# The Shape of Things to Come

Visions for the future of
Aboriginal and Torres Strait Islander health research

## About the artwork

*Family*, 2013
Acrylic on canvas
60cm x 60cm
by Ms Jaharlah Hart

Jitta Art Aboriginal Islander Gallery Workshop
(www.jitta.com.au)

*My father is William Hart, he's Aboriginal and has Japanese ancestry. My father's family is from the Mission Beach, Clump Point region, just south of Innisfail. Our tribe is called Djiru. My mother is Darlene Gesa, her Aboriginal mother comes from Atherton and her father is a Torres Strait Islander man from Murray Island. The painting I have done represents the two cultures. The white circles represent the lands; the white curvy line in the middle of the canvas is a dividing of the two cultures. The green and blue colour dots represent the Torres Strait islander flag and also the blue sea surrounding the green islands of the Murray Island. The brown and ochre dots represent my Aboriginal side, the lands and rainforest region in the Mission Beach area.*

# *The Shape of Things to Come*

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Aboriginal and Torres Strait Islander health research

Prepared for the Lowitja Institute
by
Jenny Brands
Menzies School of Health Research

# Table of Contents

# Acknowledgments

Thank you very much to the participants of the consultation workshops, who very generously contributed their thoughts and ideas about the future of Aboriginal and Torres Strait Islander health research. Their contributions inform the vision for research in 2030 contained in this report.

# About the Lowitja Institute

The Lowitja Institute is Australia's National Institute for Aboriginal and Torres Strait Islander Health Research. It is the only research organisation in Australia with a sole focus on the health and wellbeing of Aboriginal and Torres Strait Islander peoples. Our vision is to achieve equity in health outcomes for Aboriginal and Torres Strait Islander peoples and our Dreaming[1] outlines the principles and pathways we will use to get there.

The voice of Aboriginal and Torres Strait Islander people informs all our research activities, whether we're conducting community-based research or setting strategic direction. By bringing together world-leading researchers, policy makers and experts in service delivery, the Lowitja Institute enables high-quality, collaborative health research that makes a difference in the lives of Aboriginal and Torres Strait Islander people.

We believe it is important that our research outcomes are disseminated widely through knowledge exchange and that promising interventions identified by research are implemented and evaluated.

The Lowitja Institute is also committed to developing a new generation of Aboriginal and Torres Strait Islander health researchers. Our collaborative approach to research has been developed over 15 years with our predecessor organisations, the Cooperative Research Centre (CRC) for Aboriginal and Tropical Health and the CRC for Aboriginal Health. At every stage of our research, Aboriginal organisations, health services, academic institutions and government agencies work together with the Aboriginal and Torres Strait Islander community to decide priorities, conduct the research and put the findings into practice (see also Appendix – Aboriginal and Torres Strait Islander research reform: A continuing journey).

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1 | Available at <www.lowitja.org.au/our-dreaming>
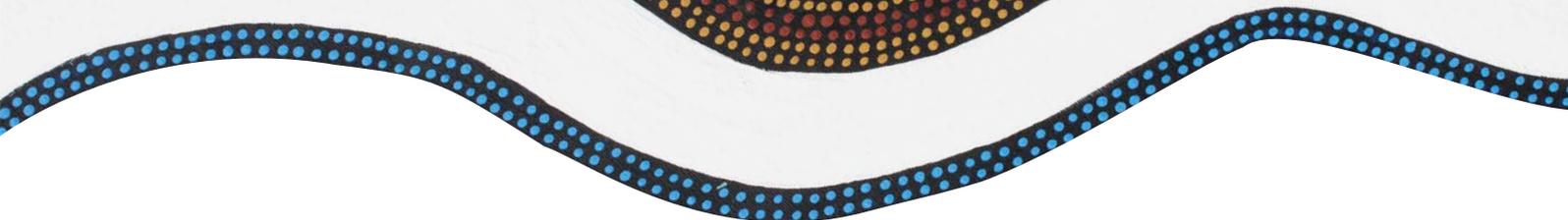
# Executive Summary

In late 2012, the Lowitja Institute embarked on a project using 'futures thinking' to consider how research might best contribute to Aboriginal and Torres Strait Islander health and wellbeing in the year 2030. The project was motivated by a desire to 'get ahead of the game': to anticipate and prepare for the potential research demands of the future. In particular, there was a desire to 'close the gap' between the point at which important research needs are identified by policy makers or service providers, and when research findings can be delivered.

To think about the research needs of the future, it was necessary to first imagine what life might be like in 2030. What might Australia be like then, and the world? And what might the lives of Aboriginal and Torres Strait Islander people be?

Workshops were held around the country to consider issues and trends visible in the current landscape, and how these might play out to influence life in 2030. A range of possible scenarios emerged, clustering around two divergent futures: an inclusive, vibrant Australia in which Aboriginal and Torres Strait Islander cultures are valued and embraced as central to the Australian identity; or an Australia in which economic and/or spiritual poverty drive a rejection of diversity and increase the divide between rich and poor.

Participants then grappled with the question: If this (or that) scenario occurs, then what will be needed from research? By thinking about the range of possible scenarios for life in 2030, what capabilities are required to deliver the research that will be needed to address emerging issues and create a healthy future?

The inspirational and empowering answer—perhaps not surprisingly—was not simply a list of research topics. Instead, participants articulated a strong and widely shared desire for a profoundly different *system* of research. A vision emerged of a research system in which research and practice are closely interwoven and which would enable greater integration of health services, policy and research. Such a system would be responsive to changing research demands, but also to changing social, economic, technological and knowledge landscapes.

Specific research capabilities were also identified. An urgent necessity to actively address the social determinants of health was articulated in every workshop, along with a growing sense that the health and health research sectors may need to play a facilitating role, inviting other sectors—such as education, justice, local government—to collaborate and maximise the impact of their collective efforts to bring about change. A need for more evidence and evaluation around early childhood development programs (social as well as physical development) was seen as a priority for the immediate future.

The Aboriginal and Torres Strait Islander health and health research sectors have played a pioneering role in the reform of research in Australia. The strength of vision articulated by participants in this project, and the desire to see that vision become a reality, suggests the sector will succeed in its drive toward a vision of a more effective research system.

# Background

Over the past 15 years there have been significant changes in the way Aboriginal and Torres Strait Islander health research is done (see also Appendix — Aboriginal and Torres Strait Islander research reform: A continuing journey).

- Research is now more likely to be done by Aboriginal and Torres Strait Islander researchers, about questions that Aboriginal and Torres Strait Islander communities and leaders, as well as governments, want answered, and is more likely to translate into genuine change and improved health outcomes.

- The capacity to carry out research about the challenges confronting Aboriginal and Torres Strait Islander communities and organisations can be in short supply. It can be difficult to find people with the right skills—cultural, practical and academic skills—to do the research that the Aboriginal and Torres Strait Islander health sector sees as important.

- The health status of Aboriginal and Torres Strait Islander people is also changing. There is evidence that some states/territories are on track to Close the Gap before the end of this decade. The population is growing at both ends—with more people living into older age, and continuing increases in birth rates.

- Science is changing too, with better understanding of how the body works, genetics, and child development opening up new ways of improving health and wellbeing.

- Meanwhile solutions to some old challenges, such as addressing the external and social factors that influence health, remain elusive.

But policy makers and service providers around the world have often expressed frustration that by the time research provides the answers to their questions, their agendas have moved on to new challenges. This frustration is felt keenly in Aboriginal and Torres Strait Islander health. This project originated in an effort to do what Professor Ian Anderson[2] described as 'get ahead of the game': to reduce the time lag between the commencement of research and its findings, and to ensure adequate capacity in emerging areas of research need.

In late 2012, the Lowitja Institute began this project using the methods of 'futures thinking' (see p. 4). The project centred around two main questions:

*What might Aboriginal and Torres Strait Islander health look like in 2030?*

*What might the Aboriginal and Torres Strait Islander health sector require from health research at that time?*

Workshop focus groups were held around the country to consider emerging issues and trends and how these might influence the future of Aboriginal and Torres Strait Islander health and wellbeing, and to identify the research needs of the of the future.

The first workshops were held in November 2012, and then a series of state/territory workshops in 2013: Adelaide (28 May), Sydney (4 June), Brisbane (6 June), Perth (12 June), Darwin (25 June), Alice Springs (27 June), Canberra (3 July), Melbourne (5 July), and a final workshop in Melbourne on 17 July. Participants included Aboriginal and Torres Strait Islander people from a variety of settings, researchers, policy makers and government representatives, and members of Aboriginal and Torres Strait Islander community controlled organisations.

In each workshop, participants discussed emerging trends that might provide clues about Aboriginal and Torres Strait Islander health and wellbeing in the 2030: what the big challenges may be, the questions that may need to be answered. A range of possible scenarios emerged. Participants then grappled with the question: If this or that scenario occurs, then what will be needed from research?

**This report summarises the issues and trends, scenarios and ideas about research that emerged from the workshops.**



Ms Jenny Brands
from the Menzies
School of Health
Research, facilitator

# Methods

This project was informed by futures thinking methods developed by Sohail Inayatullah (Inayatullah 2007, 2008), Professor in the Graduate Institute of Futures Studies, Tamkang University (Taiwan), and the Faculty of Arts and Social Sciences, University of the Sunshine Coast. Professor Inayatullah delivers the Melbourne Business School Futures Thinking and Strategy Development program, and has worked with many of the world's leading businesses and organisations.

Futures thinking or 'foresight studies' is a growing discipline in both research and management. It is not about predicting the future, but rather about identifying a number of possible and *plausible* futures. It differs from traditional research methods in that it draws on both 'hard' evidence and deeper intuitive and spiritual insight. It works in the spaces in between these poles to inform long-term planning, inspire and lead development towards a preferred future (Inayatullah 2007; Ellyard 2012; Bussey 2009).

The project involved phases of data collection, analysis and write-up.

## Data collection

Data for the project came from two major sources: the writings of futurists about global trends; and the knowledge, experiences, opinions and visions of workshop participants.

1.  A review of futurist writing on trends and scenarios for the future, to identify those likely to influence Aboriginal and Torres Strait Islander life and wellbeing in 2030.

2.  A series of ten workshops held around the country to consider issues and trends emerging in the Australian and international landscape, how these might influence the future of Aboriginal and Torres Strait Islander health and wellbeing, and the potential implications for research.

    Each workshop involved four main steps:

    » Presentation of a summary of global trends and scenarios from the review of futurist writing

    » Identifying emerging issues and trends in the current landscape that may influence the lives and wellbeing of Aboriginal and Torres Strait Islander people in the year 2030

    » Based on those trends, envisioning Aboriginal and Torres Strait Islander life in 2030. Foresight methods used to assist this process include the use of a 'futures wheel' (Inayatullah 2008) and the imagining of best and worst case scenarios. In some workshops, participants were assisted to visualise life in 2030 by imagining the life of a young Aboriginal woman, aged 12 in 2013, who would be 29 in 2030

    » In light of the trends and scenarios, considering what research may be required, what research capacity is needed, and how should research be conducted?

3.  A final workshop, held in Melbourne with some of Australia's pre-eminent thinkers in Aboriginal and Torres Strait Islander health, focused particularly on the implications for research arising from the issues, trends and scenarios identified during the previous workshops.

A synthesis of data collected from these sources was then circulated to all workshop participants for further comment, which was taken into account in the analysis and write-up.

## Analysis and write-up

1. Futures thinking methods of Causal Layered Analysis (CLA) were applied and a backcasting exercise conducted to deepen understanding of the implications of the data collected through workshops, and to imagine how a vision for a new system of research might be achieved.

   CLA is a foresight method designed to help open up new ways of thinking about an issue, by exploring different and increasingly deeper perspectives. Issues are considered in terms of their surface, systemic, worldview and archetypal meanings (see also p. 22).

   'Backcasting' (Inayatullah 1998, 2007) is a method of considering the steps that might be required to achieve a preferred future, by starting at the imagined future and working back to the present (see also page p. 22).

2. The trends, issues and scenarios from throughout the project were synthesised into a final report.

## The voices of Elders

The Elders who provided a Welcome to Country at the start of each workshop were a powerful influence in the data collection and analysis of this project. Many of the Elders stayed for the entire day, taking part in the discussions. Their inspiring and moving Welcome to Country ceremonies, each very different, personalised and localised, set the tone each day for thoughtful and grounded discussion. Their wise words and stories ensured that the people and events of the past also informed the thinking about the future. Their gracious and gentle generosity of spirit helped create a safe haven in which workshop participants could open their minds and hearts.



Aunty Ali Golding conducting the Welcome to Country at the Sydney meeting on 4 June 2013

# Structure of this Report

This report presents the data gathered and results of analysis in a structure slightly different to that of a traditional research report. Foresight thinking, while methodical, is also a journey in which pieces of the story come from different people and different places along the way. It is a journey in which insight is shifted and deepened using research methods that may be unfamiliar to many who do or use research.

The structure of this report reflects the journey of this project. Each section brings another part of the story. The major source of data, the voices of participants, are central in the story, and the analysis undertaken sought to deepen, extend and make tangible the research future they wanted to see.

The report has four major parts:

- **Life in 2030** presents data from futures literature about emerging global trends, and from workshop participants about trends and issues they see emerging in the local context, that may influence life in 2030. This section includes examples of scenarios developed by workshop participants that illustrate best and worst case scenarios of life in 2030.

- **Research needs for 2030** sets out the characteristics that workshop participants wanted to see in a future research system, the areas of research that may be important and the capacity requirements needed to deliver them. It includes examples of scenarios developed by workshop participants that illustrate their visions for research in 2030.

- **Sharpening the vision** describes a process in which the major themes that emerged from all the data sources were further analysed and deepened using foresight methods.

- **Visions for research in 2030** contains a visualisation of a future research system that embodies many of the characteristics that participants identified as critical.

Melbourne
Museum workshop,
17 July 2013

# Life in 2030

This section of the report presents data about trends and issues that may influence life in 2030. Data on the global context is drawn from the writings of futurists around the world. The local Australian and Aboriginal and Torres Strait Islander contexts are drawn from workshop participants' discussions and scenarios.

## The global context

Futurists have identified a range of emerging issues and trends that appear likely to influence the future of the planet. These include:

- A shift of economic and innovation dominance from the West to the East (China, India) and South (South America), accompanied by increasing influence of non-Western cultures (National Intelligence Council 2012; Moran 2013)

- There will be large increases in the numbers of educated and middle class people internationally, leading to dropping birth rates and ageing populations (Ellyard 2012)

- An increasingly 'planet-ist' identity arising from interconnectedness through technology and interdependence through economics and ecology. However, 'tribal' identities (ethnic, indigenous, many self-defining groups) will also become more important (Ellyard 2012; Bok & Ruve 2007)

- Health care will become more focused on prevention and wellness, rather than sickness (Peck 2005; Inayatullah 2009)

- eHealth and nano technologies, and advances in neuroscience, genetics and stem cell therapies, will transform health care (Saniotis 2008; Inayatullah 2009)

- Schools and universities will move from a controlled 'factory model' to open and fluid models of learning; individuals will choose the educational models they prefer (Ellyard 2012; Inayatullah 2012)



Professor Fiona Stanley (left) and Ms Pat Anderson in Melbourne

## Local contexts

Workshop participants identified a range of issues and trends that they felt would influence Aboriginal and Torres Strait Islander health and life in 2030. These included issues and trends in Australian society and health care, as well as those specific to Aboriginal and Torres Strait Islander people and communities. The following section contains major themes and issues that emerged from workshop discussions about local issues and trends likely to shape Aboriginal and Torres Strait Islander life and wellbeing in 2030.

### Issues and trends in Australian society generally

- Continuing competition between acute and preventive care in the health system.

- An increasing focus on evidence-based early childhood development and education.

- A growing divide between haves and have-nots economically, geographically, socially, and in terms of health—potentially within Aboriginal and Torres Strait Islander communities as well as in society more broadly.

- Continuing reductions to the size and quality of the public service at national and state/territory levels. This could impact in three ways:
  - » reduction of services, particularly to disadvantaged groups
  - » declining capacity within the public service to drive reform or respond to diversity, and
  - » reduced opportunity to enter and participate in the workforce (the public service having been a significant employer of Aboriginal and Torres Strait Islander workers).

- The potential for vocational and practice-based training to be revitalised in response to shortages in manual, artisan and technical trades.

- Racism in Australia could be reduced as a result of the increasingly open discussion of racism and its effects, and as attitudes in the broader population shift in a trend towards planet-ism and a growing interest in Aboriginal and Torres Strait Islander cultures. Alternatively, racism could increase if Australia's economy struggles as the global economy re-orients.



Mr Ray Minniecon

## Issues and trends specific to Aboriginal and Torres Strait Islander people

Workshop participants identified a number of issues and trends likely to have significance for Aboriginal and Torres Strait Islander health and wellbeing in 2030.

- In contrast to the global trend, the Aboriginal and Torres Strait Islander population will continue to be predominantly a young population, with a continuing high birthrate.

- At the same time, however, there will be more older Aboriginal and Torres Strait Islander people as life expectancy increases and more people survive to old age. However, illnesses of old age, such as dementia, are currently being seen to affect Aboriginal and Torres Strait Islander Australians at younger ages than in the broader Australian population. This may have significant consequences for care, family organisation and the transfer of cultural heritage.

- There is a growing recognition of the effects of intergenerational trauma and their implications for service provision and health care.

- The numbers of educated and 'middle class' Aboriginal and Torres Strait Islander Australians will continue to increase, although the 'middle class' transition may take a different trajectory to that of non-Indigenous Australians, based on cultural differences.

- There is already an emerging discussion of identity and culture, as younger generations redefine or struggle with their identities in an increasingly globalised and diverse culture.

- Aboriginal and Torres Strait Islander people are beginning to have greater involvement in the broader economy through entrepreneurism, small businesses, etc.

- Philanthropy could play an increasingly important role in Aboriginal and Torres Strait Islander society. In a more interconnected world, it will become much easier to create links between people with money and the situations where that money could make a big difference. There was also discussion of Aboriginal and Torres Strait Islander philanthropy—for example, using money from invested mining royalties.



Ms Diane Tate (top of picture) with Mr Dylan Daniel-Marsh and Ms Bernice Cropper

- Potential change in the place and role of the Aboriginal and Torres Strait Islander community controlled health sector was a frequently raised issue. Many participants expressed concern that a trend toward 'mainstreaming' health services might threaten the existence of the community controlled sector. Others felt the sector's maturity, together with global trends towards health care focused on prevention and wellness would support current growth in the community sector. In turn, the community sector may have great influence on reform of the broader Australian health system.

- Views were mixed on the potential impact of constitutional recognition and reform. Some workshop participants saw this as a way of moving towards a more sustainable self-determination; others were sceptical that constitutional recognition would lead to real change. There could also be a negative impact if constitutional recognition did **not** occur.

- Many young Aboriginal and Torres Strait Islanders need to leave their communities to gain access to better educational and employment opportunities. This trend is likely to continue, and result in declining populations in many Aboriginal and Torres Strait Islander communities in remote and rural areas, mirroring the migrations of non-Indigenous Australians from bush to city. However, improved technologies may also make it more possible to study and generate income in remote and rural areas.

- There is a growing trend towards revitalisation or reinvention of the role of men in Aboriginal and Torres Strait Islander communities.

- Climate change is likely to have significant effects on Aboriginal and Torres Strait Islander people. Extreme weather events and growing competition for land and resources are likely to exacerbate existing disadvantage. Vegetation and wildlife patterns are likely to change. Coastal and island communities will be at the frontline of rising sea levels. On the other hand, some Aboriginal communities are able to benefit from economic opportunities arising from climate change, such as carbon farming through natural resource management.



Ms Alyce Merritt (left) presenting to the group

## Scenarios

Drawing on the trends and issues identified in each workshop, participants imagined a range of scenarios for Australian society generally, for Aboriginal and Torres Strait Islander communities, and, to make the visualisation of the future most tangible, for a young Aboriginal woman aged 29 in 2030. Participants were asked to imagine both best and worst case scenarios to help identify the risks and pitfalls that may need to be managed or avoided in order to achieve a preferred future.

### *A crossroad for Australian society*

In the scenarios imagined, workshop participants articulated two distinctly different pathways that Australian society might take in the near future. Both are plausible given the global and local trends identified above.

- An Australia in which Aboriginal and Torres Strait Islander people and cultures are highly valued and interwoven into a broader, more caring Australian society at all levels. Diversity and difference are celebrated for the strengths they bring to society. Health care is focused on holistic concepts of wellness and prevention: keeping people strong and healthy. There would be less focus on consumerism and a greater focus on sustainability and community values.

- An Australia in which serious, long-term economic downturn leads to increasing insularity and racism, dismantling of public services and legislation such as land rights. The rights of business would override the rights and interests of communities and individuals. Health care would become increasingly privatised and medicalised and focused on acute rather than preventive care.

Examples of the scenarios that workshop participants envisioned are shown overleaf in pages 12–13.



Ms Michelle Patterson (left) with Mr Russell Taylor in Canberra

## A best case scenario – Australian society

- True reconciliation – treaty, constitutional recognition, resulting in Australian society in which Aboriginal and Torres Strait Islander people and cultures have pride of place

- Real community control in our community controlled sector

- Significant improvement in health outcomes and life expectancy

- Real cultural equity, no racism

- Aboriginal knowledge would be part of mainstream, part of the norm. 'Nunga streaming' not 'mainstreaming'

- Aboriginal models of health would be brought to the fore and privileged; for example, spirituality

- Education/employment/informed choices/control

- Diversity and difference would be celebrated

- Seamless integration of Aboriginal values, would become part of the landscape

- There would be no 'othering'

- There would be Aboriginal representation at all levels of government and society

- Aboriginal people would be influencing decisions, across all dimensions of society, not just fiscal approach

- On a broader scale across society we would have a broader approach, it wouldn't just be about money, there would be a return to values and ethics (individual and community), less focus on consumerism and capitalism, and sustainable and ecological ways of living.

## A worst case scenario – Australian society

- Negative political change: ultra conservative governments, back to the future, all the worst political nightmares come true

- Ramifications will include:

    » decrease of Aboriginal organisations (in the worst case, Aboriginal organisations are dissolved)

    » Aboriginal health funding cut

    » mainstreaming of health, privatisation of health, acute care driven

    » decrease in primary health care, promotion, prevention

    » the health gap will widen

    » child health would decrease for many reasons

    » more negative impacts on social determinants of health

    » increase in incarceration, marginalization, political control, disempowerment, suicide

    » decrease in wellbeing.

## A best case scenario – A young Aboriginal woman in 2030

- Reaches 29 years in full health

- Has higher education qualifications; is technically, socially and culturally savvy

- Mentally and socially in touch with community and family

- Non-smoker, good BMI, no drinking problem

- Stable relationship

- Has choice and control over fertility, childcare and employment

- World-aware but with a sense of individual purpose

- Well travelled/global visions

- Economically independent

- Grounded in mixed cultures

- Builds on family history for positive outcomes

## A worst case scenario – A young Aboriginal woman in 2030

Her life is characterised by:

- Family breakdown/violence

- Abusive relationship

- School dropout

- Substance abuse

- Imprisonment

- Housing crisis

- Children at risk/Social service involvement

- Stress/mental illness

- Chronic disease

- Premature death

- Her family and community deeply affected by her loss

# Research Needs for 2030

This project set out to identify the future research needs of the Aboriginal and Torres Strait Islander health sector (government and non-government), by looking at what life might be like in 2030, and the views of workshop participants about the role research might play in that future. The rationale for looking to the future of research in 2030 was to 'get ahead of the game', by developing the research capacity needed and by anticipating potential research needs.

There was some expectation that this work would produce a list of research priorities and the skills to deliver them. Some of these did emerge, and are of considerable importance. Many of the research priorities identified extend beyond the health sector (see Areas for Future Research, p. 18).

What emerged much more strongly, though, was a widely shared vision for a more effective 'system' of research that would enable greater integration of health services, policy, community and research. Such a system would be responsive to changing research demands, but also to changing social, economic, technological and knowledge landscapes.

The following sections describe the key issues and visions about research that emerged from the workshops.

> *We don't just need a process of research but systems that maximise the potential of research (workshop participant)*

## The current research system

At every workshop, discussion about the research implications of the trends and scenarios explored during the day tended to lead firstly to expressions of concern about the ways in which research is done and organised at present.

Issues raised included:

- Community-based health services continue to receive large numbers of requests to take part in research projects with which they have had no connection

- There remains a strong perception that research continues to be descriptive rather than about making improvement, and that research continues to be done on topics that have already had a lot of research attention

- There are ongoing concerns that ethics processes and ethics committees are unable to monitor whether what has been promised in research and ethics proposals actually takes place

- Traditional health research funders are seen as taking a reactive rather than determining role

- Health service providers and policy makers continue to appeal for a quicker turnaround time for research and better ways of quickly accessing evidence in useable forms.

- A continuing perception that research is not communicated back to the community or 'grass roots' level.
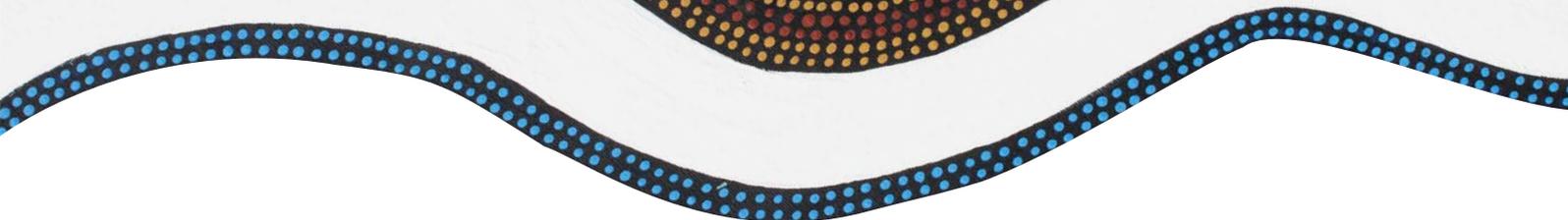
# A research system for a healthy future

Across all the workshops, participants identified a range of characteristics that they would like to see in a preferred future Aboriginal and Torres Strait Islander health research system. These characteristics fell into the following major themes:

## Partnership

- That research be driven by and done in partnership with Aboriginal and Torres Strait Islander communities and organisations, and that research funding models and reward systems enable this rather than acting as barriers

- Policy and practice research participants would be seen as co-investigators, co-producing knowledge

- Strong international alliances and partnerships draw on the knowledge and experiences of indigenous peoples around the world.

## Evaluating what works

- Program and service delivery evaluation is coherent and comprehensive, not ad hoc, and supports capacity building across the health system. Evaluation goes beyond the pilot or one-off project evaluation and applies to whole government programs and performance

- Research provides a community-centred perspective; for example, looking at programs from a community/'on the ground' perspective rather than from a program deliverer's perspective

- A specific funding pool supports evaluation of what works within the Aboriginal and Torres Strait Islander health sector.

> We know a lot already, but its not being used. Instead, we are rapidly increasing the evidence of what doesn't work (workshop participant)

## Re-orienting the role of research

- Above all, research is focused on improving health outcomes in the health and wellbeing of Aboriginal and Torres Strait Islander people.

- The role of research and the research system are re-oriented to become more facilitative and service-oriented, providing a service to communities, organisations and governments. For example, research can provide a safe and productive environment for debate, and may have a critical role to play in facilitating cross-sectoral planning and action at local and regional levels

- There is a shift to research that is about doing and improving, rather than describing the problem, and, accordingly, a greater emphasis on systems research that looks at systems that are supportive and aspirational

- There is recognition that research can be used to strengthen (or weaken) social justice and human rights, including the right to self-determination, and that promoting social justice is an appropriate role for research

- A new toolbox of research methods are developed that support the conduct of research arising from stakeholder-driven research priorities. (Stakeholder-driven research priorities often require highly complex, multi-disciplinary and collaborative mixed methods research).

> *The methods we need for collaborative research (driven by our stakeholders) are completely different to traditional methods. We are choosing from our existing toolbox of methods – but we need new ones (workshop participant)*

## Accountability and efficiency of the research system

- The level of wastage in the health research system is reduced through better coordination, gap analysis and clarity about what has already been funded. There is clarity about the value added by any particular research: what are the opportunity costs for example in funding some projects over others? (However, this idea was also contested by arguments that efforts to reduce wastage often waste more and achieve little benefit)

- The tensions inherent in competition in the research sector are managed to enhance the impact of Aboriginal and Torres Strait Islander health research. Competition can be healthy, but a healthy market relies on the consumer to make decisions about purchasing. Moving the point of decision-making closer to the consumer—the Aboriginal and Torres Strait Islander health sector and other key stakeholders including governments and communities—may increase the efficiency of the research system

- Research findings are returned to the community to be incorporated into best practice; increasing the capacity of communities and organisations—including governments—to identify and find solutions to their knowledge needs

- Research is conducted ethically, protects Aboriginal and Torres Strait Islander knowledge and maintains the integrity of Aboriginal and Torres Strait Islander cultures.

## Building capacity

- Multi-disciplinary, collaborative research teams are increasingly important to doing good research in Aboriginal and Torres Strait Islander health, and there is a need to build capacity in the skills to lead and be part of such teams

- There is widespread understanding and expertise in achieving successful translation of research into practice. Knowledge translation and implementation practice are based on evidence of what works.
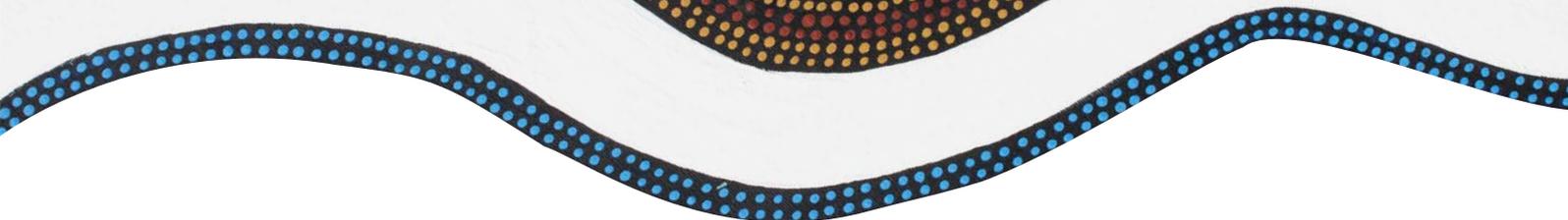
## Systems for using evidence

- Communities and organisations—including governments—have increased capacity to identify and find solutions to their knowledge needs. This may require a business model for knowledge utilisation that supports the ways in which health services integrate knowledge and apply it into practice. One participant commented: *Stop separating research and practice. Fund practice so it can be informed by research (not just research informing practice)*

- Partnerships between organisations, researchers and communities can support an ongoing 'learning organisation' model of empowerment, improvement and knowledge utilisation. These partnerships can create a responsive system that can adapt to change and complexity

- Technological change will increase the feasibility of linking data sets, potentially even in real time. But to maximise the use of data, health services and the health system need the capacity to make data useful and meaningful. This means making decisions about the measures that are valuable to decision-making. Existing data sets may not necessarily contain those measures, nor the quality of data required to make informed decisions.

## Consumer/community involvement in health and research

- By 2030 there will be a flourishing online community that will want to have a say in its health care. We will need systems to incorporate this into the Aboriginal and Torres Strait Islander health and health research sectors, but also need to ensure that these voices don't drown out all other points of view.

# Areas for future research

While participants wanted to talk most about how research is done, the workshop process identified areas or topics of research needed to contribute to improved health and wellbeing outcomes between now and 2030, and beyond. These included:

- Research that extends beyond the health sector to address actively the social determinants of Aboriginal and Torres Strait Islander health. There was a commonly expressed view that the health research sector may need to take a facilitating role in creating a safe environment in which different sectors collaborate, share what they know, and develop strategies that bring together a combined effort to tackle social determinants of health

  » social determinants that received particular mention included poverty, homelessness, social influences on child and maternal health, education, victimhood, incarceration rates, climate change (water and environmental issues), recognition of country and of people and ownership

- Early childhood development—psychological and social as well as physical—was seen as a crucial area for research now and into the future

- Research that supports building the capacity of communities, families, and individuals to be well, instead of *how not to be sick*. This area of research included the development of effective measures that reflect wellness in a holistic manner. There was considerable discussion of a wellbeing index

- Greater emphasis on research into social and emotional wellbeing, including understanding and addressing intergenerational trauma, emerging issues of identity, culture, resilience, lateral violence and racism

- Understanding the health and wellbeing needs and preferences of older Aboriginal and Torres Strait Islander people and the implications for communities, families and service provision

- Systems research and implementation of programs as a science. How do we embed good programs and practices?

> *It's not about continually coming up with ideas – what are the barriers, what is confounding the use of good practice? (workshop participant)*

- Research that provides guidance to governments in how to deliver programs that recognise the diversity and contexts of different communities and settings, and that helps hold government accountable for its performance
- Cost effectiveness or cost-benefit research that helps articulate the real costs and benefits of comprehensive primary health care in Aboriginal and Torres Strait Islander contexts
- Research that looks at the critical success factors that have worked to improve health and wellbeing, and how to embed those factors in policy and program decision-making and implementation

- Making more use of historical, social and policy case studies

- Ensuring Aboriginal and Torres Strait Islander people are not left behind in changing practice in health care (e.g. in genetic therapies) and health promotion (e.g. Australia's tobacco control programs).

## Future research capacity needs

Given the issues, themes and topics identified above, the workshop participants identified research capacity they felt would be needed in 2030, in addition to the research system capacity described above. The following needs were highlighted:

- More senior and experienced Aboriginal and Torres Strait Islander researchers

- Increasing the capacity of communities and organisations—including governments—to engage in research, but also to identify their knowledge needs (i.e. what knowledge is needed to help address their challenges) and find or create evidence-based solutions

- Researchers with good facilitative and collaborative skills, able to lead multi-disciplinary teams and partnerships working in complex adaptive systems and taking into account multiple aspects of society (e.g. social determinants)

- Research methods that support the research that arises from stakeholder-driven research priorities

- Researchers able to facilitate and carry out applied or action research on the social determinants of health

- Aboriginal and Torres Strait Islander researchers across the whole spectrum of quantitative and qualitative science, including blue sky research

- Retaining the capacity to do robust research, and increasing the capacity to do action, participatory and capacity building research

- Researchers who can work in culturally safe ways to ensure Aboriginal and Torres Strait Islander people are not left behind in the development of knowledge about genetics and gene therapies.

# Research system scenarios

These three scenarios illustrate some of the ways in which workshop participants envisaged the future of Aboriginal and Torres Strait Islander health research. Many other scenarios were imagined in the course of the workshops around the country, but we are unable to present all of them here.

# A sustainably funded research system

A national trust is established to support Aboriginal and Torres Strait Islander health system strengthening (like the Future Fund).

The equivalent of ten years of current funding to Aboriginal and Torres Strait Islander health and health research is allocated to this trust. The trust establishes five-year funding cycles for health services and research, invests the money not yet released, and reinvests the interest to strengthen the health system.

Research funding is directed through an independent strategic research coordination body, which invests equally in increasing the capacity of the health sector to identify and use evidence and data to inform decision making and implement improvements; and in research partnerships that respond to stakeholder priorities, including evaluation, translational research and the measurement of impact at all levels of the health system.

# A national institute for Aboriginal and Torres Strait Islander health research

Four major roles:

1. **Build methods** for articulating and responding to community priorities in layered, commensurate and sustainable ways. Culturally appropriate methods – 'both ways'

2. **Commission competitive research** in priority areas of research need. Commissioned research is largely, but not exclusively, applied research aimed at improving health care and thus leading to good health

3. **Influence** mainstream research systems. Ensure other health research is properly conceived, designed to be of use to Aboriginal people

4. **Ensure knowledge exchange**—the complex questions of knowledge exchange are addressed and clearly defined and answered.

## A sustainable research system

The tree is the whole of community (all stakeholders including research). The roots of the tree are: existing knowledge, education, funding, data and workforce. Its blossoms are made up of five actors: policy-makers, funders, community, service providers and researchers.

Seven steps are needed to achieve this:

1. Clarify context of the research
2. Define priorities from user viewpoint, with stakeholders
3. Set up ongoing user engagement
4. Do participatory research
5. Develop capacity
6. Cross-pollinate
7. Measure impact

- Policy-makers
- Funders
- Community
- Service Providers
- Researchers
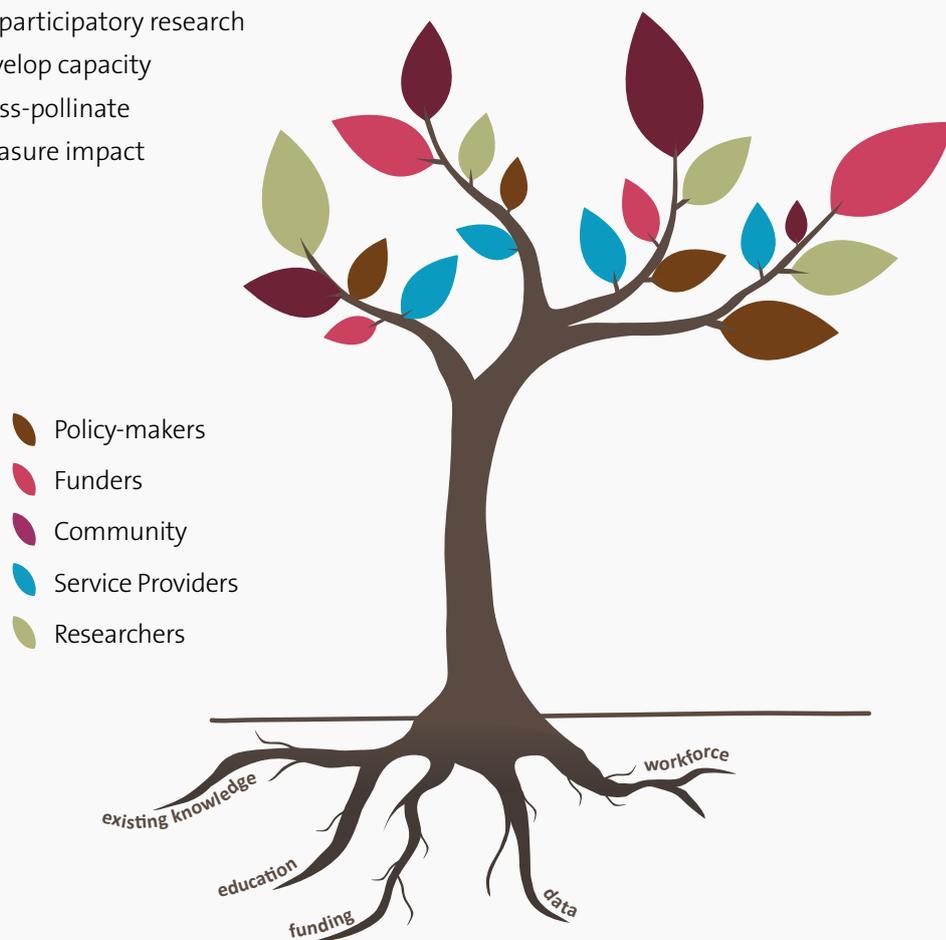
# Particularising the Future of Research

## Causal Layered Analysis and backcasting

In order to visualise more clearly a future research system, a small group trained in futures thinking worked with Sohail Inayatullah (see Methods, p. 4) to apply the foresight methods of Causal Layered Analysis (CLA) and backcasting (Inayatullah 2007).

CLA is a foresight method designed to help open up new ways of thinking about an issue, by exploring different and increasingly deeper perspectives. It involves considering four layers of understanding of any issue:

1.  **The litany:** The commonly accepted headlines of the ways things are or should be (about an issue); short term approaches

2.  **Systemic causes:** Analyses of the social, economic, political causes of an issue

3.  **Worldview:** The paradigm that informs what we think is real or not real, the cognitive lenses we use to understand and shape the world

4.  **Myth or metaphor analysis:** The deep unconscious story, core myths, often appearing in the work of artists, cartoonists and the visions of mystics (Inayatullah 1998).

Sohail Inayatullah facilitated the group to apply CLA to one of the major themes that had emerged from the workshops: **engaging sectors additional to the health sector in tackling the social determinants of Aboriginal and Torres Strait Islander health.** This helped open up visioning for what a new system of research might look like.

The CLA lenses of litany, systemic causes, worldview, and myth or metaphor analysis were applied to the contexts of Aboriginal and Torres Strait Islander people in relation to health, justice, and education. Each lens was applied to the current situation, a best possible case for 2030, and a plausible (reachable) mid-point of 2020. Participants then imagined specific scenarios that might emerge and used the technique of backcasting to track how realistic the perceived changes might be by 2030.

From this exercise emerged some further critical roles for the research sector:

*   Providing space and facilitating a 'dialogue of world views' (between sectors, cultures, situational perspectives)

*   Developing ways to measure the preferred future (indicators reflecting a holistic and strengths-based approach to health and wellbeing)

*   Taking a research and action focus on the early years of childhood, which will bring long-term improvements across education and justice as well as health

*   Applying evidence-based approaches to shape social movements

*   Supporting service providers across all sectors to develop and adapt to a more person-oriented future in which solutions are contextualised and tailored to the individual/family.
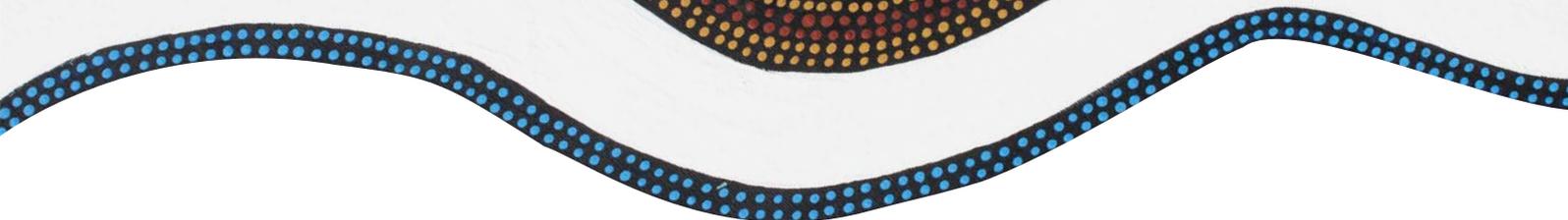
# Visions for Research in 2030

The preferred future research system that emerges from the consultations held in this project could take on a variety of forms. Workshop participants imagined many of them (see Research System Scenarios, p. 19–21). Indeed, many participants highlighted the need for a pluralistic system that can support a variety of different ways of organising and conducting research. Nonetheless, achieving our preferred futures relies on being able to visualise that future. In this section, the characteristics of a preferred future research system identified throughout this project are brought together in a visualisation of the components of a research system that can help build a healthy future for Aboriginal and Torres Strait Islander people.

## Infrastructure for collaborative research

In 2030, partnerships and networks for Aboriginal and Torres Strait Islander health research are funded to facilitate participation in the research system by not only researchers, but also by service providers, policy makers, consumers and Elders. Participation in these networks and in research work is recognised as a valuable aspect of service providers' and policy makers' roles, and resourced accordingly (the cost-effectiveness of these investments having been demonstrated conclusively in the preceding decade).

These partnerships and networks are nested, allowing for due attention to both strategic national priorities and local/regional needs. For instance:

- **Localised research partnerships or networks** bring together researchers, service providers, policy makers and Aboriginal and Torres Strait Islander leaders at a regional level to identify priority problems which research may help solve, and to shepherd the process of finding and applying evidence to address those problems. These localised research partnerships or networks play an important role in facilitating the use of evidence—both new and existing—to improve the health and wellbeing of Aboriginal and Torres Strait Islander people.

  The partnerships might be linked to an appropriate existing body, such as a state or territory Aboriginal and Torres Strait Islander Health Forum or a research group with a strong track record in Aboriginal and Torres Strait Islander health research. Ideally, they will provide an independent and 'safe' space in which people with diverse views and priorities can come together to combine their efforts to tackle shared problems.

  They also form a suitable place for the coordination and monitoring of ethical and culturally appropriate research, and of the research effort within the region.

  At this local/regional level, long-term research partnerships are possible and Aboriginal and Torres Strait Islander research capacity can be built from the ground up.

- At the national level, the localised research partnerships are mirrored by a **national research partnership or network** that fulfils three key roles:

» Identifies and directs funding towards national Aboriginal and Torres Strait Islander research priorities (including the development and refinement of new methods, program and project evaluation, strategic knowledge exchange activity, and the evaluation and monitoring of the Aboriginal and Torres Strait Islander health research system)

» Facilitates knowledge exchange between localised partnerships, and between the broader Aboriginal and Torres Strait Islander health research effort and macro-level policy bodies

» Fosters the development of localised research partnerships and a national program of capacity building in the use of evidence for policy and practice.

This national research partnership or network works closely with national and peak bodies across the political and professional spectrum to ensure evidence informs decision-making to achieve the best possible health and wellbeing for Aboriginal and Torres Strait Islander people.

• One way of addressing key national priorities is through **innovation hubs** (also known as **innovation platforms**) that bring together the best minds and keenest initiators (whether researchers, leaders/ influencers, service providers, or policy makers and community members) to focus on particular areas of work. As well as tackling the particularly intractable issues, these hubs may work with localised partnerships and networks to bring their particular expertise to help address local problems.

The research infrastructure described above does not replace the existing research system, or move Aboriginal and Torres Strait Islander health research into separatist research system. This infrastructure simply makes possible the genuine collaboration across sectors, communities and worldviews that are needed to address the challenges of Aboriginal and Torres Strait Islander health and wellbeing.

The various levels of research partnerships or networks described above still interact closely with the national health research system, but they also provide a mechanism to deliver research specifically targeted at Aboriginal and Torres Strait Islander health improvements.

These partnerships and networks also need to demonstrate performance: while they have ongoing funding, five yearly reviews are conducted to ensure accountability and quality.

This research system is not intended to be universal. Not all service providers, policy makers or communities will have the capacity—or desire—to take part in collaborative research. Over time, the level of participation may increase, particularly with the support of programs coordinated at the national level to encourage the use of evidence in policy and practice. Research partnerships or networks should be funded where there is enthusiasm and capacity sufficient to make a start, not as part of a national roll out. However, a program to foster capacity to take part in such research partnerships is an important part of this system, recognising that regions or communities least able to engage in research partnerships may be those where most benefit might be gained.

Similarly, not all researchers will want to work in the sort of research that is likely to be sought by these collaborations. Many researchers, whatever their background, will wish to be involved in traditional investigator-driven or basic science.

# Cultural shifts

By 2030, there have been shifts in the culture of research, health care and policy that enable rather than hinder a more effective Aboriginal and Torres Strait Islander health research system.

Many universities have adopted an open approach to knowledge and share their intellectual property freely. Research metrics cover a spectrum of weighted indicators ranging from collaboration to publication and impact. Researchers who average in the top 20 per cent for impact over five years are directly salaried from a national research fund; in key target areas, such as Aboriginal and Torres Strait Islander health, the top 35 per cent are funded.

Early career researchers and others are supported through five-year competitive fellowship grants. There are increasing numbers of researchers employed outside the university sector, in research cooperatives, partnerships and innovation hubs. Increasingly, the research workforce includes people with high levels of skills in collaboration, facilitation and communication, and research leadership and management are well-established disciplines in their own right.

In Aboriginal and Torres Strait Islander health care, services are person- and family-centred. Each person or family has an assigned multi-disciplinary team including an Aboriginal and Torres Strait Islander 'navigator', a broker who helps individuals interact with the health system. Members of the multi-disciplinary team may not all be based in the same place, but consistent interactions over time, facilitated by the navigator, build relationships between individuals and their health care providers even over Skype or similar communication technologies.

Community outreach programs support health care delivery, empowerment and healthy lifestyles for individuals and families. Community development programs engage with other local organisations to address systemic problems that diminish health and wellbeing (such as poor sewerage and housing, racism, poverty).

Accreditation and incentive programs for health care providers include a focus on continuous and integrated quality improvement—a 'learning organisation' orientation. High quality data from patient information and management systems is used to inform decision-making and provide opportunities for learning. Many health
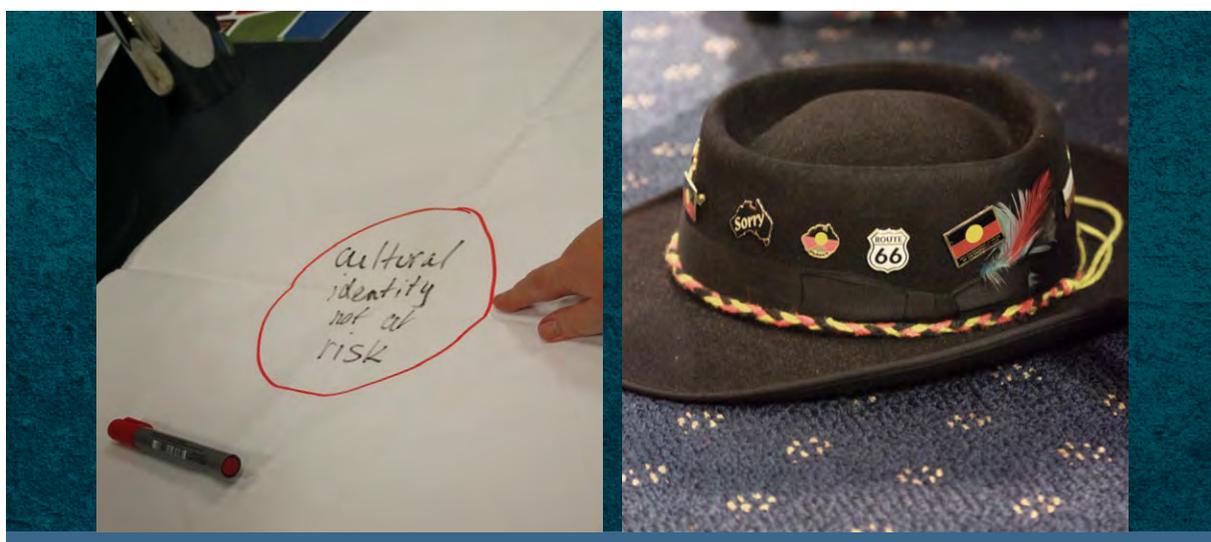
care workers are energised and incentivised by participation in research partnerships and networks that help them address pervasive problems and share learning.

There have also been cultural changes at the level of government policy. Government departments participate in continuous quality improvement programs, based on high quality data of actual performance on indicators of the quality of services provided. A no-blame culture has been fostered allowing for open discussion about how to improve government services. A checklist of 'what the evidence says we shouldn't do' is applied to all new programs and projects as part of standard risk management practice. Proposed policies are published, along with the evidence underpinning them, and public comment invited—not only on the intent of the policy, but on its feasibility. At times, brave governments proceed with policies based on evidence and principles of social justice, despite vocal opposition. Each year, the government publicly presents genuine and robust data about the performance of its policies and programs, and invites all public servants and the community more broadly to provide input on how to make improvements.

## Addressing the social determinants of health

In some areas, a localised research partnership becomes a forum to facilitate the bringing together of partners from beyond the health sector. One of the first of these begins with partners from the education and justice sectors joining their health care colleagues. A local magistrate, senior police and liaison officers, a youth worker, a principal, several teachers and Aboriginal liaison officers from local schools, and a group of Elders attend a forum convened by local Aboriginal and Torres Strait Islander health leadership to discuss responses to youth suicides. As they discuss their respective issues, it becomes apparent that a change at one point of the social system could bring profound change across all three sectors. Improved health, wellbeing and security during early childhood could result in youths and adults less susceptible to substance abuse or chronic disease. If healthy and secure early childhood is followed by schooling that responds to learner's needs rather than imposing a one size fits all approach, Aboriginal and Torres Strait Islander children may feel more at home in school, rather than alienated. They may stay at school longer, and leave school more able to find employment, less likely to end up in trouble.

This realisation spurs each sector to consider what they might contribute to bringing about this change. The prison will focus on supporting youths and adults in prisons to address issues that may jeopardise the safety and security of children, by running Family Wellbeing programs that carry over not only the period of imprisonment but also their release and return to home. Researchers collate and review evidence about what works to create positive educational experiences and outcomes for Aboriginal and Torres Strait Islander students. The school principals and liaison officers provide input to help shape this review to suit the context of the local region. The local health service increases its efforts to support mothers and babies, and adopts an evidence-based parenting program to support parents with children with behavioural problems. Developmental evaluation of the new education, justice and health programs helps iron out problems as they get underway. A longitudinal study is set up to evaluate the long-term outcomes of the initiatives.
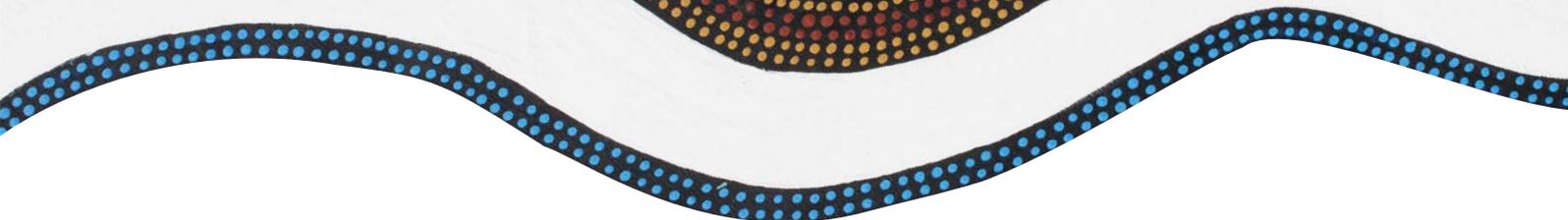
# Conclusion

Many of the themes that arose in the course of this project are not new.

However, by projecting into the future, workshop participants overwhelmingly envisioned a more effective system of research that would enable greater integration of health services, policy and research. Such a system would be responsive to changing research demands, but also to changing social, economic, technological and knowledge landscapes. And it would itself be transformative—changing relationships, behaviour and knowledge.

Workshop participants identified a critical need for Aboriginal and Torres Strait Islander health research to shift toward more facilitative, enabling ways of working with communities and other stakeholders in order to achieve effective and lasting results.

This research system for the future would include genuine and effective partnerships with Aboriginal and Torres Strait Islander people, as well as partnerships with policy makers and international alliances. Partnerships between organisations, researchers and communities would support an ongoing 'learning organisation' model of empowerment, improvement and knowledge utilisation.

It would be focused on improving Aboriginal and Torres Strait Islander health outcomes and would include research to enable wellness.

Program and service delivery evaluation would be well integrated.  Research would provide a community-centred perspective to this evaluation, rather than only that of the program deliverer. It would ensure that research findings flowed back to the community level to be incorporated into best practice.

There would be recognition that nurturing partnerships, the participation of stakeholders in research, and increasing the capacity of communities and organisations—including governments—to identify solutions to their knowledge needs, all require both human and financial resources. At the same time, wastage in the health research system would be reduced by moving decision-making about research investments closer to the site(s) at which research will be used (i.e. where the demand for Aboriginal and Torres Strait Islander health research arises).

The Aboriginal and Torres Strait Islander health and health research sectors have played a pioneering role in the reform of research in Australia. The Lowitja Institute, in its current and previous iterations, has been a leading advocate for a better system of Aboriginal and Torres Strait Islander health research. Through its own partnership model, the Lowitja Institute has enabled strong and effective collaborations between community, researchers and policy makers (see Appendix).

The strength of vision articulated by the Aboriginal and Torres Strait Islander health and health research sectors in this project—and their desire to see that vision become a reality—suggests the sector will continue its drive toward a more effective research system.

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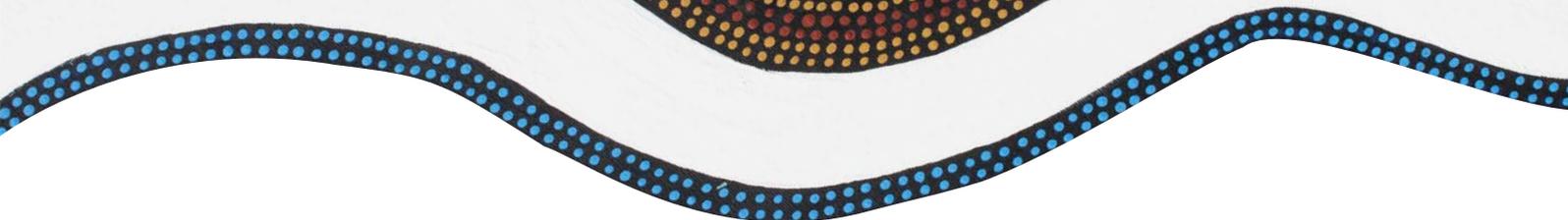
# Appendix

## Aboriginal and Torres Strait Islander research reform: A continuing journey

Historically, many Aboriginal and Torres Strait Islander communities have been either frustrated with, or deeply suspicious of research in general. This has largely been because research on Aboriginal and Torres Strait Islander peoples' lives was often undertaken without proper involvement or consultation, or did not lead to any benefit for Aboriginal and Torres Strait Islander communities.

The Aboriginal and Torres Strait Islander health and health research sectors have played a pioneering role in the reform of health research in Australia.

For example:

- The National Health and Medical Research Council's (NHMRC) first Aboriginal and Torres Strait Islander health research ethics guidelines emerged from the challenges of Aboriginal health leaders to traditional research practices and the assertion of the rights for communities to be involved in the design, execution and evaluation of research (NHMRC 1991; Humphery 2001).

- The Central Australian Aboriginal Congress set out one of the earliest statements of ethical practice in Aboriginal or Torres Strait Islander health research in the publication *Some Research Guidelines* (Liddle & Shaw c.1983 in Humphery 2001, p. 198).

- Research evidence was used to influence health policy-makers to shift Aboriginal and Torres Strait Islander health policy and programs from the Aboriginal and Torres Strait Islander Commission (ATSIC) to what is now the Department of Health and Ageing (Houston & Legge 1992)

- The Telethon Institute of Child Health Research showed with its Western Australian Aboriginal Child Health Survey that large scale studies could be done respectfully and ethically, with community collaboration and Aboriginal Health Workers as community researchers.

- At the island community of Galiwin'ku, the Yalu Marnggithinyaraw Centre has demonstrated a model of community-based health research centred on local Yolngu values and community strengths.

- The first Cooperative Research Centre (CRC) involving Aboriginal health services as partners was established in 1997 with the CRC for Aboriginal and Tropical Health (CRCATH). Partners included the Central Australian Aboriginal Congress, Danila Dilba Health Service, Menzies School of Health Research, the NT Department of Health and Community Services, the then Northern Territory University (now Charles Darwin University) and Flinders University.

## The Lowitja Institute Facilitated Development Approach

The CRC for Aboriginal and Tropical Health (1997–2003) was the earliest iteration of the Lowitja Institute. Through its reflective program of research on the ways in which Aboriginal and Torres Strait Islander health was being conducted, it clarified the conditions needed to improve the effectiveness of health research with its Indigenous Research Reform Agenda (Henry et al. 2002).

The CRC for Aboriginal Health (2004–2009) operationalised many of those conditions through its Facilitated Development Approach (FDA) (Brands & Gooda 2006) and demonstrated a model for research funders to commission research with stakeholder engagement throughout the research process.

*The core premise underpinning this approach is that:*

> *If Aboriginal (and Torres Strait Islander) people set priorities and direct research; end-users are engaged in research processes; partnerships between stakeholders are established; the capacity of Aboriginal people to direct and manage research and of non-Aboriginal people to work with Aboriginal people is strengthened; and there are clear strategies for research transfer, which will result in more useful research, more ethical practice, and the utilisation of research to produce improvements in Aboriginal health and wellbeing* (Laycock et al. 2011).

The Lowitja Institute has continued the work of the Cooperative Research Centres, and is guided by these principles. Its national profile enables a continuing strong voice for Aboriginal and Torres Strait Islander health research.

L–R: Ms Pat Anderson and Mr Russell Taylor


L–R: Aunty Ali Golding and Ms Carmen Parter


L–R: Professor Ross Bailie, Ms Wendi Ah Chin, Ms Heather D'Antoine


Professor Fiona Stanley


Ms Mary Guthrie
in the Mabo Room, AIATSIS, Canberra


Ms Tanhia Edwards (reading),
Professor Alex Brown, Ms Jenny Brands at lectern


L–R: Mr Justin Mohamed and
Professor Ian Anderson

Professor Komla Tsey


L–R: Mr Jeff McMullen, **Ms Suzanne Ingram,** Ms Heather Power


L–R: Dr Helen Cameron, Ms Alyce Merritt, Dr Ray Warner


**Mr Justin Mohamed**


**Associate Professor Gail Garvey**


Professor Judith **Dwyer**


**Mr Alwin Chong**


Workshop at the Koorie Heritage Trust in Melbourne