Mick Gooda Interview, 30 October 2014).

A report commissioned by the CRC Association in 2005 noted the intangibility of measuring all economic impacts derived from research undertaken by CRCs.[95] At the time that the CRCAH began to plan for the next round of CRC funding, a Productivity Commission Report recommended:

> *The original objectives of the program should be reinstated — namely, the translation of research outputs into economic, social and environmental benefits, rather than focusing public support on the commercialisation of industrial research alone.*[96]

The CRCAH did not enter into commercial agreements for the use of intellectual property derived from its research.[97]

The 2006 Association of Australian Medical Research Institutes' Submission to the Productivity Commission singled out the CRCAH for symbolising the 'valuable public support' for Aboriginal and Torres Strait Islander health research that helped to give medical research a good name:

> *CRCAH is a 'virtual' collaborative organization that aims to promote research partnerships involving key stakeholders, through increased Aboriginal participation and control and through better-defined ethical practices; to investigate health service delivery systems and the social determinants of health and health conditions; and to transfer research findings into policy and practice to improve primary health care practice. It also aims to reduce the burden of disease on Aboriginal communities and individuals and increase formal research training opportunities for Aboriginal people.*[98]

In 2008, the O'Kane review singled out the CRCAH as an exemplar of a public good CRC that was able to address major challenges in 'the provision of public goods and services' and to address issues of social inequity.[99] And in 2009 an economic evaluation, undertaken by Access Economics, of the research programs proposed for the new CRC for Aboriginal and Torres Strait Islander Health projected that there would be a $6 return for every dollar invested in research. Furthermore, the evaluation found that the program had the potential to return a net benefit of $455 million over 15 years.[100]

As a result of the high regard in which the CRCAH was held, the third application for CRC funding was successful, an exceptional outcome as very few succeeded through three iterations of CRC funding. This success saw the creation of the CRCATSIH, the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health, on 1 January 2010, with a further extension of funds in 2012. It also saw the establishment of the CRCATSIH's host organisation, The Lowitja Institute – Australia's National Institute for Aboriginal and Torres Strait Islander Health Research.

Clockwise from top left
CRCAH trainee Kalinda Griffiths at work in the lab

CRCAH Link people, November 2007

CRCAH Board member Janelle Sterling (centre) with QIMR cadet student Lisa Whop and postgraduate researcher Simone Reynolds

CRCAH scholarship holder Sanchia Shibasaki holding her PhD degree

CRCAH Link person Kim O'Donnell talks up the work of the CRCAH to the media

CRCAH Board 2004: Vivian Lin, Helen Evans, Stephanie Bell, Shane Houston, Chairperson Pat Anderson, Kerin O'Dea, Michael Good and Paula Arnol (Stephen Duckett, Kez Hall, Steve Larkin, Chris Marlin, Kerrie Tim, Robert Wasson, Charles Webb and Ted Wilkes not present)

CRCAH Project leader Gary Robinson with Let's Start participants

CRCAH CEO Mick Gooda, John Patterson and Mick Dodson, AMSANT Health Mini Summit, Knuckey Lagoon, NT, 2005

CRCAH staff members Leah Ahmat, Vanessa Harris, Lindy Quall, Di Walker, Arwen Nikoloff, February 2007

CRCAH staff at NAIDOC march, Darwin, 2007

2003–


Q.I.M.R


THE AUSTRALIAN NATIONAL UNIVERSITY
Doctor of Philosophy


Cooperative Research Centre for
Aboriginal Health
2003-2010

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Chairperson Pat Anderson with Justin Mohamed, Congress Lowitja, Melbourne, March 2014

James Henry Photography

A National Research Agenda: The Lowitja Institute

Incorporating the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (2010–2014) and the Lowitja Institute Aboriginal and Torres Strait Islander Health CRC (2014–2019)

The decision in 2010 to name the new organisation the Lowitja Institute and to ask Lowitja O'Donoghue to become its Patron reflected the respect that so many involved in the CRCs held for her and her leadership. Lowitja O'Donoghue's name and her leadership over decades had provided an overarching and principled framework within which the CRCs could operate in Aboriginal and Torres Strait Islander communities and in the wider medical and health research community.

Lowitja O'Donoghue herself has often reminded staff and supporters that she was flattered by the suggestion to give the Institute her name but she saw it as a name for an important cause not as a claim to an edifice. Mick Gooda also recalls the significance of having Lowitja O'Donoghue as the Patron of the Lowitja Institute. In particular, he highlights her status and the respect she enjoys across all segments of Australian society and the importance of creating something that can carry her name into the future. (Mick Gooda Interview, 30 October 2014). According to Mick Gooda, Lowitja rightly enjoys the status that she should have in this country as one of our great leaders' (Mick Gooda Interview: Part 1, 30 October 2014).

Mick Gooda, CRCAH CEO,
interview 30 October 2014 (p.188)

Mick Gooda

> **... [it] was a bit scary going... to see Lowitja down in Adelaide but she was so nice about it. It's interesting to go and read her speech at the opening. I went when it was launched and she actually stamps herself there: 'You know, it's not a matter of being happy that this is being named after me... if you are naming it after me, then this is how the CRC has got to operate.'**

Interview, 30 October 2014

Click to play video

Play online (browsers and mobile devices)

Ian Anderson

I have never worked with anyone I so deeply respect and probably never will.

Interview, 17 December 2014

Click to play video **Play online** (browsers and mobile devices)

Ian Anderson AO, CRCATH Board Member and Research Leader, CRCAH/CRCATSIH Research Director, CRCATSIH Interim Board Member, interview 17 December 2014 (p.188)

For Ian Anderson, working with Lowitja O'Donoghue shaped his approach and understanding of leadership and good governance, as 'through her chairmanship she set the ground rules for how you run with rigour, with fairness, with transparency'.

> *The ground rules that Lowitja set for the Board actually became, in some ways, the principles and ethics around how we did research practice… She expects the organisation to live up to a certain sort of ethics, that she didn't give her name lightly. The cost was that we were then morally bound with making sure that the organisation… was led in a way that honoured her and honoured her contribution…*
>
> *I have never worked with anyone I so deeply respect and probably never will.*
> *(Ian Anderson Interview, 17 December 2014)*

Patron Lowitja O'Donoghue

T8 Photography

When Lowitja O'Donoghue agreed to have the Lowitja Institute named after her, she entrusted in us her spirit and energy, her values and priorities. She told us to be a courageous organisation committed to social justice and equity for Aboriginal and Torres Strait Islander people, to match words to action, to achieve real tangible and immediate outcomes. Also, to be known throughout Australia as a strong and sustainable organisation working fearlessly for change and improvement in the lives of Aboriginal and Torres Strait Islander people. All our work will honour Lowitja O'Donoghue's vision.

Realising the vision

Lowitja O'Donoghue launched the Lowitja Institute – Australia's National Institute for Aboriginal and Torres Strait Islander Health Research at Parliament House, Canberra on 24 February 2010. At the launch, she outlined her vision for the new organisation that had been named in her honour. It was to be a place that would reflect her values and her priorities, demonstrating a deep commitment towards social equity and justice for Aboriginal and Torres Strait Islander peoples. It would continue to be a place where Aboriginal and Torres Strait Islander people and organisations would 'be fully involved – not just consulted – in the initiation, design and implementation of the research' undertaken by the Institute.[101] This research, according to Lowitja, needed to 'achieve real, tangible and immediate outcomes' that would benefit Aboriginal and Torres Strait Islander peoples.[102]

The establishment of the Lowitja Institute also saw the appointment of Kerry Arabena as its first Chief Executive Officer. A descendant of the Meriam people from the Torres Strait, Kerry Arabena had previously held the position of inaugural Co-chair of the National Congress of Australia's First Peoples (NCAFP), and been involved with the CRCAH in her role as a Link person during her time as a Research Fellow at AIATSIS.

Together with Lowitja O'Donoghue and Pat Anderson, Kerry Arabena found herself part of an intergenerational group of strong Aboriginal and Torres Strait Islander women intent on finding solutions to the issues surrounding Aboriginal and Torres Strait Islander health:

> *There are a lot of us around now who have been working really hard to overcome disadvantage and who are really going to take this working together to new levels.*[103]

CEO Kerry Arabena with Patron Lowitja O'Donoghue and Chairperson Pat Anderson, Melbourne, 2011

Photo Wayne Taylor/Fairfax Syndication the Lowitja Institute

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

About the logo

The Lowitja Institute logo consists of five blocks that stand together to form a cohesive, mutually supportive structure incorporating the blue of the waters of the Torres Strait, the green of Australia's fertile regions and the ochre of the centre's desert country.

The purple/deep magenta colour is often used to represent the flora, landscape and art of Lowitja O'Donoghue's country. It also can signify wisdom and authority, as well as matriarchal energy, imagination and intuition.

The concentric dots represent the many individuals working together on a common goal and focus.

Establishing the Lowitja Institute identity

The Lowitja Institute is the trading name of the National Institute for Aboriginal and Torres Strait Islander Health Research Limited, a limited liability company registered as both an income tax-exempt charity and a public benevolent institution, established in January 2010.

The establishment of the Lowitja Institute, which coincided with the transition from the CRCAH to the CRC for Aboriginal and Torres Strait Islander Health, saw significant changes to the structure of the organisation – principally, that the CRC would be hosted by the Institute, and that in addition to CRC Participants, the Lowitja Institute would have members. At the time of writing, these members are:

- Australian Indigenous Doctors' Association
- Australian Institute of Aboriginal and Torres Strait Islander Studies
- Central Australian Aboriginal Congress
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
- Danila Dilba Health Service
- Flinders University
- Healing Foundation
- Indigenous Allied Health Australia
- Menzies School of Health Research
- National Aboriginal and Torres Strait Islander Health Worker Association
- QIMR Berghofer Medical Research Institute
- The University of Melbourne.

The members of the Institute, and the Participants of the CRC, constitute powerful networks of knowledge, experience and leadership that strengthen the national reach of both organisations.

With an Interim Board operating until October 2010, a permanent skills-based Board was established with an independent Chairperson, Pat Anderson, and six directors, and an Aboriginal or Torres Strait Islander majority. At the Annual General Meeting held in late November 2013, the constitution of the Institute was amended so the Chairperson of the National Aboriginal Community Controlled Health Organisation (NACCHO) would be an ex officio appointment to the Board. The current Board is constituted by Directors with research, community, governance, senior management and health professional expertise (see Appendix 2).

Inaugural Board of the Lowitja Institute with Patron Lowitja O'Donoghue (seated), and L–R: Lisa Jackson Pulver, Peter Buckskin, Sanchia Shibasaki, Chairperson Pat Anderson, Robin Lonergan and Louise Morauta (Stephanie Bell not present)

The expressed goal of the Lowitja Institute is to help close the Aboriginal and Torres Strait Islander health gap by:

- promoting high-quality research through Aboriginal and Torres Strait Islander control of the health research agenda and through partnerships with the Aboriginal and Torres Strait Islander health sector, government agencies and research institutions
- undertaking strategic research to investigate health conditions, health service delivery systems and the social determinants of health
- ensuring the effective transfer of research findings into policy and practice to improve primary health care, to build sustainable prevention and to reduce the disease burden on Australia's Aboriginal and Torres Strait Islander peoples
- supporting a new generation of Aboriginal and Torres Strait Islander health researchers and the development of a workforce to address Aboriginal and Torres Strait Islander health
- providing cultural authority for non-Indigenous researchers
- advocating for research-informed changes to the delivery of health services to Aboriginal and Torres Strait Islander people.

Its overarching strategy – to undertake research that produces the knowledge, tools and resources that enable Aboriginal and Torres Strait Islander communities, health practitioners, other service providers and policymakers to improve health outcomes.

Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH)

For the first two years of operation the CRCATSIH consisted of the same Core Partners, now known as Essential Participants, that had shaped the CRCAH. In 2012–13, the University of New South Wales and Edith Cowan University were added to the organisation, which meant the CRC now had representatives from every national jurisdiction except Tasmania and broad representation from the Aboriginal and Torres Strait Islander community sector, government agencies and research institutions (see Appendix 3 for a full list of Participants).

The CRCATSIH developed three research programs, which housed the many individual projects that built upon the work of the CRCAH:

- Healthy Start, Healthy Life – focused on reducing the chronic illness risk across the life-course, and improving early intervention and chronic illness management.
- Healthy Communities and Settings – focused on the capacity of local communities and organisations to develop interventions that address the determinants of health across a range of local sectors and settings.
- Enabling Policy and Systems – enabling the reform of policy and programs, and workforce development in Aboriginal and Torres Strait Islander health.

Each of the three program areas was overseen by two Program Leaders, at least one of whom was an Aboriginal or Torres Strait Islander researcher. Appointed by the Board to advise on good research practice and how best to ensure the research is used, they brought a wealth of experience and knowledge to the CRCATSIH research programs. Strong advocates for community-driven research, they were generally researchers or representatives from community and government organisations.

The Program Leaders worked closely with three Program Managers, who were responsible for monitoring the progress of individual projects. Each CRCATSIH program included individual research projects that built upon previous CRC work.

The move to Melbourne

In March 2011, the Lowitja Institute opened its offices in Melbourne, giving the Institute a presence in that city's renowned Parkville biomedical precinct, while continuing the CRCs' national influence through their Boards, Participants, members and the many programs and research projects around Australia.

From the outset the CRCs had had a strong focus on northern Australia with many describing them as having their 'spiritual home in the Northern Territory' (Ian Anderson Interview, 17 December 2014). However, with strong networks of knowledge, practice and influence through its partners and associates from across Australia, the CRCs had achieved the long-held aim of national reach, and it seemed opportune at this point to physically relocate the Institute in Melbourne. According to Ian Anderson:

> *In this current iteration there are very strong influences on building policy relationships that connect into all Australian jurisdictions. One of the reasons, strategically, why [the Institute moved to] Melbourne, I think, in part [was] because of the influence of the biomedical research precinct here in Melbourne… probably one of the largest… in the Southern Hemisphere. And we need to be able to position Indigenous health research to actually build relationships with the biomedical research institutions.*
>
> *(Ian Anderson Interview, 17 December 2014)*

As Marcia Langton observed:

> *… and here we have the Lowitja Institute in the middle of the biomedical research precinct here in Melbourne… It's absolutely thrilling that Indigenous health research is mainstream, because it is top priority… I think it is a great credit to everybody that has been involved that finally, Indigenous health research is mainstream and it's here with the best of the best…*[104]

The Lowitja Institute Office openings, Melbourne, 2011 and 2014

Clockwise from top left
Guests at the opening of the Lowitja Institute's Drummond Street offices, October 2014

CEO Romlie Mokak at the 2014 opening celebrations

Former CEO Kerry Arabena, Wurundjeri Elder Aunty Joy Murphy Wandin and Patron Lowitja O'Donoghue at the 2011 launch

The Hon Shayne Neumann MP, Chairperson Pat Anderson and Kelly O'Dwyer MP at the 2014 opening celebrations

Michael Wooldridge speaking at the 2011 launch

Launch, March 2011

James Henry Photography


the Lowitja Institute
Aboriginal and Torres Strait Islander Health CRC
www.lowitja.org.au

Pat Anderson

So we decided that we weren't going to walk away from all this investment.

Interview 3, 14 November 2014

Click to play video **Play online** (browsers and mobile devices)

Pat Anderson, CRCATH Director, CRCAH/CRCATSIH/ The Lowitja Institute Board Member and Chairperson, interview 3 14 November 2914

One of the keynote speakers at the opening of the Melbourne office was the former Health Minister Dr Michael Wooldridge, who had also been present at the launch of the CRCATH in Darwin in 1998. He acknowledged the importance of the Institute's presence in Melbourne:

> *For the Institute to be here right where the action is shows that Aboriginal and Torres Strait Islander research is entirely serious.*[105]

This Melbourne presence continues today in the Institute's current offices that were designed by Jefa Greenaway, a Victorian-based Aboriginal architect, to embody the Lowitja Institute's ethos of using Indigenous philosophies of place-making that stress collaboration, communication and community. As Chair Pat Anderson noted in her address at the Drummond Street office opening in October 2014:

> *The new Lowitja Institute office is an important and exciting Aboriginal and Torres Strait Islander cultural and knowledge space: respectful of the wisdom of our ancestors yet contemporary, located in the heart of inner city Melbourne; a space to deliver great research into the future. It is also a space where we have room to grow and room to welcome our partners for roundtables and other collaborative work.*[106]

Campaigning for survival

By 2012 Pat Anderson and others began to think about ways to consolidate the Lowitja Institute as an umbrella organisation as well as a research institute by extending the funding base for the Institute beyond the CRC.

> *…we can only go three times (for CRC funding), three strikes and you're out and you can't apply again. 'What are we going to do? We're just going to walk away from this?' And we were quite experienced by this stage and we said, 'We're going to set up Australia's first national Aboriginal, Torres Strait Islander health research institute', which was ambitious then and remains ambitious because some of the Indigenous world internationally do have bodies like this, but we don't. So we decided that we weren't going to walk away from all this investment. We were going to build on it and create what's now the Lowitja Institute.*
> (Pat Anderson Interview 3, 14 November 2014)

At this point in its history, with the prospect of closure after the CRCATSIH funding ceased in June 2014, the Lowitja Institute received an unprecedented level of support in a public campaign initiated by the delegates at Congress Lowitja 2012, held in November at the iconic Melbourne Cricket Ground (MCG). The campaign released the MCG Congress Lowitja statement of support, reproduced here.

The MCG Congress Lowitja Statement Melbourne, 2012

The Lowitja Institute is Australia's only Aboriginal and Torres Strait Islander health research institute. It began as the Cooperative Research Centre for Aboriginal and Tropical Health based in Darwin in 1997. It then became the CRC for Aboriginal Health and has been able to secure three rounds of funding from the Commonwealth CRC program as a public good CRC. This source of funding will cease from 30 June 2014 but the need for a national research institute in Aboriginal health funded by the Australian Government remains. There is currently no commitment for ongoing funding from the Australian Government and the Lowitja Institute has been endeavouring to secure private sponsorship to make up this shortfall. While private sponsorship is a valid source of supplementary income it should not be used to replace the obligation of the Australian Government to ensure there continues to be a viable, national research institute in Aboriginal health – the Lowitja Institute.

The Lowitja Institute since its inception has been able to bridge the gap that previously existed between researchers and Aboriginal communities. It has been a leader in the incorporation of an evidence-based approach to Aboriginal health both in terms of services and programs and policy. Its research agenda has helped shape Aboriginal health policy and practice throughout the nation. It has also provided a safe place for dialogue and partnerships between researchers and their institutes and Aboriginal community controlled health services and Aboriginal communities across Australia. Now more than ever we need to build on this success and strengthen not weaken the use of research and the incorporation of evidence into practice in Aboriginal health so that the gains that have been made continue.

The function Lowitja Institute plays as a public good research institution does not end simply because one source of funding cannot go beyond three cycles. This is especially the case as the Australian Government funds the national peak research organisation, the National Health and Medical Research Council, to more than $800 million recurrent and only 1% of this budget would double the current funding to the Lowitja Institute. The Australian Government should therefore provide recurrent core funding to the Lowitja Institute, similar to the equivalent organisation in Canada and over and above the current NH&MRC 5 per cent research target for competitive research in Aboriginal health. Australia is one of the richest nations in the world with a GDP of more than $1.3 trillion but in spite of this the health status of Aboriginal people remains unacceptably below that of other Australians - there should be no question of the capacity of this nation to fund the Lowitja Institute from whatever source.

The 2012 Lowitja Congress held at the MCG, 14 and 15 November, was attended by more than 200 researchers, practitioners, policymakers and others. This meeting calls on the Australian government to continue to fund this iconic national institute as part of its overall commitment to Closing the Gap. This conference also calls on all political parties to commit to the ongoing funding of the Lowitja Institute.

James Henry Photography

Throughout 2013, Pat Anderson, then CEO Lyn Brodie, staff and Lowitja Institute supporters continued the lobbying campaign to fund the Institute. Pat Anderson remembered feeling a profound sense of pressure that, having asked Lowitja O'Donoghue to allow her name to be used for the new Institute, they could not let it collapse. Lowitja's name, however, was also a source of energy to the supporters and provided a symbol of integrity to a wide audience in and out of government.

Pat Anderson described speaking to 'pretty much anybody in that space that had even anything remotely to do with Aboriginal anything', to both major political parties, to the Greens, to bureaucrats, to community controlled organisations and to academia. She pointed out that the CRCs had resulted in a wide network of supporters in universities, government and the community controlled health services that could help to explain the value of the proposed national Institute.

Pat Anderson described the process:

So it was a huge campaign. Now, by that stage, we had already decided we were going to go for this national institute. That was the goal, that was where we were heading… We were talking about an endowment fund. We spoke to people about that, politicians in particular. It didn't get a lot of traction at the time…
(Pat Anderson Interview 3, 14 November 2014)

Pat Anderson and Lyn Brodie went to Canberra on Budget night to witness their success or failure regarding the $25 million for which they had applied.

… almost at the sort of final hour, a decision was made to fund us and we still don't know that story, how it all kind of happened… I think there was a lot of senior people within the Office for Aboriginal Torres Strait Islander Health who were very useful in pushing and promoting… we had done enough… We'd been invited to the [Budget] lock up. Warren [Snowdon] phoned me about three or four o'clock to say that we've got the funding and, of course, I was over the moon.
(Pat Anderson Interview 3, 14 November 2014)

The funds were not identified as a separate item outside the CRC as they had hoped, but had been identified from within the CRC existing budget, providing them with another round of funding for five years.

So we weren't expecting that and I don't think the department was, although I can't speak for them, but that was, I think, pretty much unprecedented… So as it's turned out – yes, we've got the money, but still, it's CRC monies, which comes with a whole lot of attachments and strings… And I have to say, we were hoping that we would have a grant and that we would be free to do all the things that we've been wanting to do for 20 years. We've done bits of it, but we thought we were free to be the Lowitja Institute. Not yet… We're grateful, very grateful but… funding does remain an issue for us, but at least we have a bit of breathing space here.
(Pat Anderson Interview 3, 14 November 2014)

With that breathing space came the opportunity for the Lowitja Institute to develop a vision and plan for its future (see p. 123).

Pat Anderson

“… almost at the sort of final hour, a decision was made to fund us and we still don't know that story, how it all kind of happened… [But] Warren [Snowdon] phoned me about three or four o'clock to say that we've got the funding and, of course, I was over the moon.”

Interview 3, 14 November 2014

CEO Romlie Mokak with Lowitja Institute Research Program Committee members at Melbourne offices, September 2015

The Lowitja Institute Aboriginal and Torres Strait Islander Health CRC

With new funding now available, the Lowitja Institute Aboriginal and Torres Strait Islander Health CRC (Lowitja Institute CRC) was established to operate over the period July 2014 to June 2019, and to build further on the strength of its predecessor CRCs. Again hosted by the Lowitja Institute, the new CRC brought together the Aboriginal and Torres Strait Islander health sector, government health agencies and research institutions to ensure that research conducted into Aboriginal and Torres Strait Islander health is controlled by and benefits Australia's First Peoples.

The Lowitja Institute CRC developed three research programs:

- Community capability and the social determinants of health – to deepen our understanding of how individuals, children, families and communities can mitigate the negative impacts of the social determinants of health, and maximise the effectiveness of positive cultural, social, economic and environmental influences.
- Needs and opportunities for the Aboriginal and Torres Strait Islander health workforce – this program is driven by the need to know how to better grow and sustain a health workforce to address Aboriginal and Torres Strait Islander health needs in all health services and systems.
- Health policy and systems – to provide evidence on the broader health policy and system settings that are most effective in supporting improvements in Aboriginal and Torres Strait Islander health.

It made significant changes to its research governance structure by establishing Research Program Committees to ensure the Institute has high-level advice from individuals with significant expertise in each Research Program area (see Appendix 4). The role of each Program Committee is to provide the Institute with strategic advice on program development, research priorities, quality assurance processes, and Aboriginal and Torres Strait Islander expertise specific to the program.

PhD scholarship holder Alister Thorpe at laneway launch of the Lowitja Institute offices, Melbourne, March 2011

James Henry Photography

Influence and Impact in the Health Research Landscape

Ian Anderson

“

… at the heart of what the CRC program is about, is how do you actually influence practice, build collaborations, focus research priorities, but in a way that it is delivered within the traditional research provider.

”

Interview, 17 December 2014

Over two decades, the various Cooperative Research Centres – the CRCATH, the CRCAH, the CRCATSIH and the Lowitja Institute CRC – and the Lowitja Institute have effectively influenced the broader research environment by placing the priorities, knowledge and leadership of Aboriginal and Torres Strait Islander people at the centre of health research practice. With the support of its collaborators, partners and stakeholders, and guided by its key research principles (see p. 56) and the unique expertise of Aboriginal and Torres Strait Islander health practitioners and communities, the Lowitja Institute and the CRC organisations have earned a place of cultural authority in the health research sector.

As Ian Anderson observed:

> *What it cleverly did is provide an organisational structure that could engage with the mainstream research agenda. So, I think that, at the heart of what the CRC program is about, is how do you actually influence practice, build collaborations, focus research priorities, but in a way that it is delivered within the traditional research provider.* (Ian Anderson Interview, 17 December 2014)

With each new successful funding round from 1997 to 2014, long-term relationships developed between institutions, researchers and organisations, creating a cohort of understanding and acceptance based on evidence and practice. The CRC and Lowitja Institute partners provide significant reach through networks of information and exchange, collaboration in research and of the capacity building and mentoring of students and scholars. A ‘critical mass’ of support at a leadership level in state and Commonwealth government departments, in research institutions and in community organisations has led to an improved understanding of ‘what the Aboriginal community were on about when they decided to set the thing up’ (Jeannie Devitt Interview Part 2, 13 March 2015).

Through each CRC, structures and processes were developed that provided for Aboriginal and Torres Strait Islander community influence on the kinds of research that was done and the way it is done (Jeannie Devitt Interview Part 2, 13 March 2015). In-kind contributions from Core Partner or Participant organisations, for example, formed a significant source of funding for the first two iterations of the CRC, and continue to be an important part of the cooperative arrangements between the Lowitja Institute CRC and its Essential Participants. This ‘trusted’ space between policy, research and community has helped the CRCs produce cost-effective research and led to their considerable success.

In 2015, Deloitte Access Economics undertook a retrospective cost benefit analysis of the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health research program, building on the methodology Access Economics developed in 2009 (see p. 57). Using this analysis – and applying usage, impact and attribution probability assumptions (as required by the Commonwealth Government Cooperative Research Programme guidelines) – the net benefit of the CRCATSIH research program was estimated as $359.1 million over 15 years. The cost for funding this research program was expected to be $106.6 million, representing a benefit to cost ratio of $3.40 for every $1 invested in the CRCATSIH research program.[107]

Deloitte Access Economics, 2016

Community-driven research

As the previous chapters outline, one of the identifiable impacts of the CRCs has been their contribution to building a national Aboriginal and Torres Strait Islander research cohort to change national discourse in health research, from 'us and them' to an approach that values evidence and Aboriginal and Torres Strait Islander research leadership. Jenny Brands emphasised that the CRC and Lowitja Institute approach to research contributed significantly to changing the long-held, sometimes negative, views of research that many Aboriginal and Torres Strait Islander communities had:

… I think that one of the symbolic aspects of the CRC and its research was that it was seen as giving Aboriginal and Torres Strait Islander people a voice and power in the research process. And it's seen as a good thing because of that. I think, often, it almost doesn't matter what the research is about. The process of working together, contesting knowledge and working out problems together by drawing on different sources of knowledge, has been as important in many ways as any individual research project. And that changes the people who are involved with those projects.
(Jenny Brands Interview, 2 March 2015)

Komla Tsey outlined a range of impacts of the research models instituted by the CRCs and the Lowitja Institute, including Aboriginal and Torres Strait Islander control of the research prioritisation process that has brought real changes to delivery and the value of research to communities. Bringing peer reviewers to the table to discuss research was not part of the accepted grant review process and this was also one of the CRCs', and the Institute's, significant contributions to the health research process. It took years to develop and to become part of the Lowitja Institute process and to be accepted by the wide range of organisations within its networks.

When Aboriginal people say, 'If we're going to do research, we want to do it on our own terms… we want to be involved', I think the CRC has come up with practical ways in which that can happen… The idea of openness in terms of… making peer review processes open, I think the CRC has made a huge impact within this community… Initially, it was unheard of to bring peer reviewers and applicants together to discuss proposals, creating that space – it just doesn't happen. It takes people with the expertise to actually facilitate the process. So I think the CRC has made a huge impact in that area. The whole idea of user-driven research, research translation or knowledge sharing, I think the CRC has made a huge contribution in those areas as well.
(Komla Tsey Interview, 25 March 2015)

Click to play video | **Play online** (browsers and mobile devices)

The Lowitja Institute CRC Particpant Forum, June 2016

***Video:** Komla Tsey, CRCAH/CRCATSIH Research Program Leader, interview 25 March 2015 (p.188)*

Participants at Systemic Racism Workshop, the Lowitja Institute, Melbourne, March 2016

Komla Tsey was mindful of the need to broaden the base of these improved processes for undertaking health research, beyond the researchers working with the Institute. Along with Terry Dunbar and Stephanie Bell, he pointed out that to reach the majority of researchers, and to increase the impact of the research frameworks developed at the CRCs, they need to be adopted as policy by major national research institutions like the NHMRC and the Australian Research Council (ARC).

Many individuals who had been closely associated with the CRCs and the Lowitja Institute, including Terry Dunbar, Ian Anderson and Ray Lovett, have contributed directly as members of ethics panels, steering groups or advisory panels, creating a certain amount of cross-fertilisation through networks of individuals and institutions.

Contributing to Closing the Gap

In the 2005 Social Justice Report, then Aboriginal and Torres Strait Islander Social Justice Commissioner Tom Calma called on the Government to take action and commit to helping to achieve equal health and life expectancy outcomes for Aboriginal and Torres Strait Islander people within 25 years.

Aboriginal and Torres Strait Islander health and wellbeing organisations and non-Indigenous health bodies, responded to this report by working together to create a National Indigenous Health Equality Campaign, which in 2007 resulted in a National Close the Gap Day.

In 2008, one year after the National Close the Gap day was established, the Commonwealth Government established the National Indigenous Health Equality Council and the Council of Australian Governments approved the National Indigenous Reform Agreement which set out the Closing the Gap targets.

The non-government organisations whose efforts preceded the Closing the Gap targets formed an ongoing Close the Gap Campaign Steering Group to continue to push for increased actions.[108] The Lowitja Institute is a member of this important committee.

In November 2011, the Lowitja Institute became a foundation member of the National Health Leadership Forum (NHLF), which brings together Australia's peak Aboriginal and Torres Strait Islander health organisations.[109] On behalf of the NHLF, the Lowitja Institute developed a number of papers that supported the wide-ranging consultations for the development of the NATSIHP 2013–2023 launched by the Labor Government in July 2013.[110] In the preface, the then Minister for Indigenous Health, the Hon Warren Snowdon MP, thanked the members of the NHLF for their 'courage and contribution' to the plan.[111]

In it submission to the NATSIHP, the Lowitja Institute was particularly forthright around the effects of racism on health:

> *Discussion about racism is difficult and highly charged in the Australian community and action should be focused on the development of respectful relationships and sanctioning of discriminatory behaviour, policies and practices, including within the health system.*[112]

The NATSIHP also highlighted the crucial role played by the Lowitja Institute in sharing 'important learnings' from Aboriginal and Torres Strait islander health research:

> *Through the Closing the Gap Clearinghouse and the Lowitja Institute, policymakers, service providers, academics and the public have access to a continually growing evidence base about addressing Aboriginal and Torres Strait Islander health and disadvantage.*[113]

Chairperson Pat Anderson (2nd from left) with Justin Mohamed (then Chair of NACCHO) and Sam Jeffries (then Co-Chair of National Congress of Australia's First Peoples) meet with then PM Julia Gillard and Ministers (Jenny Macklin, Warren Snowdon and Nicola Roxon) at Parliament House, Canberra, 8 February 2011

Photo courtesy HREOC

The research projects of the four CRCs and the Lowitja Institute have been undertaken within a framework of CRC and Institute priorities and key principles, but administered and conducted by Core Partners and Participants, together with other contributing organisations and individuals, too numerous to mention. The intellectual property they brought to the work is critical to the creation of the new knowledge that these projects represent.

Significant research projects and outputs

… what we did at the CRC, that bit about making our research meaningful, we became… experts in brokering, taking research and putting it somewhere…
Mick Gooda Interview, 30 October 2014

The impact of the CRCs is particularly evident in the quantity, quality and range of direct research outputs from its research programs and grant schemes to its scholarship support of a younger generation of Aboriginal and Torres Strait Islander health researchers. These projects and networks have influenced policy and practice in the health research area and become vehicles for training, knowledge exchange, research translation and capacity building in Aboriginal and Torres Strait Islander health research and the health workforce.

Through each CRC, significant research projects have been identified and developed; some completed within the duration of a CRC, some that have continued across more than one CRC. Others started as a small project funded by a CRC and grew, sometimes significantly, gathering external funding and interest from other research and policy organisations (see Appendix 6 for a list of projects funded by the CRCs). Some in-kind projects have also had a major impact and are representative of the collaborations possible within the CRC structure.

Each project, however, was developed within the ground-up, decision-making processes and governing structure of the CRCs and reflected the input from community-based service deliverers and researcher institutions. They also reflected the research priorities of the CRCs and the Lowitja Institute, which can be grouped under four main themes.

- Research into practice
- Evidence for good policy
- A research community and workforce
- Networks of knowledge and communication.

The following projects – listed here under each of these four themes – while far from comprehensive are indicative of the work that the CRCs and the Lowitja Institute have supported since 1997. They are also best practice examples of collaborative priority setting and research that has a positive impact on the health and wellbeing of Aboriginal and Torres Strait Islander Australians.

Research into practice

Improving the quality of and access to Aboriginal and Torres Strait Islander health care

Vital to better health outcomes for Aboriginal and Torres Strait islander peoples is research that produces the knowledge, processes, tools and resources needed to enable communities, health practitioners, other service providers and policymakers to improve the quality of and access to health care, and to lower the burden of disease. Recognising this, for two decades the CRCs and the Lowitja Institute have funded programs both in continuous quality improvement (CQI) – a system of regular reflection and refinement to improve processes and outcomes in the operations of primary health care providers to Aboriginal and Torres Strait Islander communities – and in improving the culture of and access to hospitals and other front-line health services.

Audit and Best Practice for Chronic Disease Project (ABCD)

The ABCD project – a 2002 collaborative research partnership between Menzies School of Health Research, the NT Government's DHCS, the CRCAH, and a number of government and Aboriginal community controlled health centres in the Northern Territory – is an example of the cooperative possibilities inherent in the CRC Programme. The CRCAH was one of the principal funding contributors to the project, which was carried out under the leadership of Professor Ross Bailie, a researcher at Menzies and Program Leader for the CRCAH. ABCD ran from 2002 to 2006 and the extension project (ABCDE) from 2005 to 2009.

ABCD was a pioneering project aimed at improving health outcomes by assisting Aboriginal and Torres Strait Islander primary health care centres to improve their protocols for the delivery of best practice care. Project staff worked with health centres to identify the strengths and weaknesses within their systems, to set goals for improvement, to develop strategies to achieve set goals, and then to measure the effectiveness of the strategies put in place. The 12 original participating health care centres in the ABCD Project focused initially on chronic disease, such as diabetes, and achieved significant improvements in quality of care and outcomes for clients.

A key aspect of the project was the introduction of a CQI process, which in health care requires personnel to implement a continuous process of improvements within internal systems that provide corresponding improvements to health care services that then can meet or exceed the needs and expectations of customers.[114] The concepts and techniques inherent in the CQI process have been identified as an effective means for health services to 'identify, address, and overcome the barriers to improvements in service delivery'.[115]

Jenny Brands considered the ABCD Project to be one of the most significant and influential projects undertaken by the CRCAH, as it had a huge impact on the way that governments and the Aboriginal community controlled sector worked together. Komla Tsey also noted the importance and lasting influence of the CQI protocols developed by the project:

> *… they took constructs from outside Indigenous health, sat down with people, adapted the framework to assessing health services… [It] has been taken up by some Aboriginal community controlled health services, but also government services and it has …now become a culture of many organisations… I think people have internalised the idea that whatever we are doing, we need to be asking… how can we improve the quality of this?*
> (Komla Tsey Interview, 25 March 2015)

The initial 12 centres in the Northern Territory using ABCD tools and processes increased to more than 120 health centres across Australia by the end of the project in 2014. ABCD was also instrumental in securing funding for a new Centre of Research Excellence for Integrated Quality Improvement based at Menzies.[116]

One21seventy

The success of the ABCD Project also led to the establishment in 2009 of One21seventy, the National Centre for Quality Improvement in Indigenous Primary Health Care to support Aboriginal community controlled health organisations to use evidence-based good practice in chronic illness care. The Centre's name came from its mission to 'increase life expectancy for Indigenous people beyond 1 in infancy, beyond 21 in youth and beyond seventy in the lifespan'.[117] Launched as a not-for-profit entity administered through Menzies, the centre became well established as an ongoing service provider for quality improvement training, tools and consultancy services to the Aboriginal and Torres Strait Islander primary health care sector.

Uptake of the program was strong, with multi-year contracts established in 2010 with the NT Government, and the Queensland and SA Health Departments as well as individual health service contracts established in the NT and NSW. By 2016, there were 270 health centres nationally registered to use One21seventy's services.

Support of One21seventy provides a strong example of the Lowitja Institute's commitment to knowledge exchange, translating research into service delivery and feeding that experience back into the evidence. Around 70 per cent of registered health services actively contribute their data to research. Analysis of that data over time has shown that the majority have improved their performance on most indicators, with some making significant improvements.

As well as providing general support for One21seventy, the Lowitja Institute made funding available for training, an e-learning package for clinicians wanting to interpret local data, and the development of a range of clinical 'audit tools', including the Health Promotion, Youth Health and Sexual Health audit tools.

National Framework for Continuous Quality Improvement in Aboriginal and Torres Strait Islander Primary Health Care

In 2014–2016, the Lowitja Institute led a major collaboration including NACCHO, state and territory peak bodies (two of which are Lowitja Institute CRC Participants) and three research Participant organisations (Menzies, Flinders and University of Melbourne) in a three-phase project commissioned by the Australian Government Department of Health. The first phase made recommendations for a national CQI framework in Aboriginal and Torres Strait Islander primary health care; the second produced a draft national CQI framework for Aboriginal and Torres Strait Islander primary health care 2013–2023. The third phase developed new tools and resources to support the framework. The framework aimed to guide a major investment by the government in improving the quality of primary health care for Aboriginal and Torres Strait Islander people across community controlled health services, mainstream general practice, and state/territory health services. (Also see CQI conferences on p. 114.)

Improving the culture of hospitals

The Improving the culture of hospitals project supported a program of reforms to improve cultural sensitivity in acute health care institutions, using the experience of Aboriginal and Torres Strait Islander people as the central reference point. It was initiated and funded by the CRCAH and project managed by the Australian Institute for Primary Care at La Trobe University with Onemda VicHealth Koori Health Unit at the University of Melbourne and the Aboriginal Health Council of South Australia, guided by an expert Advisory Comittee.

Run over three years (2007–10), the project examined successful Aboriginal programs undertaken by hospitals, within a quality improvement framework, to see how this work could be replicated and sustained across a wide range of hospital environments. This information was then used to generate a framework for accompanying tools and guidelines for each stage of the process so as to sustain cultural change in hospitals.

There were several critical success factors to implementing a systematic approach to an improved culture in acute care services and outcomes in hospitals for Aboriginal and Torres Strait Islander people including:

> *… strong partnerships with Aboriginal communities; enabling state and federal policy environments; leadership by hospital boards, CEO/General Manager and key clinical staff; strategic policies within the hospital; structural and resource supports; and commitment to supporting the Aboriginal and Torres Strait Islander workforce.*[118]

Subsequent projects have continued to develop and refine the framework and resources known as the Aboriginal Quality Improvement Toolkit for Hospital Staff as well as the Aboriginal Quality Improvement Workbook and Training.[119] There are also a growing number of successful case studies that both provide evidence and link to national frameworks for improving the quality and standards of acute hospital care for Aboriginal and Torres Strait Islander people.[120]

Improving the journey for remote area Aboriginal cardiac patients travelling long distances to hospital

The CRCAH supported this research project which demonstrated that large financial investments are not always needed to develop systematic changes that can deliver better health outcomes for Aboriginal and Torres Strait islander people and cost savings for the broader health system. Project leader specialist nurse Monica Lawrence noticed that a significant number of Aboriginal patients arriving at Flinders Medical Centre in Adelaide for heart surgery also had acute health-related problems, other than their cardiac condition. These problems often resulted in cancellations or long delays in treatment or surgery that in turn resulted in prolonged hospital stays and additional costs.

Her 2007 study found that the delays were a result of poor communication between the surgery units, the Aboriginal patients and the health professionals at their original clinics, which led to surgery being scheduled without patients being properly informed and prepared. The costs of this were more than financial, as the process had resulted in patients arriving in Adelaide without an understanding of their treatment or how important it was for them to communicate to medical staff what other health issues might affect their treatment.

In response to the study, the Flinders Medical Centre established a pilot Remote Area Nurse Liaison Service in early 2007 to coordinate pre-surgery care and travel between the cardiac unit and the patient's local clinic. Over three years there was a dramatic decline in cancelled surgery – due to 'no shows' or poor patient preparation – from more than 50 per cent of remote area patients to zero, with flow-on effects in improved operational efficiencies within the hospital and cost savings on patient travel bills.

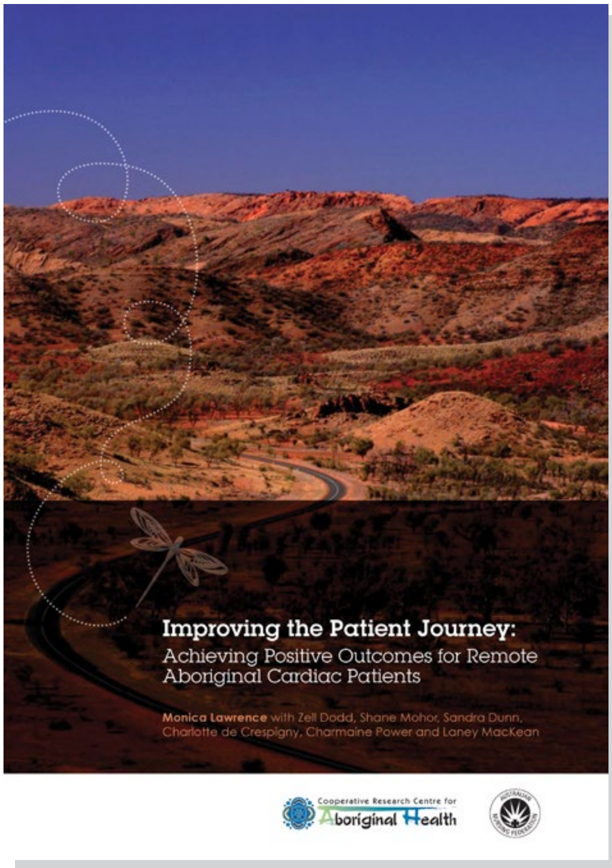
As a direct result, a permanent remote clinical/cultural nursing liaison service was established within Flinders Medical Centre.[121] For Mick Gooda the study was

> *... practical research and problem solving at its best. Monica saw a problem, put her mind to finding a solution and now all that the relevant health authorities need to do is take action and the benefits to Aboriginal health and the health budget's bottom line will start to accrue.*[122]

Managing Two Worlds Together (MTWT)

In the MTWT project, funded by the South Australian Department of Health and the CRCATSIH and Lowitja Institute CRC, researchers at Flinders University produced a series of 14 reports and practical tools to highlight critical segments and gaps in care and outcomes for Aboriginal patients needing to travel to city hospitals from remote areas for specialist care. Stage 1 of the project (2008–11) focused on understanding the problems that occur within and across patient journeys, and the barriers and enablers to access, quality and continuity of care. Stage 2 (2012) focused on possible solutions and strategies. In Stage 3, the MTWT project also looked specifically at case studies in cardiac, maternity and renal care as well as cases in city sites and rural and remote sites.

The findings of the project informed a Heart Foundation Focus Grant to map more detailed cardiac patient journeys across the NT, and work in South Australia and the NT by the Renal Focus Group on how best to



Improving the Patient Journey:
Achieving Positive Outcomes for Remote Aboriginal Cardiac Patients

Monica Lawrence with Zell Dodd, Shane Mohor, Sandra Dunn, Charlotte de Crespigny, Charmaine Power and Laney MacKean

Cooperative Research Centre for Aboriginal Health

'Practical research and problem solving at its best', Improving the Patient Journey report

Kim O'Donnell, CEO Romlie Mokak, Judith Dwyer, Uncle Lewis Yerloburka O'Brien, Janet Kelly and Chairperson Pat Anderson at launch of Managing Two Worlds Together, Adelaide, June 2015

support end-of-life journeys, particularly for those wishing to return to remote communities. Midwives have also used the tools to highlight specific issues for Aboriginal mothers and their families, and educators have incorporated them into training courses. Patient journeys and the mapping tools are also increasingly being introduced into nursing, medical and health care management training in a range of health care sites and tertiary institutions, while researchers and students have incorporated the methodology into their projects.

The NATSIHP 2013–2023 also notes that a focus on the patient journey, which meets the clinical health care needs, as well as cultural and social needs of Aboriginal and Torres Strait Islander individuals and their families, will produce better health outcomes.[123]

There are three reasons why the MTWT research was successfully translated into practice: the focus was on practical ways of improving care rather than dwelling on problems and barriers (important as it is to understand them); the idea of tracking patient journeys was recognised as useful by health care staff who were in the business of trying to make the journeys better; and the research results reached some of the people or groups with the political clout to influence change.

Reducing the burden of ill-health

The purpose of the work of the CRCs and the Lowitja Institute has been to make a difference to the health and wellbeing of Aboriginal and Torres Strait Islander peoples and, ultimately, to the highly unacceptable mortality and morbidity rates they experience. Research over this period has included broad areas of work such as addressing best practice in chronic disease care, analysing the social determinants of Aboriginal and Torres Strait Islander health, and understanding the health and health research workforce needs – both Aboriginal and Torres Strait Islander and non-Indigenous. While this work does not directly address chronic disease, it challenges the broader policies and systems that contribute to poor health.

Tobacco control

Since the earliest days of the CRCATH there was recognition that tobacco use was a significant health issue for many Aboriginal and Torres Strait islander people. In 1999 the CRCATH began an 'Evaluation of Community-based Tobacco Programs for Aboriginal People' as part of its Public Health Research Program.

Then in 2003 the CRCAH endorsed the newly established Centre for Excellence in Indigenous Tobacco Control (CEITC) as an in-kind project. CEITC had been set up to implement effective tobacco control programs, which prior to this had not generally been considered a high priority for Aboriginal and Torres Strait Islander communities.[124] A CRCAH Chronic Conditions Program Industry Roundtable held in February 2006 to identify priorities by the community controlled health sector and other service providers ranked tobacco use as a high concern.[125] It provoked some key questions such as:

- What are the successful interventions? How do you change people's behaviour?
- How do interventions work for individuals in communities where there are a majority of people smoking?
- Why aren't anti-smoking campaigns working for Aboriginal communities?[126]

Ian Anderson acknowledges the innovation and impact of some of the work conducted by the CRCAH and its partners around smoking and tobacco control. It not only reflected the agenda of health care providers, but reverberated further afield in the thinking of COAG's National Partnership Agreement in Closing the Gap in Indigenous Health Outcomes (Ian Anderson Interview, 17 December 2014).

Mick Gooda also identified that this research into tobacco control had implications for funding, for communicating health priorities set by ACCHSs and for progressing a strategic approach to health research. Of most significance was the finding that tobacco use could be accountable for 'about 17 per cent of the health gap'.[127]

> *… what we did at the CRC, that bit about making our research meaningful, we became… experts in brokering, taking research and putting it somewhere… We did a Showcase [of our research] up in Parliament House and Nicola Roxon, at the time the Health Minister, just grabbed this. And within two weeks after our presentation, they allocated $14 million to smoking. … By the end of the year after, I think, it was about a $100 million allocated to smoking and it was based on this little bit of research that we [were] able to take and put out there so people could use it.*
> *(Mick Gooda Interview, 30 October 2014)*

Smoking rates for Aboriginal and Torres Strait Islander Australians continue to decrease, with the proportion of daily smokers aged 15 years and over in 2014–15 at 38.9 per cent, down from 48.6 per cent in 2002 and 44.6 per cent in 2008.[128]

Nicola Roxon, then federal Minister for Health, addressing CRCAH Showcase, Parliament House, Canberra, March 2008

Centre for Research Excellence (CRE) to improve cancer outcomes

For a long time, cancer did not rate as a specific concern in health policies for Aboriginal and Torres Strait Islander people because they had much lower rates of early of cancer diagnosis than other Australians. However, a comprehensive review commissioned by Cancer Australia in 2010 revealed that Aboriginal and Torres Strait Islander people had, in fact, a significantly higher mortality rate in the first two years after diagnosis and higher rates of less common cancers. Indeed, cancer was actually the second leading cause of death (19%).

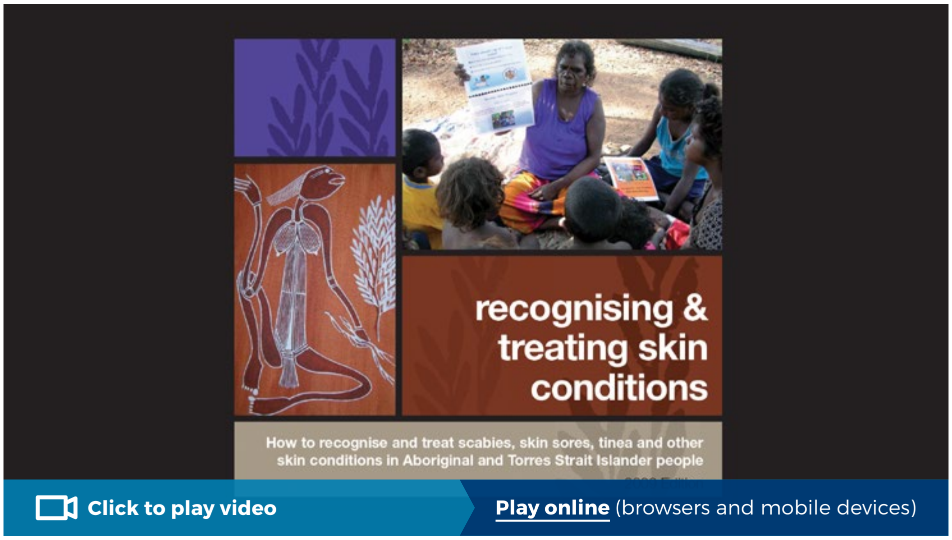
In response to the study, and in partnership with the QIMR Berghofer Medical Research Institute, the CRCATSIH hosted a national roundtable on cancer in Aboriginal and Torres Strait Islander populations. It brought together some 50 leaders in cancer research, cancer control, health care providers and others as well as cancer survivors and representatives from the community controlled primary health care sector. The roundtable identified the need for a nationally integrated approach and to ensure that Aboriginal and Torres Strait Islander cancer research be translated into health policy and practice.

In January 2011 a collaborative group of researchers, practitioners and other key stakeholders, under the leadership of Associate Professor Gail Garvey, a prominent Aboriginal cancer researcher and a Program Leader at the CRCATSIH, came together to drive the establishment of the Centre for Research Excellence in Discovering Indigenous Strategies to Improve Cancer Outcomes via Engagement, Research Translation and Training (DISCOVER-TT).

A National Indigenous Cancer Network (NICaN) was then launched in February 2013 to work alongside the newly formed CRE. NICaN's role is to encourage and support collaboration around cancer research for, and delivery of services to, Aboriginal and Torres Strait Islander people with cancer, their carers and families. Among its online resources, the network provides a virtual forum for meetings involving those with cancer, experts, community groups, carers, former patients and others.

Gail Garvey, Christine Potter, Adelaide Saylor, Alan Cass, Chairperson Pat Anderson and Ian Olver at launch of National Indigenous Cancer Network (NICAN), February 2013

Photo courtesy MSHR & Henri + Claude Photography



Flipchart produced by the East Arnhem Regional Healthy Skin project

***Video:** Terry Dunbar, CRCATH Research Leader, interview 11 March 2015 (p. 188)*

Burden of disease and injury in Indigenous Australians study

This 2007 study, and in-kind project by CRCAH Core Partner the University of Queensland, was the first comprehensive assessment of how the burden of disease and injury affects Aboriginal and Torres Strait Islander people. It quantified the contribution of more than 170 specific diseases and 11 key health risk factors and highlighted the main differences between Aboriginal and Torres Strait Islander peoples and other Australians.

The research, for example, highlighted that one-third of young Aboriginal and Torres Strait Islander men then aged 15 would die before they were 60, compared to 8 per cent in the rest of the Australian population, largely due to excess mortality from causes such as ischaemic heart disease, suicide and Type 2 diabetes.

The study noted that while there had been numerous international burden of disease studies over the previous decade, including several in Australia, the framework and tools had never before been applied to measure disease burden in Aboriginal and Torres Strait Islander populations (apart from a pilot study in the NT), which had made it difficult to develop priorities in health policies.

The study's findings had and have profound implications for priority setting in health policy, filling an important gap in the evidence base in Aboriginal and Torres Strait Islander health. In particular, they have assisted health service planners and communities to identify those specific diseases and risk factors that are most responsible for the gap in health status between Aboriginal and Torres Strait Islander peoples and other Australians.[129]

Scabies and the Healthy Skin project

Research undertaken at Menzies by Dr Shelly Watson and CRCATH Program Leaders Professor David Kemp and Dr Bart Currie, and funded by the CRCATH and published in 1998, showed that human scabies mites were different from those infesting dogs in scabies-endemic communities in the Northern Territory.[130] These results allowed the researchers to focus on the treatment of humans rather than on dogs and the perils of zoonotic infections, as had previously been the case, an approach that had caused significant concern and distress in a number of Aboriginal communities regarding the culling of dogs as a means to contain scabies infections. The results of the research eventually resulted in a change of policy regarding the management of dogs.

In her interview Terry Dunbar highlighted the efforts of CRCAH Program Leader Dr Christine Connors of NT's DHCS in the scabies project, in particular, her role in 'empowering the Indigenous voice through the project' that led to better approaches to remedying scabies in the community (Terry Dunbar Interview, 11 March 2015).

The *CRCATH Annual Report 1999–2000* identified the treatment of infectious diseases, including scabies, as a target priority and part of its new strategic focus.[131]

A CRCATH Board-commissioned feasibility study in 2000 led to a coordinated and integrated effort, using biomedical and clinical techniques, public health and service delivery strategies, and research transfer and education to tackle scabies and related infections. The biomedical research was complemented by audience-appropriate information packages, such as flip charts for scabies management that were distributed to affected communities.[132]

This was the beginning of the Healthy Skin program that would later become one of the five key components of the CRCAH's programmatic approach to research. The program's premise was that childhood skin infections, such as scabies, are linked to chronic kidney disease and rheumatic heart disease in adults, so its primary goal was to reduce the incidence of skin diseases in Aboriginal communities.[133] Michael Good regards the Healthy Skin project as one that exemplifies the collaborative spirit and ethos of the CRCs:

> *It brought together, not just the scientist stuff, like what I was doing, it brought together epidemiology, it brought together community awareness and community education, nurse education of communities.*
> *(Michael Good Interview, 3 March 2015)*

One of the significant projects undertaken through the Healthy Skin Program was the East Arnhem Regional Healthy Skin Project (2004 to 2007) led by CRCAH Program Leader Professor Ross Andrews. A collaboration between Menzies, the CRCAH, Northern Territory's DHCS, Australasian College of Dermatologists and the University of Melbourne, its goal was to develop a community-based program to control skin infections and to enhance the capacity of local Aboriginal community workers.[134] The project was able to make significant gains by halving the prevalence of skin sores in the community over an 18-month period using a suite of resources for the diagnosis and treatment of skin conditions, including radio programs and flip-charts in the local language.[135] In addition, it introduced a training package for the community workers involved, funded by OATSIH, that provided formal recognition towards qualifications in primary health care.[136]

Streptococcus A vaccine

In 2010, CRCATSIH funded the Phase 1 clinical trial of a vaccine to combat Group A Streptococcus, the germ that causes rheumatic fever and rheumatic heart disease. Aboriginal and Torres Strait Islander peoples have the highest rate of the rheumatic fever in the world. The ongoing work is being led by Michael Good, Director of the Queensland Institute for Medical Research and an inaugural Member of the CRCATH Board.

The CRCATSIH funded the first human trial of the Queensland vaccine. In 2013 the vaccine project won a NHMRC grant, 'Tropical disease – Immunity, pathogenesis and vaccine development: global translation', worth $17.1 million over five years. This program of research emerged out of earlier work backed by the National Heart Foundation, the Prince Charles Hospital Foundation and the NHMRC and linked to CRCATSIH support.

Michael Good

[Healthy Skin] brought together, not just the scientist stuff, like what I was doing, it brought together epidemiology, it brought together community awareness and community education, nurse education of communities.

Interview, 3 March 2015

Evidence for good policy

Government policies and funding arrangements set the context and parameters for the provision of health services to Aboriginal and Torres Strait Islander people. However, achieving cohesion between Commonwealth and state systems, as well as the different government departments, remains a challenge. Similarly, more effective and efficient governance – from the Australian Government to the smallest ACCHO – can improve care and support the work of health care staff.

As a consequence, the CRCs and the Lowitja Institute have funded and supported projects around two areas of research: Rethinking governance, funding and regulation; and Finding new approaches to old problems.

Rethinking governance, funding and regulation

The health system and all of the organisations within it require good governance in order to be effective. This has been an important area of focus, and work in this area has addressed some specific aspects of Aboriginal health policy to inform governments and other funding agencies as to the most effective ways of ensuring good governance.

The Overburden Project

The Overburden Project began in 2006 led by Judith Dwyer from Flinders University, one of the first four projects to be approved through the Facilitated Development Approach. It sought to investigate the complex and fragmented set of funding sources that ACCHSs had to negotiate to provide primary health care services to their communities.[137]

The onerous level of reporting and accountability that ensued from these funding arrangements was out of proportion with the funding levels they received.[138] As Judith Dwyer noted in 2011:

> *None of the funders planned to make it so complicated, but the fact that ACCHSs we surveyed were funded on average from about 22 different programs and sources, each with its own reporting and accounting requirements, made for high costs in administration, and wear and tear on working relationships.*[139]

The project aimed at finding ways to improve the effectiveness of the various funding models and regulatory arrangements put into place for Aboriginal primary health care services. Judith Dwyer said it started with the question:

> *'How could the funding be done better?' But we're in the situation where everybody in the field knew it was a mess. And I thought, 'Well, I can describe and, in some senses quantify the mess. But so what? That's what everybody already knows.' And thankfully I fell across a framework… that enabled us, the team, to analyse the mess through a theoretical framework… [and be able] say, 'This is what would work better'.*
> *(Judith Dwyer Interview, 5 March 2015)*

Jenny Brands explained that some of the causes of high levels of overburden in ACCHSs were due to the overall health system being segmented according to body parts with selective funding and reporting, for example, for eye or kidney health. More importantly, ACCHSs were focused on 'holistic health care, and treating individuals and communities as a whole', which resulted in a disconnect and a 'lack of trust between government and Aboriginal and Torres Strait Islander organisations' (Jenny Brands Interview, 2 March 2015).

The *Overburden Report* was launched in August 2009, timed to coincide with the final report into reforming Australia's health system by the National Health and Hospital Reform Commission, *A Healthier Future for all Australians*. The researchers wanted the work to feed into government policy decision-making and found that the media picked up their report because it was pertinent to the bigger issue.

The Australian Government's Strategic Review of Indigenous Expenditure in 2010 highlighted the findings of the Overburden project and recommended that DoHA should 'reduce the administrative burden for Indigenous health services' and 'lead discussions with State and Territory health funders on a coherent performance and reporting framework for all government services'. And a 2012 Auditor-General's report, *Capacity Development for Indigenous Service Delivery, described the Overburden Report* as 'significant' and identified the CRCAH as directly influential in leading to reform in the reporting required by OATSIH.[140]

OATSIH had also responded to the report's findings by introducing a 'singular head funding agreement' in 2011 to consolidate the numerous separate agreements between ACCHOs and DoHA, with the duration of the agreements extended to three-year contracts.[141] In addition, OATSIH ensured that other unnecessary reporting burdens were removed, that National Key Performance Indicators were developed and that Continuous Quality Control indicators were introduced.[142]

In 2011, Judith Dwyer's team released a follow-up survey, with the *Aboriginal Community Controlled Health Service Funding: Report to the Sector* providing further evidence of the onerous and complex system of accounting and reporting faced by ACCHSs around Australia. This report found there had been little or no change in the compliance burden faced by ACCHSs since the *Overburden Report*, with an average of 21 grants per ACCHS.

The research has led to ongoing work by the Lowitja Institute under its Funding, Accountability and Results in Aboriginal Health Services (see FAR project, this page), Planning, Implementation and Effectiveness in Aboriginal and Torres Strait Islander Health Policy Reform (see PIE project below), and the Stewardship Dialogues (see p. 95) that aim to generate new options and approaches to addressing cumbersome policy processes in programs and systems.

Planning, Implementation and Effectiveness (PIE) in Aboriginal and Torres Strait Islander health policy reform

The PIE project was conducted in 2010–2013 by University of Melbourne researchers, sponsored by CRCATSIH and the Australian Research Council. It developed a framework to evaluate the engagement of Aboriginal and Torres Strait Islander people in policy and program development for two Indigenous Health National Partnership Agreements (IHNPAs). It also assessed the impacts of this engagement on policy, programs and the implementation of the agreements. The overall aim of the project was to develop indicators to support best practice in Aboriginal and Torres Strait Islander health governance. The project addressed the processes through which Aboriginal and Torres Strait Islander community members and organisations are involved in governance, and the impact of their engagement on decisions and relationships with others. It also examined the aspects of engagement associated with greater satisfaction with the process, confidence in implementation and improvements in access to health services (e.g. health assessments).

The project report made six important recommendations, including the incorporation of Aboriginal and Torres Strait Islander communities and organisations in the governance of health programs; ensuring that Aboriginal and Torres Strait Islander perspectives are valued and inform decision-making in governance; developing strategies/activities to strengthen relationships between organisations; supporting the continuation of regional approaches to planning; improving the equity of selecting projects for funding to ensure an optimal regional service mix; and improving communication and coordination between different programs.

Funding, Accountability and Results (FAR)

The Road Is Made by Walking: Towards a better primary health care system for Australia's First Peoples was one of five reports emanating from the FAR project undertaken by researchers at Flinders University in 2011–2014. It is a study of bold reforms in primary health care for Aboriginal and Torres Strait Islander communities in the Northern Territory (2009–14) and Cape York, Queensland (2006–14) that aimed to transfer primary health care services to regional ACCHOs, in a partnership approach between the sector and federal and jurisdictional health departments. Two brief histories and a case study of the research partner organisations were prepared as part of the project, to contribute to the record of development of the broader Aboriginal community controlled health sector, to give context to the larger research study and for the partners' own use.

The FAR study drew on other Lowitja Institute studies – Overburden and PIE – all focused on how to implement health policy and health system reforms effectively, and the substance of the reforms needed to achieve the policy goal. They also consider implications for future development, in particular in regionalisation, for governance and stewardship, and in funding, contracting and accountability.

Legally Invisible

In a similar vein, in 2011 the Lowitja Institute commissioned Associate Professor Genevieve Howse to examine how the vast array of laws and policies across state, territory and federal jurisdictions create barriers to improved Aboriginal and Torres Strait Islander health. The project reviewed existing health legislation to examine the effectiveness of governance and stewardship arrangements throughout Australia's nine jurisdictions, noting that the World Health Organization (WHO) defined the concept of a national stewardship for health as 'the careful and responsible management of the wellbeing of the population'.[143]

The discussion paper that emerged from the research – *Legally Invisible: How Australian laws impede stewardship and governance for Aboriginal and Torres Strait Islander health*[144] – found there was little recognition of the specific needs of Aboriginal and Torres Strait Islander peoples in existing health legislation.[145] In fact, all of the 250 health-related Acts across the nine jurisdictions that it examined failed to create a viable structure of stewardship and governance for the health of Aboriginal and Torres Strait Islander peoples. This, the paper argued, had negative health consequences.[146]

There were three key recommendations from the project:

- a Commonwealth law that establishes federal government responsibility for important functions, and principles to guide interpretation and administration of all Commonwealth health legislation, OR
- nationally consistent laws at State and Territory level (on the model of the national health practitioner registration laws), OR
- development of model legal provisions for adoption, as required, into state and territory law.[147]

As Judith Dwyer and Genevieve Howse noted:

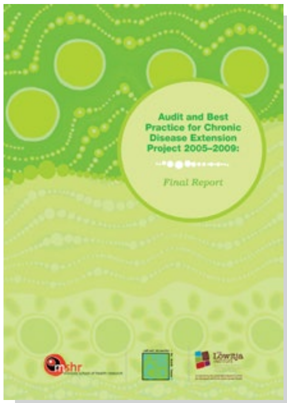
> *… the time has come to consider implementing a consistent and comprehensive national legislative framework to support the delivery of Aboriginal and Torres Strait Islander health services, with constitutional recognition of Australia's First Peoples as the cornerstone.*[148]

This recommendation led to the Lowitja Institute's Recognise Health initiative that promotes understanding of the important link between health and wellbeing and constitutional recognition of Aboriginal and Torres Strait Islander peoples. The initiative brought together a coalition of more than 130 non-government organisations across the Australian health system. With their particular perspective of health, these organisations have signed a statement in support of constitutional change. Recognise Health was launched at Parliament House in Canberra on 5 March 2015.

As well as being frequently cited in other research and policy publications, the paper was submitted to the Expert Panel on Recognising Aboriginal and Torres Strait Islander Peoples in the Constitution, which reported to the Prime Minister in January 2012, and a policy brief summarising its key points was sent to all Premiers and Chief Ministers. One of Romlie Mokak's first tasks as CEO, in 2014, was to provide evidence to the Joint Select Committee on Constitutional Recognition of Aboriginal and Torres Strait Islander Peoples in relation to constitutional reform.

Engaging First Peoples: A review of government engagement methods for developing health policy

This study, commissioned by the Lowitja Institute CRC in 2013, is an analysis of national, state and regionally constructed engagement policies and strategies in Aboriginal and Torres Strait Islander health and wellbeing to identify best practice examples and lessons learned. The project was conducted by researchers from the universities of Melbourne, La Trobe and Notre Dame. The discussion paper emanating from the research, *Engaging First Peoples: A review of government engagement methods for developing health policy*,[149] supports those working on the challenges of effective implementation of policies and programs within the Aboriginal and Torres Strait Islander health arena, and Indigenous affairs more generally. It is particularly relevant for practitioners concerned with the difficulties of contributing to the achievement of equity in health and wellbeing for First Peoples in increasingly complex policy and community contexts.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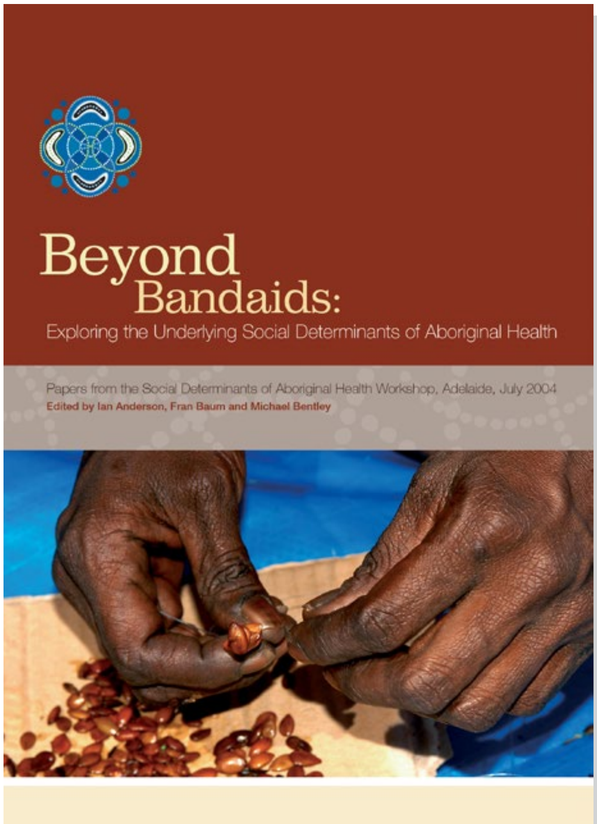
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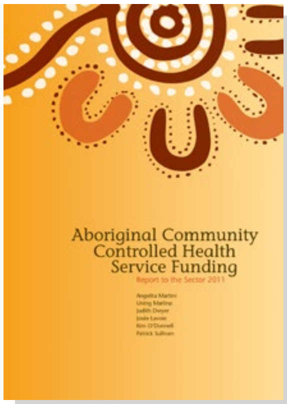
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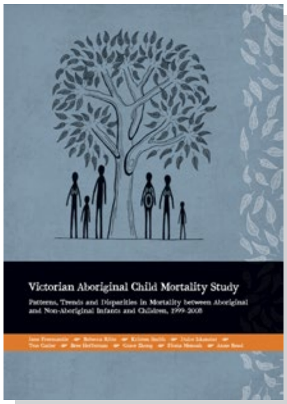
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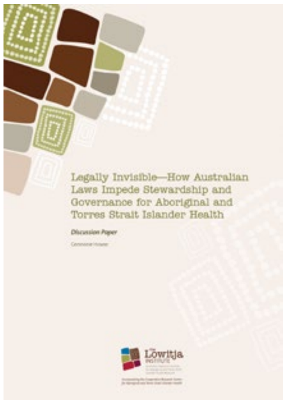
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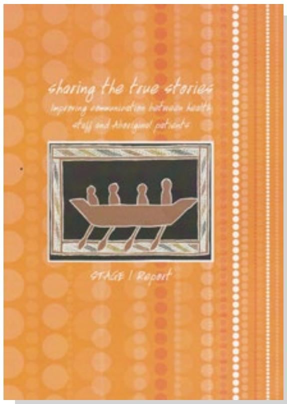
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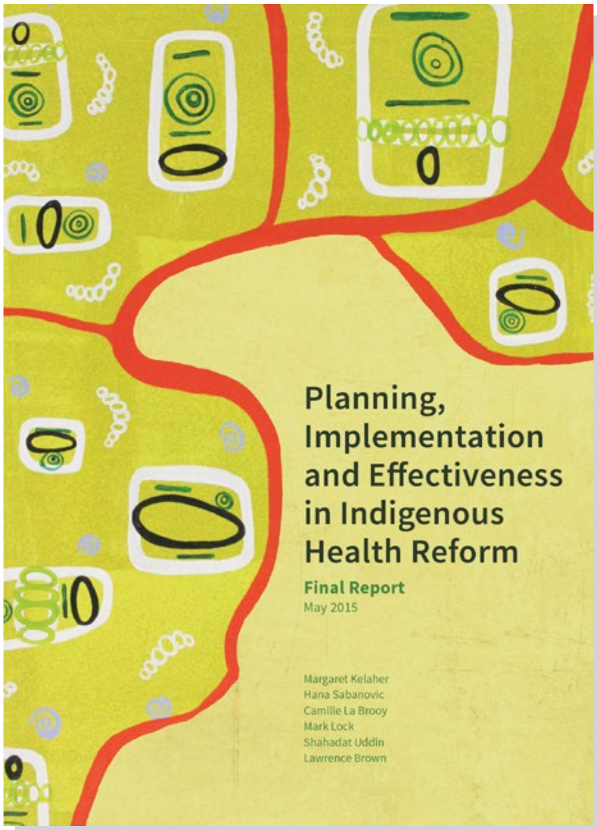
Planning, Implementation and Effectiveness in Indigenous Health Reform
Final Report
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Hana Sabanovic
Camille La Brooy
Mark Lock
Shahadat Uddin
Lawrence Brown


The Road Is Made by Walking:
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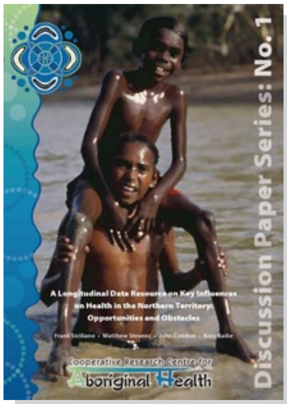
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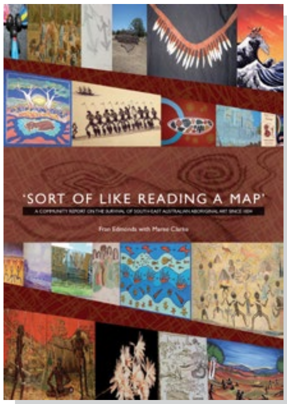

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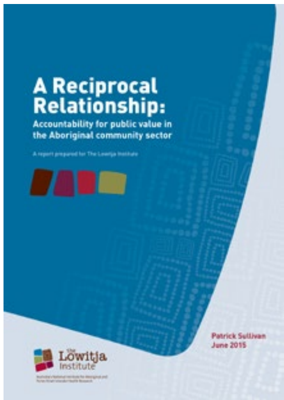

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A report prepared for The Lowitja Institute

Patrick Sullivan
June 2015

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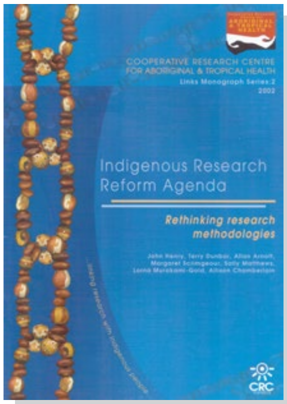

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Scott R. Davis • Jenny Brands

Cooperative Research Centre for Aboriginal Health

'It's more than machines and medicine they should understand there's a Yolngu Way'

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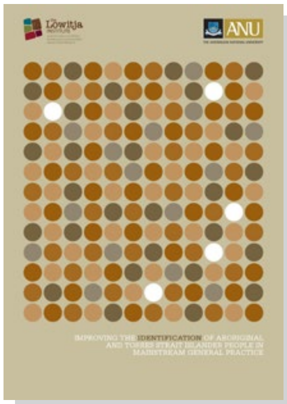
Paul Rivalland for Western Desert Nganampa Walytja Palyantjaku Tjutaku

Yanangu Providing their own Kidney Dialysis Services as Indigenous People from the Western Desert, Central Australia



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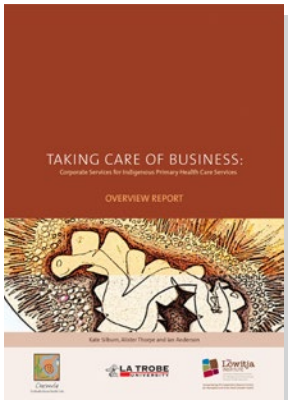
IMPROVING THE IDENTIFICATION OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE IN MAINSTREAM GENERAL PRACTICE



TAKING CARE OF BUSINESS:

Corporate Services for Indigenous Primary Health Care Services

OVERVIEW REPORT

Kate Silburn, Alister Thorpe and Ian Anderson

LA TROBE UNIVERSITY

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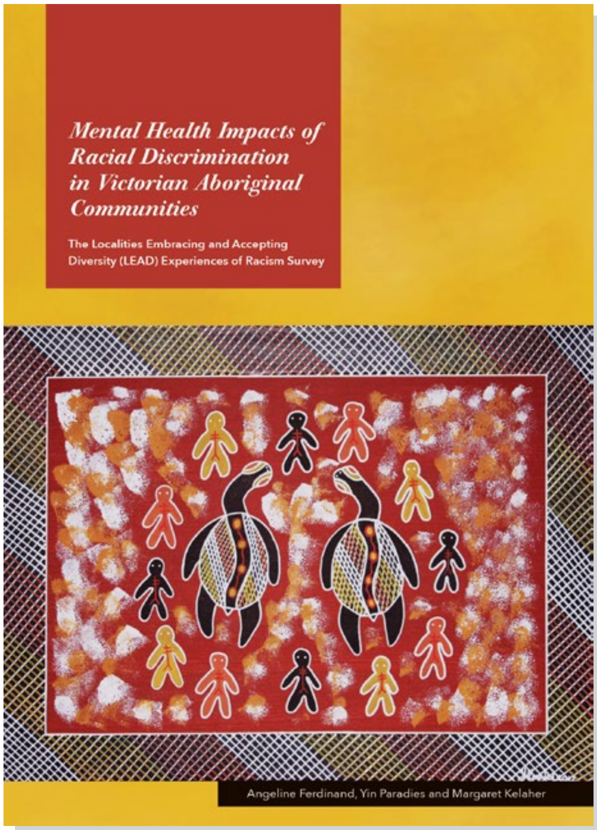

Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities

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Angeline Ferdinand, Yin Paradies and Margaret Kelaher

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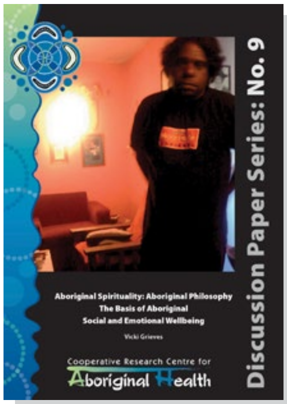
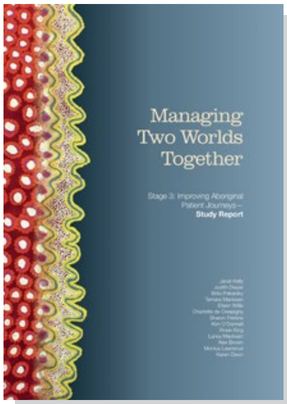


Discussion Paper Series: No. 9

Aboriginal Spirituality: Aboriginal Philosophy
The Basis of Aboriginal
Social and Emotional Wellbeing

Vicki Grieves

Cooperative Research Centre for Aboriginal Health



Managing Two Worlds Together

Stage 3: Improving Aboriginal Patient Journeys — Study Report

Above
Tom Calma, with Kim O'Donnell, Genevieve Howse and Judith Dwyer at the launch of Legally Invisible, Adelaide, December 2011

Ben Searcy Photography

Below
Attendees and signatories at the Recognise Health launch in Parliament House, Canberra, March 2015, with CEO Romlie Mokak (3rd from right)

id photo Photography

Taking Care of Business: Support systems for Indigenous primary health care services

This project, began in 2008 and conducted by researchers at La Trobe and Melbourne Universities, explored how best to support the corporate functions of ACCHOs so as to improve their viability and sustainability as corporate entities. Identified as a priority project by the CRCAH Board after consultation with ACCHOs and the sector, it found that the sector was able to develop innovative solutions to difficult issues while working in a quickly changing environment, with additional resources likely to enable further innovation. Such work has the potential to contribute to stronger and more viable health services for Aboriginal and Torres Strait Islander communities. The project also developed the Taking Care of Business web tool to help ACCHOs decide their best strategy or model to gain support for their corporate functions.

Finding new approaches to old problems

Good Beginnings: Getting it right in the early years

Good Beginnings[150] is a publication produced to address an identified need for decision makers to have access to a more systematic review of the evidence about the effectiveness of different early years interventions. The paper, prepared by the Australian Research Alliance for Children & Youth, recommended

> *That governments commit to the national implementation of proven Early Years programs for Aboriginal and Torres Strait Islander communities that decide to take up the opportunity; and that governments commit in ways that are responsive to the strengths, priorities and concerns of communities and enable local leadership and that engage with communities to maintain the integrity of programs with good evidence of effectiveness.*

The publication is the first output of a 2013 CRCATSIH project known as the Stewardship Dialogues. The purpose of the Dialogues was to generate new options and approaches to addressing implementation issues and cumbersome policy processes in programs and systems for Aboriginal and Torres Strait Islander health and health care. The project involved engaging a group of senior representatives from the Aboriginal and Torres Strait Islander health field (drawn from policy, practice, community and academic sectors) in a short series of what might be considered 'dangerous conversations'. The Dialogues were conducted using methods that enabled participants to bring underlying assumptions to the surface for discussion and analysis in a safe space.

Dialogue participants discussed the importance of a healthy start to life, for example, identifying that education and early years interventions, implemented in collaboration with Aboriginal and Torres Strait Islander communities and properly adapted to their settings, held the potential to produce significant long-term effects on health and wellbeing.

Family Wellbeing

The Family Wellbeing empowerment research program was developed in the early 1990s by a group of Aboriginal leaders in Adelaide to support Aboriginal and Torres Strait Islander individuals and communities to meet their wellbeing needs and build capacity for employment. It is an accredited six-month Certificate II training program delivered through the Australian vocational education and training sector that aims to empower Aboriginal and Torres Strait Islander people to take greater control over their lives, to participate fully in education and employment, and to improve their health and wellbeing. An evaluation in 2000, showed the program's impact in building capacity and strength to reinforce the idea that individual control over everyday challenges in life is an important determinant of population health.

> *The effectiveness of the course in assisting individual participants, through personal empowerment, to increase their capabilities – that is, enhance their awareness, resilience and problem-solving ability – thereby making them better able to improve their sense of wellbeing and those of the people around them.*[151]

This work follows on from earlier work on the Family Wellbeing Program undertaken by Komla Tsey and others.[152] Long supported by the CRCs and Lowitja Institute, the Family Wellbeing Program has been delivered to more than 3300 participants, in group settings through five 30-hour stages, across many jurisdictions of government including health, education, employment, child protection and corrections. There has been widespread demand for the program from organisations as diverse as the Royal Flying Doctor Service, youth centres, drug and alcohol rehabilitation centres, child welfare agencies, and Aboriginal and Torres Strait Islander men's and women's community groups.[153]

A book about the program, *Promoting Aboriginal Health: The Family Wellbeing Empowerment Approach*, published by Springer, was launched was launched at the 2014 Lowitja Congress by Pat Anderson, who observed:

> *It shines a bright light on a neglected aspect of Aboriginal health, it shows what can be achieved when communities embrace change and it sounds a clarion call for continued resourcing of empowerment programs.*[154]

It also shows how far we have come in our understanding of Aboriginal and Torres Strait Islander health over the past two decades, as evidenced by the unprecedented focus on social and emotional wellbeing in the NATSIHP 2013–2023.[155]

In 2014, the Lowitja Institute convened a national roundtable in Adelaide to consider the impact of Family Wellbeing and opportunities for future development, with outcomes and recommendations published in the report, *Watering the Garden of Family Wellbeing: Empowering Aboriginal and Torres Strait Islander people to bloom and grow*.[156] A March 2015 Lowitja Institute policy brief reported that evaluations of the Family Wellbeing program over the previous 10 years demonstrated that program participants experienced a decrease in domestic violence, and improvements in the management of alcohol and drug abuse, suicide prevention, school absenteeism, education, welfare dependence and employment.

Discussing genetic research with Aboriginal and Torres Strait Islander people

Many of the interviewees for this publication spoke about the role the CRCs and the Lowitja Institute have played in creating a 'safe space' for dialogue on a number of difficult or sensitive issues. That has included the vexed topic of genetic research, with two roundtable discussions held and two discussion papers published to advance and inform the conversation.

The CRCATSIH hosted the first Aboriginal and Torres Strait Islander Genetic Research Roundtable in 2010, a ground-breaking event that acknowledged the growing impact of genetic research on Aboriginal and Torres Strait Islander communities and the need to set parameters around how they could best engage and participate in such research. It was attended by genetic researchers, Aboriginal and Torres Strait Islander researchers, representatives from ethics committees, and experts in bioethics and in genetic literacy.

Among the discussions were how to provide short-term benefits to Aboriginal and Torres Strait Islander communities when the potential benefits of genetic research are so long-term, how genetic researchers can sensitively deal with Aboriginal and Torres Strait Islander communities in which people have a mixed ancestry that will be reflected in their genes, and how to control the way genetic research can be misreported in the media (such as generalising results from one community to the entire Aboriginal and Torres Strait Islander population).

The second roundtable in 2012 included representatives from Aboriginal and Torres Strait Islander organisations, ethics committees, research institutes and national bodies including AIATSIS and the NHMRC. Discussion covered issues of community consent, storage of biological samples over the long term (including biobanks), cultural perspectives on blood samples, the possible health benefits that whole genome sequencing may eventually hold for Aboriginal and Torres Strait Islander communities, and the ethical issues associated with this kind of research.

To summarise the outcomes of the roundtables and to contribute to ongoing discussion, two discussion papers were published: *Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the conversation* and *Genetic Research in Aboriginal and Torres Strait Islander Communities: Continuing the discussion*.[157]

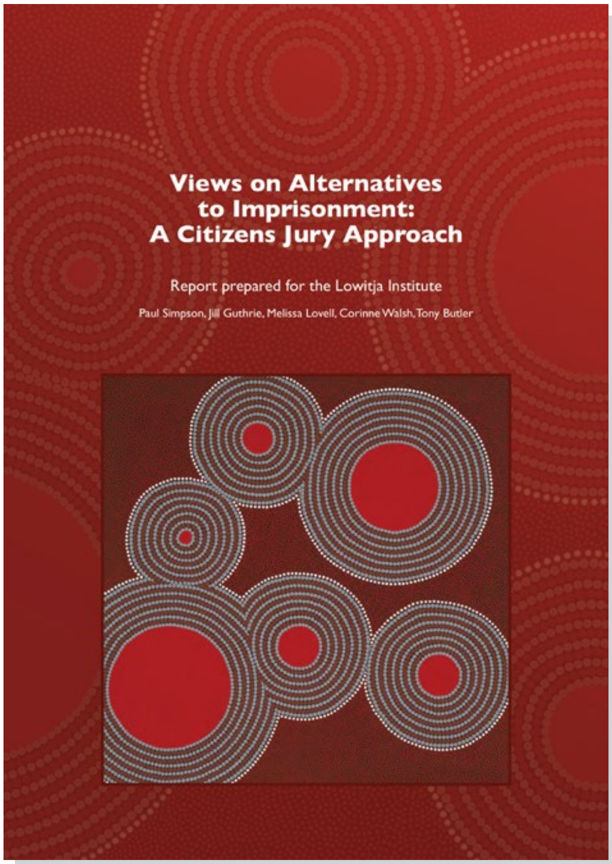
Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities

This research highlights the key findings of the Aboriginal Experiences of Racism survey, funded by CRCATSIH, undertaken in 2010–11 as part of the landmark Localities Embracing and Accepting Diversity (LEAD) program, funded by the Victorian Health Promotion Foundation (VicHealth), the Department of Immigration and Citizenship through its Diverse Australia program and *beyondblue*, and implemented with the Victorian Equal Opportunity and Human Rights Commission and Municipal Association of Victoria.

The report of the survey was launched by then Australian Race Discrimination Commissioner Dr Helen Szoke at Congress Lowitja 2012, under the title *Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities*.[158] It generated substantial interest from the media with its key finding that some 97 per cent of recently surveyed Aboriginal Victorians had experienced racism in the previous 12 months.

The report was central to submissions to inquiries on national health and Constitutional Recognition, and to support conversations that resulted in the explicit recognition in the NATSIHP 2013–2023 on the need to build a health system that is free of racism. It also informed beyondblue's successful 2014 *Invisible Discriminator* national anti-discrimination campaign that highlighted the impact of racism on the wellbeing of Aboriginal and Torres Strait Islander peoples.

The research established a link between racist incidents and poor mental health for Aboriginal and Torres Strait Islander individuals and communities, and revealed an urgent need to address racism in Victoria. In response, a number of publications, tools and resources were developed throughout the LEAD implementation and evaluation to support projects and initiatives to reduce race-based discrimination and support diversity. The research has been widely cited by the media, and in journals, presentations and other forums, and used as a catalyst for organisational change.



Views on Alternatives to Imprisonment: A Citizens Jury Approach

Report prepared for the Lowitja Institute

Paul Simpson, Jill Guthrie, Melissa Lovell, Corinne Walsh, Tony Butler

Views on Alternatives to Imprisonment report

Alternatives to imprisonment: A Citizens' Jury approach

Prisoner populations endure some of the worst health outcomes in the community in terms of mental illness, chronic disease, excess mortality and exposure to communicable diseases, with engagement in injecting drug use and tobacco smoking also common. Alarming Aboriginal and Torres Strait Islander over-representation in Australian prisons, combined with high recidivism rates and annual government prison expenditure reaching more than $3 billion, has led many to claim that incarceration is a social policy failure that needs to be redressed.

Justice Reinvestment has been touted as a possible solution to the over-representation of Aboriginal and Torres Strait Islander people in Australia's criminal justice system. Its aim is to divert funds intended for criminal justice matters back into local communities to fund services (e.g. mental health, drug and alcohol, employment initiatives, housing) addressing the underlying causes of crime – thus preventing people from entering the criminal justice system.

However, a significant obstacle to a reform agenda in the criminal justice area is public opinion, which is perceived as having punitive attitudes towards offenders and often exploited by politicians to perpetuate punitive penal policies at the expense of developing decarceration initiatives.

Citizens' Juries offer an alternative method of assessing the public's views, views that are critically informed and thus better aid policy development. Thus, this study aimed to explore, through Citizens Juries, the opinions and views of a critically informed public towards treatment alternatives to incarceration, and whether policymakers are influenced by the opinions and views of the Citizens' Juries.

CRCATSIH supported this research, the outcomes of which are published in *Views on Alternatives to Imprisonment: A Citizens Jury approach*.[159] The report explores the views of a more informed public towards how we, as a community, should address offenders in terms of incarceration and alternatives such as Justice Reinvestment. The research was conducted by researchers at the Kirby Institute at UNSW, ANU, National Drug Research Institute at Curtin University and the Indigenous Offender Health Research Capacity Building Group in 2012 and 2013.

A research community and workforce

The benefits of long-term investment in Aboriginal and Torres Strait Islander research became apparent from the early days. By creating career pathways for Aboriginal and Torres Strait Islander researchers, the four CRCs and the Lowitja Institute, have contributed to the development of high-level expertise; researchers whose work informs policy and practice that will deliver positive health outcomes. Many former researchers, trainees, managers, scholarship holders and other participants now hold key roles in the Aboriginal and Torres Strait Islander health and research and policy sector.

Students and scholarships

For two decades the CRCs and the Lowitja Institute have placed significant focus on supporting the next generation of Aboriginal and Torres Strait Islander health researchers. As part of the CRCs' education and training functions the organisations have provided postgraduate research training, coursework degrees in public health as well as undergraduate and vocational training. Often, this training was carried out in conjunction with the research programs being undertaken by the CRCs.

The CRCs and the Lowitja Institute program have awarded, to date, 53 doctorate and PhD scholarships, 31 Masters scholarships, and 15 scholarships for other tertiary courses (see Appendix 7 for details). In addition, in 2016, the Lowitja Institute CRC co-funded nine PhD and two Masters scholarships with its Participant Organisations. This monetary and institutional support has had a profound impact both on the career paths of many individual scholars, and on the numbers of Aboriginal and Torres Strait Islander people who have been assisted to move confidently into the health research area.

Many of these scholars have produced work that has had a major influence on the Aboriginal and Torres Strait Islander health research agenda, three of whom – Yin Paradies, Graham Gee and Lisa Whop – are featured here.

Professor Yin Paradies

Yin Paradies is internationally recognised for his expertise on the relationship between racism and health. He has had a long association with the Lowitja Institute commencing with his role as a project development officer in 2000. He has worked in Aboriginal and Torres Strait Islander health research since 1995, and is now Professor of Race Relations and Deputy Director (Research) at the Alfred Deakin Institute for Citizenship and Globalisation, Deakin University.

Yin Paradies' research interests include the health, social and economic impacts of racism, Indigenous identity, and anti-racism theory, policy and practice. He has taught at the postgraduate level in epidemiology, biostatistics, demography and multicultural competence for public health practitioners. He has received a range of awards including a Fulbright scholarship to study at the University of California, Berkeley, a Victorian Young Tall Poppy Science award, the Australia Day Council's Young Achiever of the Year for the Northern Territory and NAIDOC Scholar of the Year in 2007.

His highly lauded short course Race, Culture, Indigeneity and the Politics of Disadvantage, which won a national teaching award and has benefited hundreds of professionals working in Aboriginal and Torres Strait Islander affairs over the past 15 years, was developed through a CRCAH seed-funding grant.

Together with former CRCAH Director Professor Tony Barnes, and funding from the CRCAH, Yin Paradies developed a new method for estimating the populations of remote Aboriginal and Torres Strait Islander communities. He was also lead author of an influential discussion paper for the CRCAH and Flinders University in 2008, *The Impact of Racism on Indigenous Health in Australia and Aotearoa*.[160] His work with the Lowitja Institute has also included co-authoring the VicHealth report *Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities: The Localities Embracing and Accepting Diversity (LEAD) Experiences of Racism Survey* in 2013.[161] Most recently, he has been an investigator on a Lowitja Institute-funded project that will investigate and improve the quality of genetic health services in Australia for Aboriginal and Torres Strait Islander peoples.

He was recently awarded an ARC Future Fellowship (the only Aboriginal or Torres Strait Islander person to receive one to date).

Above
Yin Paradies

Above
Graham Gee

Below
Lisa Whop

Dr Graham Gee

Graham Gee is an Aboriginal man, also with Celtic heritage, born and raised in Darwin. His grandfather was born near Belyuen, an Aboriginal community just outside of Darwin, and his great-grandmother was originally from the Barkly Tablelands. He has been a registered psychologist since 2008, and has worked at the Victorian Aboriginal Health Services (VAHS) in Melbourne for 10 years.

Graham Gee has been a past steering committee member of the Australian Indigenous Psychologists Association, and was a founding Board member of the National Aboriginal and Torres Strait Islander Healing Foundation. He holds a combined Masters (Clinical)/PhD degree in psychology from the University of Melbourne.

His PhD – 'Resilience and Recovery from Trauma among Aboriginal Help Seeking Clients in an Urban Aboriginal Community Controlled Health Organisation' – focused on personal, relational and cultural strengths, and broader social and cultural determinants associated with trauma recovery in urban Aboriginal communities. Part of his research involved developing the Aboriginal Resilience and Recovery Questionnaire, which is now being trialled to evaluate and track changes in resilience and psychological distress in a VAHS community-designed empowerment program, as well as other programs in Victoria.

This work links with the research objectives of the Lowitja Institute through identifying the key risk and protective factors as they relate to trauma experiences, and using that knowledge to improve the mental health of Aboriginal and Torres Strait Islander people.

Dr Lisa Whop

Lisa Whop is a Research Fellow in the Brisbane office of the Menzies School of Health Research. A recipient of both a Lowitja Institute scholarship and a research excellence award, her PhD reported on the first population-based findings of cervical screening for Aboriginal and Torres Strait Islander women in Queensland. Her thesis findings were timely given the announcement of the renewed Australian National Cervical Screening Program to be introduced in late 2017. These results can inform policy and practice in the prevention of cervical cancer among Aboriginal and Torres Strait Islander women.

Lisa Whop has an outstanding list of achievements, which include the publication of several milestone papers regarding Aboriginal and Torres Strait Islander women and cervical screening participation and outcomes; her PhD thesis included five publications as lead author, and she has 15 peer-reviewed publications to date. She is regularly invited to present at conferences and workshops in relation to her experience of record-linkage methodology use in the identification of Aboriginal and Torres Strait Islander Australians in administrative health datasets and cervical cancer prevention. In 2014, Lisa Whop was invited to act as the MC for Congress Lowitja 2014.

Education and training

Master of Public Health (MPH)

The need for a specialist MPH Indigenous stream was raised in 2005 with a review of the Commonwealth Department of Health and Ageing's Public Health Education and Research Program, which noted that 'there is a substantial need for more public health-trained Indigenous Australians as well as more training about the issues surrounding Indigenous Australians' health for other public health practitioners'.[162] The MPH degree is recognised by the sector as the standard training award for licensing health professionals for public health and community health practice. However, historically only a small number of specialist 'Indigenous' units had been available for students to choose from at their individual universities, and never enough to make up a specialist stream. In 2012, a four-year collaborative effort funded by the CRCATSIH resulted in students at the University of Melbourne and University of Queensland being able to undertake their MPH specialising in Aboriginal and Torres Strait Islander health.

Aboriginal Health Council of South Australia's Certificate IV in Indigenous Research Capacity Building

This research training course for budding Aboriginal and Torres Strait Islander researchers was conducted by the Aboriginal Health Council of South Australia, and supported and partially funded by the Lowitja Institute along with Flinders and James Cook universities. Students graduate with a Certificate IV in Indigenous Research Capacity Building, a nationally recognised VET (Vocational Education Training) qualification that offers significant advantages both in building career paths and enhancing opportunities in existing workplaces.

The course offers basic strategies for research and evaluation, including the ethics and appropriate protocols in Aboriginal health services and communities, and builds upon the skills and knowledge that the students already have and share. Students come to Adelaide for four workshops of four days each, and the rest of the year they conduct their research or evaluation projects within their workplaces as part of their job. The entire research process is detailed in workbooks, to which students can refer when they are back in their workplaces and communities.

Literacy for Life Foundation

The Lowitja Institute is a founding partner of Literacy for Life Foundation, an Aboriginal-led initiative aiming to lift adult literacy in Aboriginal and Torres Strait Islander communities. An estimated 40 per cent of Aboriginal and Torres Strait Islander adults have minimal English literacy, a figure that rises to as high as 70 per cent in many remote areas. So long as these adult illiteracy rates exist, meaningful progress towards many Closing the Gap targets will be impossible.

The Literacy for Life Foundation uses an innovative, evidence-based, campaign approach that has been implemented in 30 countries around the world and is now delivering results in Australia. So far more than 120 students have graduated campaigns run in seven NSW communities and the organisation is working towards national expansion.

Initially, the Lowitja Institute provided funding for a pilot of the Literacy for Life Foundation approach, building on the well documented links between literacy and improved health outcomes. Support was extended following the promising results achieved during pilot phase. The graduation rate of Literacy for Life Foundation students was five times higher than existing programs and the campaigns created a range of benefits across the community.

Building on this evidence base, the Lowitja Institute helped Literacy for Life Foundation design and carry out a longitudinal study of individual and community impacts, with a focus on measuring improvements in areas such as health, education and community safety.

The Literacy for Life Foundation's campaign approach relies on community ownership and control. It is driven by local leaders and delivered by local staff. Originally developed in Cuba, the method was designed to raise adult literacy levels quickly across a region.

Literacy for Life facilitator Janelle Frail with students

Photo Erica Glynn

A high school student participant in the Science and Young Minds project in the QIMR Berghofer Medical Research Institute

Science and Young Minds

CRCATSIH partnered in 2014–15 with QIMR Berghofer Medical Research Institute in Brisbane to support the Science and Young Minds project, which hopes to inspire the scientists and medical professionals of tomorrow by relaying the importance of medical research and health-related professions in an integrated school education and capacity building program. The project targeted, in particular, the engagement of students with Aboriginal and Torres Strait Islander backgrounds.

Focusing on skin health, the project included the development and delivery of science workshops to senior high school students in remote areas of north-west Queensland during 2014 and 2015. In addition, selected students and teachers participated in a laboratory work experience program at the QIMR Berghofer Medical Research Institute.

The project aimed to engage young people, particularly Aboriginal and Torres Strait Islander students, in discussions, learning and hands-on activities about skin health and medical research; to promote discussion and reflection about science and its role in solving health problems; and to promote health science and research as possible career pathways for senior high school graduates.

Recognising excellence in the research workforce

In 2012 the Lowitja Institute introduced two awards to recognise the work of our Aboriginal and Torres Strait Islander researchers. These awards – one for a student researcher and another for an emerging researcher – are offered in association with the biennial Congress Lowitja. In 2015, the Lowitja Institute partnered with the Cranlana Program for an annual award, in recognition of excellence in Aboriginal and Torres health research, that gives a place to a senior Aboriginal and/or Torres Strait Islander researcher in the Cranlana Program's Executive Colloquium.

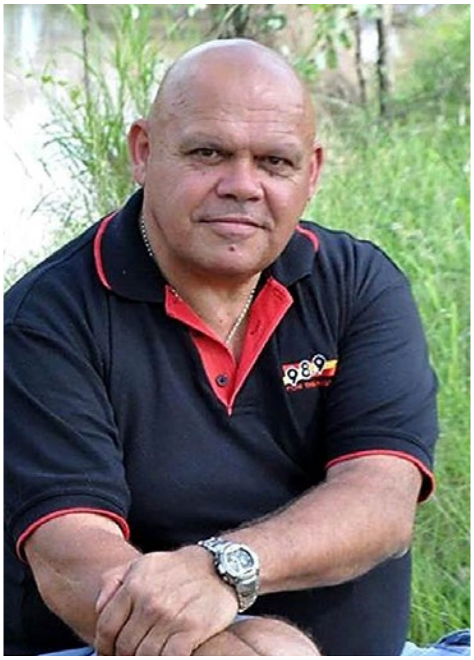
In 2016, the Lowitja Institute established the Outstanding Achievement in Indigenous Health and Wellbeing Award – for an individual who has made an outstanding contribution to the health and wellbeing of Aboriginal and Torres Strait Islander peoples, as nominated by the Lowitja Institute Board of Directors. The inaugural award was given posthumously to Mr Tiga Bayles and presented to his family at the 2016 Lowitja International Conference.

The Lowitja Institute Awards

2012	Emerging Aboriginal and Torres Strait Islander Researcher Award	Dr Chelsea Bond
	Aboriginal and Torres Strait Islander Student Award	Dr Raymond Lovett
2014	Emerging Aboriginal and Torres Strait Islander Researcher Award	Dr Simon Graham
	Aboriginal and Torres Strait Islander Student Award	Dr Stewart Sutherland
2015	Aboriginal and Torres Strait Islander Health Research Leadership and Excellence	Professor Sandra Eades
2016	Emerging Aboriginal and Torres Strait Islander Researcher Award	Associate Professor Roxanne Bainbridge
	Aboriginal and Torres Strait Islander Student Award	Dr Lisa Whop
	Aboriginal and Torres Strait Islander Health Research Leadership and Excellence	Professor Gail Garvey
	Outstanding Achievement in Indigenous Health and Wellbeing Award	Mr Tiga Bayles

Patron Lowitja O'Donoghue and Chairperson Pat Anderson with award winners Simon Graham and Stewart Sutherland, Congress Lowitja 2014

James Henry Photography



The Lowitja Institute award winners

Clockwise from top left

Lisa Whop, Gail Garvey and Roxanne Bainbridge, award winners at the Lowitja Institute International Conference 2016

Fiona Hamilton Photography

The late Tiga Bayles, recipient of inaugural Outstanding Achievement in Indigenous Health and Wellbeing Award at the Lowitja Institute International Conference 2016

Photo courtesy Bayles family

Congress Lowitja 2012 award winners Chelsea Bond and Ray Lovett with Chairperson Pat Anderson

James Henry Photography

Professor Sandra Eades, research leadership award winner 2015

Photo courtesy Professor Eades

The broader Aboriginal and Torres Strait Islander health workforce

It is well recognised that establishing an Aboriginal and Torres Strait Islander workforce is critical to closing the gap in health outcomes for Australia's First Peoples. More qualified Aboriginal and Torres Strait Islander people working across the professional and semi-professional roles, and improved skills, knowledge and cultural competence among mainstream staff working in health services are essential if we are to make a positive impact on the health of Australia's First Peoples.

Data from the 2011 Census showed almost 8,500 Aboriginal and Torres Strait Islander people working in the health sector,[163] which represented a 59 per cent increase over 10 years. The National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework 2011–15 prepared for the Australian Health Ministers' Advisory Council set an aspirational target of 2.6 per cent of the entire health workforce being Aboriginal and/or Torres Strait Islander by 2015.

In 2011, the CRCATSIH hosted a Workforce Roundtable to explore policy instruments for improving capacity in the health workforce and building better career pathways for Aboriginal and Torres Strait Islander health workers. From this, the Lowitja Institute report *Shifting Gears in Career: Identifying drivers of career development for Aboriginal and Torres Strait Islander workers in the health sector*[164] argues that policymakers need to amend current approaches to health policy development so as to address the career challenges facing a range of Aboriginal and Torres Strait Islander workers across the health sector.

The report explores how the Australian health sector might improve opportunities for career development among Aboriginal and Torres Strait Islander workers in the health sector, and identifies five key drivers of change: policy frameworks; workplace process; individual characteristics; intermediary behaviour; and professional association interventions.

The need for health care providers to make provision for the career development of Aboriginal and Torres Strait Islander workers in the long term, in a way that purposefully steps beyond access to training, represents a first order priority for health policy stakeholders.

Networks of knowledge and communication

Throughout their history, the CRCs and the Lowitja Institute have placed great emphasis on

- knowledge exchange and research translation
- developing health resources and research tools and promoting Aboriginal and Torres Strait Islander health resources
- publishing research outputs and distributing the evidence in an effective and targeted way to key audiences (see Appendix 5)
- building strong traditional and, in later years, digital communications channels
- creating opportunities to share knowledge, have meaningful dialogues and create connections through roundtables and workshops, conferences, and Congress Lowitja.

The aim throughout has been to create strong networks of knowledge and communication to underpin improvements in Aboriginal and Torres Strait Islander health and wellbeing. What follows is a sample of activities that illustrates the range of this work over the past two decades.

Improving health promotion and communication

Sharing the True Stories: Improving communication between Aboriginal patients and health carers

This five-year research project (2001 to 2005) focused on identifying and addressing barriers to effective communication between Aboriginal client groups – all Yolngu speakers from north-east Arnhem Land – and health staff in renal and hospital services in the Northern Territory.

It found that miscommunication was pervasive, that fundamental change was required for Aboriginal patients to have significant input into the management of their illness and that educational resources were needed not only on renal physiology, disease and treatment, but also on the cultural, social and economic dimensions of illness that people experienced.[165]

The project delivered many practical knowledge exchange outcomes. Aboriginal Interpreter Services Guidelines were launched and used across the NT,

Aboriginal men at one of the regular camps run by Mibbinbah Indigenous Men's Project

and cross-cultural and education support programs were developed using print, video, CD-Rom, DVD, and online formats, used and evaluated in health delivery and staff in-service training.

Mibbinbah: Men's health and wellbeing

The Lowitja Institute and the CRCs have been long-time supporters of Mibbinbah, Australia's only national Aboriginal and Torres Strait Islander male health promotion charity that emerged from a CRCAH-funded project focused on a number of Men's Sheds/Spaces located along the east coast of Australia. Also supported by mental health charity beyondblue, the project aimed to understand what made Men's Spaces safe and healthy places for Aboriginal and Torres Strait Islander men, and how this might benefit families and communities. It was driven by concern at the lack of specific action on improving health for Aboriginal and Torres Strait Islander men, who experience poorer health outcomes and shorter life expectancy than both the wider Australian community and Aboriginal and Torres Strait Islander women.[168]

The CRCATSIH continued to support Mibbinbah as it evolved into a stand-alone organisation beyond its research life and as a national support network for Aboriginal and Torres Strait Islander men. The program has included regular men's camps in bush locations providing opportunities for the sharing of life skills, cultural knowledge and health advice, and safe discussion of critical, sensitive issues such as family violence.

Mibbinbah has developed a strong online presence, helped establish an Aboriginal and Torres Strait Islander male researchers' network and broadened its role in mentoring with the establishment of the Journeying Together program, which supports older males to mentor younger men. Since 2012 Mibbinbah has worked with the producers of the successful movie 'Mad Bastards' to develop a Mad Bastards Guide for workshops and group discussions around six core themes: deciding to change, taking responsibility, relationships, identity, transformation and staying strong.

Aboriginal and Islander Mental health initiative (AIMhi)

The CRCAH and later CRCATSIH supported the long-running Aboriginal and Islander Mental health initiative (AIMhi) from its launch in 2003 as a five-year action research project. Based at the Menzies School of Health Research, it was an important mental health research project conducted in the Northern Territory.

AIMhi explored new ways of delivering mental health services in remote areas and of training mental health services and health workers operating in these areas. That work was developed into a full suite of training resources that includes flipcharts, care plans, journal articles, pamphlets, workshops, seminars, presentations and stories of recovery. The project reported that the flipcharts and Stay Strong Plan have been referenced in a number of best practice guidelines, resources and reports,[166] and used in professional and public health training at Charles Darwin University, Menzies and the Centre for Remote Health.

Creating Healthy Environments: Development and trial of an integrated model for Aboriginal health promotion

Funded by CRCATSIH in 2012, the Creating Healthy Environments project and its evaluation was an intensive case study by researchers led by Dr Kevin Rowley at the University of Melbourne of evaluation protocols for Aboriginal and Torres Strait Islander health promotion that are culturally appropriate and incorporate the social and environmental determinants of Aboriginal and Torres Strait Islander health.[167] The project looked at what helped or hindered Aboriginal and Torres Strait Islander organisations from running health promotion programs, particularly in a post-colonisation context where the physical and social environment for Aboriginal and Torres Strait Islander peoples can be particularly detrimental for health.

The project built strong working relationships between Aboriginal and non-Indigenous researchers, and academic and community-based researchers, and led to a substantial database of evidence about the purpose and effectiveness of health promotion strategies.

Resources for researchers

Supporting Indigenous Researchers: A practical guide for supervisors

Published in 2009 to improve the academic supervision of Aboriginal and Torres Strait Islander researchers, their recruitment and training, this popular guide was developed by Alison Laycock with Diane Walker, Nea Harrison and Jenny Brands. A hands-on resource in the field, it offers practical information, advice, strategies and success stories in Aboriginal and Torres Strait Islander health research.

The guide was launched at Parliament House, Canberra by the then Education Minister, the Hon. Julia Gillard, along with the discussion paper *Research Dancing: Reflections on the relationships between university-based researchers and community-based researchers at Gurriny Yealamucka Health Services Aboriginal Corporation, Yarrabah*, which sets out positive strategies for partnerships between research institutions and Aboriginal community groups. Together they were seen to represent a practical contribution to changing the culture of health research and recognised the principles under which the CRCs and the Lowitja Institute worked – that Aboriginal and Torres Strait Islander health research needs to be driven by priorities set by Australia's First Peoples, of practical use to the health sector and develop research capacity within communities.

The popular guides designed for researchers, students and supervisors

Researching Indigenous Health: A practical guide for researchers

More than 3000 copies of *Researching Indigenous Health: A practical guide for researchers*, a 2011 companion piece to the supervisors' guide by the same authors, have been distributed to research institutions, community organisations, tertiary institution libraries, hospital research departments, public health promotion organisations and researchers, international researchers (Canada and New Zealand), university-based Indigenous researchers' networks, as well as federal, state and territory departments. This guide includes the history, context, values and changing priorities of Aboriginal and Torres Strait Islander health research in Australia and the planning and management of projects. It includes step-by-step processes, tips and checklists, and uses plain words and a variety of voices to explain what research principles, values and processes look like in practice.

Beyond Bandaids: Exploring the underlying social determinants of Aboriginal health

Beyond Bandaids is a collection of 16 papers from the CRCAH Social Determinants of Aboriginal Health Workshop held in July 2007, convened by the WHO-endorsed Commission on Social Determinants of Health. Edited by Research Director Ian Anderson, and CRCAH Program Leaders Fran Baum and Michael Bentley, the collection presents a perspective on how social and economic factors affect the health of Australia's First Peoples. Authors were commissioned to review the literature on particular aspects of the social determinants of Aboriginal and Torres Strait Islander health and then made recommendations for future CRCAH research priorities based on discussions at the workshop and subsequent peer review. Their findings were used to inform the evolving agenda for the CRCAH's Social Determinants of Health research.

The book has had great longevity and continues to make an impact in research, education and policy. Available on the Lowitja Institute website by chapter and as a whole, to date 459 copies of the book and 24,855 individual chapters have been downloaded, with some chapters being particularly popular (e.g. 3279 downloads of Chapter 2, 'Indigenous insights into oral history, social determinants and decolonisation').

Lit.search

Being able to access relevant, up-to-date information quickly is vital in translating health research evidence into clinical practice and social programs to benefit patients, the health system and the community. With this in mind, the CRCATSIH funded a project by Flinders University – with a reference group of Aboriginal and Torres Strait Islander health providers, researchers, academics and students – to develop a web-based search filter tool to facilitate access to all Aboriginal and Torres Strait Islander health research on PubMed, an international bibliographic database with more than 20 million articles. Lit.Search is now one of the most popular resources on the Lowitja Institute website, and at the time of writing has been accessed approximately 16,500 times.

EthicsHub

EthicsHub is an online resource created by the Lowitja Institute to provide guidance – for researchers, the Aboriginal and Torres Strait Islander community participants, community organisations, supervisors and students, and ethics committees – as to the ethics of carrying out research in Aboriginal and Torres Strait Islander health. To enable best practice in engaging, working with and empowering Aboriginal and Torres Strait Islander communities around health research, it also provides information on ethics approvals processes, ethical guidelines, state, national and international contacts and resources, and best practice case studies.

Strong communication channels

Website and social media

The Lowitja Institute website (www.lowitja.org.au) was established in 2010 and redeveloped in 2012, with particular attention paid to ease of navigation and access to research projects and information about our activities in multiple formats: online, downloadable printed resources, audio and video files. The latter have long been used as a communication tool to distribute, through the website, important material to multiple audiences including the general public and remote communities. On average, usage of the website since 2012 has grown 25 per cent each year.

Social media – Twitter in particular where the Lowitja Institute enjoys a strong following and is regularly reported as an influencer – has become a powerful communications channel to connect with the Indigenous health sector, research partners, politicians, relevant peak bodies, media and community members, nationally and internationally. Growth of our Twitter following has grown, on average, 27 per cent each year since 2013.

Newsletters and bulletins

For the CRCAH and the following CRCs, newsletters and bulletins were seen as an important mechanism to connect with stakeholders. *Gwalwa-Gai* (Larrakia language for 'Calling people together') was a bi-monthly e-newsletter produced by the CRCAH aimed at a broad audience of those with an interest in Aboriginal health. With the launch of the Lowitja Institute in 2010, the newsletter *Wangka Pulka*, or 'Big Talk' in the Pitjantjatjara Yankunytjatjara language of Lowitja O'Donoghue's Country, was produced tri-annually, focusing on the Institute's research, knowledge exchange activities and on national stories related to Aboriginal and Torres Strait Islander health more generally. These longer format newsletters, however, were discontinued in 2013 due to limited resources.

The briefer format, online and fortnightly eBulletin is currently distributed to more than 3,100 subscribers, continues to gather information of interest – conferences, events, job, media, publications, resources and scholarships – for people and organisations working in Aboriginal and Torres Strait Islander health research, and to provide updates on the Institute's work.

Lowitja Publishing

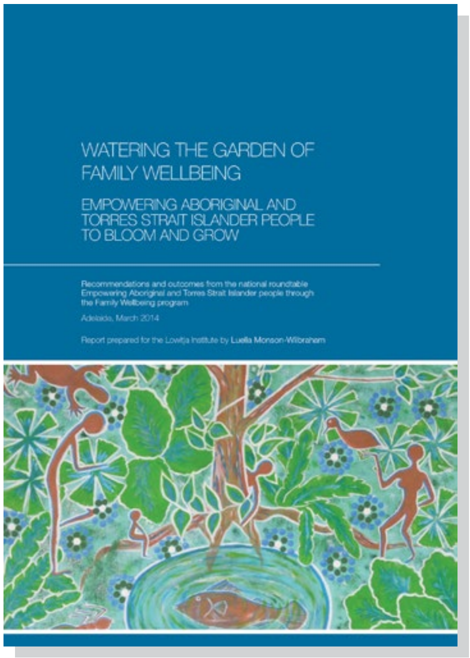
The traditional mechanism for distributing research outcomes is through peer-reviewed journal articles, books, book chapters and conference proceedings. This activity is closely aligned with academic career pathways and the Lowitja Institute encourages its research partners to publish in this manner.

However, the CRCs and the Lowitja Institute have sought to disseminate work in a manner that reflects more closely the principles of Aboriginal and Torres Strait Islander control of, and meaningful engagement in, the research process. To support this, Lowitja Publishing was set up to focus on:

- high-quality material that reflects the goals and values of project teams in terms of content, timelines and cultural values
- targeted dissemination of work to key audiences through a diverse range of formats and platforms
- publishing opportunities for researchers not on traditional academic career pathways
- developing writing, editing and production skills among project teams.

See pages 92–3 for a selection of publications.

Watering the Garden of Family Wellbeing ***report featuring artwork by Senimelia Kingsburra***



WATERING THE GARDEN OF FAMILY WELLBEING

EMPOWERING ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE TO BLOOM AND GROW

Recommendations and outcomes from the national roundtable Empowering Aboriginal and Torres Strait Islander people through the Family Wellbeing program

Adelaide, March 2014

Report prepared for the Lowitja Institute by **Luella Monson-Wilbraham**

Lowitja Publishing makes available all of its publications, either downloadable in free PDF format or for purchase as hard copies. It publishes project reports (research methods and findings); community reports (plain language aimed at non-researchers); summary reports (4-page full colour format); case studies; practical resources such as guides, flipcharts and web tools; fact sheets; policy briefs; and conference proceedings. Lowitja Institute titles were also available commercially online through the subscription-based RMIT Publishing Informit Collections, which publish research materials relevant to the Australian, New Zealand and Asia–Pacific market.

In 2006 the CRCAH instituted a Discussion Paper Series, continued by the Lowitja Institute, as a forum for its researchers, students and associates to make informed and evidence-based contributions to critical policy debates affecting the health of Aboriginal and Torres Strait Islander peoples. The series was also introduced as an effective way of disseminating research findings quickly, without the delays associated with publication in academic journals, so as to generate comment and suggestions for revision or improvement.

Creative backgrounds and foundations

Lowitja Publishing commissions striking Aboriginal and Torres Strait Islander artwork for its reports, and also engages artists in the project or research. Describing the meaning of ‘Spiritual Connection’, the artwork on the cover of the *Watering the Garden of Family Wellbeing*, artist Senimelia Kingsburra said:

> *The water in the pond represents choices in life – to live in a toxic pond or in a cool inviting clear pond. Water has a ripple effect – for me, I see negative thoughts as having a ripple effect that leads to toxic water. When you have positive thoughts, they ripple out too and the effect is like living in a calm inviting pool of water. The ripples represent growth.*[169]

Other publications, such as *Sort of Like Reading a Map – A community report on the survival of South-East Australian Aboriginal art since 1834*, and *Art into Health: Puntu Palyarrikuwanpa Aboriginal men becoming well* capture the vital role of culture in Aboriginal and Torres Strait Islander health.[170]

Showcasing the work

Congress Lowitja: A space for connection

The successful CRCAH convocations (see p. 37) have been continued at the Lowitja Institute as Congress Lowitja. An opportunity to present work, share ideas and inspiration, and contribute to identifying research priorities, these events are much more than the sum of their parts as they bring people together into a community of interest that transcends individual disciplines and silos. According to Jenny Brands

> *… [Congress Lowitja] can really encapsulate a momentum, and it creates relationships – the relationships that are needed to really bring about change… There’s an extraordinary feeling at those meetings… it’s really wonderful.*
> *(Jenny Brands Interview, 2 March 2015)*

Former Lowitja Institute CEO Lyn Brodie recognised Congress Lowitja as an event that is different to other conferences: ‘When people come to that, they are quite overwhelmed by the collegiate kind of atmosphere that exists’ (Lyn Brodie Interview, 14 January 2015).

CEO Lyn Brodie, Congress Lowitja, Melbourne, 2012

Delegates at the inaugural Congress Lowitja Aboriginal Health College, Sydney, March 2010

Congress Lowitja has not only been an opportunity for researchers to present outcomes of their research, but also for Aboriginal and Torres Strait Islander knowledges, such as that held by the Ngangkari Traditional Healers from the Anangu Pitjantjatjara Yankunytjatjara lands, to present in a cultural framework and research excellence. Indigenous knowledges became a particular focus of the Lowitja Institute International Indigenous Health and Wellbeing Conference in 2016 (see p. 117).

The first Congress Lowitja, held in Sydney in March 2010, became a venue at which the organisation's leadership could outline their vision for the future of the Institute. It also provided a forum through which participants could both engage in and shape the research agenda. Representatives from 13 community organisations, 14 government organisations, 29 non-government organisations and 110 representatives from academic and research institutions attended.[171]

At the opening of the event, Chairperson Pat Anderson told the gathered audience that:

> *We want to hear your views, we want you to challenge us, and most importantly we want you to share our journey towards a future where there is no longer a health gap between Indigenous and non-Indigenous Australians. In other words, between 'us and them'.*[172]

Ian Anderson noted at the conclusion of the successful inaugural Congress Lowitja:

> *We often talk about the emerging Aboriginal leadership in health research. What we have seen over the past two days is that this leadership has well and truly arrived.*[173]

On 14–15 November 2012, the Lowitja Institute community once again came together at the 2nd Congress Lowitja held at the Melbourne Cricket Ground, the focus of which was knowledge exchange and its translation into practice. Once again, the event brought together stakeholders from across all areas involved in issues of Aboriginal and Torres Strait Islander health and wellbeing, including representatives from research institutions, community health services and government. More than a third of the delegates attending Congress Lowitja 2012 identified as Aboriginal and Torres Strait Islander.[174]


nowledge Exchange and
Translation into Practice

Congress Lowitja 2010, 2012 and 2014

Clockwise from top left
Vivian Lin, Tom Calma, Chairperson Pat Anderson, Mick Gooda, Lisa Jackson Pulver, Malcolm King and CEO Lyn Brodie, Congress Lowitja, MCG, Melbourne, November 2012

Dancer at Congress Lowitja, Etihad Stadium, Melbourne, March 2014

Delegates at Congress Lowitja, Etihad Stadium, Melbourne, March 2014

Josie Atkinson, Shirley Nirrpurranydji and Diane Walker. MCG, Melbourne, November 2012

Dancers at Congress Lowitja, Aboriginal Health College, Sydney, March 2010

Ngangkaris Tinpulya Mervyn and Maringka Burton at Congress Lowitja, Etihad Stadium, Melbourne, March 2014

Shirley Nirrpurranydji, Congress Lowitja, MCG, Melbourne, November 2012

All photos from Congress 2012 and 2014
James Henry Photography

Building on the successes of the previous two Congresses, participants from across the Aboriginal and Torres Strait Islander health sector gathered once again for the 3rd Congress Lowitja in 2014. Keynote speakers at the event included Warren Mundine, Chair of the Prime Minister's Indigenous Advisory Committee, Dr Tim Soutphommasane, the Race Discrimination Commissioner, and long-time friend of, and advocate for, the Institute Marcia Langton, who noted that:

> *The 40-year-old tradition of Aboriginal community control remains a strong theme throughout your workforce, your frameworks, your approach and your Congress.*[175]

Research showcases

Beyond headline events like Congress Lowitja have been many other efforts to build and sustain networks of knowledge, communication and support across the Aboriginal and Torres Strait Islander health and health research sectors. On 19 November 2015, the Lowitja Institute conducted its inaugural knowledge exchange seminar, Translating Research into Action, at the National Library, Canberra. The event comprised a panel of experts who discussed what success looks like when the research is community driven. The panel featured three of our recent research projects: Family Wellbeing Program, presented by Leslie Baird; Funding, Accountability and Results (FAR) project, presented by Cleveland Fagan; Managing Two Worlds Together: Improving the Indigenous Patient Journey, presented by Judith Dwyer.

Approximately 100 people attended the seminar, primarily government policymakers, and representatives from Aboriginal and Torres Strait Islander peak health bodies and community organisations. Following the event, the Lowitja Institute uploaded on its website (and Vimeo channel) videos of presentations and interviews for the purpose of ongoing knowledge exchange.

The CRCAH also put great effort into presenting the research by holding five showcases around Australia in the 2005–2006 period, working closely with Core Partner organisations in Melbourne, Brisbane, Adelaide, Canberra and Darwin to do so. At these events, 47 research projects were presented to Aboriginal community representatives, health researchers, policymakers and planners and various peak health organisations such as the Australian Medical Association, the Heart Foundation and Kidney Australia. Approximately 100 organisations attended the five showcases, which 'brought to the fore the important role of the CRCAH's Link people in organising and presenting' them.[176]

This activity also emphasised the organisation's commitment to building and enhancing relationships between organisations at the local level, and to providing individuals and organisations with opportunities to get a better understanding of the CRCAH and its direction. The showcase held at Parliament House in 2008 had the added benefit of enabling presenters to give the 'audience of politicians, their advisers and departmental officers 'from nine government agencies' a 'direct briefing' and the opportunity to develop 'closer relationships with ministerial officers'.[177]

Continuous Quality Improvement (CQI) conferences

In 2012 and 2014, the CRCATSIH held two CQI conferences, attended by more than 200 delegates, with the stated goal of making CQI everybody's business. The conferences created opportunities for community-based service providers, community controlled services and government agencies, along with researchers, health industry and policy development government departments to:

- share knowledge about how best to embed CQI into everyday practice, ensuring better access to the highest quality and comprehensive primary health care for Aboriginal and Torres Strait Islander individuals and communities, including health promotion, dental health, social and emotional wellbeing, and alcohol and other drug programs (among others)
- learn about successful CQI examples and how best to transfer this knowledge to others working in the Aboriginal and Torres Strait Islander health and wellbeing space, including the establishment of a network and 'yarning place' in partnership with the Australian Indigenous Health*Info*Net.

Showcases, Workshops and Conferences, 2005–2015

Clockwise from top left

Viki Briggs, Director of CEITC, at CRCAH Showcase, Parliament House, Canberra, March 2008

CEO Romlie Mokak with the Hon. Ian McFarlane at CRC Association Showcase, Canberra, 2015

Cindy Shannon at CRCAH Showcase, Parliament House, Canberra, March 2008

Mark Wenitong with Justin Mohamed at Systemic Racism Workshop, Melbourne, March 2006

Panellists Ian Anderson, Donna Ah Chee, and Noel Hayman, CQI Conference, Alice Springs, May 2012

CQI Conference delegates, Alice Springs, May 2012

Bridget Robson (University of Otago), CEO Romlie Mokak, Stephanie Clark (The Lancet), Chairperson Pat Anderson, Ian Anderson, Richard Madden (University of Sydney)

Fiona Hamilton Photography

Reaching out to our global Indigenous family

The Lancet–Lowitja Institute Global Collaboration

When asked about the future for the Lowitja Institute, Ian Anderson spoke of a project he has been coordinating on behalf of the Lowitja Institute and the United Kingdom medical journal *The Lancet* to develop a global report card on Indigenous health.[178] It is, he said, an example of the impact of the CRCs' approach to effective research collaborations.

> *[The] Lowitja [Institute] has played a very key role in actually making that happen and in funding… and supporting the implementation of that project which involves, at the last count, about 30 different national contributors from South America, South East Asia, the Pacific, North America, Africa and Scandinavia. This will probably be one of the broadest publications in the field in this space. I think that, from this, there's an opportunity there, which the Institute is actively leading, to build on that collaboration and to start to strengthen our networks so that we actually start to work across a broader international context and not just within the more traditional associations that we have in former English settler colonial states.*
>
> *(Ian Anderson Interview, 17 December 2014)*

Romlie Mokak also spoke of the collaboration with *The Lancet* that has now resulted in the publication of an article titled 'Indigenous and tribal peoples' health (*The Lancet*–Lowitja Institute Global Collaboration): A population study' as a key indication of the move by the Institute into a global network (Romlie Mokak Interview, 11 December 2015).[179] The collaboration with one of the most respected and influential journals in the medical research landscape is a transactional development that builds confidence and establishes pathways to change. He pointed out that these collaborations are part of a strategic approach to increase the Lowitja Institute's influence by identifying key mechanisms for change. Having *The Lancet* article include the Lowitja Institute in its title is 'more than labelling, it's actually the business of trying to reset some of those power relations' (Romlie Mokak Interview, 11 December 2015).

Lowitja Institute International Indigenous Health and Wellbeing Conference, November 2016

In 2016, the Lowitja Institute organised its first international conference – The Lowitja Institute International Indigenous Health and Wellbeing Conference 2016 – held at the Melbourne Exhibition and Convention Centre. This was an entirely new type of event for the organisation, as it was the first time the Lowitja Institute or the CRCs had held a conference with an International focus. As a result, there was an increase in the number of delegates from 250 at Congress 2014 to just over 700, mostly from Australia but also from Aotearoa/New Zealand, Brazil, Canada, Chile, India, Nepal, Norway, the Philippines, and the United States of America.

The Conference theme of Identity, Knowledge, Strength, supported a framework of sub-themes and a comprehensive scientific and cultural program. Of the 143 oral and poster presenters, 103 identified as Indigenous, thereby meeting a key goal of the conference to celebrate, share and strengthen Indigenous knowledges and bring together Indigenous peoples from around Australia and the world. Together with non-Indigenous colleagues, they shared wisdom, learned about the best science, practices and solutions, connected and engaged with colleagues and peers, and crafted a strong statement to inform action and influence national and international Indigenous health and wellbeing agendas.

CEO Romlie Mokak (3rd from left) with keynote speakers Megan Davis, Gunn Heatta, Karina Walters, Moana Jackson, Chief Wilton Littlechild, Lowitja Institute International Indigenous Health and Wellbeing Conference, November 2016

Fiona Hamilton Photography

Conference Statement

The Lowitja Institute International Indigenous Health and Wellbeing Conference
Melbourne, 8–10 November 2016

The Conference asserts that Indigenous peoples across the world have the right to self-determination, as expressed in the United Nations Declaration on the Rights of Indigenous Peoples. The right to self-determination underpins the right to health.

The truth about Indigenous peoples must be told, heard and known for justice to ensue. Only then can we achieve genuine reconciliation.

The experience of Indigenous peoples the world over is a shared experience of colonisation. The conference heard that the primary goal of colonisation was about 'killing the spirit of Indigenous peoples' – as evidenced through the theft of land, language and culture.

We are all responsible for knowing the historical trauma and the continuing impacts that trauma has on Indigenous peoples today. This requires decolonisation of everyone's thinking and of attitudes, in order to reset the relationship between Indigenous peoples and non-Indigenous people. Indigenous intellect, knowledge, values, practice and ceremony must be at the forefront of solutions to Indigenous issues.

We honour our ancestors' resilience, strength and wisdom. In this moment in time, our obligation is to our future generations. As Indigenous peoples, we ask ourselves: What kind of ancestor did my own ancestors want me to be? What kind of ancestor do I want to be? What kind of ancestor do I want my children to be?

Based on its themes of Identity, Knowledge and Strength, the conference states that:

Identity

- Indigenous peoples must be recognised as such.
- The importance of culture in continuing our strength and resilience must be recognised.
- Indigenous peoples share common experiences but also diversity across and within communities.

Knowledge

- Indigenous thinking, intellect, wisdom must be valued.
- We must decolonise the research process. Indigenous peoples are the leaders in the research in relation to our own people. Any Indigenous research must primarily and directly be for the benefit of Indigenous people.

Strength

- We must be fully empowered to exercise the right to self-determination over our own lives.
- We must change the pathway, directed by Indigenous peoples, to deliver a promising future for our children.

Call to Action

- We call on everyone to ensure that we grow strong Indigenous children into strong and healthy adults able to reach the full potential of their lives. For this to happen, we must
  - Have a new and different way of working together
  - Enable Indigenous children to have cultural security and strong identity
  - Enable Indigenous children to have access to have culturally secure early childhood education
  - Enable Indigenous people to measure and monitor our progress.
- We call on all governments to fully implement the UN Declaration on the Rights of Indigenous Peoples.
- We call on all nations and their citizens to know the truth in relation to Indigenous peoples, and to act on that truth.
- We call on all governments to support the goals that have been identified by Indigenous peoples. This requires proper resourcing and long-term commitment to the health and wellbeing of Indigenous peoples.
- We call on governments to resource, to fund and to commit to Indigenous Institutions at all levels. Indigenous institutions need to lead the way in supporting Indigenous Peoples to achieve health and wellbeing.
- We call on all governments to establish cultural models of care, and for Indigenous peoples to define our own success and how we measure that success.
- We call on all to protect the land to which we belong. Only when the land is healed, can we achieve true health and wellbeing.

Furthermore, the Conference stands by, and with, Standing Rock Sioux in its opposition to the Dakota Access Pipeline in the United States of America.

10 November 2016


THE LOWITJA INSTITUTE INTERNATIONAL INDIGENOUS HEALTH AND WELLBEING CONFERENCE 2016
8-10 NOV, MELBOURNE, AUSTRALIA
IDENTITY. KNOWLEDGE. STRENGTH.
MELBOURNE CONVENTION EXHIBITION CENTRE

The Lowitja Institute International Indigenous Health and Wellbeing Conference, Melbourne, November 2016

Clockwise from top left
Wagga Torres Strait Islander Dancers

Chief Wilton Littlejohn, June Oscar, Karina Walters

Performers Archie Roach and Craig Pilkington

Conference auditorium

Conference logo (by Carbon Creative)

International delegations performance at conference dinner

Patron Lowitja O'Donoghue addresses delegates

Aunty Di Kerr, Patron Lowitja O'Donoghue, CEO Romlie Mokak, Megan Davis and The Hon Ken Wyatt MP

Megan Davis, Romlie Mokak and The Hon Ken Wyatt MP

James Henry Photography
Fiona Hamilton Photography

Detail from venue design by Jirra Lulla Harvey (Kalinya Communications) for The Lowitja Institute International Indigenous Health and Wellbeing Conference 2016

James Henry Photography

Vision for the Future

Romlie Mokak

> **There's a collectivity in Indigenous worlds that is incredibly powerful, and has sustained us through some of the most horrific policy responses that the world [has] known.**

Interview, 11 December 2015

Click to play video

Play online (browsers and mobile devices)

Romlie Mokak, The Lowitja Institute CEO, interview 11 December 2015

The purpose of the Lowitja Institute is to value the health and wellbeing of Aboriginal and Torres Strait Islander people.

The Institute's vision is to be an authoritative and collective voice for the benefit of Australia's First Peoples that supports Aboriginal and Torres Strait Islander priorities and collective ways of working and recognises the strength, agency and knowledges of Aboriginal and Torres Strait Islander peoples. The Institute will demonstrate the centrality of culture as it leads the coordination and translation of research on Aboriginal and Torres Strait Islander health and wellbeing; produce knowledge that is culturally, ethical and intellectually rigorous; grow strong Aboriginal and Torres Strait Islander health and wellbeing networks; provide cultural authority for non-Indigenous researchers; nurture the next generation of Aboriginal and Torres Strait Islander health researchers; and take a leadership role in the decisions that affect the health and wellbeing of Aboriginal and Torres Strait Islander communities, families and individuals.

In the late 1990s, when the CRCATH was formed, few Aboriginal and Torres Strait Islander people were leading research and policy development. This has now changed. Largely, the experts and leaders that the Institute collaborates with are Aboriginal and Torres Strait Islander people. These community representatives and policymakers, as well as the researchers, form powerful national networks of expertise and influence.

There's a collectivity in Indigenous worlds that is incredibly powerful, and has sustained us through some of the most horrific policy responses that the world [has] known.
(Romlie Mokak Interview, 11 December 2015)

Collaborations are key to the Institute's strategic approach nationally and, increasingly, internationally. Romlie Mokak spoke of the collaboration with *The Lancet* (see p. 116) as a key indication of the move by the Institute into a global network. He pointed out that these collaborations are part of a strategic approach to increase the Lowitja Institute's influence by identifying key mechanisms for change, and that the title of the collaboration is 'more than labelling, it's actually the business of trying to reset some of those power relations' (Romlie Mokak Interview, 11 December 2015).

In her interviews, Pat Anderson spoke about the benefits to Aboriginal and Torres Strait Islander health research of cooperation and collaboration through various Indigenous and First Nations international forums, especially connections with Canada and Aotearoa/New Zealand, given their common colonial history and its consequences. Both she and Romlie Mokak spoke of the expanding reach of the Institute's research and its influence as an organisational model in the international First Nations health research landscape.

As Romlie Mokak explained, the Lowitja Institute has to be more than its elements of institutions, organisations, congresses, roundtables and research projects. It has to offer leadership in research and ideas that are trusted by Aboriginal and Torres Strait Islander communities. For him, the future for the Institute is to build on cultural integrity in research and to grow an organisation that is recognised and celebrates the fact that it is working for the benefit of Aboriginal and Torres Strait Islander peoples.

I'll go back to the point that Lowitja herself made when the Lowitja Institute was launched, and I was there on the night… She said that we needed to be courageous and that's enough for me. If we can do that and not be timid, but understand the politics and work that, and having our people and those who want to support us on board, I think we can do fantastic things.
(Romlie Mokak Interview, 11 December 2015)

The Lowitja Institute will continue to embody the vision articulated by its Patron Dr Lowitja O'Donoghue (see p. 63).

What's next for the Lowitja Institute?

The Lowitja Institute has a clear vision for the future, but there are challenges. We need to ensure long-term funding of Aboriginal and Torres Strait Islander organisations for research processes that privilege Aboriginal and Torres Strait Islander voices, recognise how colonial historical relationships persist, and create effective ways of working based on Aboriginal and Torres Strait Islander cultures and knowledges.

The Institute business model incorporates the current focus on timely and relevant research and introduces innovative approaches for the growth of Aboriginal and Torres Strait Islander led solutions.

The new business areas – Lowitja Insight, Lowitja Consulting, Lowitja Standards and Lowitja Ventures – will amplify, accelerate and replicate the benefits of the Institute's work across the health and wellbeing sectors. It is anticipated that Lowitja Insight will produce longitudinal studies to build on our research, international conferences and research publications. Lowitja Consulting will undertake fee-for-service projects on strategy, public policy and organisational capacity. Lowitja Standards will include information, advice, and resources and training for Aboriginal and Torres Strait Islander health and wellbeing standards. Lowitja Ventures will facilitate commercial partnerships to jointly develop programs and solutions for service delivery and workforce development. This work will also have direct application and utility for other sectors interested in improving outcomes for Aboriginal and Torres Strait Islander peoples.

Out of the broader Lowitja Institute network, innovative ideas for change – which previously may have been misunderstood or even considered 'dangerous' – can emerge.

So when our mob say, 'It'd be great if Lowitja Institute could have one of those "ticks" like the Heart Foundation', they're not actually saying that in a flippant way at all. They're actually saying we need some process around accrediting or monitoring or approving or something to give back.

[Y]ou might establish national guidelines and any number of things but who's responsible for implementation? If there's an expectation that our communities, when receiving a request, are research literate – who makes that judgment? So we've got to get resources down firmly on the ground. Whether it's through education or training in a systemic way, so that our communities and our organisations are in a much better position to be in the negotiation in a proper way.
(Romlie Mokak Interview, 11 December 2015)

Pat Anderson shared her vision for the Lowitja Institute as an organisation that can represent the values, aspirations and intellect of Australia's First Peoples and that can, one day, become financially independent. She sees the future Lowitja Institute as the 'voice of reason' with regard to issues of Aboriginal and Torres Strait Islander health research:

For me, personally, I would like to see the Lowitja Institute as being the leaders and the promoters of Aboriginal intellect, that we are taking part in the intellectual life of the nation state and that we are a respected body. So when

The Lowitja Institute Board, December 2016:
Mr Selwyn Button, Dr Tamara Mackean, Ms Pat Anderson AO (Chairperson), Ms June Oscar AO, Professor Peter Buckskin PSE, Mr Russell Taylor AM (now retired from the Board). Not in the photo: Mr Brendon Douglas, Mr Ali Drummond, Professor Fiona Stanley AC

we speak, people think we might have something of value to say; that we're firmly part of the research landscape; that we've put the begging bowl away and that we can sit at any table equally with any of the research places; that we facilitate discussions [about] any ideas that are emerging [and] we start presenting them to people. *(Pat Anderson Interview 3, 14 November 2014).*

Romlie Mokak sees the Lowitja Institute continuing to broaden and strengthen its informal Aboriginal and Torres Strait Islander research networks beyond the immediate health research arena, therefore building on the collectivity and interest of Australia's First Nations:

Part of what I've been really focused on doing in the last 12 months is to engage our Indigenous research leadership and for our really prominent research leaders, [those] who are not part of the Lowitja Institute, to see that there is benefit in being a part of us. Doesn't have to be in a formal sense, it can just be in terms of an attitude or desire. Doesn't have to be through an agreement or a contract. Our old people didn't have written agreements, but we honoured the contract in every way. So having the Aboriginal and Torres Strait Islander leadership really firmly embedded in the organisation, speaking with a lot of our Indigenous research leaders and for them to see there's merit, there's benefit in being a part of this broader network.
(Romlie Mokak Interview, 11 December 2015)

The journey so far is a testament to the Institute's strong experience, networks and cultural authority to lead research and influence system changes with stakeholders from a wide range of sectors including health, justice and education. The future work program will build on this and include new work that is targeted, larger-scale and longer-term, and responds to the priorities of Aboriginal and Torres Strait Islander people, communities and policymakers. In achieving this vision, the Lowitja Institute will amplify benefit for our peoples.

Jindi Worabak dance performance at the Lowitja Institute Young Men's Health Workshop, March 2017

James Henry Photography

Endnotes

1 Dawn Bessarab & Bridget Ng'andu 2010, 'Yarning about Yarning as a Legitimate Method in Indigenous Research', *International Journal of Critical Indigenous Studies*, vol. 3, no. 1, pp. 37–50.

2 The CRC Programme was established to enhance the economic and social benefits of research cooperation through methods of networking and strengthening methods of research training.

3 Mary O'Kane 2008, *Collaborating to a Purpose: Review of the Cooperative Research Centres Program*, Department of Innovation, Industry, Science and Research, Australian Government, Canberra.

4 Association of Australian Medical Research Institutes (AAMRI) 2006, *A Medical Research Institute Perspective on Public Support for Science and Innovation: Submission to the Productivity Commission's Research Study on Public Support for Science and Innovation in Australia*, AAMRI, Parkville, Vic., July, p. 10.

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Wagga Torres Strait Islander Dancers performance at the Lowitja Institute International Indigenous Health and Wellbeing Conference, November 2016

James Henry Photography

Appendices

Appendix 1: Biographies of interviewees

Dr Lowitja O’Donoghue AC CBE DSG

For a full biography, see pp. 6–7.

Ms Pat Anderson AO

Pat Anderson is an Alyawarre woman known nationally and internationally as a powerful advocate with a particular focus on the health of Australia’s First Peoples. She has extensive experience in all aspects of Aboriginal health, including community development, advocacy, policy formation and research ethics. In 2014, Pat Anderson was appointed Officer of the Order of Australia (AO) for distinguished service to the Indigenous community as a social justice advocate, particularly through promoting improved health, and educational and protection outcomes for children.

Pat Anderson has spoken before the United Nations Working Group on Indigenous People, has been the CEO of Danila Dilba Health Service in Darwin, Chairperson of NACCHO, Executive Officer of AMSANT, and was the Chairperson of the CRC for Aboriginal Health from 2003 to 2009. She has published many essays, papers and articles, including co-authoring with Rex Wild QC of Little Children Are Sacred, a report on the abuse of Aboriginal children in the Northern Territory.

In 2007, Pat Anderson was awarded the Public Health Association of Australia’s Sidney Sax Public Health Medal in recognition of her achievements, the Human Rights Community Individual Award (Tony Fitzgerald Memorial Award) in 2012, and the Human Rights Medal in 2016 by the Australian Human Rights Commission. In 2013, she received an honorary doctorate from Flinders University, and in 2017 Edith Cowan University conferred on her a Doctor of Medical Science honoris causa.
In 2015, Pat Anderson won the public policy category Australian Financial Review and Westpac 100 Women of Influence Awards. She currently serves as co-chair of the Prime Minister’s Referendum Council.

Professor Ian Anderson AO

Ian Anderson is a Trawlwooway/Plairmairrereener man born in Devonport, Tasmania, and was the first in his family to attend university. In 1988, he became the first Aboriginal medical graduate of the University of Melbourne, and went on to serve as Medical Adviser to OATSIHS in the Commonwealth Department of Health and Aged Care (1996–98), and in 1999 became Director of the VicHealth Koori Health Research and Community Development Unit (later Onemda VicHealth Koori Health Unit) at the University of Melbourne.

In 2008 Ian Anderson was appointed Chair of the National Indigenous Health Equality Council, and the following year became Director of Murrup Barak, Melbourne Institute for Indigenous Development at the University of Melbourne where, in 2014, he was made Pro Vice-Chancellor (Engagement). In 2017, he was appointed Deputy Secretary in the Department of Prime Minister and Cabinet, and is the policy lead for renewing the Close the Gap Agreement through the Council of Australian Governments.

A member of the CRCATH Board from 1997 to 2003, with the advent of the CRCAH Ian Anderson took on the role of Research Director and served as Chairperson of the Research Development Group, and Project Leader for a number of research projects. In 2010–11 he was Director of Research and Innovation at the CRCATSIH/Lowitja Institute, and also served as a Non-executive Director of the Interim Board of the Lowitja Institute. Ian Anderson played a significant role in the success of the bids for the CRCAH and the CRCATSIH.

Ian Anderson was appointed an Officer of the Order of Australia in 2017 for distinguished service to the Indigenous community.

Ms Stephanie Bell

Stephanie Bell is a Kulilla/Wakka Wakka woman of Stolen Generations heritage of the Warramunga people, who grew up in Brisbane and then moved to Alice Springs. She spent eleven years as Director of the Central Australian Aboriginal Congress and was a founding member and later Chairperson of AMSANT, an Executive Member of NACCHO and Chairperson of the Northern Territory Aboriginal Health Forum.

Ms Bell joined the Board of the CRCATH in 2001 as a representative of CAAC and continued on the Board of CRCAH and of the Lowitja Institute as a Director, resigning in 2013. She was also Project Leader for a number of research projects with the CRCAH.

Ms Jenny Brands

Jenny Brands joined the CRC for Aboriginal Health in February 2003. As Research and Development Manager, she was a key contributor to the evolution of the Facilitated Development Approach and served as a member of the Research Development Group. Jenny left the CRCAH in June 2009 to take up a role with the Menzies School of Health Research. In 2014, she facilitated *The Shape of Things to Come: Visions for the Future of Aboriginal and Torres Strait Islander Health Research* for the Lowitja Institute.

Ms Lyn Brodie

Lyn Brodie served as CEO of the Lowitja Institute from 2012–14, steering it through its current funding round. Prior to that, she was for the Gandel Charitable Trust, one of Australia's largest private philanthropic organisations. She also held senior positions with the Zoos Victoria Foundation, the Baker Heart Research Institute, the Cabrini Foundation and Montefiore Homes for the Aged. Lyn Brodie became CEO of Optometry Australia in 2017.

Dr Jeannie Devitt

Jeannie Devitt took a position as a teacher in the Tiwi Islands in the early 1970s. She did a PhD in cultural anthropology and in the mid-1990s took up a job with the Central Australian Aboriginal Congress and the Menzies School of Health Research in an NHMRC-funded project investigating the experiences of Aboriginal people with kidney disease.

In 1997, Dr Devitt was appointed inaugural Research Fellow at the CRCATH in the Health Resources and Service Delivery Research Program. Her role as Research Fellow was to increase the research capacity of the CAAC and Danila Dilba Aboriginal Medical Services. During her time at the CRCATH, Dr Devitt was Project Leader for several projects, including 'Promoting ethical research in Indigenous communities' and 'Law, family and health', and a key researcher in the IMPAKT (Improving Access to Kidney Transplant) Project, an in-kind CRCATH project funded by the NHMRC. She also took on the role of supervisor for a number of PhD students undertaking their studies through the CRCATH.

Associate Professor Terry Dunbar

Terry Dunbar, born in Darwin of Warumungu/Larrakia/Iwaidjan descent, was the first Business Manager and Board Secretary of the CRCATH. She served as Deputy Director for both the CRCATH and the CRCAH, and was a key figure in the development of the Indigenous Research Reform Agenda. She also served as Director of Development and Project Leader for a number of projects with the CRCAH.

Terry Dunbar has worked with the NHMRC and the Office of Aboriginal and Torres Strait Islander Health, principally through the joint OATSIH/NHMRC Research Agenda Working Group, and spent 10 years as a member of the Menzies/Royal Darwin Hospital Joint Institutional Ethics Committee and its Indigenous subcommittee. She was involved in a review of the Interim Ethics Guidelines for Health Research with Indigenous Peoples and the development of a common national ethics committee application form, and was a member of the NHMRC's scholarship assessment panel and Deputy Chair of the Indigenous Health Research Panel.

Professor Judith Dwyer

Judith Dwyer has had a long involvement with the CRCAH and the Lowitja Institute as Program Leader and Project Leader for a number of research projects. She is one of the co-authors of the seminal Overburden Report. In 2014 Judith Dwyer was awarded the Sidney Sax Medal by the Australian Healthcare and Hospitals Association for her services to Indigenous health. She is Director of Research in the Department of Health Care Management at Flinders University in South Australia.

Professor Michael Good AO

Michael Good is an immunologist and a former Director of the CRC for Vaccine Technology (1993 to 2000). He was an inaugural Member of the CRCATH Board for the Menzies School of Health Research and a CRCAH Board member for QIMR (2000–03 and 2006–10). In 2000, Michael Good became Director of QIMR and Chairperson of the National Health and Medical Research Council. In 2008 he was appointed an Officer of the Order of Australia for services to medical research.

Mr Mick Gooda

Mick Gooda is a Gangulu man who grew up in Central Queensland. He joined the Public Service in the early 1980s, and served as CEO for ATSIC until its abolition. Appointed CEO of the CRCAH in November 2004, a role he held until 2010, under his leadership the CRCAH refocused its research agenda leading to the implementation of the Facilitated Development Approach.

From 2010 to 2016, Mick Gooda was the Aboriginal & Torres Strait Islander Social Justice Commissioner at the Australian Human Rights Commission. In 2016 he took up the position of Commissioner, with the Hon. Margaret White AO, on the Royal Commission into the Protection and Detention of Children in the Northern Territory.

Professor Shane Houston

Shane Houston is a Gangulu man from Central Queensland. He joined the Tharawal Aboriginal Corporation in the early 1980s, and in 1989 became a member of the National Aboriginal Health Strategy Working Party. He also worked for the Health Department in Western Australia as the Director of Aboriginal Health and as the inaugural Assistant Secretary, Office of Aboriginal Health, Family and Social Policy, for the Northern Territory's DHCS.

Shane Houston was on the Board of the CRCAH (2003–10) as a representative of DHCS and served on the interim Board of the Lowitja Institute from August 2009 until October 2010. In 2011 he was appointed Deputy Vice-Chancellor of Indigenous Strategy and Services at the University of Sydney.

Professor Marcia Langton AM

Marcia Langton was born in Queensland and is a descendant of the Yiman and Bidjara nations. She contributed to the creation of the original CRCATH and has provided advice and support throughout the Lowitja Institute journey. In 1993, she was appointed a Member of the Order of Australia for her service as an anthropologist and advocate of Aboriginal issues.

Marcia Langton worked as an anthropologist for the Central Land Council in Alice Springs from 1984 to 1989, and was appointed Ranger Chair Aboriginal and Torres Strait Islander Studies at the Northern Territory University (later Charles Darwin University) in 1995. She has held the foundation Chair of Australian Indigenous Studies at the University of Melbourne since February 2000.

Professor John Mathews AM

John Mathews studied science and medicine at the University of Melbourne, and researched epidemiological and cultural aspects of kuru in Papua New Guinea from 1964 to 1968, coordinating laboratory science and anthropology. From 1972 to 1975, he was NHMRC CJ Martin Fellow at the University of Oxford. In 1984 John Mathews became Foundation Director of the Menzies School of Health Research in Darwin, a position he held until 1999. He has advised governments on Aboriginal health, Agent Orange, ionising radiation, BSE, SARS and pandemic influenza. A key figure in the establishment of the CRCATH, he served as foundation Director from 1996 to 1999. He is still active in research in Melbourne.

In 1994, John Mathews was appointed an Officer of the Order of Australia for his contribution to medical research.

Mr Romlie Mokak

Romlie Mokak is a Djugun man from Western Australia and the current Chief Executive Officer of the Lowitja Institute. He has previously served as CEO of the Australian Indigenous Doctors' Association. Romlie Mokak has extensive experience in medical education and workforce development. He has also worked at community, state and national levels in Aboriginal and Torres Strait Islander policy areas, including disability, ageing, population health, financing and substance use.

Professor Komla Tsey

Komla Tsey was born in Botoku, Ghana, and moved to Australia in the early 1990s where he worked as a health educator for the Anyinginyi Health Aboriginal Corporation in Tennant Creek, NT before taking on a similar position with the Institute of Aboriginal Development. He was Head of the Central Australian Unit of the Menzies School of Health Research in Alice Springs from 1995 to 1997. In 2009 he was appointed as a Research Professor at James Cook University in Cairns.

Komla Tsey was one of the inaugural Program Leaders with the CRCATH in 1997 and in charge of the Indigenous Education Research Program. After leaving that role in 1999, he continued with the CRCAH and Lowitja Institute as a researcher and Project Leader for a range of empowerment projects. In 2012, Komla Tsey took on the role of Co-Program Leader, Healthy Communities and Settings at the Lowitja Institute.

Appendix 2: List of Partners and Participants

Cooperative Research Centre for Aboriginal and Tropical Health

Central Australian Aboriginal Congress

Charles Darwin University

Danila Dilba Health Service

Flinders University

Menzies School of Health Research

Territory Health Services (which became Department of Health and Community Services in 2002)

Cooperative Research Centre for Aboriginal Health

Australian Institute of Aboriginal and Torres Strait Islander Studies

Central Australian Aboriginal Congress

Charles Darwin University

Commonwealth Department of Health and Ageing

Danila Dilba Biluru Butji Binnilutlum Health Service Aboriginal Corporation

Flinders University

La Trobe University

Menzies School of Health Research

Northern Territory Department of Health and Community Services

Queensland Institute of Medical Research

University of Melbourne

University of Queensland

Cooperative Research Centre for Aboriginal and Torres Strait Islander Health

Australian Government Department of Health

Australian Institute of Aboriginal and Torres Strait Islander Studies

Central Australian Aboriginal Congress

Charles Darwin University

Danila Dilba Health Service

Edith Cowan University (2012)

Flinders University

La Trobe University

Menzies School of Health Research

Northern Territory Department of Health

QIMR Berghofer Medical Research Institute

The University of Melbourne

The University of Queensland

University of New South Wales (2012)

The Lowitja Institute Aboriginal and Torres Strait Islander Health CRC

Essential Participants

Australian Institute of Aboriginal and Torres Strait Islander Studies

Central Australian Aboriginal Congress

Edith Cowan University

Flinders University

James Cook University

Menzies School of Health Research

QIMR Berghofer Medical Research Institute

The University of Melbourne

University of New South Wales

Participants

Aboriginal Health Council of South Australia

Aboriginal Medical Services Alliance Northern Territory

Australian National University

Australian Government Department of Health

Charles Darwin University

La Trobe University

The University of Queensland

Curtin University

The George Institute for Global Health

Griffith University

Queensland University of Technology

Queensland Government

Government of Western Australia, Department of Health – Aboriginal Health

Central Queensland University

Appendix 3: Boards of Directors

Cooperative Research Centre for Aboriginal and Tropical Health

1997–1998

Dr Lowitja O'Donoghue (Chairperson)	
Ms Donna Ah Chee	Institute of Aboriginal Development
Dr Ian Anderson	OATSIHS/The University of Melbourne
Ms Pat Anderson	Danila Dilba Medical Service
Ms Trish Angus	Territory Health Service
Ms Edna Barolits OAM	Miwatji Health Service
Professor Michael Good	Menzies School of Health Research
Professor Paul Hughes AM	Flinders University
Mr John Liddle	Central Australian Aboriginal Congress
Professor Charles Webb	Northern Territory University
Mr Charles Tipungwuti	Tiwi Health Board

1998–1999

Dr Lowitja O'Donoghue (Chairperson)	
Ms Donna Ah Chee	Institute of Aboriginal Development
Associate Professor Ian Anderson	The University of Melbourne
Ms Pat Anderson	Danila Dilba Medical Service
Dr David Ashbridge (replaced Ms Trish Angus, February 1999)	Territory Health Service
Professor Michael Good	Menzies School of Health Research
Professor Paul Hughes AM	Flinders University
Mr John Liddle	Central Australian Aboriginal Congress
Mr Charles Tipungwuti	Tiwi Health Board
Professor Charles Webb	Northern Territory University
Vacant Position	

1999–2000

Dr Lowitja O'Donoghue AC (Chairperson)	
Ms Donna Ah Chee (resigned November 1999)	Institute of Aboriginal Development
Associate Professor Ian Anderson	The University of Melbourne
Ms Pat Anderson	Danila Dilba Medical Service
Dr David Ashbridge	Territory Health Service

Professor Michael Good	Queensland Institute of Medical Research
Professor Paul Hughes AM	Flinders University
Mr John Liddle	Central Australian Aboriginal Congress
Professor Kerin O'Dea	Menzies School of Health Research
Mr Charles Tipungwuti	Tiwi Health Board
Professor Charles Webb	Northern Territory University
Vacant Position	

2000–2001

Dr Lowitja O'Donoghue AC (Chairperson)	
Associate Professor Ian Anderson	The University of Melbourne
Ms Pat Anderson (from April 2002)	National Aboriginal Community Controlled Health Organisation
Ms Veronica Arbon (September 2002)	Batchelor Institute of Indigenous Tertiary Education
Dr David Ashbridge	Territory Health Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Ms Kez Hall (from April 2002)	Danila Dilba Medical Service
Professor Michael Good	Queensland Institute of Medical Research
Professor Paul Hughes AM	Flinders University
Professor Kerin O'Dea	Menzies School of Health Research
Professor Charles Webb	Northern Territory University
Mr Charles Tipungwuti	Tiwi Health Board

2002–2003

Dr Lowitja O'Donoghue AC (Chairperson)	
Associate Professor Ian Anderson	The University of Melbourne
Ms Pat Anderson	National Aboriginal Community Controlled Health Organisation
Ms Veronica Arbon (September 2002)	Batchelor Institute of Indigenous Tertiary Education
Dr David Ashbridge	Territory Health Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Michael Good	Queensland Institute of Medical Research
Ms Kez Hall (from April 2002)	Danila Dilba Medical Service
Professor Chris Marlin	Flinders University
Professor Kerin O'Dea	Menzies School of Health Research
Mr Charles Tipungwuti	Tiwi Health Board
Professor Charles Webb	Northern Territory University

Cooperative Research Centre for Aboriginal Health

2003–2004

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol (from June 2004)	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Stephen Duckett (to August 2003)	La Trobe University
Ms Helen Evans	Commonwealth Department of Health and Ageing
Ms Kez Hall (to June 2004)	Danila Dilba Medical Service
Dr Shane Houston	Northern Territory Department of Health and Community Services
Mr Steven Larkin	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Vivian Lin (from August 2003)	La Trobe University
Professor Chris Marlin	Flinders University
Professor Kerin O'Dea	Menzies School of Health Research
Ms Kerrie Tim	Aboriginal and Torres Strait Islander Service
Professor Charles Webb (to June 2004)	Charles Darwin University (previously NTU)
Professor Robert Wasson (from June 2004)	Charles Darwin University
Associate Professor Ted Wilkes	Telethon Institute of Child Health Research

2004–2005

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Ms Helen Evans (to May 2005)	Commonwealth Department of Health and Ageing
Dr Shane Houston	Northern Territory Department of Health and Community Services
Ms Alison Larkin (from May 2005)	Commonwealth Department of Health and Ageing
Mr Steven Larkin	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Vivian Lin	La Trobe University
Professor Chris Marlin	Flinders University
Professor Kerin O'Dea	Menzies School of Health Research
Professor Robert Wasson	Charles Darwin University
Associate Professor Ted Wilkes	Telethon Institute of Child Health Research

2005–2006

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Jonathan Carapetis	Menzies School of Health Research
Ms Jill Gallagher	Victorian Aboriginal Community Controlled Health Organisation
Professor Roy Goldie	Flinders University

Dr Shane Houston	Northern Territory Department of Health and Community Services
Mr Steven Larkin	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Vivian Lin	La Trobe University
Professor Alan Lopez	University of Queensland
Professor Terry Nolan	The University of Melbourne
Ms Lesley Podesta	Commonwealth Department of Health and Ageing
Associate Professor Janelle Stirling	Queensland Institute of Medical Research
Professor Robert Wasson	Charles Darwin University
Associate Professor Ted Wilkes	Telethon Institute of Child Health Research

2006–2007

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Jonathan Carapetis	Menzies School of Health Research
Ms Jill Gallagher	Victorian Aboriginal Community Controlled Health Organisation
Professor Roy Goldie	Flinders University
Professor Michael Good	Queensland Institute of Medical Research
Dr Shane Houston	Northern Territory Department of Health and Community Services
Mr Steven Larkin	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Vivian Lin	La Trobe University
Professor Alan Lopez	University of Queensland
Professor Terry Nolan	The University of Melbourne
Professor Robert Wasson	Charles Darwin University
Associate Professor Ted Wilkes	Telethon Institute of Child Health Research

2007–2008

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Jonathan Carapetis	Menzies School of Health Research
Dr Philip Davies	Commonwealth Department of Health and Ageing
Ms Jill Gallagher	VACCHO
Professor Roy Goldie	Flinders University
Professor Michael Good AO	Queensland Institute of Medical Research
Dr Shane Houston	Northern Territory Department of Health and Community Services
Mr Steven Larkin	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Vivian Lin	La Trobe University
Professor Alan Lopez	University of Queensland

Professor Terry Nolan	The University of Melbourne
Associate Professor Janelle Sterling	Northern Rivers University
Professor Robert Wasson	Charles Darwin University
Associate Professor Ted Wilkes	Telethon Institute of Child Health Research

2008–2009

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Jonathan Carapetis	Menzies School of Health Research
Dr Philip Davies	University of Queensland
Ms Jill Gallagher	Victorian Aboriginal Community Controlled Health Organisation
Professor Michael Good AO	Queensland Institute of Medical Research
Dr Shane Houston	Northern Territory Department of Health and Community Service
Professor Michael Kidd AM	Flinders University
Professor Vivian Lin	La Trobe University
Professor Terry Nolan	The University of Melbourne
Ms Lesley Podesta	Commonwealth Department of Health and Ageing
Associate Professor Janelle Sterling	Northern Rivers University
Mr Russel Taylor	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Robert Wasson	Charles Darwin University
Associate Professor Ted Wilkes	Telethon Institute of Child Health

2009–2010

Ms Pat Anderson (Chairperson)	
Ms Paula Arnol	Danila Dilba Medical Service
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Jonathan Carapetis	Menzies School of Health Research
Dr Philip Davies	University of Queensland
Ms Jill Gallagher	Victorian Aboriginal Community Controlled Health Organisation
Professor Michael Good AO	Queensland Institute of Medical Research
Dr Shane Houston	Northern Territory Department of Health and Community Services
Professor Michael Kidd AM	Flinders University
Professor Vivian Lin	La Trobe University
Professor Terry Nolan	The University of Melbourne
Ms Lesley Podesta	Commonwealth Department of Health and Ageing
Associate Professor Janelle Sterling	Northern Rivers University
Mr Russel Taylor	Australian Institute of Aboriginal and Torres Strait Islander Studies
Professor Robert Wasson	Charles Darwin University

The Lowitja Institute Interim Board 2010

Ms Pat Anderson (Chairperson)	Independent
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Ian Anderson	The University of Melbourne
Professor Jonathan Carapetis	Menzies School of Health Research
Professor Shane Houston	NT Department of Health and Families

The Interim Board was dissolved following the appointment of the Permanent Board of Directors in October 2010.

The Lowitja Institute

2010–2011

Ms Pat Anderson (Chairperson)	Independent
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Peter Buckskin PSM	David Unaipon College of Indigenous Education and Research, University of South Australia
Professor Lisa Jackson Pulver AM	School of Public Health and Community Medicine, University of New South Wales
Mr Robin Lonergan	Macrossan Lawyers
Dr Louise Morauta PSM	Independent
Dr Sanchia Shibasaki	Kimberley Aboriginal Medical Services Council

2011–2012

Ms Pat Anderson (Chairperson)	Independent
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Peter Buckskin PSM	David Unaipon College of Indigenous Education and Research, University of South Australia
Professor Lisa Jackson Pulver AM	School of Public Health and Community Medicine, University of New South Wales
Mr Robin Lonergan	Macrossan Lawyers
Dr Louise Morauta PSM	Independent
Dr Sanchia Shibasaki	Independent

2012–2013

Ms Pat Anderson (Chairperson)	Independent
Ms Stephanie Bell	Central Australian Aboriginal Congress
Professor Peter Buckskin PSM	University of South Australia
Professor Lisa Jackson Pulver AM	University of New South Wales
Mr Robin Lonergan	TressCox Lawyers
Dr Louise Morauta PSM	Independent
Dr Sanchia Shibasaki (until July 2012)	Independent
Mr Ali Drummond	Independent

2013–2014

Ms Pat Anderson (Chairperson)	Independent
Professor Greg Anderson	QIMR Berghofer Medical Research Institute
Professor Peter Buckskin PSM	University of South Australia
Mr Selwyn Button	Queensland Department of Education, Training and Employment
Mr Ali Drummond	Independent
Professor Lisa Jackson Pulver AM	University of New South Wales
Mr Robin Lonergan	TressCox Lawyers
Mr Justin Mohamed	National Aboriginal Community Controlled Organisation
Dr Louise Morauta PSM	Independent
Mr Russell Taylor	Australian Institute for Aboriginal and Torres Strait Islander Studies

2014–2015

Ms Pat Anderson (Chairperson)	Independent
Professor Greg Anderson	QIMR Berghofer Medical Research Institute
Professor Peter Buckskin PSM	University of South Australia
Mr Selwyn Button	Queensland Department of Education, Training and Employment
Mr Matthew Cooke (Dec 2014–June 2015)	National Aboriginal Community Controlled Organisation
Mr Brendon Douglas	Charles Darwin University
Mr Ali Drummond	Independent
Professor Lisa Jackson Pulver AM	University of New South Wales
Mr Justin Mohamed (until November 2014)	National Aboriginal Community Controlled Organisation
Mr Russell Taylor	Australian Institute for Aboriginal and Torres Strait Islander Studies

2015–2016

Ms Pat Anderson AO (Chairperson)	Independent
Professor Greg Anderson	QIMR Berghofer Medical Research Institute
Professor Peter Buckskin PSM	University of South Australia
Mr Selwyn Button	Queensland Department of Education, Training and Employment
Mr Brendon Douglas	Charles Darwin University
Mr Ali Drummond	Independent
Dr Tamara Mackean	Flinders University
Ms June Oscar AO	Independent
Professor Fiona Stanley AC	Independent
Ms Robynne Quiggin	Independent
Mr Russell Taylor AM	Australian Institute for Aboriginal and Torres Strait Islander Studies

2016–2017

Ms Pat Anderson AO (Chairperson)	Independent
Professor Peter Buckskin PSM	University of South Australia
Mr Selwyn Button	Queensland Department of Education, Training and Employment
Mr Brendon Douglas	Charles Darwin University
Mr Ali Drummond	Independent
Dr Tamara Mackean	Southgate Institute for Health, Society and Equity, Flinders University
Ms June Oscar AO	Independent
Professor Fiona Stanley AC	Independent

Appendix 4: Research Program Leaders and Program Committees

CRCATH: 1997–98

Research Program 1	Indigenous Education Research	Komla Tsey
Research Program 2	Health Resources & Service Delivery Research	Chris Silagy
Research Program 3	Public Health Research	Frank Bowden, John Wakerman
Research Program 4	Communications & Information Research	Sam Heard
Research Program 5	Biomedical Research	David Kemp

CRCATH: 1998–99

Research Program 1	Indigenous Education Research	Komla Tsey
Research Program 2	Resources & Health Services Research	Peter McDonald
Research Program 3	Public Health Research	Steve Guthridge
Research Program 4	Communications & Information Research	Sam Heard
Research Program 5	Biomedical Research	David Kemp

CRCATH: 1999–2000

Research Program 1	Indigenous Health & Education Research	Merridy Malin
Research Program 2	Resources & Health Services Research	Peter McDonald
Research Program 3	Public Health Research	Steve Guthridge
Research Program 4	Health Information & Technology Research	Tony Grivell
Research Program 5	Biomedical Research	David Kemp, Bart Currie

CRCATH: 2000–01

Research Program 1	Indigenous Health & Education Research	Merridy Malin
Research Program 2	Resources & Health Services Research	Cheryl Rae
Research Program 3	Public Health Research	Steve Guthridge
Research Program 4	Health Information & Technology Research	Tony Grivell
Research Program 5	Biomedical Research	Bart Currie, Peter McDonald

CRCATH: 2001–02

Research Program 1	Indigenous Health & Education Research	Merridy Malin
Research Program 2	Resources & Health Services Research	Cheryl Rae
Research Program 3	Public Health Research	Steve Guthridge
Research Program 4	Health Information & Technology Research	Tony Grivell
Research Program 5	Biomedical Research	Bart Currie, Peter McDonald

CRCATH: 2002–03

Research Program 1	Indigenous Health & Education Research	Merridy Malin
Research Program 2	Resources & Health Services Research	Ross Bailie
Research Program 3	Public Health Research	Steve Guthridge
Research Program 4	Health Information & Technology Research	Tony Grivell
Research Program 5	Biomedical Research	Bart Currie, Peter McDonald

CRCAH: 2003–04

Research Theme 1	Health Systems & Processes	David Legge, Yael Cass
Research Theme 2	Social Determinants – Individuals, Families & Communities	Fran Baum, Joy Savage
Research Theme 3	Social Determinants Macro-Level Change	Joan Cunningham, Ross Bailie, Steve Guthdrige
Research Theme 4	Chronic & Infectious Diseases	Bart Currie, David Kemp, Kevin Rowley

CRCAH: 2004–05

This period saw the changeover to the CRCAH’s Programmatic Approach

CRCAH: 2005–06

Chronic Conditions	Kevin Rowley, Leisa McCarthy, Brendan Gibson
Comprehensive Primary Health Care, Health Systems and Workforce	Ross Bailie, Ben Bartlett, Justin Mohamed
Healthy Skin	Christine Connors, Ross Andrews, Janelle Stirling
Social and Emotional Wellbeing	Tom Brideson, Melisah Feeney, Gary Robinson
Social Determinants of Health	Fran Baum, Michael Bentley, Joy McLaughlin, Colleen Hayward

CRCAH: 2006–07

Chronic Conditions	Kevin Rowley, Leisa McCarthy, Brendan Gibson
Comprehensive Primary Health Care, Health Systems and Workforce	Ross Bailie, Ben Bartlett, Justin Mohamed
Healthy Skin	Christine Connors, Ross Andrews, Janelle Stirling
Social and Emotional Wellbeing	Tom Brideson, Melisah Feeney and Gary Robinson
Social Determinants of Health	Fran Baum, Michael Bentley, Joy McLaughlin, David de Carvalho

CRCAH: 2007–08

Chronic Conditions	Kevin Rowley, Leisa McCarthy, Joy McLaughlin, Brian Marshall
Comprehensive Primary Health Care, Health Systems and Workforce	Ross Bailie, Ben Bartlett, John Liddle, Faye Acklin
Healthy Skin	Christine Connors, Ross Andrews
Social and Emotional Wellbeing	Tom Brideson, Melisah Feeney, Kate Gilbert, Wendy Clinch, Gary Robinson
Social Determinants of Health	Fran Baum, Michael Bentley, Justin Mohamed, Colleen Hayward, David de Carvalho

CRCAH: 2008–09

Chronic Conditions	Kevin Rowley, Leisa McCarthy, Rosemary Knight, Brian Marshall
Comprehensive Primary Health Care, Health Systems and Workforce	Ross Bailie, Ben Bartlett, John Liddle, Faye Acklin
Healthy Skin	Christine Connors, Ross Andrews
Social and Emotional Wellbeing	Tom Brideson, Melisah Feeney, Stephen Castle, Wendy Clinch, Gary Robinson
Social Determinants of Health	Fran Baum, Michael Bentley, Michaela Coleborne, Colleen Hayward

CRCAH: 2009–10

Chronic Conditions	Kevin Rowley, Leisa McCarthy, Rosemary Knight, Brian Marshall
Comprehensive Primary Health Care, Health Systems and Workforce	Ross Bailie, Ben Bartlett, John Liddle, Faye Acklin
Healthy Skin	Christine Connors, Ross Andrews
Social and Emotional Wellbeing	Tom Brideson, Melisah Feeney, Anne-Marie Mioche, Wendy Clinch, Gary Robinson
Social Determinants of Health	Fran Baum, Michael Bentley, Michaela Coleborne, Colleen Hayward

CRCATSIH/Lowitja Institute: 2010

Program 1	Healthy Start, Healthy Life	Ross Bailie, Tom Brideson
Program 2	Healthy Communities and Settings	Leisa McCarthy, Kevin Rowley
Program 3	Enabling Policy and Systems	Alwin Chong, Judith Dwyer

CRCATSIH/Lowitja Institute: 2011

Program 1	Healthy Start, Healthy Life	Ross Bailie, Tom Brideson
Program 2	Healthy Communities and Settings	Leisa McCarthy, Kevin Rowley
Program 3	Enabling Policy and Systems	Alwin Chong, Judith Dwyer

CRCATSIH/Lowitja Institute: 2012

Program 1	Healthy Start, Healthy Life	Ross Bailie, Gail Garvey
Program 2	Healthy Communities and Settings	Alwin Chong
Program 3	Enabling Policy and Systems	Judith Dwyer

CRCATSIH/Lowitja Institute: 2013

Program 1	Healthy Start, Healthy Life	Ross Bailie, Gail Garvey
Program 2	Healthy Communities and Settings	Alwin Chong, Komla Tsey
Program 3	Enabling Policy and Systems	Judith Dwyer, Kim O’Donnell

CRCATSIH/Lowitja Institute: 2014

Program 1	Healthy Start, Healthy Life	Ross Bailie, Gail Garvey
Program 2	Healthy Communities and Settings	Alwin Chong, Komla Tsey
Program 3	Enabling Policy and Systems	Judith Dwyer, Kim O’Donnell

Lowitja Institute CRC: 2015

Program 1	Community Capability and Social Determinants of Health	Kerry Arabena Roxanne Bainbridge Vanessa Harris	Suzanne Ingram Ray Lovett Adrian Miller
Program 2	A Health Workforce to Address Aboriginal and Torres Strait Islander Health	Cindy Shannon Scott Avery Marion Kickett	Janine Mohamed Roianne West Michael Wright
Program 3	Health Policy and Systems	Mark Wenitong Donisha Duff Jill Guthrie	Kim O'Donnell Ted Wilkes

Lowitja Institute CRC: 2016

Program 1	Community Capability and Social Determinants of Health	Kerry Arabena Roxanne Bainbridge Vanessa Harris	Suzanne Ingram Ray Lovett Adrian Miller
Program 2	A Health Workforce to Address Aboriginal and Torres Strait Islander Health	Cindy Shannon Scott Avery Marion Kickett	Janine Mohamed Roianne West Michael Wright
Program 3	Health Policy and Systems	Mark Wenitong Donisha Duff Jill Guthrie	Kim O'Donnell Ted Wilkes

Lowitja Institute CRC: 2017

Program 1	Community Capability and Social Determinants of Health	Kerry Arabena Roxanne Bainbridge Vanessa Harris	Suzanne Ingram Ray Lovett Adrian Miller
Program 2	A Health Workforce to Address Aboriginal and Torres Strait Islander Health	Cindy Shannon Scott Avery Marion Kickett	Janine Mohamed Roianne West Michael Wright
Program 3	Health Policy and Systems	Mark Wenitong Donisha Duff Jill Guthrie	Kim O'Donnell Ted Wilkes

Appendix 5: CRCs and Lowitja Publishing

Anderson, I., Baum, F. & Bentley, M. (eds) 2007, *Beyond Bandaids: Exploring the underlying social determinants of Aboriginal health – Papers from the Social Determinants of Aboriginal Health Workshop, Adelaide, July 2004*, CRC for Aboriginal Health, Darwin.

Andrews, R. & Kearns, T. 2009, *East Arnhem Regional Healthy Skin Project: Final report 2008*, CRC for Aboriginal Health, Darwin.

Brands, J. 2014, *The Shape of Things to Come: Visions for the future of Aboriginal and Torres Strait Islander health research*, The Lowitja Institute, Melbourne.

Bretherton T. 2014, *Shifting Gears: Identifying drivers of career development for Aboriginal and Torres Strait Islander workers in the health sector*, The Lowitja Institute, Melbourne.

Coulehan, K., Brown, I., Christie, M., Gorham, G., Lowell, A., Marr\anyin, B. & Patel, B. 2005, *Sharing the True Stories: Evaluating strategies to improve communication between health staff and Aboriginal patients – Stage 2 report*, CRC for Aboriginal Health, Darwin.

Devitt, J., Dwyer, J., Martini, A. & Tilton, E. 2015, *Northern Territory Aboriginal Health Forum: A historical review*, The Lowitja Institute, Melbourne.

Dwyer, J., Kelly, J., Willis, E., Glover, J., Mackean, T., Pekarsky, B. & Battersby, M. 2011, *Managing Two Worlds Together: City hospital care for country Aboriginal people – Project report*, The Lowitja Institute, Melbourne.

Dwyer, J., Kelly, J., Willis, E., Glover, J., Mackean, T., Pekarsky, B. & Battersby, M. 2011, *Managing Two Worlds Together: City hospital care for country Aboriginal people – Community Summary*, The Lowitja Institute, Melbourne.

Dwyer, J., Kelly, J., Willis, E., Mackean, T., Battersby, M., Pekarsky, B. & Glover, J. 2011, *Managing Two Worlds Together: Study 2 – Staff perspectives on care for country Aboriginal patients*, The Lowitja Institute, Melbourne.

Dwyer, J., Martini, A., Brown, C., Tilton, E., Devitt, J., Myott, P. & Pekarsky, B. 2015, *The Road Is Made by Walking: Towards a better primary health care system for Australia's First Peoples – Report*, The Lowitja Institute, Melbourne.

Dwyer, J., Martini, A., Brown, C., Tilton, E., Devitt, J., Myott, P. & Pekarsky, B. 2015, *The Road Is Made by Walking: Towards a better primary health care system for Australia's First Peoples – Summary report*, The Lowitja Institute, Melbourne.

Dwyer, J., O'Donnell, K., Lavoie, J., Marlina, U. & P. Sullivan 2009, *The Overburden Report: Contracting for Indigenous health services*, CRC for Aboriginal Health, Darwin. (2011 reprint: pdf only)

Dwyer, J., C. Shannon & S. Godwin 2007, *Learning from Action: Management of Aboriginal and Torres Strait Islander health*, CRC for Aboriginal Health, Darwin.

Edmonds, F. with Clarke, M. 2009, *'Sort of Like Reading a Map' – A community report on the survival of south-east Australian Aboriginal art since 1834*, CRC for Aboriginal Health, Darwin.

Elliott, A., McIlwaine, F., Stone, N. & Proctor, K. 2015, *The Bouverie Centre's Aboriginal Family Therapy Training Program: Impact analysis report*, The Lowitja Institute, Melbourne.

Emerson, L., Fox, S. & Smith, C. 2015, *Good Beginnings: Getting it right in the early years*, The Lowitja Institute, Melbourne.

Erben, R., Judd, J., Ritchie, J. & Rowling, L. (eds) 2009, *Success Stories: Environmental, social, emotional and spiritual health of Aboriginal and Torres Strait Islanders. Report of the Indigenous Health Workshop*, CRC for Aboriginal Health, Darwin.

Ferdinand, A., Paradies, Y. & Kelaher, M. 2013, *Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities*, The Lowitja Institute, Melbourne.

Fischer, K. 2016, *High School Outreach in Remote Northwest Queensland*, The Lowitja Institute, Melbourne.

Fletcher, S. 2007, *Communities Working for Health and Wellbeing: Success stories from the Aboriginal Community Controlled Health sector in Victoria*, CRC for Aboriginal Health, Darwin & Victorian Aboriginal Community Controlled Health Organisation, Melbourne.

Freemantle, J., Officer, K., McAullay, D. & Anderson, I. 2007, *Australian Indigenous Health – Within an international context*, published by CRCAH, Telethon Institute for Child Health Research and Onemda VicHealth Koori Health Unit, CRC for Aboriginal Health, Darwin.

Freemantle, J., Ritte, R., Smith, K., Iskandar, D., Cutler, T., Heffernan, B., Zhong, G., Mensah, F. & Read, A. 2014, *Victorian Aboriginal Child Mortality Study: Patterns, trends and disparities in mortality between Aboriginal and non-Aboriginal infants and children, 1999–2008*, The Lowitja Institute, Melbourne.

Freemantle, J., Ritte, R., Heffernan, B., Cutler, T., Iskandar, D. 2013, *Victorian Aboriginal Child Mortality Study Phase 1: The birth report – Patterns and trends in births to Victorian Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander mothers and/or fathers 1988–2008 inclusive*, The Lowitja Institute, Melbourne.

Glover, J. & Freeman, M. 2011, *Managing Two Worlds Together: Study 1 – Report on admissions and costs*, The Lowitja Institute, Melbourne.

Heffernan, B., Iskandar, D. & Freemantle, J. 2012, *The History of Indigenous Identification in Victorian Health Datasets, 1980–2011: Initiatives and policies reported by key informants*, The Lowitja Institute, Melbourne

Helps, Y., Moodie, D. & Warman, G. 2010, *Aboriginal People Travelling Well: Community report*, The Lowitja Institute

Kelaher, M., Parry, A., Day, S., Paradies, Y., Lawlor, J. & Solomon, L. 2010, *Improving the Identification of Aboriginal and Torres Strait Islander People in Mainstream General Practice*, The Lowitja Institute, Melbourne.

Kelaher, M., Sabanovic, H., La Brooy, C., Lock, M., Uddin, S. & Brown, L. 2014, *Planning, Implementation and Effectiveness in Indigenous Health Reform*, The Lowitja Institute, Melbourne.

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Kelly, J., Dwyer, J., Mackean, T., Willis, E., O'Donnell, K., Battersby, M. & Pekarsky, B. 2011, *Managing Two Worlds Together: Study 3 – The experiences of patients and their carers*, The Lowitja Institute, Melbourne

Kelly, J., Pekarsky, B., Dwyer, J., Mackean, T., Willis, E., Glover, J. & Battersby, M. 2011, *Managing Two Worlds Together: Study 4 – Complex country Aboriginal patient journeys*, The Lowitja Institute, Melbourne.

Kelly, J., Ramage, M., Perry, D., Tinsley, J., Auckram, H., Corkhill, W., Wyatt, S. & McCabe, N. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – Rural and remote sites case studies*, The Lowitja Institute, Melbourne.

Kelly, J., Ramage, M., Perry, D., Tinsley, J., Auckram, H., Corkhill, W., Wyatt, S. & McCabe, N. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – Cardiac case studies*, The Lowitja Institute, Melbourne.

Kelly, J., McCabe, N., McInnes, W., Kirkbride, M., Graham, A., Rigney, D. & Nori, A. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – City sites case studies*, The Lowitja Institute, Melbourne.

Kelly, J., Medway, P., Miller, D., Catt, L. & Lawrence, M. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – Maternity case studies*, The Lowitja Institute, Melbourne.

Kelly, J., Herman, K., Martin, G., Wilden, C., East, T., Russell, C. & Brown, S. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – Renal case studies*, The Lowitja Institute, Melbourne.

Kelly, J., Dwyer, J., Pekarsky, B., Mackean, T., Willis, E., de Crespigny, C., Perkins, S, O'Donnell, K., King, R., Mackean, L., Brown, A., Lawrence, M. & Dixon, K. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – Study report*, The Lowitja Institute, Melbourne.

Kelly, J., Dwyer, J., Pekarsky, B., Mackean, T., McCabe, N., Wiseman, J., de Crespigny, C. & O'Donnell, K. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal patient journeys – Workbook (version 1)*, The Lowitja Institute, Melbourne.

Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2011, *Researching Indigenous Health: A practical guide for researchers*, The Lowitja Institute, Melbourne.

Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2009, *Supporting Indigenous Researchers: A practical guide for supervisors*, CRC for Aboriginal Health, Darwin.

Lawrence, M. with Dodd, Z., Mohor, S., Dunn, S., de Crespigny, C., Power, C. & MacKean, L. 2009, *Improving the Patient Journey: Achieving positive outcomes for remote Aboriginal cardiac patients*, CRC for Aboriginal Health, Darwin.

Lowell, A., Brown, I., Marr\anyin, B., Flack, M., Christie, M., Snelling, P. & Cass, A. 2005, *Sharing the true stories, Improving Communication between health staff and Aboriginal patients: Stage 1 report*, CRC for Aboriginal Health, Darwin.

Martini, A., Marlina, U., Dwyer, J., Lavoie, J., O'Donnell, K. & Sullivan, P. 2011, *Aboriginal Community Controlled Health Service Funding: Report to the sector 2011*, The Lowitja Institute, Melbourne.

McCoy, B. 2011, *Art Into Health: Puntu Palyarrikuwanpa Aboriginal men becoming well*, The Lowitja Institute, Melbourne.

Monson-Wilbraham, L. 2014, *Watering the Garden of Family Wellbeing: Empowering Aboriginal and Torres Strait Islander people to bloom and grow*, The Lowitja Institute, Melbourne.

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Newton King, M. 2006, *Relevance of an Accredited Australian Diabetes Educators Association Course to Aboriginal Health Workers, Supervisors and Aboriginal People in South Australia*, CRC for Aboriginal Health, Darwin.

Rivalland, P. & Western Desert Nganampa Walytja Palyantjaku Tjutaku 2006, *Making all our Families Well: Summary report November 2006*, CRC for Aboriginal Health, Darwin.

Silburn, K., Reich, H. & Anderson, I. (eds) 2016, *A Global Snapshot of Indigenous and Tribal People's Health: The Lancet–Lowitja Institute Collaboration*, The Lowitja Institute, Melbourne.

Silburn, K., Thorpe, A., Carey, L., Frank-Gray, Y., Fletcher, G., McPhail, K. & Rumbalara Aboriginal Co-operative 2016, *Is Funder Reporting Undermining Service Delivery? Compliance Reporting Requirements of Aboriginal Community Controlled Health Organisations in Victoria*, The Lowitja Institute, Melbourne.

Silburn, K., Thorpe, A. & Anderson, I. 2011, *Taking Care of Business: Corporate services for Indigenous primary health care services – Overview report*, The Lowitja Institute, Melbourne.

Silburn, K., Thorpe, A. & Anderson, I. 2011, *Taking Care of Business: Corporate services for indigenous primary health care services – Summary report*, The Lowitja Institute, Melbourne.

Silburn, K., Thorpe, A. & Anderson, I. with Bila Muuji Health Services Inc, CAAC, Katherine West Health Board & Queensland Aboriginal and Islander Health Council 2011, *Taking Care of Business: Corporate services for indigenous primary health care services – Case studies*, The Lowitja Institute, Melbourne.

Schierhout, G., Brands, J. & Bailie, R. 2010, *Audit and Best Practice for Chronic Disease Extension Project, 2005–2009: Final report*, The Lowitja Institute, Melbourne.

Simpson, P., Guthrie, J., Lovell, M., Walsh, C. & Butler, A. 2014, *Views on Alternatives to Imprisonment: A Citizens Jury approach*, The Lowitja Institute, Melbourne.

Sullivan, P. 2015, *A Reciprocal Relationship: Accountability for public value in the Aboriginal Community sector*, The Lowitja Institute, Melbourne.

Tilton, R., Martini, A., Brown, C. & Strout, K. 2015, *Towards a History of Apunipima Cape York Health Council, 1994–2006*, The Lowitja Institute, Melbourne.

Watson, C. & Harrison, N. 2009, *New South Wales Aboriginal Mental Health Worker Training Program: Implementation review*, CRC for Aboriginal Health, Darwin.

Wise, M., Angus, S., Harris, E. & Parker, S. 2014, *National Appraisal of Continuous Quality Improvement Initiatives in Aboriginal and Torres Strait Islander Primary Health Care: Final report*, The Lowitja Institute, Melbourne.

CRCAH Discussion Paper Series: Titles

Frank Siciliano, Matthew Stevens, John Condon & Ross Bailie 2006, *A Longitudinal Data Resource on Key Influences on Health in the Northern Territory: Opportunities and obstacles*, Discussion Paper (DP) No. 1.

Mark Lock 2007, *Aboriginal Holistic Health – A critical review*, DP No. 2.

Jackie Street, Fran Baum & Ian Anderson 2008, *Making Research Relevant: Grant assessment processes in Indigenous research*, DP No. 3.

Yin Paradies, Ricci Harris & Ian Anderson 2008, *The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda*, DP No. 4.

Margaret Scrimgeour & David Scrimgeour 2008, *Health Care Access for Aboriginal and Torres Strait Islander People Living in Urban Areas, and Related Research Issues: A review of the literature*, DP No. 5.

Scott R. Davis & Jenny Brands 2008, *Research Priorities in Aboriginal Prisoner Health: Recommendations and outcomes from the CRCAH Aboriginal Prisoner Health Industry Roundtable, November 2007*, DP No. 6.

A. McEwan, K. Tsey & Empowerment Research Team 2008, *The Role of Spirituality in Social and Emotional Wellbeing Interventions: The Family Wellbeing Program at Yarrabah*, DP No. 7.

K. Mayo, K. Tsey & Empowerment Research Team 2009, *Research Dancing: Reflections on the relationships between university-based researchers and community-based researchers at Gurriny Yealamucka Health Services Aboriginal Corporation*, Yarrabah, DP No. 8.

Vicki Grieves 2009, *Aboriginal Spirituality: Aboriginal philosophy, the basis of Aboriginal social and emotional wellbeing*, DP No. 9.

Kerrie Kelly, Pat Dudgeon, Graham Gee and Belle Glaskin (on behalf of the Australian Indigenous Psychologists Association) 2009, *Living on the Edge: Social and emotional wellbeing and risk and protective factors for serious psychological distress among Aboriginal and Torres Strait Islander people*, DP No. 10.

N. Poroch, K. Arabena, J. Tongs, S. Larkin, J. Fisher & G. Henderson 2009, *Spirituality and Aboriginal People's Social and Emotional Wellbeing: A review*, DP No. 11.

The Lowitja Institute Discussion Paper Series: Titles

Genevieve Howse 2011, *Legally Invisible – How Australian laws impede stewardship and governance for Aboriginal and Torres Strait Islander health.*

B. Fredericks & D. Legge 2011, *Revitalizing Health for All: International Indigenous Representative Group. Learning from the experience of comprehensive primary health care in Aboriginal Australia – A commentary on three projects.*

E. Kowal, L. Rouhani & I. Anderson 2011, *Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the conversation.*

E. Kowal & I. Anderson 2012, *Genetic Research in Aboriginal and Torres Strait Islander Communities: Continuing the conversation.*

M. Hefler & D. Thomas 2013, *The Use of Incentives to Stop Smoking in Pregnancy among Aboriginal and Torres Strait Islander Women.*

A. Thorpe, K. Arabena, P. Sullivan, K. Silburn & K. Rowley 2016, *Engaging First Peoples: A review of government engagement methods for developing health policy.*

Appendix 6: List of projects

Unfortunately, the list below is not comprehensive. However, in reviewing this material we thank wholeheartedly all those who made this research possible and contributed to this endeavour, and apologise for any omissions.

CRC and Lowitja Institute projects are conducted under the auspices of the CRC, within a framework of its priorities and supported by CRC funding, but are administered by Partners and Participants (see Appendix 3). The research is conducted by those Partners and Participants and other contributing organisations and individuals, too numerous to mention. The knowledge and intellectual property that they bring to the work is critical to the creation of new knowledge.

Project title	Project leader/s
CRC for Aboriginal and Tropical Health Program: Indigenous Health and Education Research	
CRC for Aboriginal and Tropical Health Program: Indigenous Health and Education Research	The University of Melbourne
Systematic review of education and health among Indigenous Australians	B. Boughton, K. Tsey, A. Lovell
Indigenous education and health: Exploring the connections	A. Lovell, M. Katona, E. Lawurrpa
Indigenous education and health: An Aboriginal framework for practice	D. Maidment
Education and health: A study with a local community	D. White
Health and education in early childhood	C. Matthews
Evaluation of an Aboriginal empowerment program	K. Tsey
Indigenous health and education: An Aboriginal framework for practice	D. Maidment
Derive appropriate health education from research	K. Henderson
Sharing the True Stories: A participatory action research project to improve communication between health staff and their Aboriginal clients	I. Brown
Action research into the development, documentation and evaluation of multi-purpose Aboriginal nurturing centres	M. Malin
Evaluation of the Irrkerlantye Learning Centre (an Arrente integrated health and education centre)	M. Malin
Promoting ethical research with Indigenous communities	J. Devitt
Public health and teacher education program about education–health links	
CRC for Aboriginal and Tropical Health Program: Health Information and Technology Research	
Developing best practice guidelines for implementing IT in Aboriginal health care settings: A collaboration between NTU and FU	B. O'Reilly
Achievements in Aboriginal and Torres Strait Islander health	J. Wakerman
HealthConnect evaluation trial	N. Harrison
Placing Indigenous mortality in an international context (in-kind)	J. Cunningham
Community Housing and Infrastructure Needs Survey (CHINS) atlas of Indigenous housing and infrastructure need (externally funded)	R. Bailie
Refinement of national performance indicators and target Aboriginal and Torres Strait Islander health	D. Mackerras
Demographic issues: Presentation to Commonwealth Grants Commission for NT Treasury (externally funded)	Y. Paradies

Project title	Project leader/s
CRC for Aboriginal and Tropical Health Program: Communications and Information Research	
Information technology communications and standards	S. Heard, P. Morrison
CRC Information Systems	T. Dunbar
CRC for Aboriginal and Tropical Health Program: Health Resources and Service Delivery Research	
Understanding health research workshops	J. Devitt
Box-jelly fish materials	B. Currie
An investigation of the health service communication issues surrounding intensive care for Indigenous people	K. Kemp
Regional centres (Indigenous social and emotional wellbeing) research and evaluation	Moir-Bussy, P. Vidot
Maternal experiences of Aboriginal women admitted to Royal Darwin Hospital	K. Hodson
Refining national Indigenous health performance indicators	A. Barnes
Evaluation of women's services at Gumileybirra Women's Centre, Danila Dilba Medical Service	J. Hunt
Management through Aboriginal health councils and boards	
Sustainability of chronic diseases management: A follow up study of renal treatment programs in the Tiwi Islands	G. Robinson
Health services and other factors affecting survival of Aboriginal people with cancer	J. Condon
Delays in diagnosis of cancer: State of disease at diagnosis and cancer survival	J. Condon
Getting a life: Sharing health care initiative	J. Devitt
Indigenous injury prevention	E. Kowal
Evaluation of Katherine West Chronic Disease Self Management Project	E. Chalmers
Itinerants project in Darwin and Palmerston	M. Beneforti
Centre for Clinical Research Excellence	T. Weeramanthri
Health centre organisation for the prevention and management of chronic disease	R. Bailie
Law, family and health	J. Devitt
Action research into managing, undertaking and disseminating Aboriginal health research for improved health outcomes	A. Arnott
Comparative longitudinal study for NT health zones prior to introduction of Commonwealth Government's Primary Health Care Access Plan	J. Devitt
Review of specialist outreach services	R. Gruen
Potential cost savings to the health system in reducing chronic disease in Aboriginal and Torres Strait Islander populations by improving nutritional intake: Feasibility study	D. Mackerras
Evaluation of PBS Medicine supply arrangements for remote area Aboriginal Health Services	M. Kelaher
Performance indicators reporting project	P. Gollow
Feasibility study of integrated skin care program	C. Connors
Katherine West Health Board self-care of chronic disease demonstration project	B. Schmidt
Law, family and health (previously Management through Aboriginal health councils)	J. Devitt
The significance of Aboriginal women working in the health sector in the Northern Territory	J. May
Why are fewer hospital procedures recorded among patients identified as Indigenous?	J. Cunningham
Action research into managing, undertaking and disseminating Aboriginal health research for improved health outcomes	A. Arnott
Community population measurement for health services, research and decision-making	T. Barnes

Project title	Project leader/s
CRC for Aboriginal and Tropical Health Program: Public Health Research	
Adverse health effects of excessive kava and alcohol use in Aboriginal communities	B. Currie
Katherine Flood Research Project	M. Rosa, A. Garrow
Epidemiological modelling to understand endemic bacterial infection and antibiotic resistance in Aboriginal communities	
Rethinking compliance	K. Humphrey
Rheumatic heart disease – A partnership for change	B. Currie
Early treatment for prevention of chronic otitis media	A. Leach
The Tobacco Project: Development and evaluation of a community smoking intervention program	R. Ivers
Evaluation of the Tiwi Health Board's life promotion and community services	G. Robinson
Investigating indicators for Indigenous sport and recreation program	J. Cunningham
Public Health Bush Book (mental health supplement)	S. Guthridge
Exploring Together	G. Robinson
Development of parenting support interventions for	
Indigenous families	G. Robinson
Review of NT Schools Drug and Alcohol Prevention Strategy	A. Duquemin
Review of mental health promotion initiatives for Aboriginal communities in the NT	N. Clelland
Impact of conjugated pneumococcal vaccine on perforation rates in a high-risk population: A before and after study (PROMPT)	P. Morris
The impact of conjugated pneumococcal vaccine on pneumococcal carriage dynamics (including antibiotic resistance) and the clinical course of otitis media	A. Leach
Stress and chronic diseases: a systematic review	T. Weeramanthri, J. Cunningham
Improving growth promotion in the NT ('Understanding child growth')	D. Smith
Investigating approaches to a community-based nutrition program in a remote Aboriginal community	I. Warchivker
Socioeconomic and environmental determinants of health in Indigenous communities in the NT	R. Bailie, M. Stevens
Indigenous home ownership study	J. Cunningham
Health centre organisation for the prevention and management of chronic disease	R. Bailie
Fluoridation demonstration project	R. Bailie
Economics of fluoridation of water supplies to Nguiu	K. Chinna
Northern Territory burden of disease study	Y. Zhao
Informed consent: A pilot study on the quality of informed consent material given to Aboriginal participants	F. Russell
Evaluation of the Tiwi Health Board's life promotion and community services	G. Robinson
Investigating indicators for Indigenous sport and recreation program (externally funded)	J. Cunningham
Indigenous Australians and tobacco: A literature review	R. Ivers
Stories about Katherine West floods	M. Scarlett
Feasibility of establishing a residential 'like skills' program for young Indigenous people in urban centres of the NT	Y. Paradies

Project title	Project leader/s
Rheumatic fever prophylaxis (now amalgamated with Healthy skin)	B. Currie
Antibiotic treatment of middle ear infections (otitis media) in Aboriginal infants	A. Leach
Acute otitis media in Aboriginal children: A video study	P. Morris
Gastroenteritis rates in Top End Aboriginal children	K. Edmonds
Impact of conjugated pneumococcal vaccine on perforation rates in a high-risk population: A before and after study (PROMPT)	P. Morris
Scoping project on dog ecology in Flores, Indonesia (externally funded)	T. Barnes
The impact of conjugated pneumococcal vaccine on pneumococcal carriage dynamics (including antibiotic resistance) and the clinical course of otitis media (externally funded)	A. Leach
The impact of Prevenar™ on the incidence of X-ray–confirmed pneumonia in Aboriginal children under two years in the NT (in-kind, externally funded)	A. Ruben
The impact of Prevenar™ on the incidence of invasive pneumococcal disease in Australian children under two years (in-kind, externally funded)	V. Krause
Stress and chronic diseases: A systematic review	T. Weeramanthri, J. Cunningham
Improving growth promotion in the NT (understanding child growth)	D. Smith
Community infrastructure needs and health outcomes	R. Bailie
Socioeconomic and environmental determinants of health in Indigenous communities in the NT	R. Bailie
Evaluation of health impact of the ATSIC Health Infrastructure Priority Projects of the National Aboriginal Health Strategy program in the Top End (in-kind)	S. Guthridge
Aboriginal communities health information project	S. Guthridge
Homemakers program mapping project of the NT	S. Guthridge
Indigenous home ownership study (externally funded)	J. Cunningham
CRC for Aboriginal and Tropical Health Program: Biomedical Research	
Scabies research: (a) a molecular approach to the epidemiological and immunological aspects of scabies; (b) antigens, allergens and immune responses to normal and crusted scabies; (c) permethrin sensitivity	S. Walton
Anti-attachment peptides: A novel therapeutic strategy to control group A streptococcal (GAS) infection	S. Sriprakash, P. Fagan
Group A streptococcus (GAS) infections	S. Sriprakash
Prevention and control of scabies in children: monitoring for emerging resistance to current treatments in endemic communities in northern Australia	S. Walton
Molecular dissection of prtF2, a fibronectin binding protein	S. Sriprakash
Identification and immunological characterisation of surface proteins from group A streptococcus for vaccine purposes	S. Sriprakash
Optimising chronic lung disease care for Indigenous Australians	G. Maguire, B. Currie
Melioidosis and pneumonia	B. Currie, M. Mayo, D. Gal
B cell antigens as a marker of susceptibility to acute rheumatic fever	Z. Harrington
Community-based interventions to reduce the riskof cardiovascular disease and diabetes among Indigenous Australians	D. Mackerras
Markedly elevated nitric oxide (NO) production/peripheral blood mononuclear cell (PBMC) nitric oxide synthase (NOS2) expression in asymptomatic malaria-exposed adults in rural Indonesia, with highest NO production in those with asymptomatic Plasmodium falciparum parasitemia	N. Anstey, C. Boutlis

Project title	Project leader/s
Study towards a simple and rapid test for group B streptococcus for use in labour	S. Sriprakash
Towards better treatment and diagnosis of malaria in Eastern Indonesia	N. Anstey
Markedly elevated nitric oxide (NO) production/peripheral blood mononuclear cell (PBMC) nitric oxide synthase (NOS2) expression in asymptomatic malaria-exposed adults in rural Indonesia, with highest NO production in those with asymptomatic Plasmodium falciparum parasitemia	C. Boutlis
CRC for Aboriginal Health Program: Chronic Conditions	
Optimising chronic lung disease care for Indigenous Australians	B. Currie
Meliodosis and pneumonia	B. Currie, M. Mayo
The incidence of radiologically diagnosed pneumonia in Aboriginal children aged under 2 years in the NT	A. Ruben, P. Morris
DRUID: Diabetes and related disorders in urban Indigenous people in the Darwin region	J. Cunningham
Understanding current methods for clinical assessment and provision of ongoing care for Aboriginal people experiencing co-existing diabetes and alcohol related harm	C. de Crespigny
Grandmother's wisdom: Domestic violence and harmful drinking in Aboriginal communities in SA	C. de Crespigny
IMPAKT	A. Cass, J. Devitt
Cancer in Aboriginal and Torres Strait Islander peoples in Queensland	P. Valery
Predictive models and interventions for coronary heart disease in Aboriginal and Torres Strait Islander people	K. Rowley
The Centre for Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Studies	I. Kowanko
Establishing the prevalence of the Human Papilloma Virus (HPV) infection in Indigenous and non-Indigenous women in Australia	S. Garland, J. Condon
Assessment of hearing of school-aged children in the APY lands of South Australia	L. Sanchez
PneuMum: A randomised controlled trial of pneumococcal polysaccharide immunisation for Aboriginal mothers to protect their babies from ear disease	R. Andrews
Graduate Certificate in Health: Diabetes management COURSE	M. King
Ear health research transfer project	P. Morris, J. Brands, S. Hopkins
Centre for Excellence in Indigenous Tobacco Control (CEITC)	V. Briggs
A collaborative and international study of bronchiectasis in Indigenous children	P. Morris
(Student) HPV vaccine and the Indigenous community intentions to vaccinate their pre-adolescent children: What do Indigenous people think about giving a vaccine to children to prevent cancer of the cervix?	M. Heffernan
Monitoring Aboriginal tobacco control	D. Thomas
CQI and health promotion	R. Bailie, N. Clelland, L. McCarthy
Chronic conditions self-management	P. Harvey, I. Kowanko, M. Battersby
Men's sheds/spaces	R. Haye, J. Bulman
Talking about maternity and postnatal care with Aboriginal families in Victoria and SA	S. Brown
Reducing prevalence of non-communicable disease risk factors among Indigenous Australians	K. O'Dea, J. Brimblecombe
Point-of-care in Aboriginal hands	M. Shephard

Project title	Project leader/s
Assess the impact of an accredited Australian Diabetes Educators Association course on the diabetes health care of Aboriginal people in SA	M. King
Evaluating the use of the Flinders model of chronic care (incorporating care planning and self-management in Aboriginal health services)	M. Battersby
The development and delivery of online postgraduate education – Graduate Certificate in Health (Self-management) COURSE	M. Battersby
Preparation of a consultation framework and scoping paper for the implementation of chronic condition self-management within Aboriginal health worker education courses	M. Battersby
The self-management component of the National Chronic Disease Self-management Strategies	M. Battersby
Chronic condition self-management education and training for Aboriginal health workers (and others working in Aboriginal health programs) COURSE	M. Battersby
Preparation of a national chronic condition self-management curriculum resource kit for use in the Aboriginal health worker and Torres Strait Islander health worker education programs	M. Battersby
(Student) The impact of Aboriginal health workers undertaking the diabetes educators course at Flinders University	A. Eastwood
CRC for Aboriginal Health Program: Social Determinants of Health	
Identification of access and equity issues governing domestic water charges to Indigenous families in SA	E. Willis
Compositional and contextual determinants of urban health inequities: An Indigenous perspective	F. Baum
Housing improvement and child health	R. Bailie
Developing a best practice model of holistic health service delivery for Aboriginal and Torres Strait Islander inmates of the Alexander Maconochie Correctional Centre in the ACT	G. Henderson
Handwashing campaign	N. Slavin
Aboriginal people travelling well	Y. Helps
Utility costs as a social determinant of health	E. Willis
(Student) Analysis of representation of Indigenous Australians in mainstream print media: An exploration centred on the social determinants of health	J. Roberts
Stock-take and gap analysis of Indigenous drug prevention research	R. Renhard
(Student) Strengthening our voice: A comparative post-colonial narrative of the Kamilaroi people of northwest NSW and Canadian people	S. Fernando
Fluoridation demonstration project	R. Bailie
Social determinants of Indigenous health short course and textbook	R. Bailie
Water service delivery and State and Commonwealth water reform objectives – A response from Aboriginal communities in SA	M. Pearce
Water service delivery and changing household water use	E. Willis
CRC for Aboriginal Health Program: Social and Emotional Wellbeing	
Development of parenting support interventions for Indigenous families	G. Robinson
Integration of Indigenous health into Master of Psychiatry/Master of Psychiatric Medicine COURSE	S. Ewen
Coordinated Aboriginal mental health care	I. Kowanko
Australian integrated mental health initiative	T. Nagel
Learning from action: Management of Aboriginal health services	J. Dwyer

Project title	Project leader/s
Evaluating antenatal care services in the Central Australian region	L. Maidment
Social determinants of health: Publication of workshop papers	M. Bentley
Safe management of intoxicated people training COURSE	C. de Crespigny
Mental health and AOD co-morbidity: Emergency mental health and AOD co-morbidity – Intensive training courses COURSE	C. de Crespigny
Koori health: Past and present COURSE	S. Ewen, B. Genat
Development and delivery of postgraduate subject stream COURSE	S. Ewen, B. Genat
Indigenous social and emotional wellbeing and what we can do to improve it: Muuji Regional Centre research project	G. Henderson
Researching the control factor and the concept of empowerment in addressing the social determinants of health	M. Haswell
Empowerment as a strategy for health and wellbeing	M. Haswell
Scoping paper on social and emotional wellbeing	W. Edmondson
Imagining childhood: Children culture and community	G. Robinson
Developing, sustaining and evaluating health programs for Aboriginal men	B. McCoy
Take two – Aboriginal team	R. Pawsey, M. Frederico
Measuring the social and emotional wellbeing of Indigenous children	M. Frederico, M. Bamblett
Boys to men: Garbutt Magpies 25 years on	B. McCoy, J. Elston
Analysis of historical and contemporary reproductive health issues for Aboriginal and Torres Strait Islander adolescents	K. Arabena
Evaluation of the Top End division of General Practice Aboriginal Medical Health Worker Program (exploring together)	G. Robinson
Maternal and child health project	J. Boffa
CRC for Aboriginal Health Program: Comprehensive Primary Health Care, Health Systems and Workforce	
Delivery of Bachelor of Applied Health Science (Indigenous health) COURSE	R. Taylor
Audit and Best practice for Chronic Disease Extension (ABCDE)	R. Bailie
(Student) Information atlas project	S. Shibasaki
Building workforce capacity to address complex health, housing and social inclusion issues through critical systems thinking and practice	J. McIntyre, A. Roche
Capacity building in Indigenous policy-relevant health research (CIPHER)	J. Cunningham
Improved dental health for remote Aboriginal children: A cluster randomised trial	P. Morris
Teaching and learning topics in Indigenous health in Central Australia COURSE	K. Taylor
A critical analysis of the quality and effectiveness of health care communications between English speaking health staff and speakers of Indigenous languages in Central Australia	K. Taylor
National Institute of Clinical Studies Collaborative – Research transfer and knowledge brokerage in the Indigenous health context	J. Brands
(Student) The changing trends in end of life care	C. McGowan
(Student) Injury mortality of Indigenous Australians: An exploration of data quality and ascertainment bias (research component of Master of Public Health)	J. Berry
Remote health practice program COURSE	S. Knight
(Student PhD) Assessing Cost Effectiveness prevention	M. Otim

Project title	Project leader/s
Continuous improvement project (CIP) in the early detection and management of chronic disease for Aboriginal and Torres Strait Islander people	M. Roberts
Building the capacity of local Aboriginal communities to develop population health initiatives	P. Pyett
(Student) Putting cultural policy into practice	F. Smullen
Public health coursework program COURSE	C. Richardson
Developing sustainable Aboriginal health research practice	P. Pyett
(Student PhD Thesis) An inquiry into the principles that CAAC uses to negotiate the tensions that exist between different conceptual approaches to health development which leads to styles of practice conceived within either a structural determinant framework or a personal responsibility approach	J. Boffa
Study of Indigenous research reform	T. Mackean
Developing and testing the tools necessary to deliver primary health care maternity services for Indigenous women	L. Barclay
Improving the culture of hospitals project	R. Renhard
Aboriginal and Torres Strait Islander apprenticeships with Department of Health and Community Services	D. Josif
BIITE residential workshop: Public health perspectives and methods (offered jointly with MSHR) COURSE	K. Senior
Health service utilisation – Stage 1	M. Bentley, R. Walker, B. Fredericks
Frameworks for best practice in funding and regulation project	J. Dwyer
ACE prevention – Advisory committee project	R. Carter
Quality standards in Aboriginal and Torres Strait Islander health	I. Anderson, M. Gooda
Cultivating a concern for cultural competency	T. Sofra
Comparative longitudinal study for NT health zones	R. Bailie
Sharing the true stories	I. Brown, M. Christie
An evaluation of the third edition of the CARPA Standard Treatment Manual and the development of flexible methods of accessing the fourth edition (J. Wakerman, J. Grundy)	J. Wakerrman
Looking for practical solutions for quality assessment processes for grant and publication reviews in Aboriginal health	F. Baum
The burden of disease and injury in Indigenous Australians	T. Vos
Overseas trained doctors in Aboriginal health services	P. Hill
The National Trachoma and Eye Health Program (NTEHP) history project	G. Gray
(Student PhD) Feasibility of transferring an Aboriginal health program that is successful from one community to another	J. Mitchell
(Student) Improving the patient journey	M. Lawrence
Development of clinical practice guidelines for the management of alcohol problems in ATSI peoples	C. de Crespigny
Hospitalised injury of Australia's Aboriginal and Torres Strait Islander people, 2000–02	Y. Helps
Aboriginal Health Council of SA/Royal Adelaide Hospital procedures and protocols project	A. Chong
Grow well project	B. Loomes

Project title	Project leader/s
CRC for Aboriginal and Torres Strait Islander Health Program: Healthy Start, Healthy Life	
Phase 1 clinical trial of a vaccine for group A streptococcus	M. Good, M. Batzloff
One21seventy workforce development	J. Hains
Quality of care project (Stage 1)	R. Bailie
Quality of care project complimentary funding	R. Bailie
National appraisal of CQI initiatives in Indigenous primary health care	M. Wise
Implementation of innovations in Aboriginal and Torres Strait Islander health	J. Brands
Cancer Roundtable	J. Brands, G. Garvey
Cancer CRE proposal development support	G. Garvey
AIMhi Workforce development project	T. Nagel
Anaemia in Indigenous children and perinatal women in QA workshop	T. Keirns
Scabies mite intestinal proteases as targets for novel therapies	K. Fischer
Evaluating the role of Aboriginal and Torres Strait Islander primary health care networks in improving the effectiveness of primary health care outcomes for Aboriginal and Torres Strait Islander Australians	F. Cunningham
Improving health services' capacity for Indigenous health promotion – A systems approach	C. Armit
The six-minute walk test: A diagnostic tool for assessing disease severity in patients with chronic respiratory condition in remote community outreach clinics	N. Asokananthan
Extending the frontiers of continuous quality improvement: Policy, service and research development in Aboriginal and Torres Strait Islander primary health care	F. Cunningham
Measuring cultural competence of health services	D. Butler
Evaluation of FDA process	URBIS
Menzies cancer program – National approach to improve cancer outcomes for Aboriginal and Torres Strait Islander people	G. Garvey
Development and implementation of a sexual health CQI audit tool and protocol	B. Nattabi
Evaluation of Baby Basket program	J. Mein
Health Promotion and CQI: Tools and resources	L. O'Donoghue, N. Percival
Cancer CRE	G. Garvey, L. Whop
Victorian Aboriginal Child Mortality Study (Phase 2)	J. Freemantle
Consumer perception tool implementation	C. Armit
Cancer tool	B. Thewes
Pregnancy Immunisation test	R. Andrews
Let's start	G. Robinson
ABCD knowledge exchange project	A. Laycock
Learning from Central Australian Aboriginal women's experiences: Reflections on participation in the CAAC Family Partnership Program in Alice Springs	S. Fitz
Aboriginal patient journey mapping tools project: Communicating complexity	J. Kelly
Childhood anaemia – Knowledge and resource development project	T. Kearns
Insights into early origins of Aboriginal chronic non-communicable disease	S. Sayers
The effect of early life conditions and experiences on child development and learning: A whole population study	S. Guthridge

Project title	Project leader/s
Scabies mite complement inhibitors as targets for novel therapeutics	K. Fischer
Water Conservation for Amata and Mimili	M. Pearce
Comprehensive primary health care in local communities	T. Freeman
Western Australian Aboriginal intergenerational foetal growth	L. Gubhaju
Significance and Impact of perceptions of identity, authenticity and deficit language on Aboriginal peoples	K. Arabena
CRC for Aboriginal and Torres Strait Islander Health Program: Healthy Communities and Settings	
Understanding and addressing racism against Aboriginal and Torres Strait Islander Australians through the LEAD program	Y. Paradies
Scoping study of health promotion tools for Aboriginal and Torres Strait Islander peoples	M. Wise, S. Angus
Creating Healthy Environments: Development and trial of an integrated model for Aboriginal health and its evaluation	K. Rowley
Aboriginal People Travelling Well report	Y. Helps
Students – Yarning up with Koori kids	L. Thompson
Adult Literacy Project – Wilcannia Stage 2	B. Boughton
Health promotion capacity building: Tools, Resources and Training (TRT) to strengthen health promotion practice and outcomes – Stages 2–4	N. Percival
Art into Health publication	B. McCoy
Health promotion knowledge exchange: Facilitating the implementation of evidence-based tools to strengthen Aboriginal and Torres Strait Health promotion (health promotions tool website)	N. Percival
Family Wellbeing Roundtable: 'Empowering Aboriginal and Torres Strait Islander people through the Family Wellbeing program'	K. Tsey, A. Chong, L. Monson-Wilbraham
Improving the culture of hospitals (Australian Quality Improvement Toolkit for Hospital Staff)	J. Willis
Feeling Deadly, Working Deadly Workshop	A. Trifonoff, A. Roche
Impact analysis on the longitudinal impact of family therapy capacity building training on service delivery and improved Aboriginal and Torres Strait Islander family outcomes	K. Proctor
Knowledge exchange strategy for book launch of Empowerment: An Aboriginal Family Wellbeing Framework	M. Whiteside
Racism Symposium and development of communication materials	N. Priest
Innovation and knowledge translation symposium & presentations on Deadly Choices evaluation	A. Nelson
Culture mediation approach in Aboriginal primary health care: Impacts on screening and treatment for risky alcohol consumption	R. Lovett
Evaluation of a health education initiative for urban Aboriginal an Torres Strait Islander people	A. Nelson
Quantifying the health benefits of on-country activities in the remote Indigenous community of Groote Eylandt	R. Wilson
An integrated and comprehensive model of care targeting at-risk clients in metropolitan Aboriginal community controlled health service: Model development and evaluation plan	J. Kaldor
Alcohol management plans in Indigenous Australia	M. Langton
Aboriginal fathers in primary school	B. McCoy
Thursday Island and Northern Peninsula Area Youth and Relationships Networks Evaluation	M. Whiteside
Book publication: Stories of change	M. Whiteside

Project title	Project leader/s
Nindilingarri Cultural Health Services: Health promotion program evaluation	B. Genat
Mad Bastards group discussion guide	M. Williams
CRC for Aboriginal and Torres Strait Islander Health Program: Enabling Policies and Systems	
The role of planning processes in implementing National Partnership Agreements in Indigenous health. Understanding process and evaluating effectiveness	M. Kelaher
Improving the Culture of Hospitals Bridging Project	J. Willis
Options for enduring government responsibility for Aboriginal health (Stewardship 1) – Legally Invisible	G. Howes
Stewardship 2 – Stewardship dialogues	I. Anderson
Planning, implementation and effectiveness (PIE) in Aboriginal and Torres Strait Islander health policy reform (Phase 2)	M. Kelaher
Flexible career pathways for Aboriginal health workforce sector	T. Bretherton
Funding, accountability and results (FAR) for Aboriginal health services – Closing the policy implementation gap?	J. Dwyer
Models of rapid synthesis – Australian Aboriginal health search portal	J. Tieman
Engagement Methods and Policy	K. Arabena
Collaboration supporting a nationally accessible MPH specialisation in Indigenous health	L. Coombe, S. Ewen
Collaboration supporting a nationally accessible MPH specialisation in Indigenous health	G. Marks
Support for Aboriginal Health Council SA (AHCSA) Certificate IV course in Indigenous research capacity building	M. Malin
Expanding our tools to close the cap: Towards Indigenous genomic health research	E. Kowal
Administering the Aboriginal community controlled health sector for public value and robust accountability	P. Sullivan
Identifying the compliance requirements for Aboriginal Community Controlled Cooperatives in Victoria	K. Silburn
Reducing Australia's Aboriginal prisoner population using Justice Reinvestment – Assessing the public's views to incarceration versus non-incarceration using a Citizens' Jury Approach	T. Butler
From Broome to Berrima: Indigenous offender health research capacity building grant	P. Simpson
Stepping up SA: Managing Two Worlds Together	J. Kelly
Uptake of evidence to policy: The Indigenous Burden of Disease case study	P. Hill
Learning from working life: Professional development for Aboriginal health staff	J. Dwyer
What works? A review of actions addressing the social and economic determinants of Indigenous health	K. Osborne
Lowitja Institute CRC Program: Community Capability and the Social Determinants of Health	
Evaluation of a successful Anaemia Prevention Program in a remote Aboriginal community in NT	T. Kearns
Growing up children in two worlds: Building Yolnu skills, knowledge and priorities into early childhood assessment & support	A. Lowell
Empowering Indigenous individuals, families and communities to create supportive environments for children to thrive – Family Wellbeing	Y. Cadet-James
Mayi – Kuwayu: A large-scale longitudinal study of cultural Aboriginal and Torres Strait Islander wellbeing	R. Lovett
Exploring Aboriginal and Torres Strait Islander cultural identity of young people in flexi schooling contexts	M. Shay

Project title	Project leader/s
The role cultural connectedness plays in the pathways to resilience experienced by Aboriginal and Torres Strait Islander adolescents	R. Bainbridge
Analysis of key factors associated with Aboriginal and Torres Strait Islander suicide in South Australia	T. Mackean
Service integration for Aboriginal & Torres Strait Islander early childhood (collaborative seed funding to leverage further $)	J. Burton, K. Arabena
The narrative framing of Aboriginal and Torres Strait Islander health and wellbeing: A review	M. Dodson
Reframing discourse and changing the narrative of Aboriginal and Torres Strait Islander health and wellbeing: An analysis	M. Dodson
Identifying the core elements of the cultural determinants of health of Aboriginal and Torres Strait Islander people	R. Lovett
Reclaiming strong Aboriginal and Torres Strait Islander identities through a gender equity lens	A. Mitchell
Lowitja Institute CRC Program: Needs and Opportunities for a Workforce to Address Aboriginal and Torres Strait Islander Health	
A review and analysis of the progress in building a Aboriginal and Torres Strait Islander researcher workforce since 2000	S. Ewen
Models and quality of genetic health services for Aboriginal and Torres Strait Islander people	M. Kelaher
Development of framework for evaluation of policies, programs and services that aim to improve Aboriginal and Torres Strait Islander health and wellbeing	M. Kelaher

Appendix 7: Scholarships

Name	Year Awarded	Level	Funding	Project	University
Debra Maidment	1999	Masters	CRCATH project/ Institute for Aboriginal Development project	Master of Education: Indigenous education and health: An Aboriginal framework from practice	IAD La Trobe Uni
Jessica May	1999	PhD	CRCATH scholarship	Aboriginal women's participation in the health workforce in the NT	NTU Curtin Uni
Danielle Smith	1999	Masters	CRCATH scholarship	Master of Science: Child growth promotion	MSHR Flinders Uni
Robyn Marsh	1999	Masters	CRCATH scholarship	Master of Science: Study towards a simple and rapid test to detect Group B Streptococcus in labour	MSHR NTU
Damien Howard	2000	PhD	CRCATH scholarship	Hearing loss, culture, and schooling: The social and behavioural impact of urban Indigenous students' hearing loss	NTU
Colin Watson	2000	PhD	CRCATH scholarship	Masculinity as a hazard to health in a Warlpiri community	NTU
Louise Martin	2000	BSc (Med.)	CRCATH scholarship	Coursework	Flinders Uni
Sonny Flynn	2000 (left in 2000)	Masters	CRCATH scholarship	MPH: Coursework	MSHR
Anne Tangey	2000	Masters	CRCATH scholarship	MPH: Coursework	MSHR
Mark Gutchen	2000	Graduate Certificate	CRCATH scholarship	Grad. Cert. Midwifery Coursework	NTU
Aleeta Dawes	2000	Bachelor of Medicine, Bachelor of Surgery	CRCATH scholarship	Coursework	Flinders
Pallave Dasari	2001	BSc(Hons)	CRCATH scholarship	Neutrophil response to Burkholderia pseudomallei before and after the application of Granulocyte colony-stimulating factor	MSHR NTU
Jason Davidson	2001	Masters	CRCATH scholarship Became CRCAH scholarship	MATSIS: Aboriginal imagination – Aboriginal new media artist promoting health education	CDU
Pearly Harumal	2001	PhD	NHMRC grant CRCATH scholarship APA scholarship	Antigens, allergens and immune responses in normal and crusted scabies	MSHR NTU
Eddy Mulholland	2001	Masters	CRCATH scholarship	MPH Coursework	MSHR
Mandy Edwards	2002	Masters	CRCATH Scholarship	Master in Science: Anti-attachment peptides: a novel therapeutic strategy control group A streptococcal infection	MSHR

Name	Year Awarded	Level	Funding	Project	University
Zinta Harrington	2002	Masters	CRCATH Scholarship	MSc (Med): Identify susceptibility marker for acute rheumatic fever and a laboratory test for acute rheumatic fever	MSHR
Liz McDonald	2002	PhD	NHMRC Scholarship with top-up from CRCAH	Improving hygiene and children's health in remote communities	NTU
Marlene Norman	2002	Graduate Diploma	CRCATH Scholarship	Grad. Dip. Pub. Health Coursework	MSHR
Yin Paradies	2002	PhD	NHMRC Scholarship with CRCATH assistance	Discrimination, stress and the health of Indigenous Australians	MSHR
Mark Lutschini (Lock)	2002	Masters	CRCATH scholarship	MPH	MSHR
Carlie Atkinson	2002	PhD	CRCATH scholarship	To investigate and explain the relationship between violent behaviours and generational post-traumatic stress	CDU
Fay Acklin	2003	PhD	CRCATH scholarship	Koori women: What they know, feel, believe and perceive about cervical cancer and pap tests	Newcastle Uni
Julie Brimblecombe	2003	PhD	National Heart Foundation scholarship with top-up from CRCATH	Understanding perceptions of food and diet in relation to health and wellbeing and the factors influencing the implementation and sustainability of food supply interventions among Aboriginal people living in a centralised community and its homelands	NTU
Liesa Clague	2002	Graduate Diploma	CRCATH scholarship	Grad. Dip. Midwifery Coursework	NTU
Gabrielle Diplock	2003	Bachelor of Speech Pathology (Hons)	CRCATH scholarship	A pilot study of two formal language assessment tools for preschool children living on the Tiwi Islands	Flinders Uni
Tahnia Edwards	2003	Masters	CRCATH scholarship	Master of Remote Health Practice Coursework	Flinders Uni
Leisa McCarthy	2003	PhD	CRCATH scholarship		Flinders Uni
Kate Mounsey	2003	PhD	CRCATH scholarship	Molecular diagnosis of acaricide resistance mechanism in tolerant and sensitive scabies mites from northern Australia	MSHR
Nissy Ordonez	2003	Bachelor of Medicine, Bachelor of Surgery	CRCATH scholarship	Coursework	Flinders Uni
Michael Otim	2003	PhD	CRCATH scholarship	Health economics	UoM
Curtis Roman	2003	PhD	CRCATH scholarship	Explore the use of health services by Aboriginal men in the Darwin area	NTU
Tomer Shemesh	2003	Masters	CRCATH scholarship	MSc	NTU

Name	Year Awarded	Level	Funding	Project	University
Matthew Stevens	2002	PhD	NHMRC scholarship with a top-up from CRCAH	Socioeconomic and environmental determinants of health in Indigenous communities in the Northern Territory	CDU
John Condon	2003	PhD	NHMRC/ CRCATH scholarship	Health services and other factors which affect cancer survival of Aboriginal people in the Northern Territory	NTU
Chelsea Bond	2004	PhD	APA scholarship with top-up from CRCAH	Promoting positive social change within an urban Aboriginal community through the strengthening of cultural identity	UQ
Frances Edmonds	2004	PhD	VicHealth scholarship with top-up from CRCAH	Art is us: Aboriginal art, identity and wellbeing in South-east Australia	UoM
Serene Fernando	2004	BApp Health Sci (IPHC) (Hons)	CRCAH scholarship	Health and wellbeing of individuals, families and community, in terms of the health benefits that accrue from education	UQ
Tess Hudson	2004	BSc(Hons)	CRCAH scholarship	The role of streptococcal protein F2 in the adherence and internalisation of group A streptococcus	MSHR
Jane Lloyd	2004	PhD	NHMRC scholarship with top-up from CRCAH	The implementation of Aboriginal health policy, through a case study of the NT Preventable Chronic Disease Strategy	MSHR UoS
Mark Lock	2004	PhD	CRCAH Scholarship	Study to map and analyse the structure of policy networks, and undertake interviews focusing on barriers affecting research to policy transfer in Aboriginal health	UoM
Tamara MacKean	2004	Masters	CRCAH scholarship	MPH by coursework and dissertation	Flinders Uni
Tom Ogwang	2004	BApp Health Sci (IPHC) (Hons)	CRCAH scholarship	The social context of volatile substance misuse among young urban Indigenous people, and their perceptions of structural responses to the range of behaviours they engage in	UQ
Tomer Shemesh	2004	PhD	APA scholarship with top-up from CRCAH	Inflammation, oxidative stress and cardiovascular risk factors in Indigenous Australians	CDU
Sanchia Shibasaki	2004	PhD	NHMRC scholarship with top-up from CRCAH	Identifying strategic information management practices needed by Primary Health Care Services to provide quality diabetes patient management	Griffith Uni
Anke Van Der Sterren	2004	PhD	NHMRC scholarship with top-up from CRCAH	Investigating Indigenous organisational structures and processes relevant to implementing a public health approach in the context of an urban ACCHS (Victorian Aboriginal Health Service)	UoM
Nicole Traves	2004	Doctor of Teaching	CRCAH scholarship	Coursework	CDU

Name	Year Awarded	Level	Funding	Project	University
Karen Adams	2005	PhD	NHMRC Scholarship with CRCAH top-up	Research methodology to better understand and evaluate prevention of chronic disease in Victorian Koori communities with a focus on child health and otitis media	UoM
Petah Atkinson	2005	PhD	CRCAH Scholarship	Documenting effective social capital formation processes at an individual and institutional level	UoM
Simone Smith	2005	BSc (Hons)	CRCAH Scholarship	Clinical tropical medicine	QIMR
Karen Taylor	2005	PhD	CRCAH Scholarship	Chronic and infectious disease	QIMR
Movra Wong	2005	Honours	CRCAH Scholarship	Developing an appropriate Indigenous self-management program for chronic diseases and training for health professionals	UQ
Angelina Tabuteau Moore	2006	Masters	CRCAH/DHS Koori Scholarship	Master of Public Health (coursework)	Deakin UoM
Luita Casey	2006	Honours	CRCAH scholarship	Bachelor of Science (Hons)	Flinders Uni
Angela Clarke	2006	PhD	CRCAH (support with project costs)	Community development in Indigenous communities	UoM
Samuel Crane	2006	Masters	CRCAH	Master of Social Health (coursework)	UoM
Steven Kelly	2006	Honours	CRCAH/DHCS	Bachelor of Arts (Hons)	CDU
Gregory Phillips	2006	PhD	CRCAH (support with project costs)	Motivation, self-perception and coping skills among health care providers in their professional roles	UoM
Anthony Ah Kit	2007	Masters	CRCAH Scholarship	Coursework	Flinders Uni
Vanessa Clements	2007	Masters	CRCAH professional development grant	MA in Education by coursework	ANU QIMR
Serene Fernando	2007	PhD	CRCAH Scholarship	Strengthening our voice: a comparative post-colonial narrative of the Kamilaroi people of northwest NSW and Canadian people	ANU
Justin Gladman	2007	PhD	CRCAH Scholarship	To explore systems and approaches to integrate Indigenous Health Care Workers into the health workforce	Flinders Uni
Kim Kilroy	2007	Masters (Research)	CRCAH Project funding	The social determinants of Indigenous health and mental health factors in personal and community wellbeing in relation to the removal of Indigenous children from the family unit	UQ
Erin Lew Fatt	2007	BBusiness	CRCAH professional development	Coursework	CDU
Ricky Mentha	2007	Masters	CRCAH top up	Coursework	Deakin Uni UoM
Cyril Oliver	2007	Masters (Coursework)	CRCAH professional development grant	Coursework	Deakin Uni UoM

Name	Year Awarded	Level	Funding	Project	University
Elizabeth Savage Kooroonya	2007	Honours	CRCAH Scholarship	A qualitative exploration of the impact of representations and descriptions, in literature and other media, about Aboriginal women and mothers, on the emotional wellbeing of individual Aboriginal mothers	La Trobe Uni
Caroline Pennefather	2007	Masters	CRCAH top up	Coursework	Deakin Uni UoM
Angelina Tabuteau Moore	2007	PhD	CRCAH Top Up	What is the incidence of chemically dependent babies born in a Victorian Aboriginal population during 2007 and what are psychosocial risk differences between Indigenous women who do choose not to use illicit drugs during pregnancy and those who do?	UoM
Shaun Tatipata	2007	PhD	CRCAH Top Up	Coursework	Deakin Uni UoM
Daphne Toby	2007	Masters	CRCAH Scholarship	Coursework	Deakin Uni UoM
Scott Winch	2007	Masters	CRCAH program scholarship	Master of Arts in Education: Healthy skin East Arnhem	MSHR
Graham Gee	2011	PhD	CRCATSIH scholarship	Understanding resilience and recovery from trauma in an urban Aboriginal and Torres Strait Islander community	UoM
Kim O'Donnell	2011	Professional Doctorate	CRCATSIH scholarship	Aboriginal Community Controlled Health Organisations and government funders: Accountability to whom and for what?	Flinders Uni
Shirley Nirrpurranydji	2011	Masters (Research)	CRCATSIH scholarship	Enhancing strengths, researching with the community of Gapuwiyak	CDU
Megan Williams	2011	PhD	CRCATSIH scholarship	Post-prison release support experienced by Aboriginal and Torres Strait Islander people in an urban setting	UNSW
Julie Fraser	2011	Masters (Research)	CRCATSIH scholarship	Enhancing strengths, researching with the community of Gapuwiyak	CDU
Bo Remenyi	2011	PhD	CRCATSIH scholarship	Standardisation of diagnostic protocol for early detection of Rheumatic Heart Disease: Closing the Gap in Indigenous health outcomes	MSHR
Anita D'Aprano	2011	PhD	CRCATSIH scholarship	TRAK Study – Talking about Raising Aboriginal Kids	MSHR
Sarah Ireland	2011	PhD	CRCATSIH scholarship	Reproducing history: Aboriginal women in a remote community in the Northern Territory, Australia	MSHR
Elizabeth Orr	2011	PhD	CRCATSIH scholarship	Telling the good stories: Partnerships/ relationships between Aboriginal and non-Aboriginal allied health workers in hospital setting	La Trobe Uni

Name	Year Awarded	Level	Funding	Project	University
Kalinda Griffiths	2011	PhD	CRCATSIH scholarship	Disparities in care and outcomes for people with lung cancer (the DOC project)	UoS
Michael Hemingway	2011	PhD	CRCATSIH scholarship	Community control: Aboriginal self-determination and liberal democracy	UoM
Scott Davis	2011	PhD	CRCATSIH scholarship	Community capacity development for better health: The role of Aboriginal Community Controlled Health Organisations (ACCHOs) in restoring community capacity	UoS
Laura Thompson	2012	Masters (Coursework)	CRCATSIH scholarship	Critical literature review to explore and identify the most appropriate methods of engaging with Aboriginal children in research about their health and wellbeing	Deakin Uni
Scot Avery	2014	PhD	CRCATSIH scholarship	A critical analysis of disability in Aboriginal and Torres Strait Islander communities	UNSW
Julieann Coombes	2014	Masters	CRCATSIH scholarship	What's next for Aboriginal and Torres Strait Islander children after a burn injury? What are the barriers to appropriate care?	UoS
Nicky Flynn	2014	PhD	CRCATSIH scholarship	(De)constructing Attention Deficit Hyperactivity Disorder: The Aboriginal standpoint	Flinders Uni
Suzanne Ingram	2014	PhD	CRCATSIH scholarship	The Communication needs of Indigenous people whose first language is English for culturally competent chronic disease healthcare	UoS
Maree Meredith	2014	PhD	CRCATSIH scholarship	Mapping the health promotion benefits of art centres on the APY Lands	Flinders Uni
Tara Lewis	2014	Masters	CRCATSIH scholarship	Culturally responsive methodology for the communication assessment of Australian Aboriginal children	UQ
Robert Monaghan	2014	Masters	CRCATSIH scholarship	The role of management in improving sexual health service delivery in Aboriginal community controlled health services	UNSW
Jane Pooley	2014	Masters	CRCATSIH scholarship	Quality of life in Aboriginal and Torres Strait Islander children with chronic illness	QUT
Stewart Sutherland	2014	PhD	CRCATSIH scholarship	A transnational study: The effects of reconciliation on SEWB of people affected by past policies and practices of forced removal	ANU
Lisa Whop	2014	PhD	CRCATSIH scholarship	Using linked data to investigate the effectiveness of cervical screening of Aboriginal and Torres Strait Islander women in Queensland	MSHR

Name	Year Awarded	Level	Funding	Project	University
Alister Thorpe	2015	PhD	Lowitja Institute CRC scholarship	Engage–Exchange–Change: Strengthening Indigenous health research engagement, action, translation and impact	UoM
Vicki Couzens	2015	PhD	Lowitja Institute CRC scholarship	Koorramook Yakeeneeyt' (Possum Dreaming): Cloaks, cultural traditions and wellbeing in Aboriginal communities	RMIT AIATSIS
Emily Munro-Harrison	2015	PhD	Lowitja Institute CRC scholarship	Urban invisibility: Identities of young Aboriginal and Torres Strait Islander people in urban Victoria	UoM
Matthew West	2015	PhD	Lowitja Institute CRC scholarship	Development of a targeted foot complications screening and intervention program for Aboriginal and Torres Strait Islander people	Newcastle Uni La Trobe Uni
Margaret Harvey	2015	PhD	Lowitja Institute CRC scholarship	Researching my Island home – Navigating through the intersection of research and culture in the creation of live performance	Monash Uni AIATSIS
9 co-funded with Participants	2016–17	PhD	Lowitja Institute CRC scholarship		
2 co-funded with Participants	2016–17	Masters	Lowitja Institute CRC scholarship		

Acronyms

ABCD	Audit and Best Practice in Chronic Disease
ACCHO	Aboriginal Community Controlled Health Organisation
ACCHS	Aboriginal Community Controlled Health Services
AHS	Aboriginal Health Services
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AMS	Aboriginal Medical Service
AMSANT	Aboriginal Medical Service Alliance of NT
ANU	Australian National University
APA	Australian Postgraduate Award
ARC	Australian Research Council
ATSIC	Aboriginal and Torres Strait Islander Commission
CDU	Charles Darwin University
COAG	Council of Australian Governments
Congress/CAAC	Central Australian Aboriginal Congress
CQI	Continuous Quality Improvement
CRC	Cooperative Research Centre
CRCAH	Cooperative Research Centre for Aboriginal Health
CRCATH	Cooperative Research Centre for Aboriginal and Tropical Health
CRCATSIH	Cooperative Research Centre for Aboriginal and Torres Strait Islander Health
DoHA	Department of Health and Ageing (Australian Government)
DHCS	Department of Health and Community Services (NT Government)
FDA	Facilitated Development Approach
IRRA	Indigenous Research Reform Agenda
Lowitja CRC	The Lowitja Institute Aboriginal and Torres Strait Islander Health CRC
Menzies/MSHR	Menzies School of Health Research
MPH	Master of Public Health
MTWT	Managing Two Worlds Together
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHS	National Aboriginal Health Strategy
NATSIHC	National Aboriginal and Torres Strait Islander Health Council
NATSIHP	National Aboriginal and Torres Strait Islander Health Plan

NCAFP	National Congress of Australia’s First Peoples
NHLF	National Health Leadership Forum
NHMRC	National Health and Medical Research Council
NT	Northern Territory
NTU	Northern Territory University (now CDU)
OATSIH	Office for Aboriginal and Torres Strait Islander Health
OATSIHS	Office for Aboriginal and Torres Strait Islander Health Services
PhD	Doctor of Philosophy
QIMR	QIMR Berghoffer Medical Research Institute
QUT	Queensland University of Technology
SA	South Australia
UNSW	University of New South Wales
UoM	University of Melbourne
UoS	University of Sydney
UQ	University of Queensland
WHO	World Health Organization

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Interview transcripts

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O'Donoghue, Lowitja, interviewed by P. Anderson and R. Mokak, 11 March 2015, Lowitja Institute Project, AIATSIS, Mokak O'Donoghue Anderson conversation 11 March 2015 Video

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Interview method

The extended interviews were based on a focused set of framework questions to cover particular points and create some consistency of topic through each interview. This method of interviewing is led by the person being interviewed and results in discursive reflections on events and eras from the perspective of individuals who were part of the making of the organisation. It is closer to what Dawn Bessarb called 'yarning' method in health research.[i] Where possible the interview began with a brief reflection on the interviewee's origins, their family background and how they came to find themselves involved with the CRCs or the Lowitja Institute. Other questions of particular events, research projects and organisational relationships, achievements and challenges were often followed by a reflection on the future for the organisation.

Interviews were recorded with a camera or with sound alone if the logistics made it impractical to include support staff for additional camera assistance. The recording and editing aesthetic supports an oral history approach to research, concentrating on individuals' stories, words and faces. This discursive approach to recording and research shifts the relationship of the interviewee to one of participant and narrator. This method of recording and researching is aimed at providing a text that engages a wide audience and leaves a legacy recording for future researchers and family. Importantly for first nations' peoples, it also provides readers, viewers and listeners with a more direct and less mediated link to the people with authority to speak. The authors have utilised segments of oral histories as in-text quotes from transcripts and in direct audio-visual format. This addition can bring vernacular ways of speaking into the document, adding layers to the voices and making it a closer rendition to the storytellers' perspective. They can also provide small but important windows onto the characters and passion that kept individuals pushing for change in the Indigenous health research landscape. Text and audio-visual segments have been integrated into a 'voiced manuscript' where the audio-visual component compliments the texts but does not repeat it. Most in-text quotes from the recorded interviews do not repeat the audio-visual segments. This is done intentionally in order to create a text that can be read on its own or can be read with sound. In addition this approach is designed to create an audio-visual segment that can be watched instead of reading every quote. These segments work together to form a book that talks and can create a wider audience engagement but retains its researched and evidentiary base.

Because all these recordings and edited segments will be archived at AIATSIS and available under certain conditions, the voices and stories told will be available in the future. In addition to providing important primary source data for research, these recorded oral materials can be used or repurposed for many other interpretive, educational, and creative projects. Consent and agreement forms for recorded interviews were developed by AIATSIS researchers in consultation with the Lowitja Institute. Each participant owns copyright in their own interview recording and has agreed for it to be offered to AIATSIS for archiving, for it to be edited into segments and for that segment to be made public.

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[i] Dawn Bessarab and Bridget Ng'and, *Yarning About Yarning as a Legitimate Method in Indigenous Research*, International Journal of Critical Indigenous Studies, 2010; 3 (1): pp. 37-50

One Fire Aboriginal Dance Group performance at the Lowitja Institute International Indigenous Health and Wellbeing Conference, November 2016

Back cover
Wagga Torres Strait Islander Dancers performance at the Lowitja Institute International Indigenous Health and Wellbeing Conference, November 2016

James Henry Photography

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