researching Indigenous health:
a practical guide for researchers

Alison Laycock with Diane Walker, Nea Harrison and Jenny Brands

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Definition: *Within this guide, the term 'Indigenous' is used to refer both to Aboriginal people and to Torres Strait Islanders. However, individuals quoted herein use a variety of terminologies when referring to Aboriginal and Torres Strait Islander Australians.*

Warning: *Aboriginal and Torres Strait Islander people are warned that this book may contain images of people who have passed away.*

foreword

This guide is an important contribution to the practical work of The Lowitja Institute – Australia's National Institute for Aboriginal and Torres Strait Islander Health Research – in making sure that health research has real benefit in improving the life expectancy of Aboriginal and Torres Strait Islander peoples and helping to 'close the gap'.

In our view, there is no point doing research into Aboriginal and Torres Strait Islander health unless it involves Aboriginal and Torres Strait Islander peoples at every step along the way, and that their priorities are the ones that matter most. This is the underlying philosophy that drove our predecessor organisations, the Cooperative Research Centre for Aboriginal Health (CRCAH) and the CRC for Aboriginal and Tropical Health (CRCATH), which way back in 1997 began formulating what came to be known as the Indigenous Research Reform Agenda. This agenda aimed to increase Aboriginal and Torres Strait Islander control and involvement in health research and focus the research effort directly on making a difference.

To make that difference, we must continually look for ways to improve the way we involve the users of research in the research process. At the forefront of good research should be proper community consultation, using methods that benefit not only the researchers but also the research participants. Researchers need to have a good understanding of how to do research in Aboriginal and Torres Strait Islander contexts so they are able to work with communities to get the most benefit from the research. Also important is the sharing of knowledge: feeding research results back to the community and ensuring they are well communicated to inform policy and practice.

This guide is a companion volume to *Supporting Indigenous Researchers: A Practical Guide for Supervisors* published by the CRCAH in 2009. It represents a collaborative effort from many people, both within and outside of the Lowitja Institute's essential partners. It is important to acknowledge the many valuable contributions from all those people and their generosity in sharing their knowledge and experience. Their stories bring to life the principles that underpin the approach to research that we advocate.

For those who seek to learn or improve upon the way they carry out research, this guide is invaluable. It sets out steps for planning robust, culturally acceptable research, and explores the issues that affect researchers and the research process when working in Aboriginal and Torres Strait Islander health contexts. We hope it will encourage new generations of researchers – as well as those experienced researchers just getting started in Indigenous health research – to have the confidence and ability to engage fully in this important and challenging, but also richly rewarding, work.

Pat Anderson
Chair, The Lowitja Institute

Kerry Arabena
Chief Executive, The Lowitja Institute

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about this guide

Researching Indigenous Health: A Practical Guide for Researchers was written by Alison Laycock with support from Diane Walker, Nea Harrison and Jenny Brands under the auspices of the Lowitja Institute. The guide and its companion volume, *Supporting Indigenous Researchers: A Practical Guide for Supervisors* published by the CRC for Aboriginal Health, have been developed in response to a growing need for resources in this area.

Indigenous health research needs to be driven by priorities set by Aboriginal and Torres Strait Islander people, to be of practical use to the Indigenous health sector and to develop research capacity within the Indigenous community. The Lowitja Institute receives frequent requests for resources and advice about how to conduct research projects in this way, and has identified different audiences with varying resource needs.

1 **Emerging and experienced researchers looking for ways to improve their Indigenous health research practice.** Researchers want to know how to involve participants and the users of research when developing and conducting research projects—how to build Indigenous values and approaches into research processes to make the research stronger, and how to make sure research can lead to real benefits for people's health and wellbeing.

2 **Supervisors of emerging Indigenous researchers.** Many research leaders have a lot of experience in designing and conducting research but limited experience as supervisors and trainers of emerging researchers. Non-Indigenous supervisors, in particular, want to know how to provide the right type of support to Indigenous researchers and how to build strong inter-cultural research partnerships for better research projects.

Researching Indigenous Health: A Practical Guide for Researchers includes the history, context, values and change priorities of Indigenous health research in Australia and the planning and management of Indigenous health research projects. The companion volume, *Supporting Indigenous Researchers: A Practical Guide for Supervisors* is about good practice in developing the capacity of Indigenous health researchers. Both books offer practical information, advice, strategies and success stories in Indigenous health research.

Researching Indigenous Health: A Practical Guide for Researchers **has three parts:**

part a: Indigenous health research in context

Chapters 1 to 3 summarise factors that make health research in Indigenous settings different to non-Indigenous health research – the historical context, knowledge traditions and big issues that impact on research, including the reform agenda for Indigenous research. Indigenous research values and ethics are explained using examples of good practice. Information about theoretical approaches to Indigenous research highlights the work of Aboriginal and Torres Strait Islander scholars.

part b: doing research that makes a difference

Chapters 4 to 6 focus on relationships, knowledge exchange and capacity building – essential for research practice that addresses the issues raised in Part A. The chapters use real examples and stories from experienced researchers, Indigenous research participants and research users to explain how to build these elements into research projects.

part c: designing and managing a successful research project

Chapters 7 to 10 guide readers through the processes needed to plan, develop and conduct a project that takes into account the research context and includes the elements needed to make a difference. Step-by-step guidelines, examples and stories show how health research can be done in ways that increase Indigenous participation and control, and result in research outcomes that have a practical use and benefit.

There is more in the web resource

Information in this guide is available on the Lowitja Institute website, where longer case stories can be read in full and chapters are supported with more information about Indigenous health research resources, policies, structures and collaborations. There is also a place to provide feedback about the guide and to contribute your own stories.

Access the Lowitja Institute web resource for researchers at:
www.lowitja.org.au/resources-researchers

acknowledgments

Thank you from the editorial team (from left):
Alison Laycock, Nea Harrison, Diane Walker and Jenny Brands

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researching Indigenous health: a practical guide for researchers

glossary

AHCSA	Aboriginal Health Council of South Australia
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIMhi	Australian Integrated Mental Health Initiative
CCRE	Centres of Clinical Research Excellence
CEO	Chief Executive Officer
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
CREW	Collaborative Research on Empowerment and Wellbeing
CYI	Cape York Institute
HREC	Human Research Ethics Committee
ICIP	Indigenous Cultural and Intellectual Property
IP	intellectual property
MOU	memorandum of understanding
NACCHO	National Aboriginal Community Controlled Health Organisation
NEAF	National Ethics Application Form
NHMRC	National Health and Medical Research Council
NT	Northern Territory
PHC	primary health care
POC	point-of-care
SA	South Australia
SEWB	Social and Emotional Wellbeing
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
WA	Western Australia

part a:
Indigenous health research in context

The principles of ethical and productive health research apply in all settings and types of research. However, there are issues and priorities that are specific to good research practice in the Indigenous health research environment.

Good research practice in Indigenous health involves:

- respect for Indigenous values, knowledge and worldviews

- awareness of the history and relationship between the Indigenous world and the world of research

- knowing how developments in Indigenous research in recent decades have changed accepted practices

- developing, conducting, reporting and using research in ways that lead to practical outcomes and health equity for Indigenous people

- more Indigenous people and communities controlling what, why, how and when research is done, and how it is used.

Indigenous health research outcomes are stronger and more useful when people come together with commitment, knowledge, acceptance and trust.

Part A sets the scene for health research. It discusses some of the issues that impact upon researchers, including history, knowledge and research traditions, Indigenous research values, and the change agenda for the management, practice and outcomes of research.

chapter 1:
setting the scene for research

Good research in Indigenous settings comes from bringing together different cultural perspectives and different ways of thinking, learning, knowing, doing and being. The way we do research is also influenced by the values and the thinking of the times in which we live, and the experiences of the past.

This chapter outlines some of these influences. It raises issues from the history of research for Indigenous peoples that impact on present day health and wellbeing, attitudes towards research and researchers, and on the way research is now planned and conducted in Indigenous research settings. It includes important messages for all researchers working to improve Indigenous Health through research.

Professor Ian Anderson.
Photo: Max Milne Photography

Ian Anderson, Director of Research and Innovation at the Lowitja Institute and Chair of Indigenous Health at the University of Melbourne, talks about the challenge of researching Indigenous health.

It can be demonstrated through the historical analysis of research practice in relation to Aboriginal and Torres Strait Islander peoples that research is neither a value-free process, nor one that is necessarily attuned to the return of benefit to those who are researched.

It is our challenge to work in a way that changes that dynamic. We need to be critically engaged in questioning the values and practices associated with research, in order for its potential to be realised in terms of practical gains for Aboriginal and Torres Strait Islander peoples.

part a: Indigenous health research in context

Historical issues that impact on Indigenous research

Over the past few decades, Indigenous health research (and other types of research, such as anthropological, historical and sociological research) has been questioned, criticised and debated. Social changes and shifts in political and academic thinking have improved the way Indigenous research is approached. Although this book guides researchers in current good practice, it is useful for anyone interested in researching Indigenous health to understand what happened in the past and why there was a need for change.

The link between colonisation, exploitation and research

The history of research for Indigenous people is tied to the history of colonisation. In the eighteenth and nineteenth centuries, Europeans explored and 'discovered' other worlds, expanded trade and established colonies. Western scientific thought developed. As Indigenous peoples were systematically colonised, their societies and cultures began to be studied from the point of view of groups with more power and privilege, and with different systems of knowledge.

Through this imperialism and colonisation, the West came to 'see', to 'name' and to 'know' Indigenous lands, peoples and resources. Classification systems were developed to cope with the mass of new knowledge and discoveries and to help the observers make sense of what they saw. These developments gave the colonial researchers authorship and ownership of knowledge (Smith 1999:59–60, 65). History was told through the eyes of the colonisers. Indigenous people tended not to have a voice and were de-humanised or 'othered' as objects of scientific research. Cultural practices were misrepresented and described in ways that reflected non-Indigenous researchers' values, beliefs and prejudices.

The process of recording what happened automatically favours the white occupiers because they won. In such a way a whole past is 'created' and then given the authority of truth (Awatere in Smith 1999:67).

Like colonists in other parts of the world, early European settlers in Australia knew nothing about its Indigenous peoples and cultures. They observed people from the perspective of their own worldview and made grave errors of judgment that have had significant impact ever since (NHMRC 2003:2).

This early knowledge production was all about us and yet had nothing to do with us either – it was quite external to our society and concerns (Nakata 2004:4).

European colonisation continues to have a devastating impact on the lives of many Indigenous Australians. People live with the legacy of being displaced and being subjected to policies that discriminated and took away control, removed children, split families and institutionalised people (Anderson 1988 in Holmes *et al*. 2002).

Australian Indigenous researcher **Karen Martin** summed up the effects of past research as:

… mistreatment of ourselves and our land, marginalisation from structures and governance and development of misguided policy and programs resulting in feelings of distrust, caution, fear of exploitation and misrepresentation (Martin 2003:2).

Examples of exploitation through research

Aboriginal people have been treated as specimens or objects of European researchers since the arrival of the white settlers in 1788… Up until quite recently, Aboriginal people were described in scientific discussion as a 'race' of people who were physically and intellectually inferior to other humans and were headed for extinction… The bones of Aboriginal people were… kept in museums both in Australia and around the world for study and display. Only in the past twenty years have museums begun to repatriate Aboriginal remains…

Psychologists in the early 1900s gave Aboriginal people intelligence tests which were designed for European populations… When Aboriginal people did poorly on these tests, this confirmed to the Europeans that Aboriginal people were less intelligent and indeed, childlike in their thinking… These early researchers were unaware of their own ethnocentricity (i.e., judging other cultures through our own culturally biased filters) and how it resulted in racial stereotyping [and scientifically invalid conclusions].

Another way in which European researchers have exploited Aboriginal people has been through… obtaining Aboriginal knowledge about, for example, plants and wildlife, about land use and kinship structure… They have taken the knowledge back to their universities and used it in order to acquire degrees and advance their careers. Very rarely, however, would the researchers inform the communities of their findings or ensure that they benefited from the research in some way. On occasion… an anthropologist has been given sensitive knowledge or objects by Elders helping with the research, then either published the information or displayed the sacred object in a public place. This has risked the safety of the custodians who were seen to be breaking Aboriginal law.

These examples of exploitation [indicate] why many Aboriginal people today are not supportive of research (Malin, Franks & CCRE Research Course Development Committee 2007:16–17).

Some non-Indigenous researchers had good intentions, had empathy for Indigenous peoples and campaigned for better treatment. However, they were also products of the social and scientific attitudes of their times. Olive Pink, for example, lived in Central Australia and undertook anthropological studies of Arrernte and Warlpiri people in the 1930s and 1940s. A controversial figure, who campaigned strongly for Indigenous rights, she attempted to set up a 'secular sanctuary' for Warlpiri – a campaign she continued until her death. However, Pink also had strong opinions about the need to separate individuals of mixed race in order to preserve a 'pure' culture.

Another story comes from the life and work of the anthropologist Ted Strehlow whose work, with Arrernte culture in particular, led to a bitter controversy about ownership of sacred objects.

} The Strehlow Collection is held by the Museums and Art Galleries of the Northern Territory. To read one story about the controversy, see 'The Strehlow Collection' at the Central Land Council website (Morton n.d.).

As Indigenous peoples were systematically colonised, their societies and cultures began to be studied from the point of view of groups with more power and privilege, and with different systems of knowledge.

Considering cultures, knowledge traditions and research

Research has progressed a long way from the approaches of those times. However, health researchers need to be aware that many Indigenous people have good reasons to feel cautious of research, and of researchers. Researchers also need to be aware that research approaches tend to reflect the social and scientific thinking of the day. In *The Beginnings of Aboriginal Health Research in Australia*, **David Thomas** (2001:19) wrote:

> *The medical scientists I work with often believe, or at least hope, that their work is untainted by the messy world of politics – truth rather than values. Yet from the distance of the present they can sometimes see the work of earlier researchers being influenced by the values of their times.*

This is the reality of doing research. It is never truly separated from, nor neutral to, the spirit and thinking of the time.

Although historical issues pose challenges for researchers, the approaches and social values of the present make this an exciting time to be involved in Indigenous health research.

Research can be described as a study or investigation, or the production of knowledge. Research is usually different from everyday fact-finding in that researchers follow a commonly accepted way of approaching this activity, partly based on understandings of what knowledge is, and how it is made. When faced with evidence, theories are revised and new knowledge is applied.

Although this overview of research may cross cultures, cultures have their own understandings of knowledge and reality, and traditional methods of research. No culture or environment is static – beliefs, religion, attitudes, communication, technology and knowledge are always being adapted (Grieves 2002). Therefore, knowledge production is continually being reinterpreted and research approaches are always evolving.

Indigenous people have lived in the Australian environment for at least 40,000 years, and have among the oldest knowledge and research traditions in the world.

> *It is evident that Aboriginal people have always done research… about the environment, where to go and when. They knew how to measure very precisely the numbers of people needed in groups for social, emotional, spiritual and physical well being. It was very critical that research was conducted and that it had to be a continuous process, because it was a matter of survival on a daily basis. So these discussions about health and social issues were conducted with the utmost integrity and intellectual rigour* (Christine Franks in Brands *et al*. 2002:iv).

Indigenous knowledge traditions vary between places and peoples, but share common features.

> *Indigenous knowledge is understood to be the traditional knowledge of Indigenous peoples. In Australia, a common misunderstanding is that this equates Indigenous knowledge to 'past' knowledge, when in fact Indigenous people view their knowledge as continuing… Indigenous knowledge systems are now recognised as dynamic and changing, orally transmitted from generation to generation and produced in the context of Indigenous people's close and continuing relationships with their environment…* (Nakata *et al*. 2005:7–8).

Australian Indigenous knowledge systems are based on a tradition where knowledge belongs to people. Indigenous knowledge tends to be collective; it is shared by groups of people. This knowledge is held by right, like land, history, ceremony and language. This right is governed by ancestral laws that are still strong in many communities. The principles of ancestral law and oral culture of Indigenous people mean that a lot of traditional knowledge is held by respected Elders, and can only be transmitted in accordance with customary rules, laws and responsibilities.

How Indigenous knowledge is represented comes from collective memory in languages, social practices, events, structures, performance traditions and innovations, and features of the land, its species and other natural phenomena.

However, knowledge is more than how it is 'represented' by people. An Indigenous way of looking at knowledge says that people are only part of the knowledge system that is at work in the world. Language, land and identity all depend on each other (Christie 2006:78, 79; DKCRC 2007a:2).

We encoded every bit of knowledge into the plants, animals, skies, waterways not just of the present but of the past. That is the way we have survived being colonised, not because we wrote things down but because we had it embedded into everything around us. The more Stories we know, the more we become (Martin 2009:1).

In this knowledge system where identity, kinship, place and history are interconnected, the construction of knowledge is complex, multilayered and, of course, continuous.

While it is true that an Aboriginal person's traditional land has fundamental importance, it is also true that post-invasion history and experience has created an additional layer of memory and significance for other parts of the country… The 'traditional' and the colonial and the present are all a fluid history connected to place and kin in our culture… the tightly knitted kinship and family networks that exist here [in Sydney] are just as strong here as they are in more discrete rural and remote areas. And it is an aspect of contemporary Indigenous culture that kinship and family ties bind our communities in a way that reinforces our more traditional obligations but interweave more widely than they once did (Behrendt 2007:2).

Most Western research traditions are based on, and give most value to, empirical theories of knowledge – that is, knowledge that is directly observed or tested.

Western research approaches mostly aim to be unbiased when collecting and interpreting data. However, unbiased research is still built on the academic theory bases in which we work, our underlying hypotheses (what we think we will find), and the assumptions and values of the work discipline. Research observations, however direct, are filtered through the observer's worldview, which is influenced by race, culture, gender, how we have been raised and taught, and more. In these ways research approaches and methodologies are always biased.

In Indigenous research, we bring knowledge systems and worldviews together. In academic terms, this meeting place is called 'contested space' or 'contested knowledges'.

Indigenous knowledge systems and western knowledge systems work off different theories of knowledge that frame who can be a knower, what can be known, what constitutes knowledge, sources of evidence for constructing knowledge, what constitutes truth, how truth is to be verified, how evidence becomes truth, how valid references are to be drawn, the role of belief in evidence, and related issues (Gegeo & Watson-Gegeo in Nakata 2007:8).

Indigenous scholar **Martin Nakata** refers to this as the 'cultural interface', where things are not clearly black or white, Indigenous or Western. He writes that we all bring to this space our histories, politics, discourses, social practices, knowledge technologies, how we come to know and understand our everyday world, and so on.

Keep up to date by reading new publications by emerging Indigenous scholars.

} For information about Indigenous and contested knowledges, read the work of leading Australian Indigenous scholars such as Martin Nakata, Marcia Langton, Lester-Irabinna Rigney, Karen Martin, Norman Sheehan and Bronwyn Fredericks.

} International scholars include Linda Tuhiwai Smith (New Zealand); Chris Lalonde, Marie Battiste, James Sakej Youngblood Henderson (Canada); Gregory Cajete, Robert Warrior and Bonnie Duran (United States).

Although historical issues pose challenges for researchers, the approaches and social values of the present make this an exciting time to be involved in Indigenous health research.
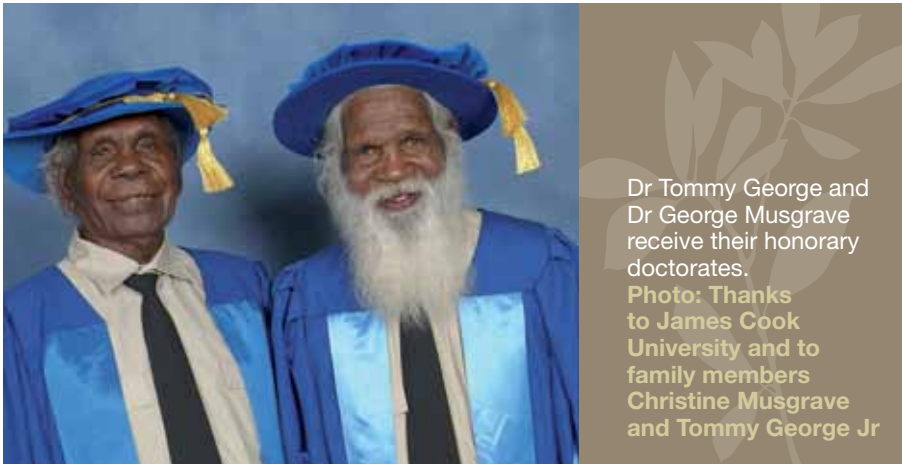
Dr Tommy George and Dr George Musgrave receive their honorary doctorates.
Photo: Thanks to James Cook University and to family members Christine Musgrave and Tommy George Jr

It is important to acknowledge our Elders and their significant contribution to research. Dr Tommy George and Dr George Musgrave, Elders from Kuku-Thaypan country, have contributed their knowledge of people and country to academic research for many years. The Traditional Knowledge Revival Pathway (TKRP) project contributed to their work done on country with the Traditional Fire Management projects and Traditional Knowledge recording processes. The project worked hard to get these Elders acknowledged in the academic world, and in 2005 James Cook University awarded Mr George and Mr Musgrave honorary doctorates. The doctorates recognised their traditional knowledge contribution to research and their role in maintaining a significant Indigenous cultural system for future generations (Victor Steffensen, Managing Director, Traditional Knowledge Revival Pathway Project).

Using the language and culture of Western research

All researchers within a Western academic approach go through the process of learning research language and the accepted way of doing things.

Western research has its own language, culture and conventions. For example, the language of research is specialised; people who do not speak the language, or those who are not used to working within the academic research culture, can feel like outsiders. Research institutions have a culture based around the role and status of people with different levels of academic qualifications and experiences. Not 'reading' the workplace culture, not understanding how it works, not feeling part of it or not feeling valued for other skills and knowledge can alienate new and emerging researchers.

The conventions of Western research set challenges that can affect Indigenous research and researchers in particular ways. For example:

- frequently the terms used in English to explain Indigenous ways of being and doing are inadequate, and Western consciousness is often inadequate to interpret Aboriginal ways of being and doing (Grieves 2003)

- Indigenous researchers carry great responsibility in projects that involve Indigenous knowledge

- sources of knowledge need to be cited and acknowledged, but how should Indigenous knowledge that is learned from Elders, and is held by a group rather than an individual, be referenced?

- some traditional knowledge may be vital to the research, but may not be 'public' knowledge – it cannot be written or shown in places where it may be seen or heard by those who don't have the right to know

- Western research has a convention of validating researchers' work through academic critique, questioning, argument and debate: public and published criticism can be especially uncomfortable and humiliating for Indigenous researchers because it can challenge the boundaries of cultural safety

- the way researchers have written about Indigenous Australians has influenced the way non-Indigenous Australians think about Indigenous people, and even how some Indigenous people think about themselves (Thomas 2001:3; Nakata 2004:15).

Most new researchers find research colleagues understanding and supportive when help is needed to understand terms and conventions. Learning about research terms and research culture should be included in a workplace induction program for new and emerging researchers, and be an ongoing part of work planning and professional development or a research study program.

...this bringing together of worldviews is critically important in finding ways, through research, of improving health for Indigenous Australians.

Valda Wallace

Case story – The challenge of learning research language

Valda Wallace is a Gugu Badhun Aboriginal woman from the area surrounding the Valley of Lagoons in the north of Queensland. She has worked for many years in health and policing, and is Deputy Head of the School of Indigenous Australian Studies at James Cook University.

Valda describes learning a new language when she began as a research student.

Research terminology was a whole new concept for me to consider… On receiving the course materials, I commenced reading and immediately reached for the dictionary; new words were popping up with almost every sentence – paradigm, ontology, epistemology and the list seemed to go on forever.

[When] the lecturer kindly explained the correct meaning of this new vocabulary… I remember thinking to myself, 'You want me to learn what language? I don't even know anyone that I can converse with in this language…'

From experience I can equate becoming acquainted with research terminology to entering a foreign country and learning a new language. To gain recognition, acceptance and survive one must comprehend and speak the language; however, many foreign countries provide a more compassionate atmosphere to learners, unlike the world of academia.

part a: Indigenous health research in context

Valda describes interpreting research terms from the perspective of an Indigenous researcher:

I… looked at the words not as foreign imposed hurdles that I had to cross but rather as having meaning and a relationship to my work and my personal being. For example… Epistemology I can relate to as knowing how I know things, who I am, how I am influenced in understanding the world the way I do. Methodology is defined as 'how we go about finding knowledge', ways of researching, data collection and analyses. For thousands of years Indigenous peoples have been collecting and analysing data as a matter of survival. [They] were accountable as guardians of their land, they lived by the clock of the seasons taking care not to damage or desecrate the environment. This was shared knowledge handed down through each generation (Wallace 2003:3–4).

In summary, working in Indigenous health research is both challenging and rewarding, partly because Western and Indigenous systems of knowledge meet in the research. The terms of meeting are not always even and the meeting place is complex. However, this bringing together of worldviews is critically important in finding ways, through research, of improving health for Indigenous Australians.

The way forward involves Indigenous and non-Indigenous researchers learning from each other and working successfully together. It involves self-reflection and questioning.

Early in my career in Indigenous health research, I had a bit of a crisis. The more I understood the issues and challenges, the more I wondered if it was appropriate for me, as a non-Indigenous researcher, to be working in this area, and what contribution I could make.

Lots of reading and discussions with Aboriginal colleagues helped me to understand that there was a role for me, but that my involvement had to be done in certain ways – ways that were respectful of Aboriginal people's knowledge and ways of doing, that fostered respectful partnerships and that supported shared understandings and the co-generation and creation of new knowledge. For me the take home message was that how I did research was equally important as the outcomes of that research. As my understanding deepened, I learned that the quality of the research outcomes or the knowledge generated was, in lots of important ways, linked to how things were done (Barbara Beacham, Program Manager, The Lowitja Institute).

} *Supporting Indigenous Researchers: A Practical Guide for Supervisors*, the companion volume to this guide, includes issues and strategies for working and learning in intercultural partnerships, along with many strategies for supporting and honouring Indigenous knowledge and local practices through health research.

} Chapter 2 of this current volume discusses Indigenous research values, including the survival and protection of cultures, languages and identities. Chapter 3 includes some Indigenous research models and approaches. Indigenous knowledge and intellectual property rights are discussed in Chapter 9, which also provides advice about working with sensitive and restricted information. All chapters focus on doing research in ways that privilege Indigenous voices.

A framework for good research

Indigenous Research Reform Agenda

The approaches of individual researchers are part of a broader agenda for changing Indigenous health research practice. A framework of research reform has been developed over several decades. This framework is known within the Lowitja Institute (which incorporates the CRC for Aboriginal and Torres Strait Islander Health) as the Indigenous Research Reform Agenda. It has strong Indigenous community support and crosses a range of academic disciplines. The most important principle of the Indigenous Research Reform Agenda is that 'Aboriginal people should control research about Aboriginal issues' (Street *et al*. 2008:1).

Reforms in health research recognise that much past research has not resulted in better health services, nor helped to build healthier, better informed communities (Giles *et al*. 2006:99). Changes to research policies, management, organisational structures, research methods and practices aim to address these poor outcomes. Strategies include better defined ethical practices, research priorities set by Aboriginal and Torres Strait Islander people, research partnerships based on Indigenous participation and control, and approaches and methods that make the most of Indigenous expertise.

There is no point doing health research for Aboriginal and Torres Strait Islander people unless it involves Indigenous stakeholders at every step along the way and where their priorities are the ones that matter most (Pat Anderson, (then) Interim Chair, The Lowitja Institute, at inaugural Congress Lowitja, Sydney, 23 March 2010).

Another important part of the health research reform agenda is capacity building. Universities and research institutions, other training organisations, community-based and government services, and other workplaces across Australia are involved in the development of Indigenous health researchers and research leaders.

In summary, the Indigenous Research Reform Agenda aims to promote:

• a focus on research that can be transferred into practice to make a difference to the health status of Indigenous people

• Indigenous control of the research agenda

• Indigenous control of the research process

• improved processes for quality control

• improved processes for consultation and negotiation of research (Harrison & CRCAH 2009:3).

} The Cooperative Research Centre for Aboriginal and Tropical Health, a predecessor of the Lowitja Institute, conducted a large project from 1998 to 2002 to investigate the Indigenous Research Reform Agenda. The results of this project were published in the *CRCATH Links Monograph Series* and are available on the Lowitja Institute website (www.lowitja.org. au/crcah/approach-research).

The Lowitja Institute website explains system-level reforms, institution reforms and collaborative structures that support the Indigenous Research Reform Agenda (www.lowitja.org.au/resources-researchers).

Big issues for Indigenous health research

Health inequity

Australia is a country with a reputation of 'a fair go for all'. We have a first-class health system and the health of Australians has improved greatly over the past century. However, there are health inequities (unfair or unjust inequalities) between Indigenous and non-Indigenous Australians that persist despite the efforts of many people who have worked to reverse these inequities (Carson *et al*. 2007:xix). Health inequity is, therefore, an important focus for research.

The state of Indigenous health is well known. It has been aptly described as Third World health in a First World nation… the statistics of Aboriginal health are dreadfully familiar…

There are other rates of disadvantage in high rates of unemployment, poorer educational outcomes, living in inadequate, overcrowded housing, and unacceptably high rates of imprisonment and juvenile detention. All of these factors are interconnected… (Lowitja O'Donoghue 2004 in Carson *et al*. 2007:xxi–xxii).

The need to tackle health inequity for Indigenous people brings a sense of urgency and responsibility to health research. It impacts on researchers and research in a number of ways:

- health research needs to be used and useful: it needs to be accountable

- research needs to benefit the researched, not the researcher: over the past few decades more people have asserted that research must not be carried out for its own sake, nor for the benefit of researchers or research institutions, but must help to bring real improvements in health and in the community

- there is an increase in research to investigate the factors that impact on health, including the social and economic factors

- it is a priority to do research that identifies the causes of poor Indigenous health, and the kind of health interventions needed to improve life expectancy

- research must address needs identified as priorities by Indigenous people

- there is more emphasis on health as a social justice issue, and more recognition of the social and economic factors that impact on health; some health research funding is tied to capacity building and community development outcomes

- many researchers and research organisations have needed to examine and change their practices

- many researchers, especially Indigenous researchers, feel a keen sense of responsibility to do research that makes a difference

- researchers and funders can be guided by the many reports and inquiries that state the kind of research wanted by Indigenous Australians to help reduce inequity (e.g. Royal Commission into Aboriginal Deaths in Custody)

- national guidelines encourage researchers and funders to do research that helps to reduce health inequity, e.g. *NHMRC Road Map II: A Strategic Framework for Improving the Health of Aboriginal and Torres Strait Islander People through Research* (NHMRC 2010).

'Close the Gap' campaign

There is growing public awareness of the health inequity between Indigenous and non-Indigenous Australians. One reason for this is the high profile 'Close the Gap' campaign, which highlights health as a human rights and social justice issue.

In the *Social Justice Report 2005*, then Aboriginal and Torres Strait Islander Social Justice Commissioner Tom Calma called for Australian governments to commit to achieving equality of health and life expectancy for Aboriginal and Torres Strait Australians within 25 years, over one generation (Calma 2005). This led to the 'Close the Gap' campaign, which uses a human rights-based framework to address the health inequity experienced by Indigenous Australians. It was launched by Oxfam Australia in 2008.

The campaign highlighted the common misconception that Aboriginal and Torres Strait Islander people's health has been well resourced and well funded, when in fact the Australian government spends less per capita on health for Indigenous Australians compared with non-Indigenous Australians (Kelly 2008:62). The campaign lobbied government to increase funding and to support programs that work with (rather than for) Indigenous communities. It called on Australian governments to take action to achieve health equality through:

- increasing Indigenous Australians' access to health services

- addressing critical social issues such as poor housing, nutrition and education

- building Indigenous control and participation in the delivery of health and other services.

The campaign led to the National Indigenous Health Equality Summit in Canberra in March 2008, at which the Australian government, Federal opposition, and leaders of Indigenous and mainstream health peak bodies signed an historic 'Close the Gap Statement of Intent' to work together to achieve equality in health status and life expectancy between Indigenous and non-Indigenous Australians by the year 2030. A commitment was made to close the Aboriginal and Torres Strait Islander life expectancy gap within a generation, and to halve the unacceptable mortality gap for Indigenous children under the age of five within a decade.

Specific benchmarks and targets have been set for partnership, health status, primary health care and other health services and infrastructure. Data collected by health researchers will be essential for monitoring progress towards these targets.

The Australian government set up the National Indigenous Health Equality Council in 2008 to provide advice on developing and monitoring health-related goals and targets. The first chair of the council is Ian Anderson, Director of Research and Innovation at the Lowitja Institute.

Action Area 4 of the *NHMRC Road Map II* (NHMRC 2010:10–11) aims to contribute to the Close the Gap health initiatives in Aboriginal and Torres Strait islander health.

} For more information about the 'Close the Gap' campaign, see the 'Indigenous Health Campaign' page of the Australian Human Rights Commission website (www.hreoc.gov.au/social_justice/health/index.html).

Lack of health data about Indigenous Australians

There is a lack of accurate, consistent and complete data about the health of Indigenous Australians. This problem is not unique to our country – it is a legacy of the colonisation of Indigenous peoples worldwide and reflects common experiences of discrimination and neglect of human rights.

Currently, the measurement of the health of Indigenous people world-wide is complicated by deficiencies in the data describing Indigenous people. These deficiencies are in part due to inconsistencies in the collection, the sources, completeness, classifications, analysis, interpretation and ownership of the data in each jurisdiction (Freemantle & McAullay 2009:67–8).

In Australia, Indigenous identity has only been recorded in datasets in recent decades. The Referendum held on 27 May 1967 gave the Australian government a mandate to implement laws and policies that applied specifically to Indigenous Australians (for more information on the 1967 Referendum, go to the Reconciliation Australia website at: <www.reconciliation.org.au>). After the Referendum, Aboriginal and Torres Strait Islander Australians could be identified in the Census and counted in population statistics. This made possible comparisons between population groups, for example, comparison of health status and life span between Indigenous and non-Indigenous

Australians. The Census did not mean, however, that the States and Territories would gather details to identify Aboriginal and Torres Strait Islander people in their datasets. This happened over the next three decades.

> *Prior to 1976, no Australian jurisdiction separately identified Indigenous persons in vital statistics or hospital-based collections… [T]here is an acknowledged under-identification of Aboriginal and Torres Strait Islander people in statutory and administrative data collections, due to a general lack of recognition of the importance of collecting accurate data, ineffective processes for the collection of data and the absence of mandates to ensure that accurate data are collected… which makes it impossible to provide a complete and accurate profile of the mortality of Australia's Indigenous people* (Freemantle & McAullay 2009:88).

Another issue for researchers is that government datasets only include data of interest to government, not data relating to the broader determinants and elements of Indigenous health and wellbeing.

Many health researchers set out on projects only to find that the background data they need do not exist. Incomplete and inconsistent Indigenous identification in datasets needs to be taken into account when planning and designing health research projects.

} For advice about using data collections, see Chapter 9, 'Collecting, Managing and Interpreting Data'.

The need to tackle health inequity for Indigenous people brings a sense of urgency and responsibility to health research.

It impacts on researchers and research in a number of ways…there is more emphasis on health as a social justice issue,… [and] it is a priority to do research that identifies the causes of poor Indigenous health, and the kind of health interventions needed to improve life expectancy.

Key messages for researchers

- Research is influenced by colonisation and the history of relationships between Indigenous and non-Indigenous peoples. It reflects the scientific knowledge, academic approaches, beliefs, social values, policies and politics of the time.

- In Indigenous health research, we bring knowledge systems and worldviews together. This is essential for finding ways, through research, to improve health for Indigenous Australians. It makes for challenging and rewarding research partnerships.

- Good practice in Indigenous health research promotes Indigenous participation and control, and approaches and methods that make the most of Indigenous expertise.

- Reducing health and social inequity should drive our research efforts.

chapter 2:

principles in Indigenous health research

In recent decades Aboriginal and Torres Strait Islander Australians, like other Indigenous communities around the world, have led action to change the way research is done. Many non-Indigenous people have joined in these efforts. Poor research practices have been actively resisted. Ethical processes for research have been strengthened. Research that does not offer benefit has been rejected. There have been calls for more accountability, Indigenous leadership and rights in research.

This chapter outlines some of the responses to these calls. It explains how guidelines were developed for ethical research in Indigenous health. It brings values like respect, reciprocity, survival and protection into reality and practice through the words of researchers and research participants.

Ethical research principles

Ethics are about beliefs, the way we think and behave. It is about the rules of behaviour and human duty, morals and values: that is, understanding right and wrong, justice and injustice, good and bad, and doing the right thing…

Human research ethics are a set of principles to help guide researchers to develop and do research in a way that is safe, respectful, responsible and of high quality (NHMRC 2006:4).

Many broad reforms in Indigenous health research are based on ethical questions such as, 'who controls the research process?', 'who does the research benefit?' and 'who owns the new knowledge?' These questions now underpin Indigenous research policy, structures and theory on a broad level, as well as changes to research practice. For example, these questions helped structure the Lowitja Institute, which is governed by a majority Aboriginal and Torres Strait Islander Board and has an Indigenous leadership team. They are reflected in the academic approaches of Indigenous scholars who have reframed the development of knowledge, or set a political agenda for change. Ethical questions have led to research practices and methods that are commonly used to research Indigenous health, such as collaborative partnerships, participatory action research methods and negotiated agreements with participating groups.

> *Mainstream [research] ethics includes justice, empowerment, fairness, the obligation to do no harm, but for Aboriginal and Torres Strait Islander peoples ethics requires that protocols should be set by the Aboriginal and Torres Strait Islander community. Ethics involves issues of control and ownership of research, and issues of Indigenous copyright and ownership of intellectual property. Ethical practice requires that Aboriginal and Torres Strait Islander peoples must be participants (as stakeholders, research participants and researchers) in any research that involves them. They should have full knowledge and understanding of what the research is and what will be the benefits from it. Consent forms should be written clearly in culturally appropriate language. Relevant groups or organisations within the community, including Elders, should be consulted and kept informed of the research* (Shibasaki & Stewart 2005:3).

In summary, ethical principles in Indigenous research are principles of reciprocity, benefit and empowerment. They are about privileging Indigenous views and voices in research, and setting up an environment both for Indigenous ownership of and leadership in research.

The idea of ethical space

When Indigenous and Western research traditions and values come together, there can be complex ethical concerns to work through and learn from. This is because ethical understandings are challenged by differing worldviews, and by different approaches to research (Durie in COHRED 2008:5). Coming together in the right ways reduces the concerns, and supports us to value and make the most of the differences.

Some scholars have written about the idea of *ethical space*. An Indigenous Canadian scholar, Willie Ermine (2007), explains that each person or group in a research relationship has the ethical boundaries of society, culture, community, family, self, history and religion, and that these boundaries help to define the ethical space of coming together. Within the ethical space differences can be explored actively, common ground discussed and people can come to a mutual understanding. Crossing the boundaries can create tension or mistrust. Ermine argues that by thinking about this ethical space people can open up communication, so that through collaborative, partnership-based approaches they can develop new ways of thinking and understanding, and new knowledge can be created.

The concept of ethical space is included in the Canadian Institutes of Health Research *CIHR Guidelines for Health Research Involving Aboriginal People* (2007). The guidelines explain the reconciliation processes needed when Indigenous and non-Indigenous cultures meet in research.

Protecting Aboriginal ethical space involves a series of stages of dialogue beginning with the conversations prior to the design of the research, through to the dissemination of results and perhaps even afterward. Fundamental to this process is an ongoing respect for both parties' ethical spaces and a continual questioning of 'is this ethical?' This requires a dialogue about intentions, values and assumptions throughout the research process (CIHR 2007:2.1).

Ethical research practice

Doing ethical health research in Indigenous settings means doing research in ways that are culturally safe and ethically acceptable to all involved – research participants, communities/organisations, other interested community members and the research team. It involves Indigenous people and communities influencing what, why, how and when research is done, as well as how it is used.

[Ethical research practice involves] treating people fairly, with respect and with dignity. In practice, ethics means that researchers should:

- *respect people's individual wishes;*

- *make sure that people are not harmed by research;*

- *only do research that will benefit the people or Community being researched;*

- *make sure people are fully informed about the aims and purposes of the research;*

- *keep people informed about the methods and the research processes being used;*

- *ensure confidentiality of individuals and communities;*

- *negotiate ownership of data; and*

- *be concerned about the way the outcomes of the research may affect individuals or the Community* (Stewart & Pyett 2005:7).

Onemda VicHealth Koori Health Unit at the University of Melbourne is one of the organisations working to improve the way Indigenous health research is conducted. The unit has run a workshop program over the past decade to hear, and act on, the Victorian Koori community's views about research.

The clear messages from the workshops are that participants want Koori health research to be controlled by Kooris, and that research ethics continues to be an issue for Indigenous health services and their clients, and for those involved in improving research practice. For example, the 2007 workshops found that despite reforms in research practice, lack of research ethics and cultural insensitivities are ongoing issues for Indigenous communities (Onemda VicHealth Koori Health Unit 2008:7, 18, 21).

} Read comments by workshop participants in the report *We Can Like Research… in Koori Hands: A Community Report on Onemda VicHealth Koori Health Unit's Research Workshops in 2007* (Onemda VicHealth Koori Health Unit 2008).

} The Indigenous Health Ethics Network promotes research that is ethical, culturally appropriate and benefits the community. It lists Human Research Ethics Committees around Australia that have Indigenous members, provides links to Indigenous health and ethics organisations, and has a library of publications relating to health ethics and other resources (www. indigenoushealthethics.net.au/about_us).

The development of ethics guidelines

Health research in Australia is guided by the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 2007). The National Statement applies to all publicly funded human research and sets out rules for researchers, ethics committees, research managers and research participants.

Indigenous health research conducted in Australia today is also guided by Indigenous-specific ethics guidelines. A history of exploitation in research led to the development of these guidelines. However, Indigenous people were not asking for protection from exploitation, but for ethical engagement.

A major event that brought about change was the 1986 national conference, 'Research Priorities to Improve Aboriginal Health', convened by the NHMRC and the Menzies Foundation and held in Alice Springs. Indigenous delegates took over the conference, speaking out in protest over the way Indigenous health research continued to be driven by non-Indigenous interests, and setting out an Indigenous point of view. The conference resulted in many recommendations related to the ethics, funding and practice of research, as well as to issues of community control and benefit.

In response, the NHMRC held a workshop in August 1987, during which Indigenous delegates worked on principles and standards for rewriting the rules of Indigenous health research practice. Decisions were made about ethical issues such as protocols for researchers to obtain consent; ownership and publication of data; and the need for researchers to consult and negotiate with Indigenous health services, community-controlled organisations and peak bodies, as well as with individuals (Humphery 2003:17–20). The workshop led to the 1991 publication of the *Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, which although not radical did show a respectful and consultative approach to research by the main health research funding body in Australia (Humphery 2003:19).

These were important steps in transforming Indigenous health research in Australia. Shane Houston, who was then National Coordinator of the National Aboriginal and Islander Health Organisation, observed that the guideline development process 'was one of the early successful examples of the community taking control of an issue and saying this is how it's going to be done, and negotiating through a partnership to deliver a result' (Humphery 2002:35).

The 1991 interim guidelines were replaced in 2003 by *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003). Key ideas are:

- focus on values and relationships rather than procedural rules

- mutual recognition and respect for social and political processes

- reconciliation and/or decolonisation – equity and partnership rather than more oppression and alienation through research.

[The process for developing ethics guidelines] 'was one of the early successful examples of the community taking control of an issue and saying this is how it's going to be done, and negotiating through a partnership to deliver a result'.

In 2006 the NHMRC published *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander Peoples about Health Research Ethics*, a resource for Aboriginal and Torres Strait Islander people to refer to when making decisions about health research in their communities. *Keeping Research on Track* is also a useful resource for researchers. It explains researchers' responsibilities and guides ethical communication between researchers and communities/organisations through an eight-step research process. Step one is 'Building relationships'.

It's because there has been bad research in the past that we have advocated for this ethical framework to work within. If you don't start with building relationships, the other steps won't have real guts… The time it takes to build relationships at the beginning needs to be factored in and seen as an investment into the project (Paul Stewart, Research and Community Development Officer, Onemda VicHealth Koori Health Unit).

} *Values and Ethics* and *Keeping Research on Track* have been published as a resource package called *Exploring What Ethical Research Means: Resource Package for Aboriginal and Torres Strait Islander Communities and Organisations*. For a print version, contact National Mailing and Marketing, PO Box 7077, Canberra BC, ACT 2610, or email <nmm@ nationalmailing.com.au>.

Current ethics guidelines:

- take into account the history of Indigenous research and the research reform agenda

- are grounded in the civil rights movement for civil and health rights for Indigenous peoples, including the right to self-determination

- are based on a set of values that are shared by Indigenous peoples in Australia

- recognise that good, ethical research is only possible when stakeholders acknowledge the reality of any intercultural differences between those involved in research – this involves getting rid of 'difference blindness', being honest and transparent, and developing trust through real engagement between people: 'Working with difference in a research context takes time, care, patience and building of robust relationships' (NHMRC 2003:3)

- are presented in different ways to target different stakeholders, including researchers, Human Research Ethics Committees and Indigenous communities

- go hand-in-hand with the 2007 *National Statement on Ethical Conduct in Research Involving Humans*.

Applying ethics guidelines

Ethics and values guidelines are practical documents. They are more than values statements to be used when writing the research proposal – they are resources to be used throughout the research project, from the concept stage through to dissemination and evaluation.

> *When we talk about research ethics, many researchers tend to think of ethics approval processes. This is because a research proposal has to be approved by an ethics committee before the research project can get underway. The ethics application is what researchers focus on, when really ethics are so much more – they are the foundations of the research. Ethics underpin every aspect of what we do as researchers, and how we do it* (Nea Harrison, Director, Pandanus Evaluation & Planning Services).

Ethics underpin every aspect of what we do as researchers, and how we do it.

The difference between the ethics proposal and ethical research is critical; it is possible for researchers to meet rule-based ethics requirements without embracing the values and principles that are relevant to the research. Ethical research is not a matter of compliance with ethics guidelines, but a more complex matter of trust and integrity. Trust and ethical behaviour are about using discretion and judgment, and these are complex and challenging matters (NHMRC 2003:3).

Ethics guidelines can be useful tools for Indigenous community stakeholders. They can be used to guide the way people work together, and to hold researchers accountable.

} For advice about completing an ethics application, see Chapter 8, 'Planning the Project'.

Six values that guide ethical research

Six core values that are important to all Aboriginal and Torres Strait Islander peoples – spirit and integrity; reciprocity; respect; equality; survival and protection; and responsibility – are defined in *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander Peoples about Health Research Ethics* (NHMRC 2006).

Our Most Important Values

Responsibility

Reciprocity

Spirit and Integrity

Survival and protection

Respect

Equality
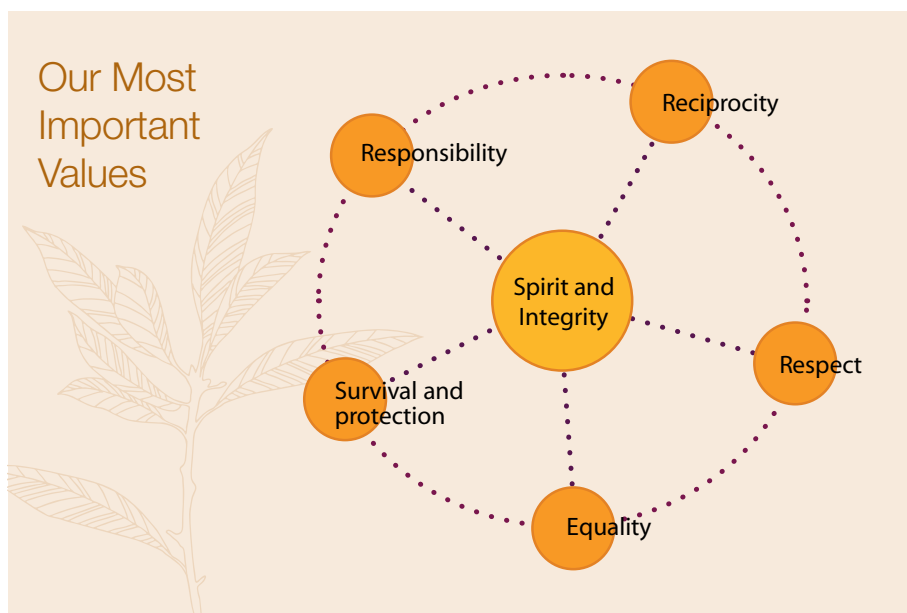
Aboriginal and Torres Strait Islander societies each have their own established and respected values and protocols, and unique ways of expressing their different values. There are, however, six common values… Each community or organisation has the right to express how these core values, and any unique values, will be addressed in research (NHMRC 2006:8).

Spirit and integrity

This is the most important value that joins all our Aboriginal and Torres Strait Islander peoples' values together. The first part, Spirit, is about the on-going connection (continuity) between our past, current and future generations. The second part, Integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together (NHMRC 2006:8).

Any behaviour that diminishes any of the [other] five values could not be described as having integrity (NHMRC 2003:19).

Researchers have an obligation to the spirit and integrity of communities, not just to individuals. This obligation involves community decision-making based on shared values, and means that the research needs to be consistent with community values.

Researchers need to question their motivation and actions, ensuring that research processes respect the richness and integrity of the cultural inheritance of past, current and future generations and of the links that bind the generations together. Community negotiations need to show credibility in what is intended and how things are done. Both the behaviour of the researcher/s, and the research processes, need to have integrity (NHMRC 2003:20).

Spirit is about the on-going connection (continuity) between our past, current and future generations... Integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together.

What do spirit and integrity look like in a research project?

We have Yolngu ways of understanding research values and how to build healthy communities. We develop programs using the Yolngu way of bringing the values together. We look into our own process of understanding the world and how everything is connected. We look at old structures and ways of being, and new ways of doing things. It's about balancing them… We have a holistic way. Everything we do connects to the land, its structures, how we live in the environment. It's always a full process (Joanne Garnggulkpuy, Galiwin'ku, Northern Territory).

By using collaborative models and the holistic view of health, my approach to research has supported concepts and experiences of spirit and integrity. I was continually guided by the co-researchers as to what was important for them, and to remember that there could be important cultural, spiritual and personal aspects and preferences that I was unaware of (Kelly 2008:90).

I am blessed with this precious tissue to do my PhD… The head is very tapu, meaning sacred… [In Maori culture] the head is thought to be the seat of the soul… We decided as a tribe that I needed to do some tikanga Maori (Maori customary practice, values and knowledge base) for my own cultural safety… I do karakia, it's a prayer, and waiata, a song, in order to cleanse myself… I pray, I mourn that person who's gone… farewell them to Hawaiiki, which is where we go when we die…and then I basically welcome them for their new function… And another part that I do… is to acknowledge the grief that the family is experiencing at that time, because you know I'm getting the tissue between six and twenty-four hours after the person's death so that's very brand new for that family, they are going to be grieving… (All in the Mind 2008).

Reciprocity

Our way of shared responsibility and obligation is based on our diverse kinship networks. This process in our communities keeps our ways of living and family relationships strong. These responsibilities also extend to the care of the land, animals and country and involve sharing benefits from the air, land and sea, redistribution of income, and sharing food and housing (NHMRC 2006:9).

For researchers, reciprocity is about mutual obligation and inclusion. Equitable and respectful engagement with research participants, and their values and cultures, depends on inclusive research processes.

Reciprocity is also about benefit. The research should benefit people in terms of capacities, opportunities or outcomes, and/or advance the interests expressed by the Indigenous people and communities involved in the research (NHMRC 2003:10).

Researchers need to ask:

• how does the research help to improve the health and wellbeing of participants and communities?

• does the research link to Indigenous health priorities and/or respond to needs expressed by Indigenous people?

• have the benefits been clearly and truthfully discussed?

• are you willing to change the research in response to community values and aspirations?

• what will the longer term benefits be in terms of developing skills, knowledge or broader strategies for health improvement? (NHMRC 2003:10, 11).

What does reciprocity look like in a research project?

The concept of reciprocity is not just about fair employment of people and the strengthening of research capacity within the community; it is about contributing to 'making a difference' in redressing the inequities experienced by Aboriginal people; sharing research information in a meaningful way with communities; and working with Indigenous people as partners in research… since the completion of this [diabetes intervention] study we have maintained a close relationship with Yalu' Marnggithinyaraw Nurturing Centre… We recently collaborated to undertake an evaluation of an electronic store food card… Yalu' trained and mentored a group of young people to assist with the qualitative part of this evaluation (Julie Brimblecombe, Menzies School of Health Research).

Julie Brimblecombe
and Joanne
Garnggulkpuy

*We care for each other – this is reciprocity. People have different cultures
and colour and traditions but blood is the same. That's the unity, that we
are one* (Joanne Garnggulkpuy, Galiwin'ku, Northern Territory).

*In addition to the expected formal written reports, the evaluation of the
Irrkerlantye Community Development Centre in Alice Springs attempted
to contribute to the functioning of the centre… When support for the…
school and training programs was withdrawn, our project helped to
facilitate the process to help the centre find alternative funding… [We also]
contributed [by]… uncovering… significant safety issues in the child care
centre. A researcher wrote to the appropriate government department
requesting funding to pay for [improvements]… The department was
swift in providing the required money* (Merridy Malin, Aboriginal Health
Council of South Australia, and Debra Maidment, Ngkarte Mikwekenhe
Community Inc.).

Respect

*Respect for each other's dignity and individual ways of living is the basis
of how Aboriginal and Torres Strait Islander peoples live. Within our
cultures, respect strengthens dignity, and dignity strengthens respect. A
respectful relationship encourages trust and co-operation. Strong culture
is built on respect and trust, and a strong culture encourages dignity and
recognition, and provides a caring and sharing environment* (NHMRC
2006:9).

Researchers have an obligation to acknowledge and respect people, their individual and collective contribution to the research, and the interests and aspirations of Indigenous people, researchers and other partners in the research process.

Respectful research relationships acknowledge and affirm the rights of people to have different values, norms and aspirations. Those involved in research should recognise, and minimise, the effect of 'difference blindness' through all stages of the research process.

Researchers need to understand that research has consequences for themselves and others. The importance of the consequences may not be immediately apparent. This should be taken into account through all stages of the research process.

Researchers need to ask:

- how does the research take into account the diversity of people and communities, and acknowledge individual and collective contribution?

- how are people's knowledge and experience being engaged?

- what agreements have been made about intellectual property rights, and cultural property rights and ownership?

- do these agreements include management of data, publication of findings and protection of identity?

- were the agreements reached in a way that reflects the values and preferred processes of participating communities, and do those communities continue to give positive feedback about the processes and agreement? (NHMRC 2003:12, 13).

A respectful relationship encourages trust and co-operation. Strong culture is built on respect and trust, and a strong culture encourages dignity and recognition, and provides a caring and sharing environment.

What does respect look like in a research project?

The importance of listening to one another, this way has the best process of consulting and negotiating how we can both give our perspectives… build a good foundation (Joanne Garnggulkpuy in Campbell & Christie 2008:29).

Having respect for someone is respecting who they are, where they've come from, keeping an open mind about how things are expressed… you don't know everything… you still need to question what you think you know… arriving at a new understanding (Terry Dunbar in Campbell & Christie 2008:29).

… the [community people] are looking at you as a researcher and… looking at ways they can see respect in you. After that, they… have an understanding of your feelings… then they can respect you (Waymamba Gaykamangu in Campbell & Christie 2008:29).

Respect for informants' intellectual and cultural property rights and data ownership involves negotiating the details of what happens to data and how it will be stored, published and used. These are critical issues in ethical research practice (Lester-Irabinna Rigney, Flinders University).

Equality

Aboriginal and Torres Strait Islander peoples recognise the equal value of all individuals. One of the ways that this is shown is in our commitment to fairness and justice. Equality affirms and recognises Aboriginal and Torres Strait Islander peoples' right to be different (NHMRC 2006:9).

Historically, Indigenous peoples have perceived the benefit from research as flowing mainly to researchers and research institutions (NHMRC 2003:14). A history of discrimination and racism, and the correlation between social and economic inequality and poor health, add to the importance of equality in health research.

Researchers need to:

- value knowledge and wisdom: collective memory and shared experience are valuable resources and inheritances. 'Researchers who fail to appreciate, or who ignore, Indigenous peoples' knowledge and wisdom may misinterpret data or meaning, create mistrust, limit quality or overlook a potentially important benefit of research'

- ensure equality of research partners throughout the research process, including analysis and dissemination: ethical research processes treat all partners as equal (while recognising and respecting difference) and build trust between stakeholders – without such trust ethical research is undermined

- ensure an equal distribution of benefit: this is a fundamental test of equality. If the research process delivers benefit in greater proportion to one partner than to other partners, the distribution of benefit may be seen as unequal (NHMRC 2003:14, 15).

What does equality look like in a research project?

Our research process promoted equity through the respectful sharing of knowledge and resources, and working in collaboration. Aboriginal women were involved in all research processes and decision making. Positioning Aboriginal community women central to this research was a strategy toward positively addressing and lessening (real or potential) power differences between community and health professional knowledge and experience (Kelly 2008:89).

There needs to be equality in all phases of the research. Real partnerships…[are] about demonstrating and showing Aboriginal people in really positive, active leadership roles… When we are trying to address …disempowerment we need to have Aboriginal people being the ones to present the research (Alastair Harris, Communications Manager, CRCAH).

Recognition as equal research partners may involve professional recognition and payment. The demands placed on cultural advisors to this research, especially the Aboriginal Advisory Groups, are not formally recognised under existing research frameworks and practices… A more appropriate recognition of all members would be to formally recognise advisory members as adjunct supervisors (for without their expertise and community relationships the study cannot be effective) with equal status as afforded to the academic supervisory team, and appropriate remuneration for their professional expertise – either to them as individuals or the organisation they represent (Margaret Heffernan, The University of Melbourne and RMIT University).

Survival and protection

We continue to protect our Aboriginal and Torres Strait Islander cultures, languages and identity. Recognition of our shared cultural identity, which is based on our shared values, is a significant strength (NHMRC 2006:9).

When researchers consider issues of survival and protection, it means understanding and taking into account the importance of values-based solidarity to Indigenous peoples. The assimilation, integration or subjugation of values is vigorously opposed, and values are defended. Researchers must be aware of the history of research, and the continuing potential for research to encroach on these values.

Researchers need to:

- have respect for social cohesion, and understand the importance of the personal and collective bond within communities and its critical function in their social lives

- find ways of working that do not diminish the right to assert or enjoy cultural distinctiveness

- have safeguards in place to protect people and cultures from discrimination or negativity

- find a balance between collective and individual identity, where necessary (NHMRC 2003:18, 19).

What do survival and protection look like in a research project?

…my aim [in the women's health services study] has been to work with Aboriginal people in ways that enhance capacity, are supportive, and avoid research activities that could undermine the women, their families or community groups. Recognising that Aboriginal people are not a homogenous group… has also been important. Where ever possible Aboriginal women's strengths and achievements have been highlighted to counter the negative stereotypes portrayed locally, as well as within the media and wider society (Kelly 2008:89–90).

The [E-Learning for Remote Family-Level Micro-Business] Project was ideal for us as we have long term relationships with each of the communities stretching back over thirty years. Through these decades of constant contact a bond of mutual trust had grown. We knew of their struggles to survive 'on country', and their determination to secure a safe, healthy and meaningful future for their children and grandchildren. We had personal obligations to work with them to improve their circumstances, not only through our Charles Darwin University commitments, but as close friends and adopted 'relatives' (Greatorex & Murakami-Gold in Campbell & Christie 2008:30).

Responsibility

All Aboriginal and Torres Strait Islander communities recognise the same most important (core) responsibilities. These responsibilities involve country, kinship bonds, caring for others, and the maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person, or any place. Sometimes these responsibilities may be shared so that others may also be held accountable (NHMRC 2006:9).

Researchers need to make sure that the research does no harm to individuals or communities, and does no harm to those things that are valued.

Researchers and participating communities need to establish processes to ensure that researchers are accountable to individuals, families and communities. This is especially important in relation to the cultural and social dimensions of Indigenous life.

Being accountable means:

- being open and transparent when exchanging ideas and negotiating the purpose, methodology, conduct and dissemination of results and potential outcomes/benefits of research

- being clear, at the start, about the demands that the research may put on partners, and what the potential implications may be

- taking steps to enable ongoing advice and review from the participating community: these processes need to include ways to monitor ethics standards and to minimise any unintended consequences arising from, or after, the research project

- giving regular and well-timed feedback to communities: feedback needs to be relevant to the expressed concerns, values and expectations of research participants and communities

- negotiating agreements about publication of the research results and other aspects of the research: the agreements need to include joint signing off for publication and the protection of individual and community identity, as necessary (NHMRC 2003:16, 17).

What does responsibility look like in a research project?

…[We] negotiated a formal partnership agreement [with QAIHC] that committed both parties [in the Learning from Action project] to our common goals, to a sharing of tasks and… resources... The project went well, and when it came time to write it up and publish the report, [the formal agreement guided] discussions about the write up, authorship, release, and future use of the material... There were some controversial issues arising from the research, so the report needed to be handled with care. But the integrity of the research results and the need to present them warts and all was never challenged. Participants were offered options about acknowledgment of their roles, and most of them chose to stand up for the results and be named in the report. The report was not launched until the QAIHC Board had approved its release… Arguably, it took a little longer. But it wouldn't have happened at all any other way (Judith Dwyer, Flinders University; Cindy Shannon, The University of Queensland; Shirley Godwin, The University of Melbourne).

Negotiation and agreement… you do that up front and you think it's finished but it's not. Negotiation on how you're doing things, the meaning of things, on who you're working with… that's a continual process throughout the whole research project not just at the end when you think you've finished… recognising and valuing the knowledge… you're being given trust… you get responsibility (Terry Dunbar in Campbell & Christie 2008:28).

This [diabetes intervention] research has been a journey where there was no quick entry and no quick exit. There is a contract of responsibility, both cultural responsibility and research responsibility. There is the responsibility that the research findings fairly represent the people involved in the research… in this study, the people of Galiwin'ku. Misrepresentation of people's views would contribute to wrongly formed assumptions and would be an encroachment of the trust given to me to undertake this research… (Julie Brimblecombe, Menzies School of Health Research).

Key messages for researchers

- Indigenous research values and ethics are central to all aspects of researching Indigenous health, and all chapters in this guide.

- Ethics is not about filling out an ethics application, but about fundamental research values and how they are put into practice.

- There is not one approach. The research values can be embedded in different ways and depend on local settings.

- Ethical research is about the way you work with people. It can only be achieved if you take time to build research relationships.

- Read the guidelines and think about what they mean before you start to design research.

- Talk with colleagues about ethics and values in research practice. The better informed you are, the easier it will be to understand and write about.

- Ethics and values need to underpin all decisions about the research and every phase of the project.

chapter 3:
Indigenous frameworks and methods for research

Different research questions require different research approaches and methodologies. Disciplines tend to use particular frameworks. Some of the methods and frameworks developed by Indigenous research and researchers significantly influence the way we think and go about research in Indigenous settings.

This chapter presents some research methods and frameworks that increase Indigenous ownership and leadership of health research. It explains theories that bring together Indigenous and Western research traditions and uses case stories to show how Indigenous approaches have been put into practice.

Shaping change in Indigenous research

This section outlines the key ideas of some Indigenous researchers and scholars who have pioneered change in research practice.

Decolonisation

The term *decolonise* is often used when referring to Indigenous research reform. Indigenous scholars in Australia and elsewhere have challenged the dominance, values and methods of Western research and traditional Western academic beliefs about how people build and hold knowledge. Decolonising approaches to research tend to put the politics of Indigenous identity at the centre, with Indigenous researchers as agents for change.

A well-known international scholar of decolonising research is Maori academic **Linda Tuhiwai Smith** (Ngati Awa and Ngati Porou), Professor in Education and Maori Development and Pro-Vice Chancellor Maori at the University of Waikato, New Zealand.

Smith's work has helped researchers understand that research methodology is a 'site of struggle' between the interests of researchers and Indigenous communities (Henry *et al*. 2002a:3). She has written about the need to change the idea of non-Indigenous researchers as 'experts' and to give Indigenous people a strong voice in all parts of research so that it can help to transform the lives of Indigenous people. These decolonising reforms, she argues, are linked to the political struggle for Indigenous community control of Indigenous research.

In *Decolonising Methodologies: Research and Indigenous Peoples*, Smith (1999) wrote about four essential processes – decolonisation, healing, transformation and mobilisation. She argued that these processes need to be built into research practices and methodologies, and referred to four tides that Indigenous communities are moving through – survival, recovery, development and self-determination.

Smith described how Indigenous methodologies can be built into research:

> *Indigenous methodologies tend to approach cultural protocols, values and behaviours as an integral part of methodology. They are 'factors' to be built in to research explicitly, to be thought about reflexively, to be declared openly as part of the research design, to be discussed as part of the final results of a study and to be disseminated back to the people in culturally appropriate ways and in a language that can be understood* (Smith 1999:116).

In summary, Smith's work is about reclaiming control. It does not exclude non-Indigenous researchers, but includes them as co-contributors in academic settings and in community research projects. It challenges non-Indigenous researchers to give up power and privilege, and it challenges academic institutions to take on non-Western ways of knowing, learning, teaching and being.

Indigenist research

Indigenist research aims to decolonise Western research practices: to reframe, reclaim and rename Indigenous research.

Lester-Irabinna Rigney is from the Narungga, Kaurna and Ngarrindjeri Nations of South Australia and is Professor and Director of Studies at Yunggorendi First Nations Centre for Higher Education and Research at Flinders University, Adelaide. Like Smith, Rigney sees the reform of Indigenous research as political, needing direct involvement by Indigenous peoples as researchers. He first described indigenist research in his 1997 article 'Internationalisation of an Indigenous Anti-colonial Cultural Critique of Research Methodologies: A guide to indigenist research methodology and its principles', and wrote about the need to change research methodology.

> *Indigenous people now want research and its designs to contribute to the self-determination and liberation struggles as defined and controlled by their communities. To do this Indigenous people themselves must analyse and critique epistemologies that are commonplace in higher education'* (Rigney 1997:632).

Lester-Irabinna Rigney

Rigney's work on indigenist research focused on the need to de-racialise and decolonise research. He pointed out that race had been used, historically, to shape society and to organise people into a system of hierarchies, with Indigenous Australians placed at the bottom of the human hierarchy. This system of classification, based on race, was used as an argument for systematically exerting power over, and oppressing, Indigenous peoples. Australian social systems, culture, institutions, attitudes and behaviours were racialised 'to the point that there is no where that we can stand that is free of racism' (Rigney 1997:634).

To develop indigenist research, Rigney looked to the work of researchers in the feminist movement. Strategies used in the feminist struggle for freedom and equality centred on the feminine experience and on the issues and knowledge that came out of a long history of oppression. It was logical to apply a similar approach to the struggles and liberation aims of Indigenous peoples.

> … my peoples' interests, experiences and knowledges must be at the centre of research methodologies and the construction of knowledge about us. Incorporating these aspects in research, we can shift the construction of knowledge to one which does not compromise Indigenous identity and Indigenous principles of freedom from racism, independence and unity (Rigney 1997:637).

Rigney presented a rationale for each of the three fundamental and interrelated principles that inform indigenist research – resistance, political integrity and privileging Indigenous voices. He summarised indigenist research as:

> … research by Indigenous Australians whose primary informants are Indigenous Australians and whose goals are to serve and inform the Indigenous liberation struggle to be free of oppression and to gain power (Rigney 1997:637).

part a: Indigenous health research in context

Karen Martin-Booran Mirraboopa

In more recent writing, Rigney (2006) points out that several factors have fostered the right conditions for current Indigenous Australian scholarly criticism. They include broad acceptance of multiple methodologies in qualitative research, the 'crisis of representation' in research about Indigenous Australians, and an increase in Indigenous postgraduates since the 1980s. Under these conditions, Indigenous scholars can re-think research methodologies and use a variety of approaches that truly match people's realities, interests and aspirations (Rigney 2006:36–7).

Researcher **Karen Martin-Booran Mirraboopa** questioned a position of resistance and expanded on Rigney's principles for indigenist research. A Noonuccal woman from Minjerripah (North Stradbroke Island) with ancestral ties to Bidjara land in Queensland, she is a celebrated leader in Indigenous early childhood education and is currently Associate Professor in Early Childhood at Southern Cross University.

In 2003 Karen Martin published 'Ways of Knowing, Being and Doing: A theoretical framework and methods for Indigenous and indigenist re-search'. In the article she highlighted the strength and position of being an Aboriginal person, and used an Indigenous knowledge system to shape a framework for doing indigenist research. Martin put her Quandamooka ontology (study of being) at the centre of the theoretical framework, using her people's ways of knowing, ways of being and ways of doing to re-describe research methods. She aimed to re-search and re-present the worldviews of her people, as 'the basis from which [to] live, learn and survive' (Martin 2003:205).

My belief as an Aboriginal researcher is that I actively use the strength of my Aboriginal heritage.

My belief as an Aboriginal researcher is that I actively use the strength of my Aboriginal heritage and do not position myself in a reactive stance of resisting or opposing western research frameworks and ideologies. Therefore, I research from the strength and position of being Aboriginal and viewing anything western as 'other', alongside and among western worldviews and realities. I have therefore expanded Lester's [Rigney's] principles to highlight this standpoint and the proactive, progressive and visionary purposes that both structure and guide my research. These principles are:

- *Recognition of our worldviews, our knowledges and our realities as distinctive and vital to our existence and survival…*

- *Honouring our social mores as essential processes through which we live, learn and situate ourselves as Aboriginal people in our own lands and when in the lands of other Aboriginal people;*

- *Emphasis of social, historical and political contexts which shape our experiences, lives, positions and futures;*

- *Privileging the voices, experiences and lives of Aboriginal people and Aboriginal lands;*

- *Identifying and redressing issues of importance for us* (Martin 2003:205).

More recently, Martin wrote seven rules to direct culturally safe and culturally respectful researcher behaviour. The rules were designed in close discussion with key people where research took place and were based on their expectations. Although these rules are a local example, they address the research principles of both the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and the NHMRC. Martin also calls for the use of traditional devices, such as First Stories and Visual Stories, to make the assumptions, theory, methodology and ethics of a research study transparent.

Researchers should:

- *Respect Aboriginal land: also encompassing respect for Waterways, Climate, Animals, Plants and Skies*

- *Respect Aboriginal Laws: to give honour to the Aboriginal Elders as keepers of their Ancestral laws*

- *Respect Aboriginal Elders: as the ultimate authority*

- *Respect Aboriginal culture: as Aboriginal Ways of Knowing, Ways of being and Ways of Doing*

Martin challenges Western research and researchers 'to engage research as an interface where conceptual, cultural and historical spaces come alongside each other based on new relationships to knowledge, to research and to self… [In this way the power of researcher over researched can be neutralised]. Thus, the Indigenist research interface is no longer a site of resistance, but a site of decolonisation and transformation' (Martin 2008:131).

In summary, the approaches and voices of these Indigenous scholars are part of a 'post-colonial discourse' (or discussion) to which many scholars and academics are adding their voices. It is a complex discourse that stems from Indigenous knowledge and Indigenous experiences. It challenges the history of Western dominance, acknowledges the continuing experience of colonisation, and seeks to find new ways to bring knowledges together and move forward to transform research.

Important terms and methods

This section summarises some research frameworks developed by Indigenous researchers and scholars. There are different ways to understand the creation of new knowledge through research and to explain methods of investigation. The following Indigenous theories of creating and sharing knowledge share a concern for respect, reciprocity and integrity in research. The section includes research frameworks developed in response to research history and to the dominance of Western academic tradition.

Ganma – Knowledge sharing

Many Yolŋu people of north-east Arnhem Land in the Northern Territory use *Ganma* to describe genuine two-way knowledge sharing, and relate it to what happens when two different kinds of water meet and mix together to create something new.
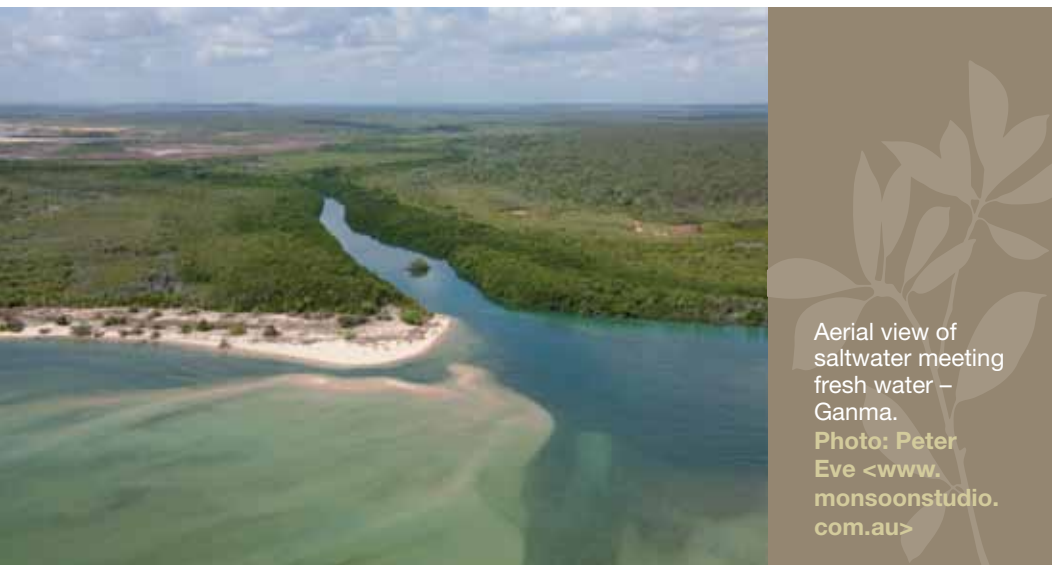
Aerial view of saltwater meeting fresh water – Ganma.
Photo: Peter Eve <www.monsoonstudio.com.au>

As explained by Dr R. Marika in her 1998 Wentworth lecture, Ganma is the name of a lagoon where saltwater meets fresh water. Water is a symbol of knowledge in Yolŋu philosophy, and the metaphor of the meeting of two bodies of water is a way of talking about the knowledge systems of two cultures working together (Living Knowledge 2008:1).

A river of water from the sea (Western knowledge), and a river of water from the land (Aboriginal knowledge) mutually engulf each other upon flowing into a common lagoon and becoming one.

In coming together, the streams of water mix across the interface of the two currents and foam is created. This foam represents a new kind of knowledge. The forces of the stream combine and lead to deeper understanding and truth. Essentially, Ganma is a place where knowledge is (re)created (Yunggirringa & Garnggulkpuy 2007; Kelly 2008:69).

Water, like knowledge, has memory. When two different waters meet to create Ganma, they diffuse into each other, but they do not forget who they are, or where they came from (Pyrch & Castillo 2001:380). Using this metaphor, people from differing cultures and backgrounds can share deeply, without losing their history or integrity.

The Yolŋu people say that if we try to capture the collaborative knowledge/ foam in our hands it evaporates; it is only through gently holding the foam that it lingers, revealing itself to us. If we force it, it disappears… 'In order to hear the quiet sounds of foam, one needs to listen with one's heart, to be aware of the experiencing not just the experiences' (Kelly 2008:70).

Ganma theory explains how Indigenous and non-Indigenous people can negotiate to create new knowledge and understanding by working respectfully together and taking time to listen, and to see what is revealed.

Yarning – An Indigenous style of conversation and storytelling

Storytelling is a feature of Indigenous societies, where oral traditions were mainly used to pass on knowledge and share information. In some Indigenous cultures people have words that mean 'let's sit down and talk'. Many Indigenous people in Australia refer to this Indigenous style of conversation and storytelling as *yarning*.

In different cultures there are different rules, language and protocols for conducting conversations. In Western Australia, Nyoongah people use the term 'yarning' when they want to talk with someone. Terszack writing about her Stolen Generation story describes yarning as 'a process of making meaning, communicating and passing on history and knowledge… a special way of relating and connecting with the Nyoongah culture' (Bessarab & Ng'andu 2010:38).

Some Indigenous researchers use yarning as a culturally safe and legitimate qualitative research method in Indigenous research settings.

Yarning in semi-structured interview is an informal and relaxed discussion… that requires the researcher to develop and build a relationship that is accountable to Indigenous people participating in the research (Bessarab & Ng'andu 2010:38).

Dawn Bessarab

Case story – Using yarning as a research methodology

Researcher **Dawn Bessarab** is an Indigenous woman of Bardi (West Kimberley) and Indjarbandi (Pilbara) descent. She used yarning to collect data in an interpretive study conducted in Perth and Broome, Western Australia.

Semi-structured, in-depth interviews were used to gather information from research participants about their gendered experiences as women and men growing up in their families. Dawn and **Bridget Ng'andu,** an Indigenous colleague who used yarning in her research in Botswana, both demonstrated that yarning could be applied as a rigorous research method. They described the different types of yarning that took place in research interviews.

- *Social yarning (before the topic yarn, when a connection is established and trust is usually developed).*

- *Research topic yarning (relaxed but purposeful, to gather information related to the research topic).*

- *Collaborative yarning (sharing information, exploring ideas in explaining new topics, leading to new understandings).*

- *Therapeutic yarning (when the participant discloses information that is traumatic, or intensely personal and emotional. The researcher leaves the research topic to become a listener)* (Bessarab & Ng'andu 2010:40–1).

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There are challenges to using yarning as a research tool, especially for emerging researchers. Having the right environment, good timing, establishing a personal connection to start up the topic yarn, keeping the informant on track, knowing when and how to draw the yarn politely to a close, transcribing and analysing the huge amounts of data collected – these are all high-level skills. Cultural protocols, such as not interrupting an Elder, can make managing an interview more complex. However, yarning facilitates in-depth discussions in a relaxed way, and provides rich data. It matches an Indigenous way of doing things.

*Its strength is in the cultural security that it creates for Indigenous people participating in research. Yarning is a process that cuts across the formality of identity as a researcher… both are learners in the process (*Bessarab & Ng'andu 2010:47).

Dadirri – Listening deeply to one another

Dadirri is a word used by the Ngengiwumirri people of the Daly River area in the Northern Territory and described in a publication by the educational leader and artist Miriam-Rose Ungunmerr-Baumann (1993). It is a concept of inner, deep listening that is shared by many Indigenous groups in Australia.

Dadirri is described as a deep contemplative process of 'listening to one another in reciprocal relationships' (Ungunmerr-Baumann 1993:36). Dadirri is quietly aware listening and watching, similar to contemplation, where people are recognised as being unique, diverse, complex and interconnected – part of a community where all people matter and all people belong (Ungunmerr-Baumann 1993:35). It is also a way of learning, of building knowledge.

Through the years we have listened to the stories. In the Aboriginal way, we learn to listen from our earliest days. We could not live good and useful lives unless we listened. This was the normal way for us to learn – not by asking questions. We learnt by watching and listening, waiting and then acting. Our people have passed on this way of listening for over 40,000 years (Ungunmerr-Baumann 1993:35).

Miriam-Rose Ungunmerr-Baumann

Case story – Using Dadirri as a research methodology

Indigenous scholar **Judy Atkinson** (2002) used Dadirri as a research methodology in her study, published as *Trauma Trails, Recreating Song Lines: The Transgenerational Effects of Trauma in Indigenous Australia*.

In reporting her research, Atkinson wrote about the importance of deep listening for healing and positive change in postcolonial Australia, and referred to Dadirri as an Indigenous philosophy that tells us about proper processes of investigation. Dadirri is used to inform ethical behaviour in research and to help ensure cultural safety in research design (Atkinson 2002:15). The principles and functions of Dadirri, as used by Atkinson, are:

- *a knowledge and consideration of community, and the diversity and unique nature that each individual brings to community*

- *ways of relating and acting within community*

- *a non-intrusive observation, or quietly aware watching*

- *a deep listening and hearing with more than the ears*

- *a reflective non-judgmental consideration of what is being seen and heard; and, having learnt from the listening, a purposeful plan to act, with actions informed by learning, wisdom, and the informed responsibility that comes with knowledge* (Atkinson 2002:16).

Atkinson advises that as researchers we first need to listen quietly, in order to gain trust and respect.

I will listen to you, share with you, as you listen to, share with me… Our shared experiences are different, but in the inner deep listening to, and quiet, still awareness of each other, we learn and grow together. In this we create community, and our shared knowledge(s) and wisdom are expanded from our communication with each other (Atkinson 2002:17).

Approaching research in the contested space

As explained in Chapter 1, when Indigenous and non-Indigenous knowledge traditions come together, researchers find themselves working with contested knowledges. In this space, research partners need to be open to different ways of knowing and finding out, so that new knowledge can be developed. At the same time, approach and meaning need to respect both Indigenous and non-Indigenous knowledge traditions (e.g. Ganma theory).

Similar issues were considered by academics in northern Europe in the 1970s, when they were working on environmental planning and using the knowledge of local farmers. They theorised the term *transdisciplinary research* to describe research that transcends disciplines and integrates other sources of knowledge. In Australia, **Michael Christie** connected transdisciplinary research practices with the work of Indigenous knowledge in research.

> *There are Indigenous knowledge practices which will never engage with the academy, just as there are some branches of the academy which will never acknowledge Indigenous knowledge practices. There is however a transdisciplinary space within the academy where claims of alternative knowledge traditions and their collaborations can be addressed* (Christie 2006:79).

Christie was not referring to the knowledge production work that Indigenous people do in their own ways and contexts for their own purposes, nor the colonising research referred to in Chapter 1. He was concerned with what happened to Indigenous research in a university. From his perspective as a non-Indigenous academic, Christie wrote about the need to prevent the assimilation of local knowledge traditions into Western academic knowledge traditions, and to question what happens when knowledge practices are translated from one knowledge context, or one scale, to another.

> *When Aboriginal knowledge is uncritically absorbed into the machine of Western science and humanities, a violence is done to it, it is misrepresented, and its owners are marginalised from the process* (Christie 2006:79).

When researching in the contested space, the rules of engagement, evidence and validation need to be negotiated. It may be that Western academics and Indigenous researchers never completely agree. They may have different agendas and different criteria for truth and effectiveness, but may still collaborate on the methodology or the knowledge exchange. They may never entirely agree upon the outcomes, and yet be satisfied by the process (Christie 2006:81–2). This messiness can still be productive as Indigenous and non-Indigenous knowledge traditions are brought together to do research that the university sees as academic, and the Indigenous world sees as respectful, respectable and useful.

Case story – The Community Harmony project

The Community Harmony project was an Indigenous collaborative research project with Yolŋu, the Aboriginal people of north-east Arnhem Land and other Indigenous researchers. Yolŋu researchers **Elaine Lawurrpa** (Maypilama) and **Joanne Garnggulkpuy** from the Yalu' Marnggithinyaraw Nurturing Centre at Galiwin'ku, used 'first language' research to look at the issues for Yolŋu people sleeping under the stars in Darwin.

Lawurrpa was worried about her brothers who were living as *long-grassers* in the Darwin suburbs and on the beaches. Something needed to be done. By Yolŋu principles, it needed to be properly negotiated. Everyone who had a stake in the issue needed to be involved in the negotiations, especially the *long-grassers* themselves.

The Yolŋu researchers knew a report had already been written about the 'problem' (Memmott & Fantin 2001), but the research had been conducted in an academic way. Lawurrpa and Garnggulkpuy needed to do the research in a different way, so that the Yolŋu *long-grassers* could talk about their own experiences in their own languages to their own people (as researchers) (Christie 2006:82–3; Maypilama *et al*. 2004).

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers). Another transdisciplinary research project on the website is 'Sharing the True Stories' (www.lowitja.org.au/crcah/sharing-true-stories).

Approaches to support Indigenous research reform

Research organisations, like individual researchers, are reflecting on their approaches and developing structures and mechanisms to shape change in the ownership and leadership of research (see Indigenous Research Reform Agenda, p. 16). The CRC for Aboriginal Health, for example, was set up in 2003 to build on the work of the CRC for Aboriginal and Tropical Health (CRCATH). It was a virtual organisation that brought together partners from the Aboriginal health sector, government health agencies and research institutions to help facilitate and broker research into Indigenous health. This approach is being continued by the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH), which was established in 2010 under the management of the Lowitja Institute.

> Information about the CRCAH and the CRCATSIH can be found on the Lowitja Institute website (www.lowitja.org.au/crcah/crcah; www.lowitja.org.au/crcatsih).

Facilitated development approach to research

The CRC for Aboriginal Health set out to develop a process through which health research priorities could be set by the Indigenous health sector – the people most likely to use the research and whose clients are likely to benefit most from it. It also needed to respond to stakeholder concerns that competitive processes of peer review in grant assessment were destructive to the work of a 'cooperative' research centre (Street, Baum & Anderson 2008).

It pioneered a method it called the facilitated development approach, now used by the CRCATSIH. Instead of the traditional 'top-down' model in which researchers set the priorities, a 'bottom-up' model gives Indigenous people a real say in controlling what is researched and how the research is done, in both urban and remote areas.

What's great about it is that you can design and conduct a project confident that you are tackling something that... needs to be done.

A CRC for Aboriginal Health industry roundtable

Case story – The CRCAH facilitated development approach to research

To commission new research in each of its program areas, the CRCAH arranged an 'industry roundtable' process in which people came together to identify research priorities around the most pressing needs in their organisations and communities. Roundtables were attended by representatives from community-controlled and mainstream health care providers, relevant government agencies, health care funders and peak bodies, and interested researchers and community leaders. CRC staff, and often the CEO, facilitated the process creating a safe environment for research priorities to be talked through in a way that reflected both community needs and government expectations.

Through this sharing process, research priorities in each program area were identified. The priorities were taken back to the CRCAH Board (headed by an independent Indigenous chair with a majority of Indigenous members) and ranked according to both the CRCAH's research agenda and to where the research could have most impact.

The Social and Emotional Wellbeing (SEWB) program used a roundtable process… we commissioned an Aboriginal woman to carry out a literature review that set out some of the key issues and history of research in SEWB. People at the roundtable were keen to… focus on a more holist approach… We talked about how to support resilience, emotional, physical and spiritual/ cultural wellbeing of individuals, families and communities. Fifteen priority areas for change were identified. From those we set seven research priorities (Vanessa Harris, Program Manager, CRCAH and The Lowitja Institute).

The CRCAH then facilitated the development of research proposals to address the priority issues.

The facilitated development process is not easy for researchers – you need to respond to a research focus defined by representatives of end-users and endorsed in general terms by the CRC Board, and it can be a real challenge to develop workable questions matched with effective methods… But in practice, it is really helpful and the ground rules make it positive and safe for all participants, including the nervous researchers.

What's great about it is that you can design and conduct a project confident that you are tackling something that not only needs to be done, but also has an interested constituency and a high probability (assuming you do it well) of being influential in the policy and practice arenas… (Judith Dwyer, Program Leader, the Lowitja Institute and Flinders University).

The CRCAH found that doing more work to identify and develop priorities with industry, community and other key stakeholders early in the process, and working closely with project teams, helped knowledge exchange and capacity development, and coordination of effort across program areas. The facilitated development approach helped to link people into research partnerships and supported collaboration. It has led to higher quality and more strategic research that:

- is community driven and reflects the priorities of Indigenous people
- is based on collaboration, not competition
- provides mutual benefits to Indigenous communities and researchers.

An independent evaluation of the CRCAH's work and impact was carried out in 2009–10 (see Silburn *et al*. 2010). This research approach has had a positive impact on the relationship between Aboriginal people, governments and service providers.

We know that nationally research in the past hasn't often been done for the best outcomes for Aboriginal people themselves… this process puts that back into Aboriginal hands (Angelina Tabuteau-Moore, PhD scholar and Regional Aboriginal Coordinator, Albury NSW TAFE, at the Chronic Diseases Self-Management Project Quality Assurance roundtable).

} For further details about the CRCAH facilitated development approach, see the Lowitja Institute website (www.lowitja.org.au/crcah/approach-research).

Collaborative, participatory and multidisciplinary research

Some research approaches tend to be used in Indigenous research projects because they line up with the principles of the reform agenda and encourage researchers to bring other views and ways of doing things into the research. Such approaches include:

* collaborative research, which brings together different types of expertise: for example, researchers, community decision makers, health services workers and policy makers may make collaborative decisions about the research processes and the use of findings

* participatory research, in which the people who are the subjects of the research are usually involved in planning, conducting and interpreting the research and disseminating the findings

* multidisciplinary or interdisciplinary research, which brings different academic traditions together or involves working with a range of theoretical perspectives and methods (e.g. using biomedical and social research methods in a project).

The benefits of collaborative, participatory and multidisciplinary research are:

* Indigenous communities have opportunities to set research priorities and guide research processes

* a range of knowledge and ideas are brought to the research

* they are more likely to build Indigenous ways of doing things into the research project and can 'privilege' the voice of Indigenous participants

* these approaches encourage input from people at the grassroots level and involve community members in all stages of the research project

* Indigenous community members can be involved in collecting and interpreting data

* timeframes are likely to be more realistic and research more responsive to events in the community

* more people can be involved, which can mean there are more researchers to do the work and more stakeholders committed to project success

* outcomes and recommended changes are more likely to be practical and widely supported

* knowledge exchange and sustainable change is more likely

* knowledge and skills can be shared.

part a: Indigenous health research in context

Challenges when using participatory and collaborative approaches include:

- identifying key and appropriate stakeholders
- identifying community and mobilising communities of interest for the research
- creating ownership of the issue being researched
- negotiating shared concerns that become the basis of the research question and approach
- the possibility of very different views about an issue
- getting community consensus about action (e.g. to tackle a problem)
- competing time demands
- having the research skills needed
- the need for funding bodies to be flexible, especially about time-consuming processes and delays (adapted from Dunbar *et al*. 2004:39–40).

Joanne Garnggulkpuy, senior researcher at Yalu' Marnggithinyaraw Nurturing Centre at Galiwin'ku, explains how Yolŋu values and participatory methods come together to drive the design of research projects in her Arnhem Land community.

Our way of planning a project is by action research. We used this process for planning our healthy lifestyle program. It came from doing research the Yolŋu way – looking at ideas, people talking and working together, taking people out to explain things and then talking about what needs to be done. We sit down and talk about where to go, what to do, where we are up to. It takes three to four weeks to organise things before starting actions. We all need to agree on how things will be done – whoever is selected to be involved (Joanne Garnggulkpuy, Galiwin'ku, Northern Territory).

We sit down and talk about where to go, what to do, where we are up to... We all need to agree on how things will be done – whoever is selected to be involved.

Case story – Gapuwiyak child health project: collaborative and participatory research

The Community Action to Promote Child Growth in Gapuwiyak project was collaboratively managed between three organisations and collaboratively planned with research participants. The aim of the project was to work with the community and clinic to document Yolŋu and clinic stories about child growth and then to use these stories to take action to improve child growth. The project was intended as a pilot to inform the Growth Assessment and Action program and community action in other Northern Territory communities.

Community engagement was a central aspect of the research program… The employment of local people (workers and advisors) on 'real' wages… demonstrated to the community that the CRCAH [which funded the project] took the project seriously. The second critical decision was that I would spend significant time in the community… These two decisions were seen as a form of investment in the project and assisted in allowing the community to understand the project as a serious and important response to child growth that they too could invest their time and effort in.

Once the project began the team spent a lot of time working out how to implement the project, and how the community needed to be involved and consulted throughout. Significant time and effort was required by the Yolŋu participants… to develop a supervisory governance structure for the project that was grounded in traditional governance arrangements. This work was often complex and required careful negotiation, but [was] subtle and not always obvious to a non-Yolŋu observer…

The engagement aspects of the project that underpinned its success depended on having someone (i.e. myself) from the world of health bureaucracy located in Gapuwiyak for significant periods of time. This allowed issues from both sides of the project to be worked through. My ability to fulfil this role depended on my relationships both in Darwin and Gapuwiyak… I had to work hard in Darwin [and in Gapuwiyak] to build relationships and earn professional trust and respect… This required that I spend significant time in the community, learn the language and work to earn trust and respect (Danielle Campbell in Campbell & Christie 2008:32–3).

Empowerment approaches in research

Empowerment is a social action process through which people aim for more control, better quality of life and social justice. To be empowered implies *power with* rather than *power over* others, and the capacity to live one's life in harmony with one's values. Empowerment approaches in Indigenous health research are aligned with social and emotional wellbeing, identity and belonging, spirituality and the capacity to work with others to achieve self-determination aims. As a result, empowerment programs have influenced the research reform agenda.

Case story – The Family Wellbeing program: empowerment research

The Family Wellbeing program was developed in the early 1990s by a group of Indigenous leaders in Adelaide who had been affected by the Stolen Generations. The 150-hour program is enriched with material from complementary philosophies and empowerment principles and seeks to empower participants through personal transformation that involves harmonising physical, emotional, mental and spiritual aspects of life and applying this to practical, day-to-day living (Tsey & Every 2000:510).

One way of researching empowerment is to identify initiatives that Indigenous people themselves identify as empowerment, and use them as the mechanisms for investigating empowerment limits and possibilities. This approach is the basis of Family Wellbeing programs, Men's Groups and other empowerment programs (Komla Tsey, Program Leader, Far North Queensland).

Evaluation reports across four settings confirmed that many participants learned to deal with emotions and avoid conflict, and found more peace in their lives. They were able to analyse situations more carefully, and participate more actively. Participants became aware that, for social change to occur, they needed to play greater leadership roles and maintain a positive attitude towards the possibility of change.

I didn't expect these kind of changes but it showed me that once ordinary community members get knowledge then they are able to act in a more constructive way to deal with issues such as housing. Knowledge is power (male participant in Tsey *et al*. 2010:176).

} For the full case story of the Family Wellbeing program, see the Lowitja Institute website <www.lowitja.org.au/case-stories-researchers>.

Key messages for researchers

- It is important to know about Indigenous scholars and approaches that continue to shape change in Indigenous research. It helps us all continually to reflect on, and question, our research practices and partnerships.

- When Indigenous and non-Indigenous knowledge practices come together in research, the rules of engagement, evidence and validation need to be questioned and negotiated.

- Collaborative, participatory and multidisciplinary approaches are more likely to result in acceptable, practical research outcomes, compared with approaches where the researcher 'informs' or 'consults' research participants.

- Research approaches that have the potential to empower research participants align with the Indigenous research reform agenda.

part b:
doing research that makes a difference

The aim of Indigenous health research is to make a positive difference to the health and lives of Indigenous peoples. Collaborative partnerships, good knowledge exchange and capacity building in research can lead to practical outcomes, necessary policy changes, skill and leadership development and real, long-term benefits for Indigenous services and communities.

Productive relationships and partnerships involve:

- real collaboration, participation, equality and power sharing in researcher–community partnerships

- recognising that different perspectives, knowledge and ways of working strengthen the research

- managing relationships with a variety of stakeholders, and recognising they have different purposes and priorities

- good manners, communication and information sharing

- structures and systems that support good project management.

Good knowledge exchange involves:

- doing research that has the potential to meet real needs as identified by the services and communities that use research evidence

- thinking beyond the project, and building knowledge exchange into the research plan

- working with the people and organisations that use research findings

- looking beyond the academic world when disseminating research findings

- good communication, real relationships and practical approaches.

Good capacity building involves:

- building and supporting the Indigenous research workforce

- building sustainable skills, structures, resources and commitment

- working with existing strengths and opportunities

- different target groups

- strategies that are realistic, developed collaboratively with those who benefit and well supported.

Part B offers practical advice for doing research that makes a difference through good relationships and partnerships, knowledge exchange and capacity building strategies. These processes are often inter-related in research projects. Together they support change and maximise research benefits.

part b: doing research that makes a difference

chapter 4:
relationships in Indigenous health research

Research relationships are working partnerships between researchers and others involved in research. That there is a link between productive, trusting relationships and quality research is well established. The need for good relationships is emphasised in Indigenous research forums, protocols and ethics guidelines, and the Indigenous research values that are needed for spirit and integrity in research all describe relationships and interactions. How does a researcher 'build' these relationships, and with whom?

Most researchers think about relationships between researchers and participants at the research site. Although these relationships are critical, other relationships are needed for successful, ethical Indigenous health research. This chapter identifies those different relationships. It gives tips for good practice when working with the individuals, groups, organisations and institutions involved in research projects.

Many things impact on research relationships

Many factors affect the ability to establish research relationships and keep them going. Some factors are helpful, but some can hinder relationships.

If you are an Indigenous researcher, many factors support the building of relationships with participants, other partners and stakeholders. For example, if you are a working in your own Country, you may have long-term relationships and valuable language skills. You may already have networks and knowledge of local Indigenous organisations. You may have the respect and authority that comes with being a community Elder. If you are from another place, you are still likely to have valuable contacts, communication skills, cultural understandings, perspectives and ways of working that will help you to build respect and to work with the local community.

Being an Indigenous researcher can also put stress on relationships, especially within the Indigenous community. For example, not having time within project timelines to do things the right way, being the face of the project and being held personally accountable if something goes wrong, or being caught between work and cultural or family obligations, can all strain relationships.

} These issues are discussed in Chapter 2 and Chapter 3 of *Supporting Indigenous Researchers: A Practical Guide for Supervisors*.

If you are a non-Indigenous researcher, your relationships with Indigenous organisations and individuals also depend on whether you are already known and respected, or whether people need to get to know you. Organisations will want to know if you have a good track record in your cross-cultural partnerships, or to see that you observe cultural and communication protocols. All Indigenous stakeholders will want to know that you are prepared to invest time into research relationships and negotiations before, during and after the research.

Other things that can impact on relationships are your personal communication skills and your understanding of the realities of many Indigenous people's lives. Establishing good research relationships can take longer when there is a negative history. Some things, such as past events, are outside your control, and people may mistrust you, for example, on the basis of being let down by another researcher. An organisation may have had negative experiences with a past research project or with your institution. Community-based researchers may be less willing to join or support the research team if they feel their work has been undervalued or poorly acknowledged in the past. Another possibility is that a person in a position of authority may have an issue with the research; this can slow your relationship building with others.

Good relationships are more likely to develop when you show that you are willing to listen, watch, contribute and be guided by community mentors and leaders. You need to allow time for people to get to know you, and to show that you are genuine and not there to serve only your own needs.

Establishing research relationships

Having adequate time to build trust and understanding is critical. Partner organisations and participants involved in research need to adjust to different ways of communicating, new languages and ideas, and different authority structures when:

- people involved in research have different first languages, communication styles, knowledge systems and experiences

- stakeholders are not familiar with the language and culture of research

- researchers are not familiar with the social, cultural and political environment where the research is done

- people from different professional backgrounds and disciplines do research together (e.g. biomedical and social health researchers, education and health)

- a research project has a number of partners with different core business and ways of working.

Indigenous health research is often multidisciplinary, intercultural, collaborative and participatory, so these challenges can occur at the same time. No matter what the history or issues, some people involved in the research project are likely to be working in a way that is new to them or with people who are new to them. These things will impact on your efforts to build productive relationships.

The nature of relationships will determine how you tackle some of the challenges of the research. Different situations and personalities may test these relationships as the project progresses. This is to be expected.

> *Partnerships aren't easy. We can't overlook that fact. It is a true test of a partnership or a relationship if it has been through a few fights or disagreements* (Sandra Bailey in Sweet 2008:6).

A shared commitment to project outcomes is a strong motivator to keep people working together.

Indigenous stakeholders will want to know that you are prepared to invest time into research relationships and negotiations before, during and after the research

Good relationships are more likely to develop when you show that you are willing to listen, watch, contribute and be guided by community mentors and leaders. You need to allow time for people to get to know you….

Types of research relationships

When you are planning who needs to be involved in the research, or coming into a project, ask yourself:

- what is the purpose of the working relationship I will have with this organisation or individual?

- who are the stakeholders?

The purpose of the relationship will determine the way you make contact and the type of interaction you have (e.g. to negotiate a funding agreement, to conduct research). It will determine who initiates contact, how often and how well you get to know each other. Your role on the research team also determines who you have a working relationship with. For example, if you have a community liaison and data collection role, you are less likely to have contact with the funding body than the project leader. If you are one researcher doing a small study, you will probably have contact with more types of stakeholder.

Relationships at the project site

The main purpose of relationships with people at the project site is to get the research done. You are likely to have working relationships with:

- community research partner/s

- Elders, cultural advisors or community mentor/s

- the community council

- interest groups and community organisations

- interpreters

- frontline workers (e.g. health workers)

- research participants

- visiting workers in the community and other researchers.

Relationships within the project team

The main purpose of relationships within the project team is to conduct the research. You are likely to have working relationships with:

- the project leader and other researchers on the team

- community research partner/s.

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Relationships with project managers

The main purposes of relationships with the people or organisations that are managing the project are to fund the project and to get support and advice to achieve the project outcomes. Depending on your role in the research team, you are likely to have working relationships with:

- funders
- advisory or reference groups
- managers and administration people in your university or organisation
- community research partner/s.

Relationships with people who support the project

The purposes of these relationships vary according to the type of organisation and its involvement. Those who support the project do not necessarily have an oversight role (but often do). Depending on your role in the research team, you are likely to need support from:

- the advisory or reference group to help achieve research outcomes and knowledge exchange
- the CEO, Board and staff of a community-based health service or organisation to provide access to research participants or data, and promote and use the findings
- peak bodies (e.g. Victorian Aboriginal Community Controlled Health Organisation, Aboriginal Health Council of Western Australia) to give advice, help to access research participants or help with knowledge exchange
- institutions and staff (e.g. The Lowitja Institute or a university) to provide in-kind support, infrastructure and resources
- government and non-government agencies (e.g. health departments, National Heart Foundation) to help with information and knowledge exchange.

Other relationships that may be important for project success are with:

- academic supervisor/s
- other researchers (outside the project team) whose work is relevant
- mentors who are not directly involved in the research.

Working at the project site

Introducing yourself

Community partners need to feel confident that the research team (or researcher) has the knowledge, skills and experience to do the research. The way you introduce yourself can set the scene for successful research relationships, or for difficult interactions or misunderstandings. Your approach will depend on things like:

- whether you are being introduced by another person who is known to the community or group and how they are regarded

- whether you are being introduced by an organisation that is already a research or service partner (e.g. a peak body)

- whether you are approaching the community with no connections

- your contacts and their roles in the community or organisation.

One thing that will not vary is the need for a good personal introduction. You need to ensure that people know who you are, what organisation you come from and why you are there.

Aboriginal people introduce themselves: who they are, their country, their mob, their role. An external researcher could introduce themselves in a similar way (Rea & Young 2006:12).

Be sincere, upfront and transparent. People will be observing you, and can read you like a book (Robyn Ober, Batchelor Institute of Indigenous Tertiary Education).

Community or service representatives are busy people with many demands and responsibilities, so arrange introductions well in advance and confirm in writing if possible. If unsure, ask advice about what is expected. Ask staff at the service or the community organisation/council about who you need to meet, who can help to set up meetings and the information you should provide. People may be busy, but don't rush introductions – it doesn't make a good impression.

If it is difficult to identify which Indigenous organisations might have an interest in the research (e.g. in a metropolitan area), ask the Indigenous health peak body, and each organisation you go to. Common answers will establish a starting point.

Observe local protocols as advised, such as introducing yourself to community Elders.

> *If a researcher comes to our community they have to approach a mala-mala (elder), and introduce themselves. Go through that process… and your research will be acceptable, and you'll get support* (Elaine Lawurrpa in Campbell & Christie 2008:28).

When you are not known to the host organisation or community, being introduced and guided by people who are known and trusted can be very helpful.

> *When a balanda [non-Indigenous person] comes into the community the people would like to know… who that person is, someone might be wondering who is this? Unless you have someone there who knows that you're coming in to do your research in the community, that the person has a contact person. That sort of relationship [is] what good research is about* (Gwen Rami in Campbell & Christie 2008:29).

Although you can be recommended by another person, you need to earn respect. There are no short-cuts.

Tell people a bit about your work background. Ask about the criteria you need to meet in order to do research with the community or organisation. Be honest about what you don't know. This will earn more respect than appearing to know things you don't – which is likely to get you into trouble later. You will normally find that allowances are made for inexperience, and that people are willing to give advice about the right way to do things when asked. However, people need to know that you are open to guidance and learning, and committed to ethical research with practical benefits. As Maori researcher Linda Tuhiwai Smith (1999:10) writes, 'Is her spirit clear? Does he have a good heart?… Are they useful to us? Can they fix up our generator?'.

When you have a limited role on a research team or are replacing another researcher well into a project, the way you engage will tell people a lot about you as a researcher and whether you are tuning in to the local environment.

The way you introduce yourself can set the scene for successful research relationships, or for difficult interactions or misunderstandings.

Danila Dilba
Health Service,
Darwin

Case story – A health service's criteria for a research partnership

Paula Arnol is the Chief Executive Officer of Danila Dilba Biluru Butji Binnilutlum Health Service, the main Aboriginal Medical Service for Darwin and surrounding areas, where **Cyril Oliver** also works as an Aged Care Health Worker. Paula and Cyril talk about what they want to know when a researcher approaches the service to talk about doing research.

[There are two types of approaches we get.] One where the researchers have already won grants, they want to come and work with us, and a second [type] where they're writing up a research proposal and applying for a grant, and they want to involve us.

What is the research about? What will it involve?

When a researcher contacts us about doing research, we tell them to come and meet with us and we hear out what their research proposal is, what's in it for Danila Dilba and for our patients within the Darwin area. Is it a need for us, or are we just doing it to tick their box for their funding grant? If there is gain for us, then what's the partnership?

Then we start to develop up the research methodology based on that, and we go through the whole process. We want to have a say in the methodologies, because [often] we find that they don't think through the logistics of [the research]. They write it up from a researcher's point of view and then they try to do that whole community engagement and participation process, but

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they don't think about the obligations on behalf of the services that they want to work with. [But for us,] we need to know our obligations and in-kind contribution under the research proposal – and can we do it?

We have a check sheet that steps out the process needed to negotiate research with us.

- *Has it been through ethics approval?*
- *How does Danila Dilba benefit? What are the gains for Danila Dilba?*
- *What's the contribution for Danila Dilba to the research team?*
- *What are the financial and resource allocations?*
- *What is the plan for the transfer of knowledge from the research?*
- *What is the process for bringing that knowledge back into services?*
- *Is there a presentation to show the findings and talk about what we can actually do, strategically, to use the findings?*

[Another] process is Board endorsement. So there is a check sheet sits over the top of [the research proposal], all the research documents sit underneath it… The Board can see the ethics approval, they can see that we've had the discussions, who the researchers are, who are the team leaders, all of that.

Working together

Community settings are diverse and complex. If you are not from the community it can take a while to work out the best way of going about the work, and who represents whom.

Researchers and community partner relationships can also be complex. People don't necessarily have the same expectations, experiences, views and goals. This is a good thing – differing perspectives are needed for well-considered decisions in the research. It is often advisable to formalise expectations and responsibilities through a memorandum of understanding (MOU).

In community settings there may be expectations that a relationship is more than a work relationship in the Western sense. People want to get to know you, trust you and like you. This means getting involved in community life.

Good working relationships need patience and flexibility to work around the demanding roles and responsibilities of key community representatives and managers. Your research project may not be the highest priority, even when they are committed to the project.

Research is often conducted within busy frontline services. The success of the relationships and the research can depend on how well you understand the service, and how sensitive you are to the priorities and workloads of frontline staff. An orientation program can help you get off to a good start.

Researchers need to understand the organisation… so before they come in, we do… orientation with them. Rather than just talking to the research leader in the institution, we talk to the people that they've employed…

[The orientation is done] just like they're staff members, so they understand what being located in our facilities actually means. They need to know bio safety stuff, occupational health and safety… the clinical services that they're working within, and have that cultural awareness. They need to know who to talk to, who's in charge of what, what's the line of responsibility, authorities, etcetera…

[We all need to] be really clear about… their roles… so that they don't put extra pressure or burden on our services and other staff members, and… there's no confused resource allocations. So that our researchers don't… go 'well, I need your doctor and I need your health worker now for these days'… So that's clear and worked out up front in that orientation process… (Paula Arnol, CEO, and Cyril Oliver, Aged Care Health Worker, Danila Dilba Health Service).

Be aware that there are risks for organisations that have a stake in the project. Frontline services, in particular, need to know that the benefits from the research will outweigh any negative impact. Their first priority is, quite rightly, to their clients.

We'll make sure there's a clause in our MOUs with researchers for us to be able to pull out if we're not happy with where the research is going, like if we're not happy with the methodology and we think it's gone off track. If the research is going to compromise us – impact on our credibility, our professionalism or ability to deliver services – then we should have the right to pull out (Paula Arnol, CEO, Danila Dilba Health Service).

There may be people and groups who do not step forward but who could provide important input if engaged. Keep inviting input, and keep in place the mechanisms that bring people together in the project. Sometimes people hold back to watch and listen for a while before getting involved. If it is difficult to get some people actively engaged (and their involvement is important), try different strategies and make it as easy as possible. For example, offer 'sitting fees' to

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pay people for their time if you can, work around events where people socialise as a group, offer transport to the venue and put on lunch. Reciprocity is especially important when asking people to volunteer their time and expertise.

In some settings working with one group tends to exclude another (who may, for example, feel disempowered in that community). Or, as a community-based researcher, you may be seen to represent a particular family or group, which discourages others from getting involved. The best way to avoid this risk it is to discuss it openly. Raise the need for a true cross-section of community views and experiences at the beginning of the community engagement process. Strategies for including all relevant groups can then become part of the project plan, and the management group can monitor progress.

Don't get drawn into community politics if groups or organisations involved in the research don't have a history of working well together.

I don't know all the relationships between all the organisations, but my strategy is just being very sensitive with every single organisation, being transparent with everybody. If you know there are politics, ignore it, 'My trial is about this stuff. I want to talk to you about this.' Keep politics to the people who are the political players. It's definitely not our business (James Ward, Program Manager, National Centre in HIV Epidemiology and Clinical Research, University of New South Wales).

You will also need to work sensitively around the events that will affect people's availability. Funerals, traditional ceremonies, sporting festivals and important meetings can interrupt research activities. Traumatic events in a closely connected community can affect a lot of people for a long time. Cyclonic weather, floods and dust storms can close roads and airstrips. If you are unsure about whether it's appropriate to schedule a meeting or data collection visit, ask.

Frontline services, in particular, need to know that the benefits from the research will outweigh any negative impact

Case story – Identifying community groups in south-west Sydney

This story explains how researchers in Sydney identified different stakeholder groups. As the study began, the groups were involved in different ways, using strategies that matched their project roles.

Over the past 13 years, researchers from the University of New South Wales Research Centre for Primary Health Care and Equity have been working with the local Aboriginal community to study the health, development and service use of Aboriginal infants and children in the Campbelltown area of south-west Sydney. Data are being collected in a longitudinal cohort study, known as the Gudaga Study, of 150 infants and children.

At the start of the study, the researchers identified four relevant community groups in south-west Sydney:

- Gudaga mothers and their children

- the local Aboriginal community of Campbelltown

- local Aboriginal health care workers

- Aboriginal health organisations.

They identified two other relevant groups with strong Aboriginal representation (mainstream academic and health organisations) and other research activities in the region that had similar aims. Various strategies were used to engage the groups (Knight *et al*. 2007:7).

} For the full case story of the Gudaga Study, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

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Tips for good working relationships

- Offer/give community partners a copy of *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander Peoples about Health Research Ethics* (NHMRC 2006).

- Don't make assumptions about what people already know, need to know or want to know about the research. Relationships will suffer if you seem to be withholding information or not respecting what has gone before.

- Give people regular opportunities to raise concerns, ask questions, offer suggestions and talk about research-related issues.

- Check and re-check whether people wish to be involved, and assure them it's okay not to be. Sometimes people feel obliged, even though they don't have the time or motivation to be involved.

- Clarify roles, expectations and arrangements for working with community partners. This might include questions about what will happen after the research is completed, who will own the information and whether you will continue to be involved in how the findings are used.

- Always remember that information sharing is a two-way process. As a general rule, the more you give, the more you get, the more you listen, the more people tell you, the more open you are with others, the more they are open with you.

- Schedule meetings around community processes for decision making. Is time needed for people to talk together, without you being there? Do people who are not attending need to be consulted? Indigenous networks are often complex (e.g. in large urban centres or places where families move between remote communities and towns).

- Meet deadlines (e.g. progress report deadlines).

- Don't offer or promise anything you can't deliver. Don't agree to do anything you can't do.

- Be aware that there are risks for local people who work on a project with an outside researcher. Agreements that are not honoured may create relationship problems for co-researchers or cultural brokers and their families for a long time.

James Ward

Case Story – Building relationships for a clinical study

James Ward is a Program Manager at the National Centre in HIV Epidemiology and Clinical Research at the University of New South Wales. He is from the Pitjantjatjara and Narunga people of Central and South Australia.

James is a Chief Investigator with the STRIVE (Sexually Transmitted infections in Remote communities: ImproVing and Enhancing primary health care services) project, which is being rolled out in Central Australia and across the north of Western Australia, the Northern Territory and Far North Queensland. It is Australia's first clustered randomised community trial in Aboriginal health with adults.

James discusses the steps taken to explain the STRIVE project and establish working relationships in communities.

The two primary issues are making sure we're being transparent and that we've allowed plenty of time for consultations… It's quite difficult to explain such a complex trial, even to clinicians and other researchers… You've got to really take your time and put it in a language that everyone can understand…

We've always offered to the Aboriginal health workers, 'If you want us to come back and talk to you as a group alone, or if you want to organise a meeting while we're here, we're very happy to explain it in a different way than what we're explaining to the doctors and to the nurses here in the clinic.' And it's been taken up. Often Aboriginal health workers will [also] say, 'We want to talk as Aboriginal people alone about this research 'cause it involves our young ones, and we want to make sure that what we're doing is good…'

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I think people feel more comfortable if there's an Aboriginal person involved in the research. The community feel very assured when they know I'm from Central Australia and have worked in this area for a little while and they know some of my family… [I want to] spend time in the communities to give some reassurance that [I'm] there for the long haul and [I'm] not going to fly in and never come back…

The community controlled health services have been good at making sure that we come and present to health boards. That's another way to really make sure community are aware of what's happening. Both of our coordinators in the Territory are females and often I'll get a call to say, 'Can you come and address the Board because most of the Board are males and I don't feel that comfortable?'… And if that's what the Board want, or if that's what our coordinators want, we make sure we're there 'cause we want to make sure that things are done properly… If people say, 'Can you send us something that explains it a little bit easier?', we send it.

Good manners

Good manners go hand-in-hand with productive relationships in all research settings. Arrive on time for meetings and events, let people know if you are held up, respect workplace routines and acknowledge the generosity of those who participate in the research.

If you are a visitor to the research setting, good manners mean doing your homework about the community. Revisit information that was collected when writing the grant application – about local research protocols, the history of Indigenous organisations in the area and how they relate to each other. Ask if there are local protocols for the way you are expected to dress and behave (e.g. in remote areas). Unwritten protocols might include gendered spaces (e.g. men sit with men, women with women), parking well away from camps to reduce dust and waiting to be invited to approach a sitting group.

Ignorance about, and inability to accommodate, cultural and research protocols, policies, practices and values is offensive to the cultural group that you seek to work with. It also delays relationship building and data collection. No excuses… do your homework before engaging with anyone! (Margaret Heffernan, The University of Melbourne and RMIT University).

There are cultural differences in manners. People may agree with what you ask in order to bring a meeting to an end or to avoid offending you, but this does not mean they will feel obliged to follow through. Also, people may not want to disagree or correct someone in front of the group.

Find out if you need to consider traditional kinship rules, such as avoidance relationships, especially in rural and remote communities, so that you can avoid shaming and embarrassing people in meetings and group settings. Before you visit, find out names of recently deceased people who cannot be named. Your contact person should be able to pass on this information.

Don't try to imitate to fit in (e.g. way of speaking): when you are in a new cultural setting be yourself at all times.

Communication tips

- When you share any information about the research, plan carefully and pitch your presentation for each group at the site, using resources to suit the audience. Rehearse what you will say. Know what you want to ask. You might be presenting in an informal way, but don't confuse informal with unprepared.

- Be aware that even when you share a language, differences in tone and the use of slang and non-verbal signs can mean you don't send the message you want to send, or don't pick up on accurate meaning.

We do full-bodied listening – to absorb ideas totally. We nod and agree but it doesn't mean agreement overall. We are open-minded people. It's easy to misunderstand that the Yolngu person is nodding to show that she respects your ideas and your right to say them (Alison Wunungmurra in SNAICC 2010:10).

- Communicate in plain English. Avoid academic or medical terms when they are not needed. Don't 'dumb down' information, which is disrespectful and can be offensive. Don't be tempted to give less information because the information is difficult to communicate. These actions would be poor foundations for the trust, reciprocity and equality you are aiming for in your community research partnerships.

- You may wish to use visual resources – diagrams, graphics and/ or photographs – to make information more accessible for your audience.

- Pitch presentations to children using resources and language that are right for the age group. Be guided by parents, teachers and carers.

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- Talk clearly and slowly. Be aware that ear infections and hearing loss are common among community people. If talking or listening is difficult and you have to ask a person to say something again and again, it can cause stress. Stop and get help (Rea & Young 2006:17). A public address system may help in large meetings.

- Use an interpreter when you do not have the same language as people at the site. Learn how to work with an interpreter (see Chapter 9, 'Collecting, Managing and Interpreting Data'). When you explain specialised health or research terms, check if the specialised terms are known to the interpreter and can be interpreted accurately. Take time to meet first to go through the information. Factor this time into the translator's pay.

- Be aware that singling a person out in a group can be shaming. To avoid shaming, people may not ask for things to be explained and wrong information may not be corrected by others. A person may not have authority to speak in some circumstances (e.g. because of relationships with others who are there).

- Non-verbal communication is powerful (e.g. a subtle gesture to show others you disagree). Choosing to remain silent is a way of communicating. Therefore, audio recordings (and especially transcripts) may only tell part of the story of what was 'said'.

- Listen for misunderstandings and miscommunications about the research. Explain what the research can and cannot do (e.g. can/will refer patients but cannot provide a clinical service).

- Get used to 'wait time' silences. People often need time to take in information or questions, to translate what is said into their own language, to think about it and respond. Be patient and wait.

- Give people opportunities to break into small groups to discuss and share information. This may happen a few times before a decision is made.

- Respect the judgment of community representatives who are guiding you in your ongoing negotiations or actions, even if you have trouble fully understanding the why, how and who. In some places, cultural protocols for important decision making are more complex, subtle and carefully timed than written guidelines can describe.

Raymattja Marika-Mununggiritj talks about protocols for negotiation in her community in north-east Arnhem Land.

> *At certain times, the community leaders will come to a place where they will have a negotiation… within this, the first starting point are underlying step by step plans or strategies which they know that they have to go through. All the steps for the negotiations must be shared. Sometimes it does not work like this. Sometimes people can take everything into their own hands and act as if they can produce the truth and the right way of doing things without the full cooperation and negotiation with other people. Then things become more like the European way of doing things, and the negotiation process is lost* (Marika-Mununggiritj 1991:21).

These protocols set out who coordinates the bringing together of the people and what their roles are – who should do the talking to all the people involved to get the important issues out in the open, get the plans made and get agreement, and even where meetings should take place. Where they apply, the protocols are time consuming, difficult to understand and often nerve-wracking for outside researchers (both Indigenous and non-Indigenous). But they are essential for respectful, successful research negotiations (Christie 2006:86).

Intercultural training and resources

Intercultural training and resources may be useful if you are a non-Indigenous researcher, or an Indigenous researcher working in different Country. Courses, resources and mentors may be available through local Indigenous organisations and groups, universities and Technical and Further Education (TAFE) colleges, some government departments, private providers or church-based organisations.

Useful resources are listed at the end of this guide. To find courses:

- ask people you work with who they recommend
- find out what is offered through your employer, local services and institutions
- find out what is offered through, your emploer, your professional support organisation, local services and institutions, and online resource networks
- do Internet searches using key words such as 'cultural awareness', 'Indigenous' and your State
- see business listings in the local telephone directory.

Community relationship issues for Indigenous researchers

If you are an Indigenous researcher conducting research in your own community, there are issues that may impact on your relationships with family and community members, and with research team members. For example:

- your language, cultural understanding and communication skills may mean that other researchers and community members rely on you to ensure that Indigenous research values are upheld: this can place extra pressure on you and your relationships

- you are likely to be working under the close scrutiny of community Elders

- your relationships with community Elders, or perhaps your own position as an Elder, may be valuable to the research and the research team

- you may feel pressure to be the 'expert'

- it may be feared your academic knowledge might compromise your community obligations and accountability (e.g. do you have the right to speak about an issue?)

- there may be times when you are accountable to community leaders ahead of project leaders

- if you are the main community contact and communicator for the project, you may be vulnerable to criticism about the research.

Indigenous knowledge is often generated through a collaborative and highly structured process that involves two-way obligations.

> *… once I have shared my knowledge with them, then they are in a way obligated to me, that we have responsibilities together, which come from the knowledge we have shared together* (Marika-Mununggiritj 1991 in Christie 2006:85–6).

Don't assume that non-Indigenous research colleagues are aware of these issues, even if they have worked in Indigenous settings before. You may need to raise them with team members and others who support and manage the research. You need a safe environment to talk about the type of support that will be helpful and work together to develop some ongoing support strategies.

Community support and ownership of research are not abstract concepts – they need to happen through practical day-to-day actions to have real meaning and to benefit the research. Above all, people at the research site need to be confident that you are willing to work with local priorities, processes and structures to conduct ethical, quality research that will have community benefit. Earning this confidence is an ongoing process and it takes time.

Relationships within the project team

Indigenous health research teams typically bring together people with diverse education, work and cultural backgrounds, different skills and knowledge, and different levels of experience in research, health and Indigenous matters.

Many emerging Indigenous researchers have cultural skills and years of life and work experience, but limited academic research experience. A growing number of Indigenous researchers bring both to the research. Many skilled non-Indigenous researchers and academics have mainstream research experience, but limited experience in Indigenous settings and limited knowledge of Indigenous cultures. Many project teams have members whose main work is not research (e.g. health care workers who help with data collection or interpretation). This mix makes work both rewarding and challenging.

Team relationships are learning relationships

Although the highest priority is the development of Indigenous members, everyone in a research team has learning needs to be identified, planned around and met. There is potential to learn from each other, for example, when:

- community partners lead induction or cross-cultural training for the team
- experienced researchers train partner organisation staff in research techniques
- experienced researchers mentor less experienced researchers
- Indigenous team members are cultural mentors for non-Indigenous colleagues
- there are academic supervisor–student relationships between researchers on a team
- events bring community partners and researchers together to share information, learn from each other and make research decisions
- a research leader mentors another member in research leadership.

It can take time for Indigenous and non-Indigenous researchers to adjust to each other's ways of working and to different 'rules' of communication and interpretation. Miscommunication can affect team relationships. Be prepared for surprises – things are not always as they seem because of the way we see and experience things differently. Avoid making assumptions. Remember that culture is not the only thing that determines how we interpret situations and each other's interaction (Eckerman *et al*. 2006:104).

Successful teamwork and learning depend on respect and trust between members. Trust comes from working closely and being consistent, reliable and honest. It comes from transparent, open communication – sharing information, ideas, views, doubts and worries. This can be risky but also enriching, and makes for true collaboration and good research.

> [Our] project was a collaborative endeavour with Debra providing an Arrernte researcher's perspective and Merridy a western, non-Aboriginal, researcher's perspective. We each learned from the other and neither's skills would have been sufficient on their own to undertake the task. Neither of us believes that we could or would want to try to acquire the other's expertise. This is not necessary in a truly collaborative research relationship (Malin & Maidment 2005:7).

Team relationships are usually stronger when you have opportunities to get to know each other and find out what you have in common. Plan and reflect on achievements as a team. Talk without judgment about difficulties and what hasn't worked, about different perspectives and ways of doing things. Share workloads and support each other when needed (e.g. to meet professional, family and cultural obligations or when sick). Do professional development activities as a group when possible.

Don't assume that team members have the teaching skills needed to share cultural and research knowledge. Remember, too, that people have different ways of learning. An academic way of learning, for example, doesn't match an Indigenous way of building up knowledge through time and relationships. This can be a problem within a research team, despite effort and goodwill from everybody. Sometimes it underpins the feeling that many Indigenous researchers have of not being listened to. You need to be aware of these issues and feel comfortable to talk about them when necessary (Laycock *et al.* 2009:137).

Team relationships are usually stronger when you have opportunities to get to know each other and find out what you have in common.

CREW team members (L–R): Vicki Saunders, Roxanne Bainbridge, Rachael Wargent, Liz Clarke, Melissa Haswell, Lyndon Reilly, Teresa Gibson, Victor Gibson (back), Geraldine Gundrum, Annita Virzi and Arlene Laliberte

Case story – Research values are team values: a way of working

The Collaborative Research on Empowerment and Wellbeing (CREW) team in far north Queensland focuses on building the capacity of communities and primary health care centres to provide everyday support for social and emotional wellbeing, as well as culturally appropriate and accessible mental health services. The team works with many Indigenous community-controlled, government and other non-government organisations, and university collaborators. It has joint leadership of the Empowerment Research Program with James Cook University.

The team writes about team values, relationships and processes.

Our team values come from a number of important qualities – Honesty, Integrity, Pride, Respect, Love and Laughter…

From its beginnings, the CREW team has operated mainly on a collective leadership basis. Each member of the team has been encouraged to consider their contribution to the team's direction and way of working to be that of a uniquely valued leader. Each individual brings knowledge, experience, skills and perspectives into the complex work and linkages the team has built. This mechanism has served the team well…

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

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Long-distance relationships and multiple research sites

Many Indigenous health research projects involve a number of research sites or a number of teams that undertake different studies within one program. Sometimes a multi-site project involves not only other teams in different places, but long distances, remote locations, different government jurisdictions and a number of local advisory or management groups. It is likely to involve staff changes over long timelines.

Many small, single-site projects have a supervisor offsite in a regional centre or institution, while researchers collect data onsite. When long distances are involved, day-to-day support and back up are essential. Team members can feel isolated from each other, so good relationships are especially important. Managing them successfully takes effort and time, and special strategies are needed.

Research leaders and team members can:

- identify the strengths of research partners and how best to use these strengths at each site for team support, as well as for strong research

- put time and resources into maintaining communication and sharing information: send updates to colleagues about what you are doing if you haven't talked or met for a while; encourage others to do the same

- pass on relevant articles and resources to team members: when others send you information, thank them

- sort out small arguments, misunderstandings or assumptions before they grow into conflict

- schedule meetings regularly: put resources into bringing people together to attend meetings; organise social time together, as well as work time

- visit colleagues at different sites or travel with others, which can be very good for building relationships

- make contact with new team members and explain your role

- display photographs of offsite colleagues in the office.

The starting point of good research is a team that brings together the range of skills needed to complete the project.

Supervisor–researcher relationships

Good two-way relationships between research supervisors/leaders and team members are essential for successful research.

} See the companion volume to this guide, *Supporting Indigenous Researchers: A Practical Guide for Supervisors*.

Relationships with people/ organisations who oversee the project

Funding organisations

Funding organisations need to be assured that their money is used for its intended purpose. There is normally a funding agreement, which sets out legal obligations of the funder to provide the money and the obligations of the administering organisation (e.g. university or health service) or individual to spend the money as agreed. You are bound by the agreement to conduct the research in specified ways, submit written and financial reports by specified dates, and achieve specified outcomes. A good relationship with the funder depends on meeting these obligations.

Many mainstream funders are aware that successful research projects in Indigenous health often have high levels of community involvement. However, they may not be aware how real community involvement can extend timelines and add to costs. You may need to raise awareness and make a case for extra resources.

Reporting requirements differ between funders. In Indigenous health projects funded by the Lowitja Institute, for example, project leaders are required to report on:

- community involvement

- a knowledge exchange plan

- a capacity development plan (e.g. to train Indigenous workers)

- processes for sharing information with industry and community stakeholders

- activities, outputs and lessons, as well as research findings

- in-kind contributions to the project.

Funding agreements often require that project-related publications or media activity be authorised by the funder, and that its logo appears on project publications and presentations. Overlooking these obligations can damage researcher–funder relationships, so be clear about any such requirements and ensure that all research team members are aware of them.

If trust breaks down or if you lose credibility to deliver the agreed outcomes, the funder may withdraw. If you have a good relationship with the funder and keep the funder informed (e.g. early notice that a project is not going to finish on time), you will have more scope to negotiate.

In-kind funding

Many research projects use in-kind funding. In-kind funding means a contribution other than cash. Examples of in-kind funding are when:

- a service gives researchers office space and administrative support

- another project, department or organisation gives researchers use of a vehicle or equipment

- health care professionals who are not project staff collect research data

- an institution provides training to research team members (free of charge)

- research project staff do work for a host service.

In-kind contributions may be informal arrangements between partners or formalised through agreements. They can be *ad hoc* (e.g. when an organisation hosts a project event).

In-kind funding tends to involve personal, local relationships. Benefits need to be two-way, so share ideas, experiences and findings with people in the organisations that contribute to your project.

Steering and advisory/reference groups

Most health research projects have a management group of some kind. Project management groups aim to give advice and support to keep the project on track, and to make decisions about project management. The role and decision-making power of a group varies from project to project. Ensure you understand the powers and limits of a group's role.

You are accountable to a management group to deliver the project outcomes. Members need to have trust and confidence in you. Make it a priority to attend meetings. Be clear about the advice, decisions and support you need from the group at each stage in the project.

} Chapter 8, 'Planning the Project', provides information about setting up a management group.

Managing relationships with the project advisory group and keeping members engaged

- Seek out people who are prepared to contribute actively

- Avoid 'tokenistic' appointments: make sure Indigenous representatives are clear about their role and have the skills to provide the support you want

- Give the support needed so people can contribute advice in the right way (e.g. facilitate in a way that allows Indigenous community members a strong voice)

- Set dates well in advance

- Make everything as easy as possible

- Only take things to the group about which you need their input

- Use clear, concise language

- Report openly; avoid surprises; if you give early warning when things are not going to plan, you will usually have support when you need to vary the project (e.g. a longer timeline)

- 'Keep the person, not the position' – when a representative of a membership organisation leaves a position, it is often assumed that the replacement in the organisation takes over as a group member. This can be a real loss if the person has been actively involved and supportive, so keep that person on if you can (Jenny Brands, former Research and Development Manager, CRCAH).

Take early steps to avoid misunderstandings or confusion that can damage your relationships and get in the way of the decisions you need from the group.

Giving all members a strong voice might call for strategies such as meeting in different locations and breakaway sessions for language groups.

The [all-Aboriginal] reference group now comprises individuals from six major language groups across Central Australia… Meetings are held at various venues, creating opportunities for group members to see and be seen inside various organisations involved in bush food research… The main meeting is in plain English but Arrernte and Pitjantjatjara prevail in preliminary discussions. A cultural emphasis on respect and deference to seniority prevails within the group. Group discussions are active, often intense and sometimes heated (Douglas & Walsh in Campbell & Christie 2008:36).

If a relationship loses direction

Sometimes a management group disengages, provides limited or confusing direction, or has disagreements between members. Your priority is to keep the research on track until problems are resolved.

To keep the research on track:

- try to involve some key members in any decision making that you need

- keep your own relationship with the group working well – make sure you deliver what is expected of you (e.g. progress reports)

- if necessary, ask for advice and support from organisations supporting or hosting the project.

Sometimes matters are outside your control and it is necessary to revisit management structures.

University/organisation managers and administrators

The staff members in your institution who help manage and administer the project are crucial to its smooth operation. They enable you to concentrate on the research processes.

Invest in relationships with administrative staff and managers. Keep them updated about the research and explain why particular arrangements are necessary. Do your best to follow procedures, keep accurate records, meet budget requirements, report on time and respond to administrative requests promptly. The research will benefit.

Sometimes Indigenous health projects present unusual administrative challenges. For example, research-related jobs may fall outside usual awards and wage structures, or a university's financial accountability procedures may need to be adjusted so that Indigenous consultants can be paid in cash. Be aware that these arrangements involve goodwill and time-consuming paperwork for administrators (e.g. receipts, invoices, reimbursement forms).

Relationships with people/ organisations who support the project

Different types of support are needed at different stages of the research: for example, to access the site or data, to communicate with stakeholders. Support may be needed to help you understand what the findings mean, as well as for dissemination and knowledge exchange.

Support can be at different levels, through national, State and local groups. Issue-based support groups often champion research, raising public awareness about a health issue and generating research funds.

Support may be peer to peer: for example, when health workers talk up a project with colleagues, or when powerful people champion your findings at high levels.

Often the people and organisations that give support also have a management role (e.g. steering group members).

Support from peak bodies

Indigenous health peak bodies have a major interest in ensuring that research evidence can be used by their partners to improve the services they deliver, and are key stakeholders in many research projects. Some National Aboriginal Community Controlled Health Organisation (NACCHO) affiliates convene Indigenous research ethics committees.

Involving peak bodies in your project is a courtesy – it shows respect for their leadership role and expertise in Indigenous health. Depending on their resources, peak bodies may also be able to steer you towards priority research for their partners, broker research, help to refine proposals, 'open the doors' to research sites and give advice as the project progresses. They can help with dissemination and take up of research findings with their partners as well.

Case story – What a peak body looks for in a research partnership

The Aboriginal Health Council of South Australia (AHCSA) is the peak body for community controlled Indigenous health services in South Australia. **Alwin Chong** is Senior Research and Ethics Officer. He explains what AHCSA looks for in a researcher–community partnership.

One of the major elements to getting creditable research evidence for Aboriginal communities is the partnership we form with researchers. The relationship is about us being very clear about what we mean by partnership and what the expectations of the partners are. Ideally, this would be established when developing the research grant. Issues like ensuring that the research will be ethically bound, being sensitive to community/cultural issues, using an appropriate methodology, having an Aboriginal advisory group, the feedback process, and accepting the communities' timelines, priorities and values – in the past, some researchers have talked about having a partnership with us but it was more about the expertise they had, and their outcomes, which often centred on intellectual property – the powerbase was more about them being in control and less about how they were going to help Aboriginal people.

If we don't know the researcher, then the first thing we need to talk about is their expectations and outcomes. Just as important is them knowing who we are, what our guiding principles are, what expertise we have and what we mean when we talk about a partnership. Many Aboriginal communities are still cynical of research, so it is important that we all understand how the partnership will have any value or benefit to Aboriginal communities.

A lot can be gauged from these initial talks and if we feel comfortable with what we have heard and talked about, we will then proceed… However, there have been times when the partnership never worked because the researcher's notion of a partnership and ours were different – some minor, others significantly different. However, it is the researchers who have demonstrated good practice, respected cultural principles and achieved good research outcomes that we want to promote.

We have had some great researchers work with us. They bring their expertise to the table, at the same time respecting our principles, to achieve a common goal. They tick all the boxes, which allows the project to move along and, more importantly, adjust to any unplanned community issues in a timely manner.

We look for an established researcher to be an advocate.

One of the major benefits of having a great working relationship with researchers is the likelihood of them becoming positive advocates. They are able to engage other researchers and put the Aboriginal side to the debate, like separating perceptions from facts and promoting the need for further creditable research. At the end of the day, we're only making up 2 per cent of the population nationally, so we need these researchers to advocate on our behalf.

Good researchers… can talk about the research from a methodological and ethical point of view, and at community level because they understand how these issues are connected to achieve valuable positive outcomes.

The way you interact with people at the research site can impact on relationships between others. If you let people down, or behave disrespectfully, it can have negative consequences for those who have introduced or supported you. An organisation that has supported the research is often seen as the face of the project, rather than a distant university or institution with which people have no connection.

> *We get blamed every time if a project has gone wrong, because we seem to be the face of it, because it's all happening on our turf, and under our banner. People aren't aware that it's being driven out of another research institute and they don't really care that we're not employing the research staff. [People will say], 'you mob brought them out… We did this one last time and it never finished.' And they've got long memories* (Paula Arnol, CEO & Cyril Oliver, Aged Care Health Worker, Danila Dilba Health Service).

Support relationships are two-way and influence the success of the research.

Support from other researchers and organisations doing similar work

Many researchers find themselves part of a support network with others who are doing similar work: for example, projects in the same community or large projects in the same field.

Although a formal arrangement between project managers may be needed for cost sharing of transport and accommodation, informal support between researchers can be very helpful. This might include practical information about where to stay, what's happening in a community and road conditions in remote areas.

A partnership model for research relationships

'Figure 1: Partnership model for ethical Aboriginal research' shows four elements needed for productive research relationships between research partners and how these elements can be integrated into practice. It was developed by a team of Indigenous and non-Indigenous researchers in South Australia, and came from the team's experience when researching medication management issues for people with mental health, alcohol and other drug problems.

Figure 1: Partnership model for ethical Aboriginal research

respect
- For Indigenous history
- For Indigenous culture
- For ethical principles
- Genuine & reciprocal
- Positive & progressive

collaboration
- Sustained communication
- Mutual goals
- Joint decision-making
- Aboriginal & non-Aboriginal partners

partnership

participation
- Active involvement
- Action research oriented
- Democratic & cyclic
- Empowering & outcome focussed

meeting needs
- Plan for tangible benefits
- Keep projects locally relevant
- Identify needs collaboratively
- Implement & evaluate initiatives within scope of project

Source: adapted from de Crespigny, Emden, Kowanko & Murray 2004

Good relationships need time

When researchers met to discuss what should be in this guide, the importance of having adequate time was emphasised at every meeting. Time is needed to:

- negotiate the research properly
- develop trusting and respectful relationships with research partners and participants
- make sure that research processes involve stakeholders
- work around community priorities and events and the availability of research participants
- share and use information.

In summary, a generous amount of time is essential for productive partnerships and good research practice in Indigenous settings.

> *We've had a couple of researchers, where they kept coming back and saying, 'Well, we're in a hurry to do this, we have to do it really quickly'. They wanted to work with us but didn't respect our processes or timelines, which went against the principles of our partnership agreement* (Alwin Chong, Senior Research and Ethics Officer, AHCSA).

Long, strong relationships are a feature of many Indigenous health research projects. For example, the University of New South Wales Research Centre for Primary Health Care and Equity first became involved in the Aboriginal community of south-west Sydney in 1997. First results for the Gudaga Study started coming through in 2007 – 10 years later – and the project is continuing.

> *[In all, thirteen years] has been spent developing and nurturing respect, trust and reciprocity. The past decade has enabled the non-Aboriginal researchers to demonstrate to the local Aboriginal community that they are prepared to make a commitment over a long term period and they are not 'fly-by-nighters': that they will advocate for the local Aboriginal community; work with the community's agenda (rather than a predetermined research agenda); and, if necessary, stand up to the bureaucracy on their behalf* (Knight et al. 2007:10).

Sometimes there is a long story behind a research project, and for many Indigenous researchers, a project is based on lived experiences and the need to make a positive difference for family and for the future. Some research projects take a long time to evolve as people slowly develop an idea or become aware, over time, of a gap in knowledge that needs to be bridged before services can meet needs.

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In this painting Fabian Polly Tjampitjin, a young man in his late twenties, recounts the time when summer floods prevented *maparn* (healers) from two of the desert communities travelling to another community to heal someone who was sick

Case story – Strong research built on a long relationship

Not many 'outside' researchers have the opportunity to sustain long relationships with research participants. The long and close relationship between the researcher and the community in this story led to deeply engaged, sensitive and robust research.

Brian McCoy's research project was built on a relationship of more than 30 years with the people of the south-east Kimberley in Western Australia (the Kutjungka region).

It was from this relationship, and from relationships with other Aboriginal men, that my interest and motivation to explore men's health arose.

In 1973 I first arrived in the Kimberley as a lay missionary for the Catholic Diocese of Broome… I spent one year on the community and… I revisited the region over the following years and accompanied some of the men to the 'hand-over' of Uluru to Anangu in 1985. In 1990 I also conducted research with some of the men as part of the Western Australian component of the Royal Commission into Aboriginal Deaths in Custody. Finally, in 1992 I was asked to return to the region in a formal church capacity as parish priest… and stayed there until April 2000.

In the more than seven years that I lived in the Kutjungka region in the 1990's I found myself being increasingly drawn into the culture of the people and issues around men's lives and health… (McCoy 2008:2–6).

} For the full case story of Brian McCoy's research, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Key messages for researchers

- Research relationships are working partnerships.

- There are different types of research relationships – within the team, with people at the research site and with those who manage or support the research. Different groups need different strategies for respectful and productive relationships.

- Good relationships need time.

- The time and effort you put into building research relationships is well invested. Without good relationships, research efforts are unlikely to make a difference.

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chapter 5:
using research for change

This chapter defines knowledge exchange in research, and talks about how to make research more effective in the Indigenous health research sector. It identifies factors that impact upon knowledge exchange and offers strategies to help ensure that knowledge from research is used to improve Indigenous people's health and health-related services.

What is knowledge exchange?

Knowledge exchange is a two-way process in which research is *used* to change *what* is done (policies and planning) or *how* things are done (practice and systems).

> *The research that we contributed to was important and we thought that was the hard bit when we were doing it, but now I realise the most important thing is to get it used* (Ian Frazer, University of Queensland, speaking as developer of the cervical cancer vaccine).

Knowledge exchange is 'a process of moving what we learn through research to the actual applications of such knowledge in a variety of practice settings and circumstances' (Sudsawad 2007:6). It is the foundation of evidence-based health practice.

Knowledge exchange in research can be challenging because it is a dynamic and complex process that occurs between people. It usually involves:

- all steps between creating new knowledge and applying it

- combining knowledge from research with other types of knowledge

- an interactive process, with communications that go in different directions

- ongoing collaborations between people and organisations

- people from different disciplines

- multiple activities and diverse user groups

- activities that are user-specific, context-specific and have real impact (adapted from Sudsawad 2007:6).

When a research project gets knowledge exchange right, it usually means that all of these strategies and parts have come together, and a range of people have been involved in different roles.

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Other terms with similar meaning are *research transfer*, *research uptake*, *knowledge utilisation* and *knowledge translation*.

Researchers in Western Canada asked people from different sectors how they talk about using research to improve health or health system outcomes. The preferred and most common phrase was *research use*. Other terms included *application of research, evidence-based, knowledge exchange, knowledge translation, knowledge transfer, uptake, research transfer* and *using research to create change*. A common opinion was that, whatever term is used, it should acknowledge that this is a two-way, interactive, repetitive process (Birdsell & Omelchuk 2007:17).

Knowledge exchange is the term preferred by the Lowitja Institute. This is because two-way knowledge sharing is needed between researchers and research users in order to change services and to sustain those changes. The term needs to take people beyond the idea that research transfer (or knowledge exchange) is achieved when research findings are disseminated at the end of a project. The knowledge exchange process should start before the project, when research priorities are set. It should continue throughout the research and well beyond the project timeline, as shown in Figure 2.

Figure 2: Knowledge exchange can happen before, during and after the project

| Project start | | Project finish | |

| Priority setting | User involvement | Regular updates to users | Concise report of findings | Findings accessible to users | Advocacy |
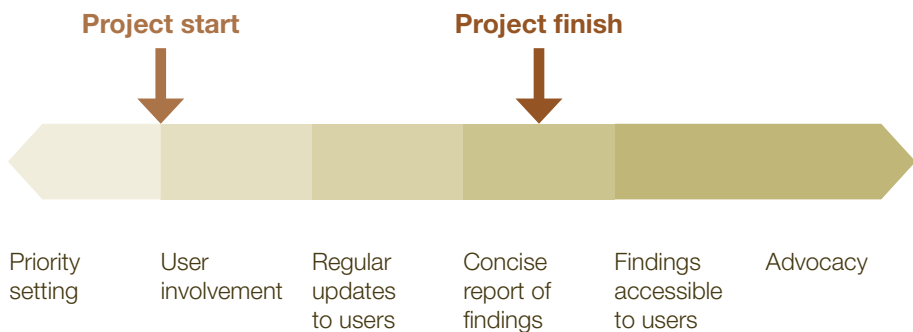
Knowledge exchange in Indigenous health research needs time, expertise and resources, and researchers are not usually trained in the skills needed. The CRCAH recognised this and created a unit of skilled and resourced staff to help researchers with knowledge exchange planning, activities and publications. In the Lowitja Institute, knowledge exchange is part of the role of the Program Managers supported by the Communications team.

The language of knowledge exchange

When people talk about knowledge exchange they often use these terms.

Knowledge brokerage means connecting people with other people, and connecting people with information, to help solve problems.

'Push' strategies push research out to an audience, and usually come from researchers or research funders.

'Pull' strategies are when research users, such as health services, draw on research for their own use.

End users refers to the people who use knowledge that comes from research. The knowledge is put into 'evidence-based' improvement of services and practices. End users include Indigenous organisations and health services; health policy makers, planners and managers; service workers and practitioners; other researchers and academics.

Capacity exchange or **capacity development** can involve the exchange of knowledge, skills and resources. Capacity building can be at the individual, organisational, community and workforce level. It might involve the development of different types of skills – in frontline service delivery, research, staff supervision, management and policy, training, partnerships and so on.

The knowledge exchange process should start before the project, when research priorities are set. It should continue throughout the research and well beyond the project timeline.

Case story – A Canadian survey about knowledge exchange

The Alberta Heritage Foundation for Medical Research conducted an 'environmental scan' of health research transfer in Western Canada. As part of the survey, researchers asked people from different sectors (e.g. research units, health services, funding bodies, government) what supports or hinders health research transfer.

The key factors that support research transfer were early engagement of decision makers, evidence that research use works and government leadership. People also talked about needing issue-focused teams (rather than research transfer-focused teams); clear knowledge about what research transfer is; trusting, respectful relationships between researchers and decision makers, with regular feedback; capacity building programs; good timing in relation to 'hot topics' with government or powerful interest groups; good administrative databases; and rewards such as personal enrichment and recognition (Birdsell & Omelchuk 2007:37–8).

Some factors that were seen as barriers to health research transfer related to knowledge (e.g. most research knowledge can't be used directly and needs to be interpreted to make it relevant in a specific situation; 'researchers know the problem, but not the situation; decision-makers know the situation, but not the problem'). Other barriers related to research production (e.g. 'Universities do not value knowledge use, other than for commercialization'; there is a lot of funding available to generate research, but not a lot to support its translation into policy; higher demands and expectations on researchers (e.g. teams and collaborations); researchers who value pure research more than applied research) (Birdsell & Omelchuk 2007:39).

Knowledge exchange is a two-way process in which research is *used* to change *what* is done (policies and planning) or *how* things are done (practice and systems).

Thinking about the project in a broader context

Thinking about your project and role as part of a bigger health research picture is likely to result in more strategic research, and findings that are useful and useable.

> *Most of our thinking around better ways to do Aboriginal health research has focused on the project. It has tended to focus on participatory action research and models for working effectively with Indigenous communities… we need to think about the broader environment in which we do the research. It is the policy process and issues around uptake of the research that are important. We need to move beyond good ways of doing projects, to thinking about research within broader systems…* (Ian Anderson, Director of Research and Innovation, The Lowitja Institute).

Anyone working in Indigenous health research will find knowledge of Indigenous health research policies and structures useful. The more experienced you are as a researcher, the more likely it is that you will need to know about the policy and funding environment as you take on leadership and supervision roles, negotiate research partnerships and apply for research funds. However, new and emerging researchers can also put this information to use when planning for knowledge exchange.

A healthy knowledge exchange environment

Common messages have emerged about how to increase the uptake of research findings by different research users. For example, when evidence is bundled together (different types of evidence, or different sources of evidence), it is more likely to have an impact on research users than evidence from one project.

Many factors in the Indigenous health research environment impact on knowledge exchange. Some of these factors are helpful, some can get in the way, but they need to be taken into account when planning. Figure 3 shows what the CRCAH found out about creating an environment that fosters knowledge exchange.

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Figure 3: Elements of a healthy knowledge exchange environment

Research is done about
the right questions

Research users
have the capacity
to use evidence

Evidence is tailored for
specific user audiences
and findings are
communicated clearly

Research users
have the desire
to use evidence

Evidence is accessible
to research users
when they need it

Researchers and research
users can interact to help
apply findings to local contexts

Evidence is credible
and useable

There are mechanisms to
build relationships between
researchers and research users

Source: Brands 2009:3

Research about the right questions

For health research to be useful it needs to address the right questions and be based on real priorities. The best way to ensure this is to involve, at the design stage, the organisations, individuals and other people most likely to use the research.

We want to know that what we do works, and also that the research agenda has actually been driven by the needs that we've identified, because at the end of the day it's our sector, it's our people and we need to make sure that we're responding to their needs, rather than the needs of others (Adrian Carson, Queensland Aboriginal and Islander Health Council).

The CRCAH, for example, found that doing more work to identify and develop research priorities with industry (community and other stakeholders) early in the process, and working closely with project teams, helps researchers to:

- do research that is useful and credible to the Indigenous health sector
- develop strong research methods that will work in real settings and are acceptable to participants
- build knowledge exchange processes into their projects, so users are engaged throughout the project
- develop findings that can lead to problem solving and change.

The earlier research users are involved, the better. It is best to set up links with policy makers and service managers in the planning stage of a research project, when the questions are being refined.

Our approach… is to involve policy makers from the very start of actually setting up a research project, and service providers are also involved in project reference groups and the implementation of projects, so that by the time projects are completed, people are actually already in the communication loop (Ian Anderson in CRCAH 2007a).

Tailoring evidence and communicating research findings

It rarely happens that a set of recommendations based on evidence from research findings is put directly into action, even when the research is high quality, about something important and in the public domain. Knowledge from research often needs to be modified, translated, partly used or used differently to suit the users and the context in which it will be applied.

In Indigenous health research the main audiences are Indigenous communities and organisations, politicians, health policy makers, planners and managers, practitioners, the general public (including opinion leaders) and other researchers or academics. Just as there are differences in the priorities and work of these groups, there are differences in the type of information that is most relevant and useful to them. Ways of sharing evidence include reports, community meetings, training events, clinical guidelines, websites, policy briefs, radio programs, conferences and professional journals. There is evidence that shows which methods and formats are best suited to each group.

Tailoring research information for knowledge exchange may require skills in:

- seeing and understanding things from different viewpoints
- pitching information carefully and presenting it in a particular format to suit an audience

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- collaboration and intercultural communication

- planning and facilitating workshops on how to use resources

- running sessions about how to translate and apply research evidence

- developing training materials

- using information technologies (e.g. computer animation)

- motivational speaking and negotiating

- understanding mechanisms needed to get systems and policies to change (e.g. adding a rebate for a new Medicare item).

Few researchers are trained in these skills. Use your professional networks and colleagues to work out what is practical, possible and likely to work well. Link up with suitable experts. Take opportunities to learn new skills.
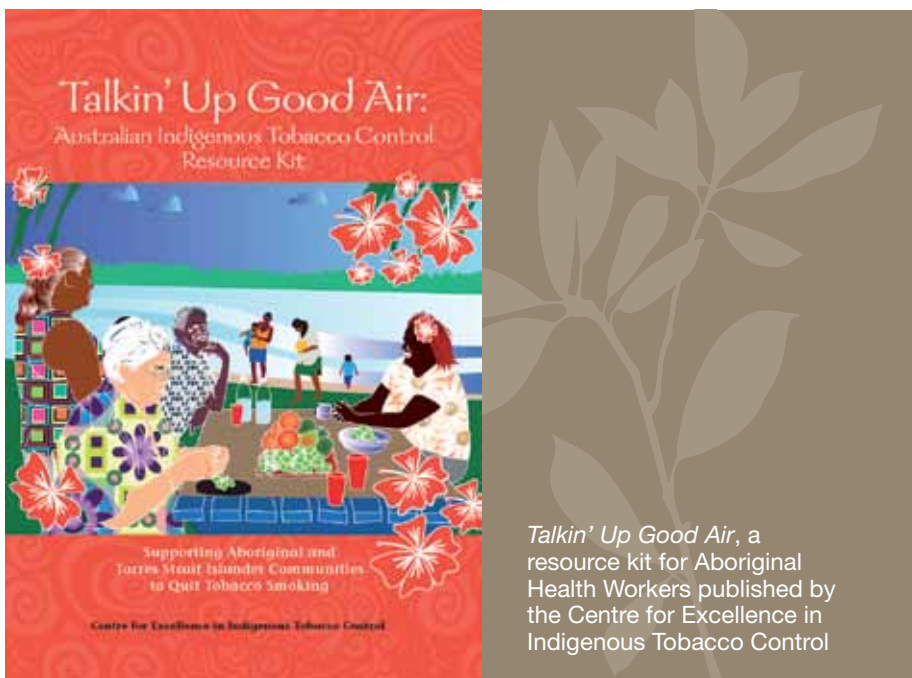
Talkin' Up Good Air, a resource kit for Aboriginal Health Workers published by the Centre for Excellence in Indigenous Tobacco Control

When developing the Centre for Excellence in Indigenous Tobacco Control's kit for Aboriginal Health Workers, we worked with an Indigenous researcher and illustrator to try to get the voice right, and we pitched the language at a suitable level… We used dot points, lots of pictures, other ways of explaining something – even cartoon characters, just to make it more fun (Jane Yule, Research Communications Manager, The Lowitja Institute).

In western NSW… people said they wanted access to local information about alcohol problems because the lack of available information had led to some poorly informed decisions. The Alcohol Community Development Project (based in Broken Hill) negotiated for access to… data from government and non-government agencies... They made up a simple package of documents on alcohol related harm for each town, with one graph or illustration on each page and a sentence explaining the graphic. The [data] included alcohol-related assaults, most common alcohol-related problem presenting at hospital, place where alcohol-related problems occurred, days and times when problems are occurring, qualitative data – people's concerns and what they are already doing.' [Community working parties used the information to plan harm reduction strategies] (Brady 2005:70).

A good way to ensure that information is well tailored for the intended audience is to involve the target audience in designing and presenting it.

To develop a workplace resource about research supervision, our team (which also included Jenny Brands and Nea Harrison) started with consultation meetings with potential users, then gathered published evidence and collected stories from researchers about supervision issues and the support strategies that work well. The draft publication was reviewed by about 50 people in the target audience. Consultation, review and revision processes were time consuming, but when Supporting Indigenous Researchers: A Practical Guide for Supervisors *went to print, we could be confident that the information and format were tailored to meet user needs. Also, a lot of people were aware of the resource and were willing to promote it through their networks* (Alison Laycock, Writer, and Diane Walker, Workforce Development Officer, The Lowitja Institute).

} See Chapter 10, 'Methods for Reporting and Dissemination', for advice about which methods suit each group and how to tailor the information.

Tailoring research information for knowledge exchange may require skills in... pitching information carefully and presenting it in a particular format to suit an audience.

Evidence is accessible to research users when they need it

To have the greatest impact, researchers often need to time the release of information, especially if aiming for media attention.

When The Overburden Report: Contracting for Indigenous Health Services *was launched in August 2009, it was carefully timed to coincide with 'A Healthier Future for all Australians', the final report into reforming Australia's health system by the National Health & Hospital Reform Commission. The researchers wanted their research to feed into government policy decision making. When* The Overburden Report *came out it was picked up by the media because it was pertinent to that bigger issue* (Jane Yule, Research Communications Manager, The Lowitja Institute).

There are many ways to reach an audience. For example, research evidence may form the basis of professional development and networking sessions for practitioner groups.

A group of District Medical Officers… meet regularly to network and exchange research knowledge via computer-generated teleconferences. People hook in from all over the NT as well as from interstate… These brief and intensive regular sessions give opportunities to revisit health issues that should be on the radar. Helping [the officers] to stay informed and involved helps with professional development but also makes remote work less isolated and more supported.

Managers see the sessions as valuable and provide paid time for staff to participate, and there is a doctor in a dedicated Education and Training role. These factors contribute to the success of these sessions (Karen Piper, Centre for Remote Health, and Jessie Johnston, Senior Rural Medical Practitioner, Darwin).

As well as targeting specific audiences, you need to put research findings into the public domain. If information is not available to people, or can't be found when needed, it will not be used.

Some ways to make research accessible are via:

- The Lowitja Institute website, which has been developed to support the adaption and adoption of products and resources from its research in practice and policy environments, to promote access to information, and to facilitate communication and collaboration in Aboriginal and Torres Strait Islander health research (**www.lowitja.org.au**).

- Australian Indigenous Health*InfoNet*, which is an Internet resource that makes published, unpublished and specially developed material about Aboriginal and Torres Strait Islander health freely accessible; it also supports information sharing through its 'Yarning places' (**www.healthinfonet.ecu.edu.au/**).

- health information clearinghouses, which have research information about specific topics, for example:

  » Closing the Gap Clearinghouse (**www.aihw.gov.au/closingthegap**)

  » Australian Clearinghouse for Youth Studies (**www.acys.info/resources**)

  » Drug Information Clearinghouse (**www.druginfo.adf.org.au**)

  » National Child Protection Clearinghouse (**www.aifs.gov.au/nch**)

- peer-reviewed journals and other professional health publications (e.g. *Medical Journal of Australia, Aboriginal and Islander Health Worker Journal*), which offer up-to-date research information

- open access journals, which are available online without charge. Many are peer reviewed and there is a push to make more Indigenous health articles open access. BioMed Central is one open-access publisher of health journals (**www.biomedcentral.com/browse/journals**).

Evidence is credible and useable

For research evidence to be credible, research users need to see that a research project is being done in the right way, by skilled people with appropriate expertise.

The traditional way for academic research to get credibility in the research community is through publication in peer-reviewed journals. It is standard practice for some research users (e.g. groups who review clinical guidelines) to check whether research project findings have been reported in journals.

Other types of review ensure credibility and useability. Human Research Ethics Committees check proposals to ensure that Indigenous health research will have credibility and a useful purpose. Community reference groups have a role in guiding research processes and ensuring outcomes are useable. The Lowitja Institute approach is to have research proposals reviewed by people who represent academic, government and the Indigenous community interests.

Researcher credibility is needed for the research evidence to be credible:

- personal credibility is essential – if a researcher has behaved unethically in the past, his or her evidence may not be seen as credible, regardless of its quality
- scientific credibility of a researcher gives credibility to findings
- community credibility is needed – someone in the team needs to have experience and credibility in the Indigenous sector.

One person doesn't need to meet all credibility criteria – that would be a big ask, especially of emerging researchers – but the team and/or management group should collectively meet them.

When the CRCAH applied for a five-year extension… we commissioned Access Economics to carry out an economic evaluation of our proposed programs. We knew that Access Economics had credibility and the expertise we needed, and that their findings would therefore be highly regarded (Jenny Brands, former Research and Development Manager, CRCAH).

Community support adds to credibility. Evidence is more likely to be seen as credible when:

- the participating community or group has said 'yes' to the research
- peak bodies have supported the research
- other organisations or services are already using the findings
- the research has been championed or 'talked up' by respected leaders.

[Organisational, professional, academic, clinical and community] leaders told stories about how the ABCD [Audit and Best Practice for Chronic Disease] project could work and, based on their experience, knowledge and status, they brought credibility and conferred legitimacy to the process. This gave people confidence and authority to proceed (Gardner et al. 2010:28).

Credibility generally comes from a body of evidence. A single piece of research is rarely taken up and used to change policies or practice guidelines. Decision makers usually need to see a body of evidence that supports the same findings before changing the way things are done. This is also true of the research community, which is unlikely to lobby for change on the basis of one project.

Mechanisms to build relationships with research users and opportunities to interact

> *'[R]esearch use is like the AFL – it's a contact sport'* (Lomas 2004:21).

When 24 Canadian studies asked more than 2000 policy makers what facilitated or prevented their use of research evidence, the No. 1 facilitator was *'personal contact between researchers and policy makers'*. The No. 1 barrier was *'absence of personal contact between researchers and policy makers'* (Innvaer *et al*. 2002 in Lomas 2004:21).

Getting research information to research users is critical to doing research that makes a difference, but it doesn't happen naturally.

Researchers/academics and managers/policy makers usually work in different organisations. They have different occupational cultures that limit opportunities to exchange information. The groups are rarely at the same meetings. They attend different conferences and read different journals. They speak different professional 'languages' and messages can get lost in translation. There are limited opportunities to cooperate in research.

Mechanisms that build relationships between researchers and research users include:

- the research brokering role of some peak bodies
- collaborations such as Centres of Clinical Research Excellence and the Coalition for Research to Improve Aboriginal Health
- roundtable meetings, research showcases, support for project reference groups and presentations of findings to workplaces
- formal arrangements between organisations (e.g. research agreements).

The earlier research users are involved, the better. It is best to set up links with policy makers and service managers in the planning stage of a research project.

Jenny Brands

Low-cost, small-scale mechanisms for knowledge exchange can be very effective if the audience and timing are right.

When research produced interesting results about skin disease treatment in remote health clinics and how follow-up by community-based workers had improved treatment success rates, the CRCAH organised a meeting where the skin disease researchers could talk about their findings with managers from the NT Health Department. It wasn't a simple matter of saying 'This is what the research has shown, make this change'. It required dialogue and clarification to get the implications of the research for practice just right. The Department was going through some structural reforms at the time, and the findings helped validate the policy direction it wanted to go in. So in 1½ hours a small, inexpensive, well-timed process was effective in linking research findings directly to those who could put them into practice (Jenny Brands, former Research and Development Manager, CRCAH).

When you take steps to include people from the community and services in planning, overseeing or conducting research, it is more likely that the research will be valued and the findings applied. Interaction is easier when relationships are already established and people understand each other's priorities and views, such as when:

• Indigenous researchers conduct research and help to facilitate change in their own communities

• practitioners do research related to their own work setting and practice

• frontline staff get involved in collecting and/or interpreting data that are used to revise their guidelines

• research advisory groups bring together researchers and research users with decision-making power. Terms of reference can include dissemination planning.

Priscilla Pyett, now Honorary Principal Fellow in the school of Population Health at the University of Melbourne, was funded to work part-time within an Indigenous health peak body when employed as a researcher with *Onemda* VicHealth Koori Health Unit at the University of Melbourne. She discusses her role within the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) and the mechanisms that helped to build relationships.

I held an honorary position at VACCHO for six years that was established under a Memorandum of Understanding between Onemda and VACCHO. I was accountable to the Victorian Aboriginal community through the CEO and Board and worked on projects alongside VACCHO staff.

I began by working there one day a week, getting to know staff, providing advice and supporting ideas for research. Eventually this increased to two days a week and involved me responding to staff requests, providing advice on ethics and research, developing research proposals in response to funding opportunities, and carrying out research for VACCHO and its member organisations. I travelled to community organisations around the State with VACCHO staff, co-presented at conferences. I supervised students at VACCHO and co-authored community reports, a book chapter, peer-reviewed articles and newsletters with VACCHO staff.

I believe that this arrangement contributed to fostering a climate of tolerance, acceptance and finally an embracing of research at VACCHO, culminating in the establishment of the Public Health and Research Unit.

Mechanisms that build relationships between researchers and research users include... formal arrangements between organisations.

Research users have the desire to use evidence

The take up of research findings always depends on how much users want or need it. When research is commissioned by a group or organisation, you can be reasonably confident that they want to use the findings. In other projects, you need to rely on dissemination strategies to get your research to targeted audiences, and into the public domain. People can also be quite determined to find evidence when there is a powerful motivation to use it.

> *[When I was at the CRCAH] we did a media release highlighting the empowerment program at Yarrabah in Queensland and, randomly, it got picked up by a newspaper in the Pilbara in WA. By coincidence a woman who had just been appointed as CEO for the local drug and alcohol corporation saw it and said, 'This is exactly what we need'. She tracked down the researchers… and it has now been presented to the Board of Elders from that organisation in Geraldton, as part of their business plan. So they're taking an empowerment model to deal with alcohol and other substance abuse in their community. Now, you know, if that had gone just through a peer-review journal, the likelihood of the project making that hop across the whole continent and becoming a really useful bit of knowledge for a small community-based organisation in Geraldton is really unlikely, I think* (Alastair Harris, former Communications Manager, CRCAH).

One area in which it is difficult for research to make an impact is government policy. Governments' desire to use evidence is strong when it validates what is already known or believed. However, governments tend to reject evidence that doesn't support belief or have political benefit. For example, mandatory sentencing was introduced in Western Australia (in 1996) and the Northern Territory (in 1997), based on the idea that tougher sentences deter more people from committing crime. Yet evidence says there is no consistent correlation between imprisonment rates and crime rates, and that rates of re-offending are higher for those imprisoned than for people directed to alternative sentencing programs. It was found that mandatory sentencing resulted in over-representation of young Indigenous people (Beyond Bars: Alternatives to Custody n.d.). Although mandatory sentences for minor property offences in the Northern Territory were repealed in 2001, tougher mandatory sentencing laws were passed in Western Australia in 2009.

Remember that findings can be used for incremental, rather than radical, change. For example, governments may take small steps towards changes that are likely to attract undesired attention, or to delay change until the time is politically right.

Evaluation is the most common user-commissioned research. It measures the value or effectiveness of a program or activity, so often leads to change (or informs a decision not to change).

Captain Starlight
team at work

*In 2008 [the Starlight Children's Foundation] engaged the CRCAH
to evaluate the acceptability and success of the program in the NT,
which had been in place for two years. The findings were presented at
a roundtable meeting which brought together people from Aboriginal
organisations, government, research groups and other services and fed
directly into the Foundation's planning of the ongoing NT program.*

*Changes were made as a result of the evaluation… [and] Starlight has
[since] established programs based in Darwin Hospital, regional visits
including visits with health professionals to remote communities, and a
Darwin metro program to Bagot community and local special schools…
Since the evaluation Starlight has increased its reach to sick children
in collaboration with the hospital and various community-based health
organisations* (Louise Baxter, CEO, Starlight Children's Foundation).

Progressing from what is known from research to what is practised can be
complicated. Within research user groups, people will have different goals and
priorities, backgrounds, knowledge systems, work cultures, interpretations of
what needs to be done, different levels of interest and power, and so on. In
reality the knowledge that comes from research is just one of the things used
to decide policy and practice, even in a small organisation. Politics, cultural
viewpoints, budgets, resources, worker numbers and skills, training needs, law,
media messages, lobbying, expertise, values and habit all affect people's desire
and ability to use evidence.

Research users have the capacity to use evidence

Having the capacity to use research evidence can depend on various factors. They include having funds to make and sustain change, having enough staff, having necessary facilities or equipment, having a 'learning community' that is receptive to change, having management support to change policies and practice guidelines, and having access to the latest information and training to upgrade skills. The Canadian Health Services Research Foundation, for example, has a training program called Executive Training for Research Application (EXTRA). The program develops capacity and leadership to use research evidence in the management of Canadian health care organisations.

} For information about EXTRA, see the Canadian Health Services Research Foundation website (www.chsrf.ca/extra/index_e.php).

Factors that can make knowledge exchange challenging

Good knowledge exchange in the Indigenous health research environment can be challenging. This is mainly because it asks researchers, funders and policy makers to change the way some things have traditionally been done. Success is more likely when you are aware of these challenges, open to new ways of doing things and prepared to advocate for change.

Peer-review system and academic culture

Peer review is the system whereby research proposals and publications are reviewed by other researchers (peers). It is the internationally accepted method of judging the quality of proposals, and is based on Western principles of democracy, competition and volunteerism. It values expert academic opinion and objectivity (Street, Baum & Anderson 2008:11).

Publication of research findings in peer-reviewed journals is the accepted way to establish credibility for research and to disseminate information in the research community. The number of published articles and how often they are cited by others are important measures of a researcher's track record – more important for academic reputation than community publications and other knowledge exchange activities. Focusing on broader knowledge exchange strategies may result in fewer publications, and is seen to slow down academic careers.

Peer-review publications are also an important measure of a university's track record. Universities must report on publications produced. They win significant funding on the basis of these publications, with established, high-impact scientific publications such as the *Lancet* carrying more weight than lesser known journals. Therefore, peer review impacts on the way researchers are employed and funded in universities, and there is great incentive for researchers to produce peer-reviewed publications.

However, channelling effort into publishing doesn't always support good knowledge exchange in Indigenous health research for a number of reasons:

• it tends to support a competitive, rather than collaborative, research culture

• it often happens at the expense of knowledge exchange activities (with which academics can feel less familiar and confident)

• some journals will only publish findings that are new (i.e. not published elsewhere), which can be a dilemma for researchers whose priority is to report to community and research users because there can be long delays between submitting articles and having them published

• professional journals are rarely accessible to community users.

Also, peer judgments about quality tend to reflect the worldview of the reviewer, so cultural bias can impact on appraisals. In health research, peer review has tended to support the dominance of biomedical research.

The emphasis on peer-review processes in Indigenous health research is beginning to be challenged. For example:

• in 2004 a researcher's 'track record' was given a 40 per cent weighting in the NHMRC guidelines for reviewers, an emphasis that could block community-initiated research and new Indigenous researchers: in 2010 track record counted for 25 per cent of the assessment criteria (Street et al. 2008:15; NHMRC 2008:12)

• more researchers are using approaches such as participatory action research, in which knowledge exchange is built into research methods

• some academic leaders are promoting a shift from pure research to approaches that build capacity in exchanging and applying knowledge.

Universities must… examine how they can be more effectively involved in the processes through which knowledge is disseminated or exchanged. In this context, universities should further develop a system of knowledge exchange that sees students take the knowledge developed through research, and implement it in a real-world setting that will result in better health policies and practices for Indigenous Australians… we need new tools that underpin timely and effective communication strategies. For example, we cannot rely just on peer review publications to get our message out: we should be directly engaging Indigenous communities and Indigenous health stakeholders in the research process whenever and wherever possible (Anderson 2008:1).

Inadequate resources to carry out knowledge exchange

Knowledge exchange involves time, money, skills and forward planning. Some activities happen within the project timeline (e.g. regular updates to partners and reference group, final reports.) However, knowledge exchange activities often need to go beyond the boundaries of project timelines and funding. This can compromise processes and outcomes and cause ethical and financial problems for researchers.

I worked closely over four and half years with many Aboriginal artists, curators and arts administrators… [and] all participants were assured that on the conclusion of the study they would receive feedback about the research findings… It was decided that a 'community report' would be the most appropriate, a report that showcased the artwork and allowed the artists' voices to be pivotal in the telling of the story.

Because of the colour images we were hoping to use, I knew that the overall cost of the publication would far exceed the dissemination funding offered by the university department in which I was based, as well as my main scholarship funding body… I attempted to acquire funding for the final 'community report'.
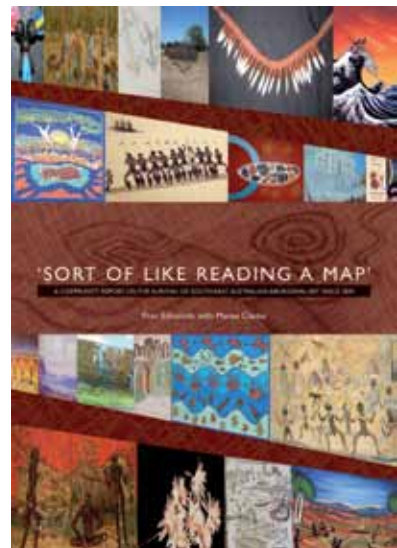
'Sort of Like Reading a Map' community report

Tips for planning knowledge exchange

The amount of knowledge exchange possible depends on the type of research (e.g. a review of the literature versus a participatory action project in the community), and the stage of the project.

- Plan for knowledge exchange as early as possible when planning the project. Involve relevant research users.

- When the research has been requested by an organisation or group, find out if there are plans for using the research. Are there built-in expectations or contractual obligations for knowledge-sharing products?

- Include a budget for knowledge exchange activities and product development in research grant applications and in timelines. They should not be ad hoc or added on.

- If extra funding is needed for knowledge exchange, start the search as early as possible. If funds are inadequate, work out your knowledge exchange priorities (e.g. community feedback in the preferred format is not negotiable).

- Involve relevant experts in planning and carrying out knowledge exchange (e.g. to cost it, to develop a product, to present at an event).

- Work on your relationships with research users. Research results can be rejected by the group or community if people are not happy with the way you worked, if your credibility is doubted or if something went wrong in the research process.

- Ask leaders and organisations who 'champion' the research project to help with knowledge exchange. Make the most of opportunities for advocacy or lobbying as they come along.

- Think about your commitment beyond the project. Researchers at the research site, who have good relationships within the community and who know culture and local resources, are in a good position to promote research information and support local initiatives for research use.

- Develop a dissemination list for knowledge exchange products as the project goes along, rather than at the end.

- Send project information and links to suitable newsletters and websites. Use the expertise of the communications unit in your institution or workplace.

- Be clever and accurate with citation. Referring to the work of other researchers in your publications means that they are more likely to circulate and cite yours.

Not all research justifies the same efforts in knowledge exchange. For example, inconclusive or preliminary findings may need careful consideration: are the findings important for people to know? If so, important to whom?

Resources for planning knowledge exchange

The Primary Health Care Research and Information Service is a source of information about Australian primary health care practice, policy and research, and provides knowledge exchange information and advice: **<http://www.phcris.org.au/knowledge_exchange/index.php>**

Canadian Health Services Research Foundation has many resources to support researchers with knowledge exchange: **<http://www.chsrf.ca/PublicationsAndResources/ResourcesForResearchers.aspx>**

Health research organisations and professional journals publish guides for planning knowledge exchange. For example:

- *From Research to Practice: A Knowledge Transfer Planning Guide 2006* (Reardon, Lavis & Gibson 2006): **<www.iwh.on.ca/system/files/at-work/kte_planning_guide_2006b.pdf>**.

- Ward V., Smith S., *et al.* 2010, 'Planning for Knowledge Translation: A researcher's guide', *Evidence & Policy: A Journal of Research, Debate and Practice*, vol. 6, no. 4, pp. 527–41: **<www.ingentaconnect.com/content/tpp/ep/2010/00000006/00000004/art00006>**.

- The Lowitja Institute website has resources and information about knowledge exchange (**www.lowitja.org.au**).

Stories about using research for change

The research projects in the case stories in this section have common factors that support the use of research for change.

The research questions arose from problems that were real, lived experiences for people. There was a strong belief that change was possible and the researchers worked closely with project partners. Research outcomes were clear. The researchers were aware of what they couldn't do and called on other expertise.

Knowledge exchange activities focused on multiple stakeholders. Careful planning went into the formats and messages needed by each audience. Reporting involved face-to-face contact, not just reports on paper. People with authority to make decisions about change were targeted. They got involved in negotiating changes. The suggested changes were practical and real (e.g. a real job, measurable continuous quality improvement (CQI) processes, revised clinical guidelines).

} For more knowledge exchange stories, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Universities should further develop a system of knowledge exchange that sees students take the knowledge developed through research, and implement it in a real-world setting that will result in better health policies and practices for Indigenous Australians.

Case story – Using evidence from a diabetes study to change local clinical guidelines

In 2006 the Kimberley Aboriginal Medical Services Council, the Rural Clinical School of WA and the WA Country Health Service, Kimberley, conducted a study to see whether point-of-care (POC) capillary blood glucose meters were sufficiently accurate to diagnose or exclude diabetes as part of remote primary health care practice.

The Kimberley Capillary POC Glucose Study compared POC capillary glucose results across seven health care sites in the Kimberley with venous glucose levels measured in a reference laboratory. The researchers found a high overall correlation between the laboratory and POC samples (i.e. the results obtained by each method were quite similar). Local changes were made based on the results. The method of diagnosing Type 2 diabetes in the Kimberley was modified, and the Kimberley Chronic Disease Protocol for Type 2 Diabetes was updated.

The study contributed to changes to the *National Evidence Based Guidelines for Case Detection and Diagnosis of Type 2 Diabetes*, which now state that 'POC capillary glucose testing is sufficiently accurate to be a useful component in the diagnosis of diabetes in remote communities throughout Australia' (Colagiuri *et al*. 2009:54).

Factors that contributed to knowledge exchange were that:

* people involved in the research were well placed to use the findings
* stakeholders were engaged and consulted throughout the study, including regional and local health services
* findings were disseminated in various ways, including publication in scientific literature
* plain language reports were produced for clinic staff and community members, and sent to all clinics in the Kimberley (Marley *et al*. 2007:500–03).

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

} For plain language reports, see the Kimberley Aboriginal Medical Services Council website (www.kamsc.org.au).
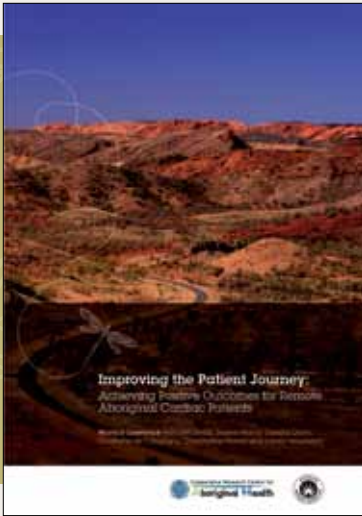
Improving the Patient Journey community report

Case story – A small research project is leading to better care and outcomes for cardiac patients from remote areas

Many Indigenous people in rural and remote areas need to travel vast distances to hospitals for surgery, often with life-threatening conditions. Language issues, poor inter-agency coordination, cultural misunderstandings, emotional and physical stress, travel and financial problems can all make this a difficult, dangerous and inefficient process for the patient and the health system.

These concerns led **Monica Lawrence**, a nurse in the cardio-thoracic ward at Flinders Medical Centre in Adelaide, to initiate a research project to test whether better system coordination and cultural support could lead to better patient outcomes and hospital efficiencies, as well as reduced waiting time and costs. Monica started her own quality improvement study in the ward, and this led to her undertaking a Master of Nursing by Research. Other project team members were Zell Dodd, Shane Mohor, Sandra Dunn, Charlotte de Crespigny, Charmaine Power and Laney MacKean.

The research, which used the hospital's continuous quality improvement (CQI) framework and case studies, found that improved cultural competency in a clinical setting led to better clinical/cultural liaison, more cultural respect for remote area Indigenous patients, better informed patients, improved patient care and safety, lower travel costs, less disruption in the hospital system and more efficiency in the hospital.

Towards the end of the Masters research, I collaborated with Barbara Beacham, a Program Manager at the CRCAH, who helped me take a strategic point of view. We decided the best way to implement the findings was through

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a role that could trial them. We proposed the Remote Area Cardiac Liaison Nurse position… I had to transcribe patients' experiences into bed numbers and stays, costs and savings for managers. I also had to think politically… The CRCAH helped to write a policy brief and summary report. Good media promotion and the launch of the summary report at a primary health care roundtable in Canberra were the main drivers. They sparked a high level of interest on the national stage and SA Health regions took notice.

As a result of the research, Flinders Medical Centre now has a full-time remote liaison nurse position, and CQI processes reflect these clinical/cultural competencies. There is a cardiac rehabilitation program for Indigenous patients.

The research has helped develop 'step-down' programs for Indigenous patients after discharge. Country Health SA has rolled out the model in the 'Clinical Networks' program, and other health care programs are looking at using the learnings.

The evidence adds to a push to improve Patient Assistance Transfer Schemes across Australia. The research has influenced national health care policy, through a submission to the 2007 Senate Inquiry and inclusion of three standards for acute care services to Indigenous people by the Australian Council on Healthcare Standards.

Factors that contributed to knowledge exchange included:

- research that was based on needs identified by a practitioner

- clearly stated, practical key messages

- targeting people or groups who had political clout to influence change and talking in their language

- timing the research to influence change

- persistence by the researcher

- support by others with links and expertise to help get messages across.

Many times… I thought 'this is too hard, I can't do it'. Here I was, a clinical nurse stepping outside my professional domain and trying to change broader practice in a hospital setting. I had to keep knocking on doors [and to]… wear the hat of a bureaucrat and talk in terms of dollars and cents, and quality and safety. [When it got] too hard… I'd put my nursing hat back on and reflect on why I undertook this research work in the first place. I still keep thinking about the first woman from a remote area that I ever looked after. She was the reason I did this research.

Key messages for researchers

- Knowledge exchange is about thinking beyond the project. It is a two-way process between researchers and people who can use the research for change.

- There are many strategies researchers can use to support knowledge exchange.

- Knowledge exchange requires good communication, real relationships and practical on-the-ground approaches.

- Change is often incremental and takes a long time. Even small changes are good, especially if they lead to sustainable change.

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chapter 6:
building capacity through research

Research projects in Indigenous health can build capacity in a number of ways and at different levels. Projects can build the capabilities of researchers, research participants, others involved in the project, community organisations, services and systems. This chapter looks at different types of capacity building. It explains how health research projects can build in learning and development opportunities, so that research benefits can be sustained and can make a real difference to people's health and wellbeing.

What is capacity building?

International thinking about *capacity* has moved from a focus on individual training to include the development of organisations and systems. New definitions emphasise *capacity building* or *development* as a continuing process of strengthening abilities to perform core functions, solve problems, define and achieve objectives, and understand and deal with changing needs. Capacity needs to be built on what already exists. It does not start from a deficit, but focuses on strengths and opportunities.

Capacity building is based on ideas that match the concerns of the Indigenous health research reform agenda. Both aim for a shift in power relationships, from depending on external skills to recognising and building community strengths, resilience, resources and creativity (Mayo, Tsey & Empowerment Research Team 2009:2). Both aim for local ownership of programs and projects, self-reliance and Indigenous control. Both recognise is that long-term commitment is needed to make and sustain changes. Definitions of community capacity building are especially relevant.

At a community level, capacity building is:

The building of sustainable skills, structures, resources and commitment of health improvement (Hawe *et al*. 2000:2).

Strengthening people's capacity to determine their own values and priorities and to act on these… (Eade 1997:2).

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Hawe *et al*. (2000) suggests that capacity building in health refers to at least three different activities:

- building infrastructure (to deliver programs or services)

- building partnerships and organisational environments (to help sustain programs, services, gains or positive outcomes)

- building problem-solving capacity in communities and systems (to ensure appropriate responses to new problems in unfamiliar contexts) (Hawe *et al*. 2000:1).

At an individual level, capacity development includes formal and informal education and training, and other hands-on opportunities for development (CRCAH 2006a:3–4).

Indigenous research capacity building

Key aims of capacity building in Indigenous health research are to have more Indigenous people involved at all levels of research, a growing number of Indigenous researchers, research supervisors and managers, and ongoing system support for researchers.

The *NHMRC Road Map II* (NHMRC 2010) and the CRCAH (2006a) *Aboriginal Health Research Capacity Development Strategy* both highlight the need to strengthen the capacity of Indigenous people to undertake health research.

Many organisations are working to build Indigenous research capacity. For example, universities and other training providers offer academic supervision, and research courses that target Indigenous students. Funding organisations such as the NHMRC prioritise Indigenous health research grants. Various scholarships and traineeships target Indigenous researchers. Research institutions and partnerships such as the Lowitja Institute involve Indigenous people in designing and overseeing research projects that concern Indigenous people, as well as using research. They support the development of management skills needed for successful research projects.

Projects are often designed and funded to support the mentoring of emerging Indigenous researchers by experienced researchers, and to support two-way learning within research teams. Indigenous health research practice tends to emphasise community/researcher partnerships and participatory research, which help to build community research capacity.

Although most policies and strategies focus on building the capacity of the Indigenous health research workforce, they also help to develop the capacity of non-Indigenous researchers to carry out research that makes a difference. Experienced researchers can learn from working with Aboriginal people, organisations and communities, or with researchers from other disciplines.

> *I learned a lot from my involvement with the CRCAH… In particular, to think more deeply about how research transfer and capacity development can be built into projects. What the CRCAH has done is [to work] hard at making the principles and priorities for Indigenous research explicit, and [to] put good processes in place to work those through. It's given people like me access to that information, and created a space for people to talk and learn about a whole lot of things, including the politics of Aboriginal health research, how that's evolved, and how to work within that environment… And we continue to learn as we go through the research development process* (Ross Bailie, Program Leader, The Lowitja Institute).

} Subscribe to the Lowitja Institute's free e-Bulletin and *Wangka Puḻka* newsletter for updates about capacity development opportunities (www.lowitja.org.au).

Capacity needs to be built on what already exists. It does not start from a deficit, but focuses on strengths and opportunities.

Capacity building in research practice

A health research project can help to **build research capacity** or other types of individual, organisation or community capacity. A project can assist others to develop research skills and knowledge, for example, when:

- project development involves community representatives, frontline workers, managers and researchers

- researcher/s and a community reference group work and learn together

- community or workers are involved in participatory action research

- inexperienced researchers are supported to undertake accredited training (e.g. Certificate IV in Indigenous Research Capacity Building)

- different types of mentoring are offered through the project

- community members are recruited and trained to collect data

- local practitioners or community members and researchers work together to interpret findings and prepare reports.

A health research project can **build skills other than research skills**. This capacity building is important for reciprocity and helps to sustain community benefit in the longer term, for example, when:

- skills developed through being involved in research are applied to other fields (e.g. priority setting, planning, project managing, evaluating)

- research identifies learning needs and helps people to access courses (e.g. literacy and numeracy training, Indigenous language training)

- projects develop training as a research outcome – providing opportunities for community members to train as trainers or develop mentoring skills

- data collection processes involve participant learning (e.g. collecting data about parent/child interactions while parents participate in play sessions)

- research projects develop resources for information sharing – the process of developing resources involves learning new skills (e.g. making films); the resources can provide information/capacity for informed decision making

- findings are used to update practitioner guidelines and training programs

- research projects support the capacity of organisations and sectors to work together – building the capacity to use research findings to change policy and protocols may be another research outcome.

Getting to know each other. Parents and children (L–R): Kayleen & Ronaldo, Michaela & Tracey, Cindy & Ian, Lisa (out of view) & Fredo, with Gary, Roger & Celeste (group leaders). (The Let's Start project has written consent from the parents to use images taken in the program.)

Case story – Building capacity through a research and parenting intervention program

Let's Start is a targeted research program. It promotes positive parent–child interaction, and improves children's social and emotional competencies and capacity to transition to school. A manual sets out structured activities over eight to 10 weeks for children and parents, delivered by group leaders. About 40 schools in metro and rural Darwin, Jabiru, Palumpa and on the Tiwi Islands have taken part.

Project leader **Gary Robinson** and senior researcher **Anita D'Aprano** explain how the program builds capacities.

The Let's Start program includes the research and the service. While we collect data, we can develop parenting skills. Formal research instruments include questions about family life and checklists to rate children's behaviour. It is the first time some parents have encountered that language and way of thinking about behaviour problems. Over time we see parents get more and more proficient in answering the questions.

The program trains community-based workers in pre-schools, health and childcare to work with the parents' groups or child/parent groups. Some workers help with data gathering – it depends on their skills, experience and interests. Within the team, the program generates quality dialogue around families and the determinants of children's behaviour. After every group session we debrief and that's a powerful learning experience for all of us. It's a key mechanism for building team capacity and developing strategies to support individual children and their families.

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There's learning for teachers as well, in terms of engaging with the issues, referral reasons, assessment processes and then providing evaluation data. We have meetings with teachers to monitor children's progress during the program and discuss what we are doing. We provide qualitative feedback at follow-up.

Some research projects are narrow and discrete, but ours engages with providers in health, education, community services, childcare, etc. We have helped to develop early childhood services networks across the three Tiwi communities, for example. There are important reasons for building networks that help integrate services. Children in difficulty often 'fall through the net'. Single providers may see part of the picture but the various reasons for the child's vulnerability are not fully examined and no one service really knows enough to respond to the child's needs. By building strong collaborative processes, providers of parenting programs like Let's Start can link up with health, mental health, child protection and other services, to ensure that the needs of vulnerable children are properly understood and acted upon.

We can't ensure that the networks we contribute to are sustained. The activities are only there while we are there, because research funds used for these structural links are usually not replaced by the service providers when the research is completed. It's an issue.

A big question for researchers is: What's left behind? We seek to build parents' capacity, resources and inner strength, and create shared parent and child resources that continue to support the children. Our big focus is the parent/child interaction – the program creates a protected space and it gives them an experience they take with them after the program. We also want to see community services and individuals better enabled to take effective, collaborative action to support children and families.

Capacity-building strategies for emerging Indigenous researchers

There are many issues for emerging Indigenous researchers and their supervisors (or mentors) to take into account when planning learning and support strategies. Many are unique to being an Indigenous researcher and to working within an Indigenous framework. As well as learning the skills, language and culture of research, there are issues that relate to being an 'insider' researcher – that is, doing research with Indigenous participants as an Indigenous researcher – that can be challenging. It does not mean that research is easier – it is complex and at times confronting, even for trained and experienced researchers.

Case story – An emerging researcher's experience

James Coulthard-Stanley writes about his learning journey as an emerging Indigenous researcher.

I was doing the CCRE's [Centres of Clinical Research Excellence] Certificate IV: Indigenous Research Capacity Building course when I began a study to track the journey of rural Aboriginal people with symptomatic coronary heart disease through the health system. Previous to this, I had worked on another CCRE project, Factors Affecting Chronic Disease Self-Management in Aboriginal Communities in Rural SA. I presented these findings at a Population Health conference in Alice Springs and have attended several research courses.

I acknowledge that although described as a qualified researcher, there is much to learn, primarily writing reports and having them up to professional standards… As an Aboriginal researcher I found a major learning curve was the ability to be able to record facts without becoming personally impacted by the communities' stories. I was adding personal attachment to the reports, almost forgetting that I needed to remain 'neutral'.

Strong support from an experienced researcher and mentoring is vital for Aboriginal researchers, as is having your own designated space to work in (James Coulthard-Stanley, Pika Wiya Health Service, Port Augusta).

}   Capacity-building strategies for emerging Indigenous researchers are described in *Supporting Indigenous Researchers: A Practical Guide for Supervisors*, in particular Chapter 7, which gives advice for applying professional development strategies in culturally safe ways. Strategies include doing a skills audit to identify training needs, investigating education and training options, linking study and work so that theory is translated into practice, and mentoring.

Capacity-building activities at different levels

Your research project can help to build capabilities at different levels: individual, group, organisation, inter-organisation/partnerships, and community.

Individuals

There are many opportunities for individual learning through research projects, ranging from academic study to mentoring and learning goals, on-the-job training and other possibilities. When projects provide opportunities for Indigenous people to develop skills there are usually benefits for the research as well. Benefits are likely to be better access to local knowledge, more community awareness about the project, a good basis for relationships and trust, more people willing to participate in the research and, ultimately, stronger research with more cultural relevance.

> *We recruited a total of 18 young [Indigenous] people as peer interviewers [for the Victorian Aboriginal Health Service's Young People's Study]. They were of different ages, both sexes, living in a range of suburbs, and representing different family groups and networks. We trained them to administer the questionnaire and conduct a health check, and provided each with a detailed manual… our experience suggests that young people are more likely to be genuinely willing to participate in a study when asked by a peer* (Holmes *et al*. 2002:1272).

Most researchers think of capacity building in terms of developing local workers. However, there may be other opportunities. In 2006 the Healthy Skin East Arnhem project (400 to 650 kilometres east of Darwin) hosted two students in their Advanced Medical Science year.

> *We've gained more from the past year than our degree can possibly show. [It] has been a truly eye-opening experience into an area of health which seems a world away from medical practice in urban Melbourne. Through experience we've learned about the health issues faced by Aboriginal communities, become aware of the extent of their access to health care, and recognised the true impact that social determinants have on health. We've learned a lot about cultural awareness and cross-cultural communication. And finally we've learned that… researching in Indigenous health is a two-way process* (Danielle Clucas and Nyree O'Connor, University of Melbourne).

Organisations

Organisations often benefit and learn by being involved in research. Research can provide evidence about client and staff needs, and new ways to meet them. It can help organisations to set up systems or resources to improve management services and research capacity.

When the Victorian Aboriginal Health Service carried out a study of the health and wellbeing of urban young people, it found that:

> *The process of the study has already increased awareness of the issues that face young people, and we expect that our results will trigger ideas for new responses and stronger services… [It] has… increased the capacity to gather information for monitoring and evaluation, and to answer specific operational questions. A further significant [capacity development] outcome has been the strengthened network of young Kooris. Several Koori health workers and young people have been trained in research and public health skills. They have gained confidence and now play important advocacy and management roles in a range of community organisations. An outcome of the successful participation of young people in the study process was that their presence at the health service increased* (Holmes *et al.* 2002:1267, 1269, 1275).

There are obvious benefits for an organisation when staff learn research-related skills that can be applied in the workplace. Real learning requires a real role in the research.

> *When we have our staff working on research projects, we expect that they're part of the learning experience around (1) the research processes, (2) the framework of the research, but (3) upskilling – rather than being just a dog's body and the 'doer', that they get an opportunity to see, at an equal level, what the research involves.*
>
> *So [the researchers'] job is to make sure that our staff out there know why they're asking certain questions, what's the framework, what are the skills that the researchers could share so that our mob [staff] know that they're asking those questions for that particular reason, because that's where it fits into the framework, or this is how we collect the data. So they start talking the same talk* (Paula Arnol, CEO, Danila Dilba Health Service).

Indigenous communities

Research projects have the potential to mobilise the strengths and resources of a community. Many projects give community members opportunities to get qualifications and skills: for example, further leadership development opportunities for Elders involved in research advisory groups and ethics committees; and career and skill development opportunities for community members on research teams. People can also learn by participating in a project – about the value of each partner's knowledge and how research can benefit them. Benefits are reciprocal as community members bring knowledge and experiences that are vital to the project's success.

Employing a Yolŋu project adviser and Yolŋu workers on the [child growth] research team was central to the project's success… The successive project advisers guided the research and both mentored and supported the [non-Indigenous] project officer so that she was able to work effectively in the community… All Yolŋu team members were involved in data collection, analysis and feedback, and they developed research skills through their involvement in the project… Community members [also] participated in assessing the 'problem' of poor child growth and potential action, and then in developing and implementing action strategies, mobilising resources, forming partnerships and critically reflecting on their actions.

The partnership between local community researchers and the non-Indigenous researcher eventually led to the development of a coalition of community members taking a direct role about what they identified as priorities around growing children up strong. This led to the establishment of a family centre, and to several local men and women training in early childhood care (CRCAH 2006b).

Community capacity building is most successful when driven by a group or community involved in the research, and when people share capacity-building goals.

One project can develop capacity at several levels

Activities often focus on several levels within one project. For example, a project might train individuals to collect data, then set up mechanisms for data linkage between partner organisations. Services may use the findings to adjust practice guidelines and develop staff resources, growing organisational capacity to deliver better services supported by staff training.

A project that develops capacity at several levels is more likely to bring about and sustain change. Change driven by one person is not good capacity building – it usually 'falls in a heap' when that person stops driving the project. It is important to look for, and act upon, opportunities for capacity building through the life of the project, in the same way that you think about opportunities for knowledge exchange.

The Northern Territory Preventable Chronic Diseases Program uses an interactive storyboard to share evidence about disease prevention and interventions and to plan change in communities. The program's Aboriginal Health Promotion Officers are now training community workers to tell the stories.

Storyboard training session, Alice Springs

Women (L–R): Nerissa Mineri, Nola Wilson, Christine Long, Colleen McCormack, Lynette Windsor.

Men (L–R): Allan Palmer (standing), Gaydon Malbunka, Carl Inkamala, Vincent Nipper, Malcolm Fry.

After hearing the chronic diseases story, community-based workers have asked for training and resources, so they can tell the stories and the messages stay there, they don't leave with us. So far, we have trained 12 workers in Alice Springs (from different communities in Central Australia) and 11 at Galiwin'ku on Elcho Island. During the training they develop their own storyboard and their own chronic diseases stories based on evidence and their family experiences. The feedback we get from the workshops is, 'This is the proper way, an Aboriginal way of teaching. Now we can go back and teach our people in our language.'

Some workers want to use the storyboard to tell stories around petrol sniffing and kava. Others want to look at the importance of antenatal care. People want to use their skills to share new research evidence and make changes.

Other Aboriginal Health Promotion Officers will be trained to lead the training program, so it's not dependent on me, on one person. This way we can keep building capacity and other people will take the program in the right direction in the future (Bernadette Shields, Senior Aboriginal Health Promotion Co-ordinator, Chronic Diseases Program, NT Department of Health and Families).

This is good capacity building because:

- people are encouraged to find their own solutions to local problems
- it motivates people to learn new skills and information
- training is included, and the training has a multiplier effect (i.e. train the trainer)
- people become confident to apply a familiar process to a different purpose
- there is a plan to sustain the activity and its benefits
- communities develop more capacity to understand and tackle health issues.

A project that develops capacity at several levels is more likely to bring about and sustain change…. It is important to look for, and act upon, opportunities for capacity building through the life of the project.

Planning for capacity building in your research project

As explained throughout this chapter, capacity building through research is not just for large organisations and big research projects. It happens within small research projects and through the efforts of individual researchers. Researchers in Indigenous health are expected to plan for capacity development within their projects.

Capacity building is linked to research funding

The NHMRC is the main funder of Indigenous health research in Australia. Applications are assessed using *Criteria for Health and Medical Research of Indigenous Australians*. The criteria include 'building capacity'. All proposals must show how 'Aboriginal communities, researchers and others will develop relevant capacities through participation in the project' (NHMRC n.d.).

Projects funded, endorsed or managed by the Lowitja Institute need to show:

*   potential for developing the capacity of individuals, communities and organisations
*   the extent to which capacity development plans demonstrate consultation and collaboration with stakeholders.

Decisions need to come from the learning community

When planning capacity building activities, don't make assumptions based on your own experiences or ideas about opportunities or training that people want. Decisions about capacity building activities need to come from the learning community. Proper consultation and collaboration will lead to relevant learning opportunities, better organised around people's needs, interests and workloads.

A study of the needs of Indigenous illegal drug users in the Australian Capital Territory brought together researchers from the Australian National University and workers from Winnunga Nimmityjah Aboriginal Health Service in two-way skills exchange. Frontline workers were asked to decide their research roles and were offered relevant training options.

> *[We wanted to achieve] a comfortable 'learning community' to facilitate multi-directional learning between… health workers and… researchers. We aimed to build [workers'] general knowledge of the research process, and their specific knowledge of this particular study, through training in areas of direct relevance to them… Responses by 16 Winnunga staff to a questionnaire shaped our objectives. [The questionnaire asked] how they wanted to be involved in interviews [and areas of interest in] technical skills training.*
>
> *Considerable discussion went into achieving the best possible outcomes. We wanted to ensure that all Winnunga staff wanting to participate could do so. Equally, it was important not to remove a large section of… Winnunga's workforce from its core activity of providing health services to the local Indigenous community* (Guthrie *et al*. 2006:517–18).

Capacity is more complex than ability or skills. It includes motivation, commitment, resources and other elements needed to achieve and sustain outcomes. *Building* is about creating or developing this capacity over a period of time. Neither the processes nor outcomes can be created or controlled by researchers.

However, you can facilitate the processes and outcomes by recognising pre-existing capacities and helping to identify suitable, available and practical capacity-building options. Avoid pre-packaged ideas and strategies – what works for one community or individual may not work for another. Work to develop capacity-building activities that are well planned and integrated into the priorities and goals of those involved. Take opportunities to respond to capacity development needs during the project – either directly or indirectly as an advocate.

Although you and your research colleagues are working to build the capacity of others, you are developing you own capacities as facilitators, mentors or trainers. These are valuable skills.

This advice fits well with Indigenous health research values. It applies whether a research project is large or small, multi-site or local, urban or rural, or whether you are a member of a large research team or a single researcher.

Remember – from little things, big things grow…

Capacity-building checklist for researchers

The following CRCAH checklist was designed to help researchers think about capacity building when planning a research project.

❑ Does the project promote and involve Indigenous contributions and leadership in each stage of the research?

❑ Are Indigenous individuals and industry representatives effectively engaged in the research process?

❑ Are there opportunities for scholarships, traineeships and/or professional development for Indigenous people?

❑ What are the training needs of the project team, including the training needs of Indigenous industry representatives to effectively engage in the research and training needs of researchers to work in an Indigenous context?

❑ Does the project help an organisation or community bring about change/ improvements? For example, supporting Indigenous organisations to understand and use research data to improve services.

❑ Does the project identify, demonstrate and evaluate how the health system can be improved? For example, by contributing to government policies on how research data is collected and used by health services (adapted from CRCAH 2006c:3).

Work to develop capacity-building activities that are well planned and integrated into the priorities and goals of those involved

Capacity-building stories

The Lowitja Institute has collected some great best practice in capacity building case stories. The following four stories present a variety of settings, needs, approaches and outcomes.

Case story – Developing capacity and community training through an action research project

The Mending the Broken Spirit research project was conducted through the Institute for Aboriginal Development in Alice Springs. Project leader **Debra Maidment**, an Arrernte researcher from Artekerre outstation, about 80 kilometres out of Alice Springs, worked with **William Jungarrayi Wright** and **Doug White**. They used action learning and participatory research methods to find out what people thought would be the best way to improve their health and education outcomes, and to develop an Indigenous curriculum based on local priorities.

Debra had observed that even educated Aboriginal people are still very much a part of the high mortality and morbidity statistics, and struggling to obtain employment and a good quality of life. She was concerned that the younger generation in the town camps of Alice Springs are coming from poor environments not conducive to learning, and struggling to learn in the mainstream. Also that people on outstations were feeling disempowered about being unable to get the resources they needed to improve where they lived. Debra and her co-researchers wanted to find out what people thought would improve their health and education outcomes. They used interviews and workshops to consult with people in three homeland communities and with relevant Aboriginal stakeholders around Alice Springs.

During our consultations… the Elders and people on the outstation… kept saying; 'Well, how can you educate anybody if you don't look after your roots, if you don't look after your history… your identity? That's when we came to the metaphor of the Artekerre Tree, to develop a curriculum (Debra Maidment).

} For the full case story (including the 'Artekerre Tree Metaphor'), see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Case story – Mentoring emerging Indigenous researchers to present at a conference

In 2008 **Paul Stewart**, **Ngarra Murray** and others at Onemda VicHealth Koori Health Unit worked with 11 Indigenous health workers to help document and present their unique community health programs at the *2008 From Margins to Mainstream: 5th World Conference on the Promotion of Mental Health*.

The health workers aimed to share some of the positive ways in which local Indigenous community organisations are working together to build a healthier community, and to demonstrate how cultural and community activities can contribute to better health outcomes.

Ngarra Murray was engaged by Onemda to run the project:

Aboriginal health workers are often too busy actually 'doing the work' to contemplate presenting at a conference, and certainly most are unable to find the time to work on abstracts or presentations. All of the Aboriginal presenters who took part are known for their enthusiasm and dedication to their work and commitment and advancement of our communities. This project was a perfect opportunity for Onemda to work with our community health workers on preparing presentations that would allow them to share the excellent programs done in our communities…

Leadership is about confidence. There is a leader in all of us but sometimes we need to be given opportunities and support.

part b: doing research that makes a difference
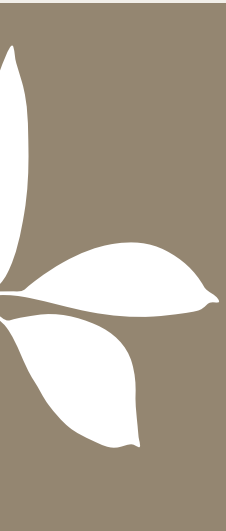
Paul Stewart and
Rachel Reilly

Belinda Briggs was a program participant:

I participated because it helped our mob to be the experts that present on a subject that we know best about, as opposed to non-Aboriginal presenters. Our points of view are personal and not just work; it's our very livelihoods and makes our messages that we want mainstream Australia to hear stronger!

Paul Stewart was a mentor and project leader:

It's about giving [participants] the opportunity, the confidence and just the tools to be able to get up there and talk in front of a large audience about what they do… We negotiated with the organisation, as well as the participants, about taking people out of the workplace [for workshops]… aspects of support [included] the support process to get people there in the first place, and to build the confidence to present, but also supporting each other at the conference.

Rachel Reilly was a mentor in the project:

Mentoring was an opportunity to be involved in some capacity exchange, and to build stronger relationships with a community that I already work with. I knew Belinda before the conference and was aware of her work…

} For the full case story, see the Lowitja Institute website (www.lowitja.org. au/case-stories-researchers).

} A film, *Sharing Our Stories and Building on Our Strengths*, and project report is available on the Onemda VicHealth Koori Health Unit website (www.onemda.unimelb.edu.au/multimedia/film.html).

Mibbinbah men's camp.
Photo: Mibbinbah Ltd

Case story – Mibbinbah Indigenous Men's Project, an action research project centred on capacity building

The Mibbinbah Indigenous Men's Project is a participatory action research project that aims to understand the factors that make Indigenous Men's Spaces safe and healthy places for men, and how this might benefit families and communities. The project is based on principles of community development and empowerment. Seven Men's Sheds/Spaces are involved, with local Indigenous men employed as Project Associates/researchers. The joint project leaders are **Jack Bulman**, Mibbinbah CEO, and **Rick Hayes** of La Trobe University.

Participatory action research methods are being used to collect data about which types of Men's Sheds/Spaces are most likely to lead to better health, especially for chronic diseases; to identify what enables and hinders men to support each other in learning new skills and taking leadership roles to promote wellbeing; and to follow through so that the research findings are translated into learning activities and health actions. **Jack** talks about how the project methodology develops capacity:

Through collaborative work with institutions and organisations, Mibbinbah is aiming to assist and find new pathways for Indigenous males to be able to take their rightful place in society, whatever that may be, and then this way we can begin to change the way research is thought of both now and in the future.

We need to recognise that the men are already doing research each day as they seek to understand and solve their problems for themselves and with their communities.

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

part b: doing research that makes a difference

AimHi research leader
Tricia Nagel (left)

AimHi researcher
Carolyn Griffin (right)

Case Story – Developing a mental health research team, community resources and training

The Australian Integrated Mental Health Initiative (AIMhi) Northern Territory project was a five-year multi-site project that aimed to improve outcomes for Indigenous clients of mental health services in remote Top End communities. The project developed mental health promotion resources for health professionals, clients and carers, and new approaches to service delivery.

It aimed to build capacity at several levels: training Indigenous mental health researchers; developing the capacity of residents and service providers to manage mental illness; and improving the mental health literacy of community residents and service providers. The program has continued as the Aboriginal and Islander Mental Health Initiative. Research leader **Tricia Nagel** talks about capacity-building:

When training the Indigenous team members, we started at the beginning point and said: 'What is an Indigenous researcher? What are the tasks and capacities and the competencies that you want to build?' From there, we've developed a framework that helps us to know what the components are…

Indigenous researcher **Carolyn Griffin** talks about developing resources for mental health literacy:

The mental health storyteller mob consulted with a range of non-government and government organisations in the first 12 months of the AIMhi project, including health boards and land councils. We visited remote communities hundreds of kilometres from our base in Darwin – Kalano, Nguiu, Groote Eylandt, Yirrkala, Numbulwar, and a wide range of urban services… We worked with local Aboriginal Mental Health Workers to develop mental health stories…

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Reflecting on capacity building

The capacity-building case stories describe a variety of activities and opportunities within Indigenous health research projects. Although the stories tend to focus on the capacity that research participants have gained, all involved in research projects have a lot to gain. This is another example of reciprocity in ethical Indigenous health research.

It is important to reflect continuously on the mutual learning and capacity building that happens throughout a research project.

Both participants and researchers may not recognise… when or how they have begun to change – to know something new or to be able to do something differently – unless there is critical reflection on the research process. It can also be empowering to participants when researchers acknowledge that they are learning from them, and from the experience of being involved in the research (Lyn Fasoli, Batchelor Institute of Indigenous Tertiary Education, Northern Territory).

Plan opportunities to:

- reflect on the research processes: ask, 'what have I learned from others?', 'what have I learned from the research processes?'
- share views on learning with team members and research partners/participants
- record this learning – include it in project reports
- share what has been learned with others.

Work to develop capacity-building activities that are well planned and integrated into the priorities and goals of those involved.

Key messages for researchers

- Capacity building in Indigenous health research includes the building of sustainable skills, structures, resources and commitment.

- Capacity needs to build on what already exists. It focuses on strengths and opportunities.

- Health research projects can help to build individual, group, organisation, partnership and/or community capacity, as well as research capacity and other capabilities needed for community benefit and health improvement.

- The best capacity-building strategies are developed through consultation and collaboration with learners, are designed realistically around people's resources, priorities and needs, and are properly supported.

- Capacity building is two-way. Take time to reflect on what you have learned and what you are doing differently as a result of being involved in the research. Share and celebrate these gains with others.

part c:
designing and managing a successful research project

Indigenous health research projects can be planned and conducted in ways that take into account the Indigenous health research environment, develop productive relationships and support Indigenous control, and build in knowledge exchange and capacity development.

Setting the research question involves:

- working on issues that have been identified as priorities by Indigenous people

- finding out what is already known about the research topic

- making contacts and getting support early in the process

- working with stakeholders to frame the question in a way that matches identified priorities and can lead to useable research outcomes.

Planning a successful project involves:

- awareness of other research and work on the research topic

- getting input from others with an interest or suitable expertise

- working collaboratively with research partners

- accurate planning for resource needs, and realistic timeframes

- using a range of processes to get the plan right

- setting up structures and procedures for good project management.

Collecting, managing and interpreting data involves:

- awareness of data ownership issues, and intellectual and cultural property rights

- developing culturally safe processes and resources for informed consent of research participants

- careful consideration of confidentiality issues, especially in Indigenous community settings

- awareness of the issues that are specific to being an Indigenous researcher researching Indigenous health

- strategies to ensure valid data, such as adapting methods to local circumstances and working with an Indigenous language interpreter

- steps to protect records of Indigenous knowledge and to work safely with culturally restricted information

- being aware of issues concerning use of data collections

- processes for including local knowledge and community perspectives when interpreting data.

Good reporting and dissemination methods involve:

- applying what is known about the factors that support knowledge exchange to the way information is shared

- up-front planning and resource allocation – different methods and products are needed for different audiences

- reporting to stakeholders, especially community, throughout the project

- understanding the concerns and language of target audiences, so that reporting methods can be designed for maximum impact and take-up of findings

- accessing the expertise of non-researchers when deciding on dissemination methods and developing products

- being aware of ethical issues and procedures when using images, artwork, music and digital media in research products.

Part C sets out steps for designing, conducting and reporting robust, culturally appropriate research that meets the needs of the research reform agenda and has the potential for practical research outcomes.

chapter 7:
setting the research question

This chapter and the next draw on the advice in previous chapters and set out practical steps for designing a robust project that upholds Indigenous research values and has the elements needed to make a difference. The focus of this chapter is on developing the research idea and building a strong foundation from which to plan a successful project.

Develop the idea – what, why, who and how?

There are many possible starting points for a health research project. You may be asked to do the research, or you might form the idea. The research idea might come from the concerns of community members, service staff or others. It may aim to fill a gap in knowledge about a health issue. It might come out of another research project, where findings lead to more questions that need answers. It may come from who you are as an Indigenous person seeking change for your community. The research idea might be specific to one site, or be widely relevant.

No matter where the idea comes from, the initial questions will be similar.

Questions to ask about your research idea

1. What is this research about and why does it need to be done?

2. Has anyone else done this research?

3. What difference will it make? Who will benefit?

4. What is the research issue that is most important to this community or organisation now?

5. Is there a manageable contribution that my research can make? (If the answer is 'no', it might mean rethinking the site and proposed partners, or the whole research idea.)

6. What are the benefits from this research? What are the risks?

7. How can I/we make the research relevant, robust, acceptable and useful? Who needs to be involved or informed? How will we work together?

Research values

8. Do I/we understand what Indigenous research values mean in practice?

9. Are we prepared, as researchers, to share control?

10. Am I/are we prepared for the Indigenous community, group or organisation to suspend the research, or stop it altogether, if it is not meeting ethical and cultural standards (NHMRC 2006:17)?

How the research will be done – approach and methodology

11. What is the research question we are asking?

12. What type of information are we collecting?

13. How will information be collected?

14. How will information be analysed?

15. How will knowledge exchange be built into the research?

16. What are the general rules for how we conduct the research (e.g. cultural respect protocols)?

What is already known?

The next step is to find out what is already known about the proposed topic. Mainstream research courses and resources cover how to search for published literature relevant to your topic. Published literature includes books, journals, media articles, reports, conference papers, theses, transcripts, audio and film clips, and other formats. A research supervisor can give direction and advice about what to look for, and how to appraise the quality and reliability of information. Library staff can help you through the practical steps. When drawing on literature, strategies can be used to privilege Indigenous voices.

When choosing written texts to discuss colonisation and Aboriginal experiences of health care, I have devised a hierarchy of texts that prioritised those written by Aboriginal authors, then those written collaboratively between Aboriginal and non-Aboriginal authors, and then those written by non-Aboriginal people that are considered an accurate account by Aboriginal co-researchers and mentors (Kelly 2008:19).

In Indigenous health research, specific issues are likely to influence your search for what is already known. They are:

- the recognition that you do not need to 'reinvent the wheel'

- the value of grey literature and oral histories

- the importance of Indigenous knowledge

- dataset reliability.

Do not 'reinvent the wheel'

This is an important issue in a research environment where many feel 'over-researched' for little benefit, and where there is an urgent need for research that can help to close the health gap.

We cannot justify researching questions to which we already know the answers, or questions that satisfy professional interests rather than real needs. For example, why test a biomedical treatment in one population, when the answers are known in another? Why assume there has never been a local project to develop diabetes education, when diabetes has been a concern for decades? Why rule out the usefulness of a resource because it was developed 10 years ago?

Not respecting work that has been done before can make people weary and cynical. Be rigorous in finding out what is known about your proposed research subject and what has been done in the research setting, or in similar settings. One comment made by Indigenous ethics committees is that they see many similar projects being submitted for approval, especially by postgraduate students and often from the same university (e.g. in diabetes research).

So make sure your research will be new, or will build on previous research. Don't just rely on published resources, but track down old records and people with long memories. Ask:

- 'can you remember a similar study in the past?'

- 'do you know of anyone who has researched this topic?'

- 'have you seen anything new on this topic?'

- 'who else should I ask about this?'.

The value of grey literature

Grey literature is literature that is not published. Examples are theses, in-house reports, discussion and working papers, fact sheets, brochures, conference papers, media releases, oral history and film footage. Grey literature can be valuable when designing research, and as data.

The Indigenous health sector is rich in grey literature. Changes of government and policies, departmental restructures, high staff turnover, scattered services, changing agendas and priorities in Indigenous health all result in a lot of good work going unpublished and being put aside.

Grey literature helps to avoid 're-inventing the wheel'. It offers research that has not been peer reviewed and other relevant work. It can lead to helpful contacts and experts. It can tell you about past services, events, community consultations, recommendations and resources you might not hear about because people have moved on, forgotten, don't realise the information is relevant or assume the information is already known.

To find grey literature:

- contact government departments, community-based organisations, universities and research centres, community sources and special interest groups

- ask program and services staff, community groups and other researchers

- search library collections and archives

- use Internet search engines such as Google Scholar

- search the Australian Indigenous Health*InfoNet*

- search clearinghouse websites, which collect, analyse and put up topic-specific information, research, resources and links

- use networks, ask people, follow up suggestions

- use the old-fashioned search tool – the telephone: you may need to phone three or four people to find what you are looking for, but it is often worth the effort.

} See Chapter 5, 'Using Research for Change', for a list of health information clearinghouses.

Case story – Searching for grey literature

Researchers **Peter d'Abbs** and **Sarah MacLean** needed to draw heavily on grey literature when they wrote two overviews about the available information (literature reviews) on inhalants: *Petrol Sniffing in Aboriginal Communities: A Review of Interventions* (2002) and *Volatile Substance Misuse: A Review of Interventions* (2008).

We used a range of strategies to gather literature… Searches were conducted at libraries with relevant specialist collections and through online databases (d'Abbs & MacLean 2002:65).

Peter and Sarah explained:

Our approach was in part systematic: we identified all the agencies that had formal responsibility for dealing with alcohol and drug issues and the research institutes, and wrote requesting assistance. But it was also in part a matter of following leads wherever they emerged – from our own knowledge of people and programs in the alcohol and other drugs field, as well as from individuals who had been working in relevant areas, and who sometimes knew of a report that had been written by so-and-so.

The authors contacted more than 30 organisations as part of the literature search. They included drug and alcohol services, youth accommodation and support services, Indigenous health services and community-based intervention programs, and Indigenous health or drug and alcohol sections in State and Commonwealth government departments. Repeated contacts were required to get responses from some agencies.

In 2006 the Commonwealth Department of Health and Ageing engaged the researchers to update the review, which was expanded to cover other volatile substance misuse. Where the earlier version focused only on Indigenous people, the updated review included interventions with non-Indigenous people.

Once again we found that – while a limited amount of material had been published in refereed journals and other readily accessible sources – much of the potentially useful material was still confined to unpublished sources. We needed to repeat the earlier approach, contacting relevant organisations. By this time the Internet had become a far richer source of unpublished reports and evaluations. Electronic databases were searched, alongside Google

part c: designing and managing a successful research project

Oral histories

Oral history is an important source of information about Indigenous experiences and knowledge. It records people's memories, traditions and opinions first-hand, using the spoken word – a powerful tool for transmitting Indigenous culture for more than 50,000 years. It is only since colonisation that Indigenous Australian history has been recorded in writing.

The National Library of Australia has a website that brings together thousands of oral histories from collections across Australia. State and municipal libraries and museums also hold oral history collections, as do many local organisations and groups, universities and individuals.

} The National Library of Australia's oral collections can be searched via the Internet (www.nla.gov.au/apps/ohdir).

The importance of Indigenous knowledge

There may be extensive Indigenous knowledge about the research topic. This knowledge (and its custodians) may be essential to project success, even if it is not central to the research question. Use your networks and local contacts to ask about Indigenous knowledge that relates to your research idea and to determine the key people to talk to.

Access Indigenous cultural materials through collections such as:

*   AIATSIS Library and Audiovisual Archive of materials on Aboriginal and Torres Strait Islander culture, history and societies (www.aiatsis.gov.au/collections/library.html)

*   oral history collections

*   publications by researchers of Indigenous knowledge

*   catalogues of publishers with a specific Indigenous focus, e.g. Aboriginal Studies Press (www.aiatsis.gov.au/asp/docs/200910AcademicCatalogue.pdf).

Think about what this knowledge will mean for your proposed research. How will it influence methodology? How will Indigenous and Western research traditions come together? Who needs to be involved?

Dataset reliability

Health data collections impact on research design. Chapter 1 of this volume discusses the lack of reliable and consistent health data about Indigenous Australians. Datasets have critical implications for planning a research project because they may impact on:

- research design

- time and resources needed

- feasibility of the study

- ability to compare data across time and place.

The lack of reliable health data about Indigenous Australians is caused by incomplete and inconsistent Indigenous identification. Identification relies not only on whether Indigenous status is collected with other data, but also on whether people self-identify. Willingness to self-identify as Indigenous differs according to whether people see it as an advantage or disadvantage. For example, a family may identify at a health service established to serve Indigenous people but may not identify at a childcare service that is open to everyone if they fear they may be discriminated against (Madden & Al-Yaman 2003:8). This is understandable, given our history of racism, but it results in inconsistencies between datasets.

In a recent study in Victoria, data custodians were asked to identify barriers to obtaining information about a person's Indigenous status.

The three responses selected most often [from a list] were:

- *Indigenous person may not feel comfortable declaring their status;*

- *Administrative staff fear a negative response to the question being asked; and*

- *Administrative or medical staff may feel that the question is irrelevant* (Heffernan, Sheridan & Freemantle 2009:16).

Fundamental national reporting in areas such as life expectancy, hospital morbidity and disease prevalence [is] compromised… The extent and even nature of health problems, particularly in more urbanised Aboriginal populations, may be under-reported and even overlooked. The related issue is that there is a substantial bias in reporting toward remote (well-identified) Aboriginal populations and so that, for example, the life expectancy of the NT Aboriginal population may be misrepresented as being common across all Australian Aboriginal populations (Steve Guthridge, Director, Health Gains Planning, Northern Territory Department of Health and Families).

These factors mean that available data about the health and wellbeing of Indigenous populations reflect different reporting methods and data sources, varying data quality and different clinical details. Similar issues apply to data about education, employment, childcare and so on.

} You need to be cautious about using the knowledge from datasets to inform research design. See Chapter 9, 'Collecting, Managing and Interpreting Data'.

} Over the past decade there has been progress in the quality and availability of statistical information about Indigenous peoples. Resources developed to guide service sectors and researchers are listed on the Lowitja Institute website (www.lowitja.org.au/resources-researchers).

Are other people interested in the research question?

Whether you are proposing a project as sole researcher or a team, a student or a career researcher, whether you are Indigenous or non-Indigenous, you will need support from others to develop a project.

The type of research being proposed determines the stakeholders. For example, you may need input from a peak body with interest in the issue (e.g. childcare, mental health) or to collaborate with others who have researched in the setting or topic. No matter who else is involved, it will be difficult to get past the research idea unless you have support from the Indigenous sector.

To take the first step towards community consultation, you may need advice and support from:

- peak Indigenous organisations (e.g. NACCHO affiliates)

- Indigenous research ethics committees

- local Indigenous organisations and other service providers who can provide contacts

- researchers with relevant experience

- research, health, family and community networks to make useful contacts

- Indigenous colleagues, if you are non-Indigenous. Talk about the research idea and the best approach (but don't assume that your colleagues can, or should, open doors for you).

Indigenous peak bodies are experienced in representing the diverse and sometimes conflicting interests of the people they represent, and in interacting with outside agents (Cunningham & Dunbar 2007). However, they are often under-resourced, which may limit how much practical help or brokering they can do.

Refer to peak body websites for staff roles and partner organisations. Some suggest steps for consulting with Aboriginal community groups, for example:

- the Victoria Aboriginal Community Controlled Health Organisation has an 'Advice to researchers' web page (**www.vaccho.org.au/resources/resources_advice.asp**)

- the Ethics Committee of the Aboriginal Health and Medical Research Council of New South Wales provides advice on 'Developing an application – obtaining Community support' (**www.ahmrc.org.au/Ethics%20and%20Research.htm**).

- the Aboriginal Health Council of South Australia provides a research checklist, which includes a section about community involvement (**www.ahcsa.org.au/media/docs/ahrec_info.pdf**).

} The way you approach an Indigenous organisation or group to talk about the research will determine your success: be open, listen, take advice. See Chapter 4, 'Relationships in Indigenous Health Research', for how to introduce yourself.

Community partners may need extended time to make a decision about being involved in a research project. Several visits or meetings are often needed.

A lot of consultation with communities [doesn't] leave enough time for people to think about what was said, or how the ideas fit into people's lives.

Yolngu people don't like it if they're expected to make a decision too quick… and people in communities need to talk to the people in outstations to find out what they think… It could take weeks or even months. They need that time to think about it really hard and then, they'll come together and have a community meeting. Traditional leaders need to speak from each tribe, to listen to what the others think. They like people who can talk to the mainstream to be the spokesperson.

So a better way [for authentic consultation] would be to make 3 or 4 visits to give people time to identify important issues and think together about what is important. Sometimes visitors will just talk to the people they know and that work for them, but they find it hard to tell you something you don't want to hear. When consultation is 'one-off' and 'too much information' people's minds are listening but they can't think about it at the same time. Only later will they reflect on what they have heard and think about what that means (Alison Wunungmurra in SNAICC 2010:10).

Before community stakeholders agree to work with you on a research proposal, they need to know:

- who you are and what organisation you represent

- whether you have the skills and integrity to do the research or, if you are a student or new researcher, whether you have expert supervision and support

- why you have approached a particular community, service or organisation

- which other communities or organisations have been invited to participate and whether they have concerns and, if so, what those concerns are and why (NHMRC 2006:17)

- whether you are aware of issues, priorities and sensitivities in the community (e.g. service needs, governance or programs that might impact on, or be affected by, the research)

- how the community can be involved: what is the scope for negotiation? What are your assumptions or expectations about this?

- whether there is scope for the project to build local capacity: will there be opportunities for local people to work on the research team and get training/qualifications (NHMRC 2006:17)?

- which ethics committee or committees will be approving the research and the names of the committee contact people (NHMRC 2006:17).

Alwin Chong

Case story – Making contacts and getting support

Alwin Chong is Senior Research and Ethics Officer at the Aboriginal Health Council of South Australia (AHCSA). He explains the steps a researcher can take when approaching a community to find out if a research idea is acceptable and to get community input.

We have a good example – a researcher from Sydney who wanted to do research in Ceduna. Francesca Panzironi had initially communicated with the Aboriginal Health Service in Ceduna about the proposed research, which would involve looking at the use and role of ngangkaris [male or female traditional healers] in health care services. The service directed her back to us for ethics approval and we were able to work through the major issues that needed addressing before commencing the research: these included Francesca introducing herself to the community, explaining her project, describing how the research would benefit the community, working with services to recruit participants and having a feedback process.

I explained she needed to write letters to the peak Aboriginal health bodies in Ceduna seeking their support. The CEO of Ceduna Koonibba Aboriginal Health Service wrote back and said, 'That's a great idea because Ceduna is doing that with the hospital. We have all these issues around that topic, so if you can actually do some work and help us, that would be great.' So she said, 'Well, if I come over for a visit would you be able to introduce me to some other people?'

Francesca met with the health service and they introduced her to the hospital. They went to other services, like mental health, and they talked about what she's doing with her research. They all agreed that it would be good for the town. After getting agreement she said, 'The next thing I need to do is talk to clients who may have had that experience'. 'Well, okay, you need ethical approval.' So she got a letter of support from this mob, came to us, got ethics approval and then sat down with the services, and said, 'Well, you pick out some clients that I would like to talk to, who could help me understand what are some of the barriers and some of the enablers about this issue'.

This research has the potential to promote and advance the knowledge, understanding and utilisation of a specialised service provided by ngangkaris, which will raise its profile and encourage broader acceptability by mainstream agencies. This is because the researcher approached the community in the right manner, obtained ethical approval from the appropriate bodies, informed the Aboriginal community about the project, achieved active participation and established a feedback process to participants before the final report is completed – this project has positive outcomes on many levels.

Francesca Panzironi

Francesca Panzironi talks about her experience of developing the research idea into a project. What came out of the process was a collaborative project involving Aboriginal health care services, ngangkaris and mainstream health service providers. The project aims to document the role and use of ngangkaris in health care agencies and to inform policy development in South Australia. Francesca works as a lecturer in the School of Social Sciences and International Studies at the University of New South Wales.

The research proposal could not have been developed without the support, insights and inputs of community members and health professionals I met in Ceduna and the advice I was given by AHCSA. At that time I was looking at international and national documents dealing with the recognition and inclusion of Indigenous medicine in different countries, as part of my PhD study in law. I was shocked that Indigenous medicine in Australia was not even mentioned in these documents. I asked myself, 'How it can be possible that more than 40,000 years of Aboriginal knowledge of healing practices and remedies have been omitted, forgotten or deliberately set aside from the international and national Indigenous health agenda?'

I decided to search some answers at the community level. I am a non-Aboriginal person and foreign to this country, and I wasn't sure whether it would be appropriate for me to undertake research in Aboriginal health. This is when I made contact with Mr Tauto Sansbury, former CEO of Ceduna Koonibba Aboriginal Health Service (CKAHS), to talk about my ideas. I had heard that ngangkaris were requested and accessed through CKAHS. We chatted over the phone and Tauto invited me to visit the health service in Ceduna. Tauto welcomed me and took me around to see the country and meet different people in the community, at the hospital and other health services.

Talking to Tauto and other community members and health professionals in Ceduna has been the keystone for the development of my research proposal. When people said, 'Yes! We want ngangkaris in town to help us healing', 'It is hard to access ngangkaris in town and demand by Aboriginal and non-Aboriginal people is increasing', I decided to craft the research proposal according to what people were saying. Talking to them, listening to their views determined the aims and key issues of my research project. They helped me to take the right directions, including the need to contact the AHCSA for ethics clearance, so I arranged the first meeting with Alwin Chong, who explained the process to gain ethics clearance and approval by AHCSA.

The consultation in Ceduna has been critical not only to understand and follow the right protocol… but also and foremost to build what I consider to be the heart and soul of this project: the web of relationships and trust between the participants and the researcher. People have connected me with key stakeholders and health professionals of other communities and Aboriginal health services across SA.

While the research proposal has set the foundations of the research project, it is the consultation processes that continue to shape the research agenda, priorities, and outcomes. The participants are the keystones of the research process: without them this research project would not exist.

Getting the question and scope right

All successful research projects need the right *questions* – questions that are specific, feasible, can discover something new, can be answered in an ethical way and so on. What you will do (and will not do) as part of the research is the project's *scope*. Indigenous health research has specific criteria for questions. Research questions should:

- be relevant to real needs

- have input from Indigenous people involved

- be acceptable to Indigenous research participants and users

- lead to research methods that are culturally safe

- give answers that can be applied to the work of improving health outcomes.

As the 'Making contacts and getting support' case story shows, the best way to achieve the aims of getting the question right and scoping the project is to involve research users.

The most common pitfall at this stage is that emerging researchers pose questions that are too 'big' and make the scope of the project too broad. This is understandable. Most Indigenous health researchers know that health issues are complex and urgent. They are highly motivated and keen to make a difference. Although these are strengths, they tend to result in over-ambitious project proposals.

Sometimes the most valuable help an experienced researcher can provide is help to narrow a project so that it is manageable and realistic.

Talking to [the community], listening to their views determined the aims and key issues of my research project. They helped me to take the right directions...

Considering the outcomes

Think ahead to the research outcomes. Because the aim of research is to produce knowledge that can improve services and health, you need to go beyond questions such as 'what will the research find out?' to ask:

- what can be done with what is found out?

- what positive, lasting changes may happen as a result of the research (benefit and sustainability)?

- how can we plan for knowledge exchange?

- is there potential for the project to build capacity and how can we plan for this?

- What are the short-term outcomes and benefits for these partners/ participants?

} For information about these questions, see Chapter 5, 'Using Research for Change'; Chapter 6, 'Building Capacity through Research'; and Chapter 10, 'Methods for Reporting and Dissemination'.

Our project is real for the health services. It gives them the chance to work as a clinic team [using a quality improvement framework] to come up with strategies that will help the clinic achieve best practice targets in sexually transmitted infections control.

We are making changes to the patient information systems that will enable communities to collect data relevant to their population in the area of [sexually transmitted infections], and after we've left, that system will be still there. We've really got to think about our research and what it is that we're going to leave those communities – they'll still struggle after we've left, but they'll have tools (James Ward, Program Manager, National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales).

Key messages for researchers

- A strong foundation is needed for a robust research project.

- The need to close the health gap means research questions need to be new, and offer real benefits.

- Indigenous knowledge, grey literature and oral histories are important sources of background information for research design, while datasets are often unreliable.

- Indigenous stakeholders need to be involved as early as possible.

chapter 8:

planning the project

This chapter sets out practical steps for designing a successful project that upholds Indigenous research values and has the elements needed to make a difference. If you follow the steps in this chapter and document what you do, you will have the information needed when the time comes to write your research proposal. Grant application guidelines, university research guidelines and your project leader or supervisor can help you adapt the information to meet the criteria and proposal format required by a particular funding organisation or university.

What do you bring from your own background and discipline?

Are you studying public health, sociology or economics? Are you more familiar with quantitative or qualitative techniques? Are you an experienced Aboriginal Health Worker, a skilled facilitator in cross-cultural work, or just out of university and have never set foot in an Indigenous community setting? We all bring our personal experiences, and the theory and practice of our discipline or work, to the research. We bring our motivations, goals, values, strengths, flaws, characteristics and skills. We bring our cultural backgrounds and approaches.

Cultural background, in particular, can influence how we understand knowledge, truth and reality – 'what we know' and 'how we know it'. As discussed in Chapter 1, Indigenous and non-Indigenous people, or different Indigenous groups, tend to have different ways of seeing knowledge and how it is made. The term for this is *epistemology*.

All research carries an epistemology. It helps to inform the theoretical framework (or paradigm) – the connected ideas and theories that establish there is something to be investigated – and tells us there is a feasible way to approach it. The theoretical framework is the foundation of any research project and usually relates to a researcher's field or discipline (e.g. biomedical, sociological). It guides the questions we ask, what we measure, what data relationships we will look for and so on.

In summary, your background, epistemology and theoretical framework are 'where you are coming from' in the research. They help to decide the literature you read, the approach, methodology and study design – all of which help decide the best methods for collecting and analysing data (e.g. surveys, interviews, focus groups, observations, experiments).

} See Chapter 3, 'Indigenous Frameworks and Methods for Research', for frameworks developed by Indigenous scholars.

How have other projects approached this type of research?

This question is about other people's research approaches in *Indigenous settings*. Search for Indigenous health projects that have things in common with your own (e.g. similar health issues, settings or population groups) and bring the lessons learned to the design process.

When asking how other projects have approached this type of research look at:

- approaches that have been acceptable and most successful

- how other researchers worked with various stakeholders – what factors led to success or to problems?

- how others resolved ethical concerns raised by the project design (e.g. you predict that a clinical screening project will identify many new cases that need treatment. You are aware that the local health service is already overstretched and will not be able to meet an increased patient load. How will you resolve this?)

- the research team (or researcher), in particular, skills and roles – how do successful intercultural teams give priority to Indigenous voices, and learn and work together?

- the timeframes – when people say a project needs a long lead-in time for consultation and negotiation, and flexible timelines to allow for local priorities and events, what does this actually mean in weeks, months, years? How do experienced researchers calculate the extra time needed?

- which methods have provided valid data from a similar participant group in that type of setting – do you need to adapt methods for cultural safety? For example:

  » telephone surveys are unlikely to work in a research environment where researcher–participant relationships really matter, where many residents are not listed in telephone directories and where language can be a barrier

  » group interview techniques may need to be adapted in some settings; for example, Indigenous group discussions often aim for consensus, while you seek to record a range of views

  » a strong oral tradition in many Indigenous cultures means that narrative or storytelling approaches may be useful to collect, enrich or validate qualitative data

» Indigenous culture favours collective responsibility and approaches to problem solving – are one-on-one interviews/consultations always necessary for your research? Should a participant have the option of inviting another person?

- how all settings, participant groups and topics have their own characteristics and norms that influence methods

- similar scope projects that included capacity building strategies – this information is unlikely to feature in mainstream health research publications

- how similar projects built in knowledge exchange (think beyond reporting and dissemination, and look at change) – contact the researchers and ask how they planned for knowledge exchange. Ask what did and didn't happen, and why.

Experienced researchers designing a Victorian study wrote about the cultural differences they took into account when developing a questionnaire:

We were aware that the use of questionnaires is problematic in the Aboriginal community. Questionnaires are often associated with officialdom. In the past being identified as Aboriginal by officials often had serious consequences, including removal of children, so that Kooris often respond to requests for information with fear, distrust or anger. Some Kooris may not read well enough to understand and answer the questions, but may be reluctant to say this to an outsider and so complete the questionnaire by guessing. Kooris tend not to like to refuse a request, especially from another Koori, so may complete a questionnaire quickly, especially if they do not understand the purpose of the study. During consultations young people were in favour of a questionnaire programmed on lap-top computer rather than on paper (Holmes *et al*. 2002:1270). *One reason for a computer questionnaire was more sense of privacy – young people felt safer to respond honestly about sensitive health issues. Anonymity can be a challenge in a closely connected community.*

} For information about research relationships and communication strategies, see Chapter 4, 'Relationships in Indigenous Health Research'.

How do other people think the research might be done?

Many academics and researchers who might advise you about the research are not Indigenous. This means you need to take steps to make sure there is strong Indigenous input at the planning stage, especially when planning methodology. This is critical if you are not Indigenous.

Many of the people who need to be involved in designing Indigenous health research projects are not researchers. The skills and approaches needed to engage them may be different from those you use when working with other researchers.

Many of the people who need to be involved in designing Indigenous health research projects are not researchers.

Case story – Getting input from others with an interest in the research

In this case story, people were brought together to share expertise and ideas before helping to shape a research plan. This approach gave people a professional development opportunity while building ownership and support for the research.

The Cape York Institute (CYI), based in Cairns, has been developing strategies to reduce smoking rates in four Cape York communities. The strategies aim to change individual behaviour and build a consensus that smoking is damaging and non-acceptable, a social norm already achieved in many parts of Australia. The CRCAH and the Centre for Excellence in Indigenous Tobacco Control… supported CYI to develop ideas into a research proposal.

In August 2008, a one-day roundtable was organised to bring together staff from CYI with key experts on Indigenous tobacco control and Indigenous health. Researchers and experts presented information to CYI staff, about tobacco control programs, the impact of smoking, and evidence about what interventions have and haven't worked in Australia. In the second half of the day staff talked about what is currently happening in Cape York communities around smoking and what strategies they would like to implement. Having tobacco control expertise around the table gave staff direct feedback on how to best implement their strategies and guided their thinking on interventions likely to have the most impact.

Since the roundtable a research proposal has been developed to establish baseline data and commence community education campaigns; focus on teenagers and family members as change agents; enforce the idea that smoking in homes around children is unacceptable (CRCAH 2009:23).

Getting community input for project design

There are many ways to engage a community in the design of a project; for example, meeting with people in community centres, services and workplaces, calling public meetings, approaching community leaders and relevant interest groups, and using focus groups to help identify issues that will shape the research.

part c: designing and managing a successful research project

Case story – Talking up the research: forum and follow-on consultation

Indigenous researcher **James Ward**, Program Manager at the National Centre in HIV Epidemiology and Clinical Research at the University of New South Wales, explains how researchers talked up a large multi-site project. A long consultation and planning phase proved successful, with more communities asking to be included.

A real trick for researchers is how [to] engage with the amount of health services that we wanted to engage with [particularly in remote areas], without having any funding… We'd submitted once, it didn't get up and the main critique from the NHMRC was 'not enough community engagement'. The way we did it the first time was to say, we've spoken to the Department in the NT and the Aboriginal Medical Services Alliance Northern Territory… and sought their in-principle endorsement. But really it isn't enough…. You've got to have engagement with communities before applying for a grant. I think that's number one, it can't be a totally researcher-driven agenda, it has to have the perspectives of the health services and communities within your research project.

For the [second] application, we said the only way we're going to get engagement was to bring everyone together. So we held a community forum for two days in Alice Springs to get their perspectives on this study before the grant application went in. Fifty-five people from community-controlled and government health services came, and they were the right people – we really targeted the audience. We got clinic managers, CEOs where possible and board members. We set about to explain why we were applying for this funding. We talked about the rationale, the processes, how it would work for communities, how it might fit in with their current practice, and [we broke] down the stigma associated with research and a randomised trial. People got to know who we were.

After the forum we gave a feedback report to all the participants. Sure enough, the grant got up. From then on we have kept them in the loop. After we got the grant, we applied to Ethics Committees for one year of consultation with communities…

Initially we said we'd have 21 communities, but Queensland and WA asked to come into the trial. So we extended our consultation and what's happened now is that over 60 communities have signed on. And I think that's really down to this consultation and planning phase. It's almost two years of consultation since we got the grant and soon we will start our intervention. If you add on the year before that, when we got knocked back, it's three years of consultation. We will run our intervention for the next three years.

} Some processes for getting community input are described in the Aboriginal People Travelling Well project. For information about the project, see the Lowitja Institute website (www.lowitja.org.au/crcah/aboriginal-people-travelling-well).

Community representatives may be new to research planning. They bring different skills, work and education backgrounds, cultural backgrounds and life experiences, and different attitudes towards research and researchers. This diversity brings rich input. It also brings scope for miscommunication. People have different ways of processing information and communicating ideas, such as through visual images, writing, storytelling, singing and dancing. To make the most of input:

- follow local protocols for research planning (e.g. peak bodies, hospitals and services may have guidelines)

- give clear information about the research (e.g. background, purpose, approach, progress of plans)

- give adequate information for people to make informed input

- use presentation tools and language that suit the audience (e.g. avoid academic terms with non-researchers, but don't 'dumb down' information)

- get people's ideas and visions flowing around a theme or issue by using techniques such as brainstorming, drawing and mapping ideas on diagrams

- be in tune to the different and subtle ways people might offer suggestions and feedback (e.g. telling stories about other projects without comparing directly to yours)

- explain what will happen to people's ideas and information: if they get translated into research jargon and end up looking different in the proposal, people may think they have not been listened to

- keep people informed.

Case story – 'Visual mapping' as a design tool

In this case story, project workers used a visual mapping process to create a community plan for using research findings. The process can be used to map a research project.

The Galiwin'ku Healthy Lifestyle Program is a broad community-based intervention that started as a research project. The Menzies School of Health Research negotiated with the community to collect baseline data about diabetes and cardiovascular disease. Researchers worked with local health workers to conduct a health screening, which included a questionnaire about lifestyle. Questions were asked about food, exercise and so on.

The screening and questionnaire got people thinking. Community representatives went to the researchers to talk about what the community wanted from the research – a program that could promote a healthy lifestyle in a holistic way using the local cultural framework and values.
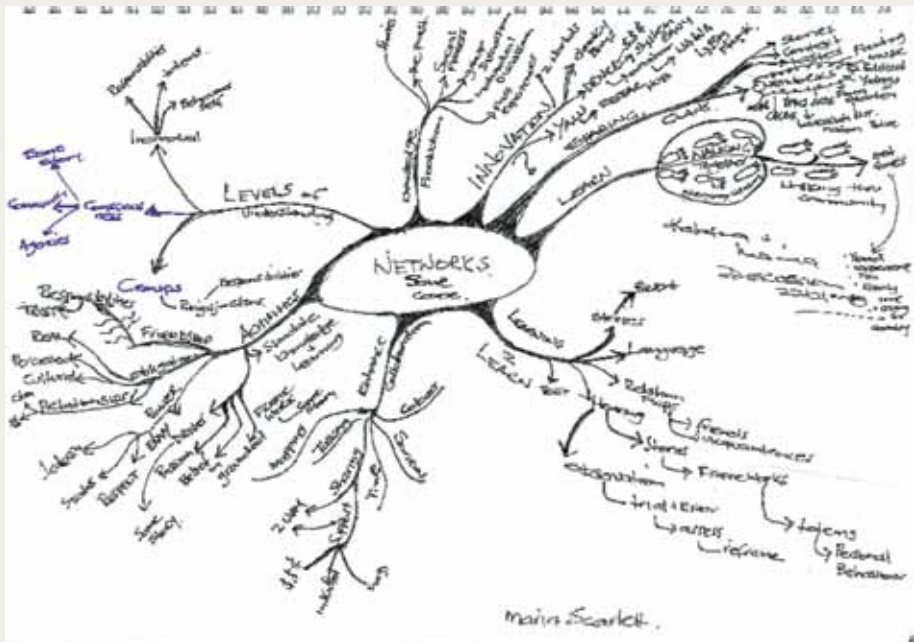
'I worked up a picture of how I understood the connections between the groups'.

As outside researchers we needed to make sure we truly understood and followed the conversations. We were working within different cultural frameworks and a lot of the talking was in language. I started to draw as I listened because this is how I learn best. I worked up a picture of how I understood the connections between the groups. Then I showed my drawing to the women and asked if I had understood correctly. Other people got involved in the drawing and it grew from there (Maria Scarlett, Project Officer, Menzies School of Health Research).

} For the full case story of the Galiwin'ku Healthy Lifestyle Program, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

What resources are needed to do the project?

In Indigenous health research special factors impact on the resources needed. Traditionally, not all resource costs are funded by research grants. Check the funding guidelines.

Consultation, negotiation and ongoing engagement processes need to be properly resourced. Capacity development can add major costs (e.g. salaries, training delivery, paid study time, resource development, site supervision visits), as can knowledge exchange, the extended timelines needed for collaborative approaches and the engagement of interpreters, cultural consultants and/ or cultural mentors. Research in rural and remote communities often involves costly long-distance travel and multiple trips to work around participants' availability and local events.

Projects need to be conducted in ways that are culturally acceptable and have the best chance of delivering the outcomes. Cutting corners/costs can compromise these priorities.

It is also important not to rely on the resources of community-based services (e.g. staff, vehicles) when conducting research. This can burden already over-stretched frontline organisations.

Case story – Consider all resources needed for a project

Paula Arnol, CEO of Danila Dilba Biluru Butji Binnilutlum Health Service in Darwin, talks about the need for a realistic budget and detailed costing.

Researchers need to tell us up front what resource allocations they're going to need. Often the research dollars aren't enough but because researchers are in our services and we've made an obligation to the patients we get left with it – we get half way through a research project and we're robbing Peter to pay Paul. So we make them talk through and think through exactly what is involved.

So when they say, 'We'll have focus groups', we say, 'Okay, that's great. Who's going to pick people up? Have you got funding for organised transport? Have you got funds and facilities in terms of providing lunch? Have you planned the venue, where are you going to meet?' That can become an issue when it falls back as a cost to our service. Or if we don't provide transport and nobody comes, then it's a reflection on us.

[For larger projects] we will always insist that they ask for funds for someone who's located within our service, or if it's interstate research, someone who acts as a connector or 'go between' here. If it's a national project then we want a body on the ground who is managing that… a [liaison person] with a partner organisation is fine, but we just want one contact person who's here, local.

Researchers also need to make sure they've got contingency money for unexpected expenses, even just to pay local people for on-the-spot advice, cultural advice. Otherwise that's something that our organisation will have to bear.

There are many places researchers can get help to identify resource needs and funding sources. Often this help is closer than you think. Find out if there is someone in your organisation or university whose job it is to find grants and help with applications (e.g. HR department, Indigenous development unit). Look beyond your own workplace to research centres, peak bodies and services that work in Indigenous settings.

Resources checklist

When working out resource needs, think through all steps that are required to make the research happen:

- who will do what, with whom, how, where, for how long and how often for each phase of the project

- work roles, the number of people, and types and levels of expertise

- the products that are to be developed

- the cost of managing and supporting project activities (e.g. venue hire, sitting fees, travel to advisory group meetings)

- direct costs (e.g. salaries plus on-costs such as leave loading and superannuation, consultancy fees, equipment, travel, consumables, laboratory services, software, reporting costs)

- indirect costs (e.g. rent, power, water, communication networks)

- in-kind or unfunded support: put a value on support provided by research partners, such as staff time in project meetings, administrative support, space, and use of telephones and vehicles.

When you estimate the budget:

- involve research partners in working out resources needed

- use the budget pro forma of your research institution or funder to estimate project costs

- to help justify the budget, do a separate break-down of capacity development and knowledge exchange costs

- build in contingency funds – it is easy to underestimate needs (including time)

- get an experienced research leader and/or manager to talk through resource needs and check estimates.

Avoid reducing the project budget beyond what is feasible in order to have a competitive grant application – you will end up with a poor project. And be prepared to seek funds from more than one source to cover all parts of the project (e.g. scoping funds for consultation).

Getting the plan right

When you have gathered information, looked at similar projects, involved others in planning and worked out resource needs, you will be ready to finalise the project design. Decisions need to be made about research processes, project structure and management, formal partnerships need to be agreed, the proposal needs to be written, and ethics clearance sought. Getting the plan right involves exploring options and negotiating details. Accurate and detailed record keeping will pay off when written agreements are drawn up.

QIMR's Gail Garvey at a Lowitja Institute Cancer Roundtable

Using a quality assurance workshop

The CRCAH developed a quality assurance approach to refine research design. Under this approach, copies of a proposal for a research project are given to reviewers from different sectors who are asked to comment on the project's scientific quality, feasibility and importance in Indigenous contexts, likelihood of achieving outcomes and potential to build capacity. Unlike a traditional (usually anonymous) peer-review process, review is open. Importantly, reviewers are also brought together with the researcher/s to workshop the proposal, talking through issues to make the proposal the best it can be. Although some researchers find this face-to-face process daunting, most appreciate how much it helps to make a project workable, stronger and more robust.

In addition to testing the research idea and bringing different perspectives into the proposal, the process has other benefits, such as:

* linking people who work on the same health issue but don't normally meet (e.g. when health, welfare, education and housing workers discuss a proposal about social determinants of health)

* two-way exchange and learning: research users have an opportunity to tell researchers what will be most useful to them, and researchers can share findings from related studies

- time efficiency

- forming relationships with research users even before the project begins

- participants becoming 'champions' for the research.

You do not need a large-scale project, or the resources of a large organisation, to organise a quality assurance workshop. It can be a small, local meeting but it does need to bring together diverse stakeholders and be carefully planned and well facilitated.

How to plan a quality assurance workshop

1 **Decide what you want to come out of the workshop – the outcomes**

Will it develop a research idea, evaluate a draft proposal and/or take it to the next level of project design?

2 **Decide who needs to participate**

Who is needed to achieve the outcomes? What expertise and advice are needed? Think about all stages of the research, including capacity development and use of the findings.

- Who are the research stakeholders?

- Who are the experts in this area of health and research?

- How will cultural and community perspectives be represented?

- Who can speak for people at the site (if decided)?

- Who will be invited to join a management or advisory group?

- Which institutions or organisations are hosting and managing the research?

- Who will use this research? Who are we trying to influence (e.g. policy makers)?

- Are there other people whose support is needed to get the project up?

3 **Arrange a facilitator**

An important roundtable principle is that all participants have equal status. The facilitator needs to manage the process in a way that gives voice to all viewpoints – community, government, non-government and researcher. The research leader is not usually the best person to facilitate the process.

- Who will be record keeper?
- Is a co-facilitator needed?

4 **Plan the agenda and processes**

People process information and communicate ideas in different ways. This needs to be taken into account when presenting and feeding back information. Everybody needs to feel culturally safe, valued and able to contribute – especially those who are out of their comfort zone. Plan to:

» discuss 'rules of engagement' at the beginning of the workshop

» present information in a variety of formats

» enable people to put forward ideas in a variety of ways (e.g. pictures, stories)

» allow plenty of discussion time

» get written consent to use photos in project materials (if relevant)

» record information (e.g. filming, audio, note taking)

» provide feedback and follow-up after the workshop.

5 **Arrange resources**

- Work out what resources you need: for example, whiteboard; butcher's paper, pens and masking tape; DVD player and television; computer and projector; camera).
- Ask other presenters what resources they need.
- Write a checklist.
- Check equipment, and how to use it, before the workshop.
- If possible, arrange 'sitting' fees for community members who are not attending as part of their job.

6 **Arrange venue and refreshments**

- Write a checklist of what is needed for a suitable venue (e.g. disabled access, toilets, seating and table/s, space, lighting, Internet access) and refreshments.

- Provide lunch at a full-day meeting if possible (this keeps sessions on time, and keeps people focused).

7 **Send information to participants before the workshop**

People need time to think about the research and collect relevant information.

8 **Follow-up after the workshop**

Send participants:

- a meeting report and a thank you letter

- a new or revised research design

- updates (e.g. when funding is granted).

People who have undertaken to provide more input may need deadlines and reminders.

Whatever processes you use to get input, you will need to be realistic in your expectations of people outside the research team, especially those who volunteer their time. Keep an open mind about when and how a person gets involved. A key person who is unavailable at the ideas stage may want to help fine tune the plan or join an advisory group.

Getting agreement on the plan

Whether or not you have brought stakeholders together to refine the research design, you will need agreement on the research plan from the organisations, groups and services involved as main partners. In-principle agreement may be needed from organisations that represent the Indigenous sector (e.g. peak bodies). Specific parts of the plan will need agreement from different stakeholders – both the knowledge exchange and a capacity-building plan will need agreement from the community. If you are a student researcher, you will need agreement from your supervisor.

How you approach this step depends on the scope, the partners and the processes that have gone into shaping the project. It is good practice to have a written project agreement between a research team (or researcher), community or other partners. This is separate to the legally binding agreement with the funder.

> *Although not legally binding documents, [project agreements] provide a written record of the expectations and commitments each person and each organisation has and can be useful in avoiding or resolving disputes. The principles on which the agreement is based should include a statement to the effect that 'Aboriginal peoples have a fundamental right of ownership over their own knowledge and information' as well as detailing processes for consultation, collaboration and communication throughout the project* (Pyett, Waples-Crowe & van der Sterren 2009:53).

The written agreement should include details such as:

- the project plan and timeline

- what the budget includes (e.g. salaries, equipment, travel etc.)

- in-kind contributions from the community or organisation (e.g. staff time, use of facilities, other expenses)

- training and employment arrangements

- the Human Research Ethics Committee contact person

- the informed consent process with participants, and how confidentiality will be protected

- agreements about storage, ownership and use of data (see next chapter)

- what happens to biological specimens after the project

- recognition that negotiation needs to be ongoing through the project and open to scrutiny

- the criteria for renegotiating, suspending or stopping the research

- arrangements for overseeing the project

- project management structures (including community feedback arrangements)

- likely outcomes of the project

- intellectual property rights/copyright of published results and how contributors will be acknowledged.

(Adapted from NHMRC 2006:21; Pyett, Waples-Crowe & van der Sterren 2009:53; AHCSA n.d.)

Do not start the research before each partner has signed the agreement/s.

} A sample research agreement, prepared by the World Health Organization, is available on the International Indian Treaty Council's website (www. treatycouncil.org/about11.htm).

Planning for project management

Management arrangements vary according to the type of project, scope, host institution, research partners and site. As explained in Chapter 4, most Indigenous health research projects are guided by an advisory group or steering committee that represents the research stakeholders. Some projects need more than one group for different management roles, and many Indigenous health research projects have an Indigenous reference group to help manage the project. At the very least, a management group needs strong Indigenous membership.

To avoid confusion, the title used for the group should reflect the role and decision-making power of the group. That is, a steering/management group 'runs' or directs the research, and an advisory group guides, rather than directs, the research team.

Some projects have more than one management group, with different roles (e.g. clinical guidance, community guidance). Group members may represent community or government partners, practitioner or research groups, or have individual expertise and knowledge. Don't automatically assume, however, that every research project needs an advisory or management group. Many community leaders and managers are already overburdened in these roles, and it may be that existing management structures and processes in a research setting can meet project advice needs.

Planning an advisory group

Sometimes advisory groups are already in place when a project starts. More often, a research application states that a project advisory group is planned.

...most Indigenous health research projects are guided by an advisory group or steering committee that represents the research stakeholders.

> *Researchers are often quite anxious about who should sit on such a committee and how to ensure it is representative of the relevant community. In our experience, we have found it useful to begin by identifying two or three Aboriginal stakeholders and ask them to nominate a range of representatives from relevant organisations or communities. At the first and possibly subsequent meetings, the members can be asked if they feel there is anyone else who should be invited to join the steering committee. However, too many changes in committee membership can introduce conflicting advice, so it is advisable to establish a consistent membership early in the project* (Pyett, Waples-Crowe & van der Sterren 2009:51).

An Indigenous community representative may struggle to have a voice in a group with a majority of non-Indigenous members, or may not have authority to represent the wider community. Membership and meeting processes should take these factors into account.

The terms of reference need to set out the intended work of the group, with sufficient detail, and ensure responsibilities and decision-making powers are clear.

> *Although the [peak bodies] and government departments are not the people we're working with on the ground, they represent the services we're working with. We set up a governance arrangement for the trial that includes people from [various departments and peak Aboriginal organisations]. The Executive has eight members and it's a very workable, practical group that meets twice or three times a year. The Executive signs off on protocol, on making sure that progress is happening, and has the ability to stop the trial if it doesn't work – providing overall strategic direction to us as the investigators. I don't mean 'tick the box' sign off, we really have meaningful engagement* (James Ward, Program Manager, National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales).

Consider factors like how often the group will need to meet and report at different stages of the project, the cost of bringing people together, and whether members are selected for individual skills or to represent an organisation.

Sue Moore (researcher) with reference group members (L–R): Catherine Jacka, Gail Garvey and, seated, Vanessa Clements. Absent, Sandra Angus

Case story – Planning and managing a study across Queensland

In 2006 researchers from the Indigenous Health Research Unit at the Queensland Institute of Medical Research conducted a biomedical study comparing cancer stage at diagnosis, treatment and survival of Indigenous and non-Indigenous people treated in the public health system in Queensland. The study found that Indigenous Queenslanders had poorer survival rates than other Queenslanders, despite similar proportions being diagnosed with late-stage cancer. Prior to this it had been assumed that Indigenous people were diagnosed much later in their disease progression, when the disease was more difficult to treat.

Meetings and discussions were held with Indigenous groups across Queensland as part of the research transfer of these findings. As a result of these meetings, it was felt that further investigation was required to ascertain the reasons for differences in survival.

Researcher **Suzanne Moore** and **Gail Garvey**, Coordinator, Indigenous Health Research Unit, describe the process used to ensure there was Indigenous input and management in the follow-on study.

The [Indigenous Health Research Unit] invited Indigenous health professionals working in the area of cancer care to… discuss the viability of conducting a study to investigate this further. The group consisted of Indigenous Health Workers from the Royal Brisbane and Women's Hospital, the Indigenous Cervical Screening Unit, and the University of Queensland General Practice,

Inala, representatives from the Queensland Aboriginal and Islander Health Council and several other agencies from around south-east Queensland. The proposal for a new study was outlined and a non-Indigenous PhD student who would undertake this project was introduced to the group. After discussion, recommendations were made and the proposal was endorsed in principle by the group. An Indigenous Reference Group was then established…

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

} For advice about managing your relationships with a project management group, see Chapter 4, 'Relationships in Indigenous Health Research'.

Applying for ethics clearance

Most health research has to be approved by an ethics committee before you start any fieldwork. This is needed if you are doing research that involves people as participants in the research, or if the research will have a direct impact on people. The job of an ethics committee is to consider all ethical issues that may arise from the way in which the research is to be conducted.

A research proposal often needs approval from more than one Human Research Ethics Committee (HREC); for example, a university ethics committee, and a hospital or government department ethics committee. A proposal to conduct health-related research involving Aboriginal people or communities also needs to be submitted to the State or Territory Indigenous Health Research Ethics Committee.

} For information about ethical research principles, see Chapter 2, 'Principles in Indigenous Health Research'.

The job of an ethics committee is to consider all ethical issues that may arise from the way in which the research is to be conducted.

Frequently asked questions about ethics applications

1   **Will my research need ethics clearance?**

If the research project involves clinical or epidemiological research, data linkage or data release, health services or population health research, or qualitative research you will usually need ethics clearance. If it is submitted through a university system or research institution, you will usually need ethics clearance.

If you are collecting ideas and information to plan a local health promotion project, or an in-house evaluation of the service you provide, you may not need ethics committee approval. Of course, ethical responsibilities still apply to the way you do the research.

2   **Where do I find relevant ethics committees?**

The NHMRC publishes contact details for HRECs in each state (www.nhmrc.gov.au/health_ethics/hrecs/hreclist.htm).

HRECs that have Indigenous members are listed by the Indigenous Health Ethics Network (www.indigenoushealthethics.net.au/hrec).

3   **How do I figure out which HRECs I need to get ethics clearance from?**

Identify the most obvious HRECs. They will be the:

- HREC of your university or place of employment
- Indigenous HREC in your State or Territory
- HREC of your research discipline or specialisation if relevant.

To find out if you need clearance from them:

- go to the websites
- send an enquiry to the secretary or executive officer
- ask each committee which other HRECs are likely to be relevant to your research
- ask your supervisor.

4 **What do I need to include in the application?**

Refer to the website of each HREC for the information each requires. Most will ask for at least:

- a completed ethics application form (available online)
- evidence that you have done a review of relevant literature and are aware of similar research on the topic
- a brief statement addressing criteria such as Indigenous community consultation, community benefit and Indigenous research values
- a copy of approval letters from other HRECs
- letters of support (or a signed consent form) from relevant Indigenous bodies such as Indigenous community-controlled health services
- a summary of the research protocol
- *pro forma* consent forms for individual participants
- information sheets to be given to potential participants, and other relevant materials (e.g. survey questions).

Telephone each HREC for advice about your application if necessary.

5 **How long will it take to get clearance?**

The time taken to get clearance varies – some HRECs meet every month, some every three months. Find out when committee meetings are and work around deadlines. Be prepared for the process to take some months if a number of committees need to assess your proposal.

You may be asked for more information before clearance is given. This could happen more than once, and by more than one HREC.

} The Aboriginal Health and Medical Research Council of New South Wales and the AHCSA provide online resources for applicants (www.ahmrc.org.au/Ethics%20and%20Research.htm; www.ahcsa.org.au/content/research-ethics).

Completing an ethics application form

There is a National Ethics Application Form (NEAF), which is based on the *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 2007) and other NHMRC ethical guidelines.

The NEAF aims to be easy to understand and fill out, and to 'streamline' ethics approval. The same form is used by most HRECs in Australia, and takes you through a set of questions that help you think through the research project. When you create an account online, step-by-step guidance text assists you in filling out the form. You can work on your application, save it online and come back to it many times until you are ready to submit. You can invite other team members to add their sections to the e-file.

Specific questions relate to research that involves Aboriginal and Torres Strait Islander peoples. If you have gone about negotiating and planning the research in the right way, the answers will be descriptions of who has been involved, the processes used to engage partners, what has been agreed in terms of the research processes and data ownership and so on, and community benefit and plans for using the research.

} Information about NEAF is available at the NEAF website (https://www. neaf.gov.au). *Pro forma* applications are available to guide researchers on the types of questions that may be asked when working through an application. A *pro forma* for research involving Aboriginal or Torres Strait Islander people can be downloaded from the NHMRC website (www. nhmrc.gov.au/_files_nhmrc/file/health_ethics/ahec/neaf/neaf-proforma- application-research-involving-aboriginal-torres-strait-islander.pdf).

E: neafassist@nhmrc.gov.au
T: 1800 823 993

Like other planning tasks, writing an ethics application can be collaborative. At the least, your application needs letters of support from any community organisations involved in the project. A letter of support from a peak body alone will not be enough, unless it is clear that this organisation has consulted and is passing on community approval.

Writing about Indigenous values

You may be asked how the research will address Indigenous research values when you apply for ethics clearance.

If you reflect on the values of spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility from the beginning, and build them into your negotiations and expectations, it will be easier to write about how the research meets these criteria. Many health researchers negotiate research

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in culturally acceptable ways but think of the Indigenous criteria in ethics applications as something separate. If you can avoid this way of thinking, negotiations and proposal writing will come together more easily.

For example, many researchers sit down with community partners to plan the project but don't think about this as being 'equality'. When Indigenous knowledge and ways are respected in the project, all research processes are open to scrutiny and Indigenous stakeholders have rightful ownership over their intellectual property, then the project supports 'spirit and integrity'. Training opportunities, paying people for sharing their knowledge, and project resources that stay in the community are examples of 'reciprocity'.

} See Chapter 2, 'Principles in Indigenous Health Research', for the six values that guide ethical research in Indigenous health.

Before you submit the ethics application

- Check that you have met every requirement of a committee.

- Ask a research leader with a track record in Indigenous health research to review your application.

- If you are a student, the application needs to be signed off by your supervisor. Make an appointment to go through the draft proposal and ethics application together.

Ethics committees are not there to knock back research. They support research and assist where they can. However, one of the problems faced by ethics committees is that they find themselves coaching students through research proposals, when coaching is not their job (Maria Scarlett, Secretary, HREC of the Northern Territory Department of Health and Community Services and Menzies School of Health Research).

Writing a grant application

The best base for a grant application that reflects the needs and realities of working in an Indigenous health context, in ways that are culturally safe, is real engagement with Indigenous research partners. There are no short cuts.

The structure of your grant application will need to follow the headings and format required by the funder or institution. Avoid borrowing from other applications with a 'copy and paste' approach. This is not good practice – it is unlikely to paint a true picture of your project and is obvious to funding assessment panel members who see many similar applications.

Ask a successful grant applicant (in Indigenous health research) to read the proposal and give you feedback.

The NHMRC criteria for funding Indigenous health research – community engagement, benefit, sustainability and transferability, building capability, priority and significance – set the benchmark used by other funders.

If you uphold Indigenous research values, and follow the steps outlined in this chapter (and Chapter 7), you will cover what the funders of Indigenous health research want to see in a grant application. The Lowitja Institute and other Aboriginal and Torres Strait Islander health research organisations feel strongly that researchers should work in this way to develop research proposals, whether funders ask for it or not. This is because these criteria and processes are true to the Indigenous research reform agenda.

When Indigenous knowledge and ways are respected in the project, all research processes are open to scrutiny and Indigenous stakeholders have rightful ownership over their intellectual property, then the project supports 'spirit and integrity'.

Project design checklist for researchers

❑   Are you clear about the question, methodology, outcomes and scope of the project?

❑   Have you searched for relevant literature, information and research?

❑   Have you identified community partners?

❑   Have you negotiated with community?

❑   Do you have letters or evidence of support?

❑   Have research methods, data management and reporting been agreed by community partners?

❑   Have you identified and negotiated with other research partners?

❑   Are you clear what resources are needed for the project?

❑   Have resources been committed to the project?

❑   Do you have agreement from relevant services and community groups?

❑   Do you have community agreement on a knowledge exchange plan?

❑   Do you have community agreement on a capacity development plan?

❑   Do you have an advisory or reference group?

❑   Have you applied for ethics clearance?

❑   Do you have a detailed project plan?

Key messages for researchers

- The more you involve Indigenous stakeholders in research project design and planning, the more likely you are to have a feasible project with useable outcomes.

- There are many effective ways to engage community and other partners in research planning. Collaborative approaches often work well.

- Good project planning in Indigenous health considers benefit, sustainability and knowledge exchange, capacity building and adequate resources for culturally acceptable and robust research processes.

- Put time into gathering background information, seek advice from others with relevant expertise, work through ethics and grant application procedures in a systematic way.

- There are no short cuts when planning the project.

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chapter 9:
collecting, managing and interpreting data

Methods for collecting and analysing data are included in all courses that teach research skills. This chapter identifies specific data issues in Indigenous health research that have not been raised in earlier chapters. It explains legal and ethical obligations in data collection. It offers tips for good practice on the ground when managing intellectual property and confidentiality, using informed consent processes, working with interpreters, and collecting and interpreting data.

Data ownership and intellectual property

Ownership and control of information and knowledge are important in both Indigenous and non-Indigenous cultures. In Australian law, rights to ownership of information are referred to as intellectual property (IP) rights. Rights to the IP that goes into, or results from, Indigenous health research need to be established before collecting data.

IP is difficult for most researchers to understand fully – and even more difficult to manage with confidence. The difference between Indigenous approaches and Australian laws about the ownership and control of knowledge complicates an already complex issue. However, understanding IP issues in Indigenous health research will help you understand the principles of IP more broadly.

Researchers need to respect the IP rights of *all* people participating in research. Certain protocols must be followed to use and acknowledge IP. Authorship and copyright of any published materials should be determined with full respect for, and acknowledgment of, the origins and source of knowledge.

Intellectual property in Australian law

Intellectual property refers to things that people have created on the basis of their ideas and creativity and which exist in some material form. Examples of IP are original thoughts and ideas that are written down in papers, reports or books, made into sound, film or video recordings, or put into other media. IP in general is something new, unique, distinct and original.

Under Australian law, IP can be owned and traded (bought and sold). IP rights are the rights held by the owners or holders of IP, which are created and protected by law. These laws particularly protect the use or misuse of IP in relation to commercial gain or advantage; that is, the laws are largely about the right to make money from IP use.

The laws can only protect something in physical form, which means information needs to be written down, filmed or recorded in some other way. IP can only be held by individuals (singly or jointly) and cannot be held collectively. IP rights only exist for a limited time (DKCRC 2007a) – usually 70 years after first publication, depending on the form of publication (e.g. book or film).

Copyright is one type of IP law. We are most familiar with copyright in relation to books and music. Copyright exists from the time an idea or creative work is put into a material form. An example of how copyright operates is the way that 'ownership' of copyright in the songs of The Beatles was able to be purchased by Michael Jackson. That meant that each time a song by The Beatles was played or reproduced, a small payment would be made to Michael Jackson as the owner of that copyright. Illegal or 'pirate' copies of music or films are examples of IP law infringement – in such cases the owner of the copyright is not receiving the payment or recognition to which he or she is entitled.

Under the *Copyright Act 1968 (Cth)*, the copyright owner of a research report that includes traditional knowledge can end up with the exclusive right to reproduce, publish, broadcast, translate or adapt it, or give consent for others to reproduce it. The copyright owner may be the university that employs the researcher, or the agency that commissions the research. The researcher holds the moral rights to be named as author (Janke 2009a:11). However, by taking care to clarify ownership and rights of use, IP agreements can ensure proper and respectful treatment of Indigenous knowledge.

Indigenous cultural and intellectual property rights

Indigenous lawyer **Terri Janke** is an international authority on Indigenous Cultural and Intellectual Property (ICIP). After extensive consultations with Indigenous Australians, she compiled a list of ICIP rights (Janke 1998:47–8).

Terri Janke

Based on this list, Indigenous people have the right to:

- *own and control Indigenous cultural and intellectual property*

- *ensure that any means of protecting Indigenous cultural and intellectual property is based on the principles of self-determination*

- *be recognised as the primary guardians and interpreters of their cultures*

- *authorise or refuse to authorise the commercial use of Indigenous cultural and intellectual property according to Indigenous customary laws*

- *maintain the secrecy of Indigenous knowledge and other cultural practices*

- *be given full and proper attribution for sharing their heritage*

- *control the recording of cultural customs and expressions, and the particular language which may be intrinsic to cultural identity, knowledge, skill and teaching of culture* (Janke 2009b:11–12).

These rights should be used to guide health research.

The focus of Indigenous protocols around the ownership and control of knowledge is different from that embodied in Western law. Where Western law focuses on private ownership, commercial gain or loss, and material items, Australian Indigenous laws generally focus on group custodianship (rather than ownership), with knowledge handed down through family lines and only when a person is ready to take responsibility for it. Knowledge is often not recorded in a material form, but passed on orally.

The Copyright Act provides very little protection for Indigenous culture. It fails to recognise communal ownership or the way Indigenous cultures, stories, information and knowledge are passed orally from generation to generation. Because Australian law is inadequate in this respect, it falls on the ethical integrity of researchers, and the IP policies of research institutions, to make sure that ICIP rights are upheld in research. AIATSIS publishes the following advice for researchers:

PLEASE do not include in your Informed Consent Form a clause stating that indigenous people 'retain' 'intellectual property rights' in 'indigenous knowledge'. This is misinformation: the law recognises no such rights in knowledge which has not been converted into a material form, scientific discovery etc. (AIATSIS Human Research Ethics Committee n.d.:8).

You can honour your responsibility to those who pass on Indigenous knowledge by:

- following your institution's IP policy relating to Indigenous knowledge: if there isn't one (and there should be), raise awareness of the need

- explaining copyright and ownership to research participants in plain words

- considering shared authorship when appropriate, and respecting it by; for example, asking permission before presenting participants' stories in academic forums

- using copyright notices in publications to tell readers that there are also customary laws governing the use of content.

An example of using copyright notices in publication is how the Arabana author and academic **Veronica Arbon** used the following notice, in addition to the standard copyright notice, in her book *Arlathirnda Ngurkarnda Ityirnda: Being – Knowing – Doing: De-colonising Indigenous Tertiary Education*:

> *This publication contains Indigenous knowledge of the Arabana people, in particular the Strangways, Hull, Hodgson and Arbon families, informed by Arabana language, stories and art. All rights reserved. Dealing with any part of this knowledge for any purpose that has not been authorised by the custodians may breach the Copyright Act 1968 (Cth) and amendments* (Janke 2009a:14).

Other ways of upholding ICIP rights are through research consent agreements, sharing of research products and benefits (e.g. royalties), promotion of cultural maintenance by making research available to communities, and archiving data, tapes and field notes (Janke 2009a:18).

} See *Writing up Indigenous Research: Authorship, Copyright and Indigenous Knowledge Systems* (Janke 2009a) for a discussion paper about these issues.

...by taking care to clarify ownership and rights of use, IP agreements can ensure proper and respectful treatment of Indigenous knowledge.

Managing intellectual property in Indigenous health research

IP management in Indigenous health research is still a developing area. The main focus of Indigenous health research is on outcomes that can lead to better health for Indigenous people. The Lowitja Institute, for example, believes that the organisation's IP is best realised through the uptake of research outcomes. Disseminating knowledge widely and quickly can help to achieve health, social and economic benefits for Indigenous Australians.

However, the research environment has particular challenges for IP management. They include the bringing together of multiple research partners with IP interests and use/delivery of practical research products (e.g. work resources, training packages) in addition to protection of Indigenous knowledge. Poor IP management can damage relationships, when it is crucial that partners work together to put findings to use. It is important when designing a project to:

- get help from experienced researchers in Indigenous health to help identify IP issues in your project and the steps to take

- identify any background IP that partners are bringing to the project, and any IP products that will come from the research – will you need to negotiate release conditions or royalties?

- make yourself familiar with IP policy and management within your own institution (universities usually have a research office that deals with IP matters) – does your organisation/university have an IP policy for Indigenous knowledge? What is the university's IP policy for use of students' work? Do you have IP conditions in a scholarship agreement?

- ask research partners for their IP policies – how will they affect your project?

- check IP clauses in research funding agreements (government departments can be particularly demanding about ownership of IP in research they fund) – don't be afraid to question what is proposed and to state your preferences, and make sure you are clear about who will own what

- include IP agreements in research partnership agreements

- include IP and copyright clauses in participant consent forms.

When collecting data:

- always think about the ethical and legal IP rights of participants

- explain IP and copyright carefully

- discuss and check what each person understands (including yourself) before a consent agreement is signed

- encourage people to get independent legal advice about IP issues, especially if a patent application may come out of the research

- ask experienced Indigenous scholars and health researchers for advice whenever you feel unsure about the right thing to do.

} See the *Desert Knowledge Cooperative Research Centre Aboriginal Knowledge and Intellectual Property Protocol: Community Guide* (Orr *et al*. 2009) for more information about these issues.

Informed consent

Free, prior and informed consent from research participants is a right, a standard in international law and essential for ethical research. Free, prior and informed consent means that:

- consent must be given *freely*, without the person being pressured

- consent needs to be given *prior* to starting the research

- the research needs to be explained clearly in accessible language or format, and in enough detail for the person to make a truly *informed* decision about participating.

How much information is needed to be 'informed'? Before deciding to say 'yes' or 'no' to being involved in research, a person needs data collection details, including:

- how the research will benefit him/her, the family or community

- what you are trying to find out (e.g. what helps Aboriginal kids to learn better at school) and what data you are collecting

- where the data collection will take place (e.g. in clinic, on Country)

- how you are collecting it and exactly what is required (e.g. clinical consult, a filmed focus group, one-on-one interview)

- when the research will happen and the time it will take

- what will happen to the data

- what the outputs of the research will be (e.g. book, film), who will own them and who will have access.It is essential the person understands:

- any possible risks (e.g. feeling depressed after talking about grief or trauma) and strategies that have been planned to deal with those risks (e.g. counselling)

- if there is payment or other incentive, and how much

- who is funding and managing the research

- who to contact if unhappy with the way the research is going

- that he/she can change his or her mind about being involved at any time during the research, without consequences

- that involvement or not will not affect their treatment or other relationship with the partner organisation in any way.

Consent forms are legally required when recording people on film or sound recordings.

Many researchers find they need supporting paperwork, such as letters of introduction and lists of 'frequently asked questions' written in plain English, or presented in audio-visual format. Depending on the type of research and risks, supporting paperwork may include debriefing, counselling and referral paths. Participants can be encouraged to think about the information and discuss it with family members, friends or colleagues before making a decision.

} Most researchers give people a 'plain English research statement'. However, the explanation can be presented on a DVD or in a picture book. A sample statement is available from AIATSIS (www.aiatsis.gov.au/research/grants/docs/PlainEnglish2010.dot).

} Research consent forms recognise free, prior and informed consent. Participants sign an agreement that sets out terms, and conditions state that informed consent is given freely. For templates used in Indigenous research, see examples and links on the Lowitja Institute website (www.lowitja.org.au/resources-researchers).

Informed consent in community settings

New researchers are sometimes unclear about consent processes in community settings. When an organisation gives consent to collect data from clients or staff, it is also necessary to obtain consent from individuals to be part of the study.

Although researchers get approval from the organisation and go through an Aboriginal medical service, there's no guarantee… We can provide the space and the place but it's up to the researcher to gain consent and engage the patient, not the organisation (Cyril Oliver, Aged Care Health Worker, Danila Dilba Health Service, Darwin).

Various issues can impact on getting informed consent. Many people are wary of complex forms and the legal risks they may carry. Some are suspicious of researchers and may feel the forms aim to protect the researchers, not the participants. The words *investigation* or *study* can suggest they are being experimented or practised on. Words take on different meanings and associations. For example, health workers advised researchers not to use the word *intervention* with participants in a clinical trial in Northern Territory communities, concerned that the trial might be confused with the unpopular government program. Another complication is that people sometimes have difficulty understanding the difference between clinical research and clinical practice, especially when practitioners are conducting the research.

Consent processes often need to be adapted, especially in remote communities. Disregarding or underestimating local and/or cultural priorities causes offence, so you need to collaborate with communities and households about the consent process they want rather than make assumptions. Local protocols may require decision making to be a collective process involving family leaders.

Participants have the right to take the time they need to decide. It is not unusual for the informed consent process to take several visits.

Experience taught us that, wherever possible, on site people employed by the study should take control of the consent process [in Top End remote communities]. It is often complicated, requiring extended household discussions and negotiations in local language. In many remote communities, as is tradition, individuals are not empowered to give consent for themselves. The communal (household and/or extended family) process may take less than an hour [but] sometimes days or weeks and sometimes several months. Much of the communication may be non-verbal and people from outside cultures are likely to miss subtle but vital cues. When all parties are satisfied, the head of household is likely to convey the outcome, not the person whose consent is sought, and maybe only to an Aboriginal member of the research team (Malcolm McDonald, NT Department of Health and Families, Darwin).

Situations like this can raise ethical dilemmas for researchers. Did every participant understand all the details? Was anything lost in translation? Is the participant giving voluntary consent? Will the participant feel free to withdraw after his or her participation has been agreed to by the household head? Each scenario will be different and your priority is to maintain cultural safety while upholding research ethics. Keep reflecting on your processes. Ask for advice from community mentors and colleagues when you need to.

Consent (or non-consent) may be communicated in subtle ways. Researcher **Dr Brian McCoy** used different forms and processes, depending on the way people communicated their decision to participate in an ethnographic research project in the Kimberley region of Western Australia.

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Participants have the right to take the time they need to decide. It is not unusual for the informed consent process to take several visits.

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During the research trips I offered people a plain language statement outlining the research and a choice of two consent forms in relation to interviews. I also sought individual permissions when I wanted access to particular health records, locally composed songs and paintings that were publicly available but had not arisen from within the research.

As most of the people of the region do not speak English as their first language, I did not wish to pressure people to read and sign a consent document, composed in English, prior to an interview… I was conscious of culturally appropriate ways in which people often express choice, such as leaving a meeting, not attending an appointment, or wishing to postpone an interview. The two consent forms recognised that some might prefer to sign a consent form before the interview; others might indicate their consent by availing themselves for an interview after being present when the issues around the research and importance of choice had been discussed (McCoy 2004:263).

Consent is an ongoing process through the life of a research project. You may need to renegotiate each time you collect data – not formally, but in a way that respects local ways and puts control in the hands of participants.

> *Over the course of our project, it became clear that the consent process was not finished once people agreed to take part and the consent form was signed. Consent required renegotiation at each household visit. Mostly it was non-verbal. Study personnel waited outside on the roadway and, if the head of the household came out to greet the researchers and accept the previous month's results, consent [to proceed with data collection] was implied. Other family members would then appear* (Malcolm McDonald, NT Department of Health and Families, Darwin).

As you collect data, remind a participant about his or her rights in consent:

- the person doesn't have to answer any questions he/she doesn't wish to answer

- you will not write down or record anything unless consent has been given

- you will turn off the tape/stop filming if asked to

- you will not collect/use any bio-specimen unless agreed

- if the person pulls out, he/she decides whether the data already given can be used in the research

- you will need his/her agreement about how photographs or film can be used.

Consent may be withdrawn on a temporary basis or permanently. It is the right of *all* research participants to change their minds at any time (including during an interview), to ask for more information at any time, and to renegotiate the terms and conditions. They should not need to justify why or feel uncomfortable about their decision.

Consent is an ongoing process through the life of a research project. You may need to renegotiate each time you collect data – not formally, but in a way that respects local ways and puts control in the hands of participants.

Developing and using informed consent resources

A Central Australian study by Russell *et al*. (2005) developed the following suggestions for delivering informed consent materials for medical research involving Indigenous participants.

Design

- *Consult widely on the design and content of materials including with: indigenous staff (preferably from the region/s of the participants), health and medical practitioners, language and communications experts.*

- *Ensure that content abides by international [and NHMRC] guidelines.*

- *Identify concepts likely to be unfamiliar and explain them in locally relevant terms.*

- *Enlist the help of local design experts.*

- *Use trained interpreters.*

- *Minimise written text.*

- *Use multiple means of delivering materials: spoken, written, visual.*

- *Use clear, appropriate visual materials – for example, videos, diagrams.*

- *Pre-test the materials.*

Delivery

- *Have an indigenous health worker and doctor or nurse (preferably known to/trusted by the participants) present the materials.*

- *Explain the meaning of 'research'.*

- *Give initial presentations to community organisations, families, and groups.*

- *Plan to make the presentations more than once.*

- *Allow time for discussion and questions at presentations.*

- *Be flexible in regard to presentation setting, time, numbers, etc.* (Russell et al. 2005:494).

Ricky Mentha

Case story – Making a DVD for informed consent processes

The Kanyini Vascular Collaboration is a partnership between the George Institute for International Health, Baker IDI Heart and Diabetes Institute, and 10 primary health care services in Central Australia, New South Wales and Queensland. It aims to identify and overcome barriers to best practice chronic disease care for Aboriginal and Torres Strait Islander people.

Ricky Mentha is an Indigenous Research Fellow at Baker IDI in Alice Springs, and works with principal investigator **Alex Brown**. Ricky talks about making a DVD for use as part of the informed consent process for a clinical trial of a combination polypill.

The team decided to make the DVD… because of the English and medical language barriers… The DVD will be used in conjunction with the traditional means of getting informed consent, where you sit down with a piece of paper and go through it with potential participants…

We wanted the DVD to come from the community, so we collaborated with the Indigenous research team at Tangentyere Council and tapped into their expertise. We basically said, 'We need to inform your community [so people can decide] whether they want to participate in the study. This is the information we want to put in it and these are all the vital ethical considerations. You guys come up with how we go about doing it, who gets involved, what language is spoken.'

We wanted the DVD to come from the community, so we collaborated with the Indigenous research team at Tangentyere Council and tapped into their expertise.

We developed this script… We give a history of the issues we're trying to research and how we can improve access and health outcomes for people, but that we need to study 300 people from Central Australia. Alex Brown gives the background information on the DVD. Then we set a scene up [to show] someone being recruited through the health service… [It shows that] the person can in fact say 'no' and walk away and that recruiting process stops, or 'yes, you want more information', and someone will come and sit down with you and go through the paperwork and explain it a bit more clearly.

We give the information [about] what… we're going to be doing once they've signed up. And [we explain that] people get put into a control group that just stays on their normal medication, [or another group]… who get this new polypill with four medicines in one tablet. And we follow up and do four interviews over an 18-month period… We make the whole research process very clear throughout the DVD.

It's being edited with voice-over into five languages and an English version. We don't know yet – we haven't tested it – but we think the DVD will assist people to make a decision whether they want to be part of the study or not.

} For full details of the Kanyini Vascular Collaboration, see the program's website (www.kvc.org.au/).

Case story – Training community workers to deliver local informed consent materials

Ross Andrews is an epidemiologist, Associate Professor and Associate Director Research and Education at Menzies School of Health Research. He is a project leader for the East Arnhem Healthy Skin project. Ross explains the process of developing and using informed consent materials for a drug trial in the community of Galiwin'ku in Arnhem Land.

Dingupuy Dhäwu flipchart

We initially had a long period of discussions and meetings with the Yalu Nurturing Centre at Galiwin'ku. We went through what we would normally describe as a plain language statement that had all the information we wanted to provide [about the proposed trial]. Yalu then worked with us and with ARDS, the Aboriginal Resource Development Service, to rewrite that research story in consultation with the Aboriginal women's groups and so forth. They used their own story about cycad nuts, which is a traditional story about a process, and rewrote the story on a flipchart. There's a Yolŋu Matha version and an English version and the pictures are the same, just the words are different.

The Healthy Skin Program Community Workers are participating in a training program for a Certificate II in Child Health Research. Out of that they learn about research methods and consent processes. So we had a group of Community Workers come together and provided some training for them to use the resource…

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Confidentiality

A person's right to confidentiality and privacy is fundamental in research ethics and is the responsibility of the researcher. Any personal information shared with you as part of the research must be kept between you and that person, unless it is public or open access information.

Protection of confidentiality needs to be explained as part of obtaining informed consent. Explain what will happen to the data, including:

- how you will protect personal information (confidentiality)

- how the data will be used and who else will see/hear the data (e.g. other researchers, transcriber)

- where raw data will be stored, under what conditions and for how long

- how you will protect culturally restricted information (as relevant). Explain that you are aware that not all stories can be shared – some are public, some are private.

You may need to:

- clarify what information will, and will not, be confidential

- undertake to delete and not pass on private information – sometimes people worry about accidentally talking about things that are private or culturally restricted

- explain what the research products are likely to be (e.g. publications), and how confidentiality will be protected in those products: as a rule, reports and other research products should not include names and other ways of identifying people unless participants have given permission, or they are co-authors

- ask about any concerns the participant has about confidentiality.

Things that need to be considered when protecting confidentiality include de-identification of raw data, secure storage of any data with identifying material, and who has access to the data during and after the project. Steps to protect confidentiality might include hand delivery of data (e.g. interview tape or transcripts) rather than by post or email, consent forms kept separate from data, data stored without names and all materials kept in locked cabinets. Arrangements need to be made for what happens to data after the project. Will it be destroyed, given back or transferred somewhere else for safekeeping? If raw data or research findings are archived, should there be personal information that identifies the participant, and who should be allowed access?

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These decisions do not have to be made at the start of the project. However, you need to undertake to discuss them at a later date. The undertaking should be written into the informed consent agreement.

} A good example of an informed consent agreement is the 'Informed Consent Menu and Template for a Plain English Research Statement' (AIATSIS Human Research Ethics Committee n.d.).

People will not be assured by a written agreement about confidentiality unless they trust you to follow it. They also need to trust the organisation named on the consent forms. It comes down to demonstrating integrity and having good relationships and a good reputation.

In Indigenous health research, maintaining confidentiality and de-identifying data can be difficult where:

- people live in a closely connected community and share long histories

- decisions about who participates are bound up with kinship obligations

- data are collected in large households and outdoors

- unqualified interpreters are used

- you are doing research within your own community and with family members

- you are collecting data from staff in a small workplace.

Methods for data collection can be shaped around these factors. For example, online questionnaires can collect data about sensitive personal issues, and staff can be interviewed away from the workplace. Methods for reporting may need to be adapted. For example, avoid quotes that easily identify the speaker in a community report, and don't describe characteristics that identify the person in a case study (unless people wish to be identified).

Collecting data in community settings

Collecting data in community settings can offer challenges that – while similar to those in any field research – take on more sensitivity in Indigenous settings. This section offers data collection tips not covered in earlier chapters.

Data collection and management are influenced by:

• local networks, family and kinship structures – if you want to do research in a hospital, you need the backing and support of the right people in the hierarchy. Indigenous families and communities operate in the same way to get things done, but the 'right people' are usually determined by local networks, family and kinship structures.

I went to a remote community where the school principal and nurse were in full support of the study. But it wasn't until I sat down with a quietly spoken local, and explained the program, that things started to really flow. Systems fell into place and key people were identified. As well meaning visitors, we don't always know who to talk to and the best way to work with a community (Kylie Tune, Research Assistant, gECHO Project, Menzies School of Health Research).

• local working relationships – recognise the value of your professional networks and the critical importance of good relationships with staff. Local staff and community members can be important partners in recruiting participants, giving advice on the best approaches, and solving problems in data collection.

Janet Kelly (left) and Kim O'Donnell

Researchers **Janet Kelly** and **Kim O'Donnell** are taking this view in their study of people's experiences as patients travelling from Country to Adelaide for health care. When collecting data, they speak to Aboriginal Health Workers (staff interviews) and then to patients and carers (patient journey interviews).

We have renewed existing networks to seek advice about ways to approach people – Elders or specific stakeholders we should visit in organisations, communities and towns. We use chance encounters… and strike up conversations at meetings and events to expand networks and relationships. We make phone contact prior to visits and arrange times that suit local people and organisations, and arrange to stay for two to three days in each place.

On data collection visits we meet informally first over morning tea or meals, at community events or health clinics; it gives people opportunities to 'check us out' in spaces they feel comfortable. If possible we help with local tasks, (e.g. set up for meetings, confidential debrief of local issues). We always ask if there are other people we should meet (e.g. managers, staff and community members) while we are visiting and we are open to opportunistic conversations and interviews that may connect us to other people. When meetings or interview schedules are changed or cancelled by participants/organisations it's important to accept them positively and arrange other tentative times and dates that suit local schedules (Janet Kelly and Kim O'Donnell, Flinders University).

Practical issues in community settings

People may move frequently between remote communities and large towns where there are more services, or between family houses in a community. Families might move seasonally between outstations and towns. Strong family ties and networks support this mobility.

Population mobility was taken into account when researchers designed a study of the epidemiology of acute rheumatic fever in three remote Indigenous communities in the top end of the Northern Territory. Rather than following up each enrolled individual for a prolonged period, the researchers followed up households. A household was defined as a family group that lived in one house or two houses on adjacent quarter-acre blocks. For the purposes of calculating household size, people were considered as belonging to a household if they said they belonged at the time of enrolment and were present when the household was visited on at least two subsequent occasions… Forty-nine households and 1173 people were enrolled in the study (McDonald *et al*. 2006:684–5).

Practical help means a lot to people when resources are limited, such as giving people a lift when vehicles are scarce. In small communities where shop hours are restricted and many houses don't have fridges, providing food and a cup of tea can set up an opportunity for conversation and a more relaxed form of

data collection. Helping with day-to-day tasks or making arrangements to meet immediate needs identified through the research can reduce hardship and build relationships.

Structured and unstructured interviews will often identify people's immediate and long-term needs. Don't just document the problem and walk away. Make sure you have some time and money allocated to meeting people's immediate needs. If you are doing a survey of old people's needs, be prepared to collect firewood. If you are conducting a survey of toilets, take a plumber with you to fix the broken ones… We call this approach 'ethical surveys' (Miller & Rainow 1997:96).

Responding to needs along the way might involve presenting a training session with health workers, tracking down resources and equipment, or advocacy work. Occasionally, researchers find their other professional skills in demand when services are lacking, especially in remote areas.

I had worked as a [priest and a] volunteer St John First Aid Instructor and Ambulance Officer during my years in the desert. I was asked whether, as a health researcher, I would be able to assist either the church or health agencies while I was doing this research… In the Kutjungka region [of Western Australia], [Aboriginal people] had little choice over the services that were available to them, and I would need to work with some flexibility if church or health needs arose and local [people] sought my assistance…

Twice during my fieldwork, nurses absented themselves from Wirrimanu itself, and on one occasion from the region… [Aboriginal people], particularly health workers, sought assistance from me during those times (McCoy 2008:6).

Giving back in this way adds to trust and goodwill, as well as being a practical help. People in remote communities, like elsewhere, live busy and demanding lives.

People may not be in paid jobs, but may be caring for old people or sick family members, or may be involved in the community council, the committee for the health service, the women's council, mining negotiations or land claims… They may be waiting for the garage to open to get fuel, the store to open to get food, the office to open to get money, or the clinic to open to get medications. Other priorities may compete with a request for an interview… (Miller & Rainow 1997:97).

Data collection may need to be organised around meetings, sport or after the store has closed. Respect for competing priorities and willingness to work around cultural obligations and events are important principles.

My research depended on the availability of people, their disposition at the time and the information they chose to give or not to give. Over the years I became aware of the ways in which [Aboriginal men], subtly and skilfully, indicated their desire to postpone, avoid or decline requests. In addition, my place of accommodation was always uncertain and required negotiation on each field trip. I needed to gather research within the parameters of sorry business, law ceremonies and sporting carnivals, each of which focused individual and communal energies at particular times. Clearly, as a researcher… I was dependent on whether men wanted to talk and in what context. Not only did it enable [Aboriginal men] to share further the reciprocal nature of our relationship, but it also provided opportunities for [them] to share… when and as they preferred (McCoy 2008:11).

Adapting data collection methods to local circumstances

Sometimes it is necessary to make changes to data collection methods after a project is underway. A methodology such as participatory action research builds in some flexibility to adjust research processes. Even so, one of the unspoken rules is that research will not be given priority over more pressing issues that impact on research participants' lives. If data collection methods are not working out to be practical on the ground, find out why. Explore other ways to collect the data if necessary, looking for processes that everyone can work with.

For example, when local events and the introduction of the Australian government's 'Intervention'[1] interrupted data collection for a leadership capacity-building project, researchers from Batchelor Institute of Indigenous Tertiary Education and the Australian Catholic University began to wonder if they were asking too much of the schools they were working with. They decided they needed a new data collection method:

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[1] In August 2007 the Australian Parliament passed a package of five Bills resulting in a compulsory intervention in 73 Northern Territory communities. The NT Emergency Response, which became known as the 'Intervention', abolished the Community Development Employment Program, quarantined a percentage of welfare payments, deployed Australian Federal Police as 'special constables', removed the permit system that governed access to Aboriginal land and acquired leases over prescribed townships.

that would fit more conveniently (and less stressfully) into the lives of those with whom [they] were working. [They] talked about how to access participants in a context where they would be free to reflect on, rather than perform, leadership… The researchers thought [centralised] workshops would offer a better space for thinking and reflecting on leadership (Fasoli & Frawley 2009:82–3).

Major changes to research methods can make research partners anxious when they have invested time and resources into a project. Depending on how major the changes are, it may be necessary to go back to ethics committees to ask for approval to vary methods. Our advice is that extra time and effort are well invested when they result in more robust data. However, sometimes the research cannot go ahead if the research methodology is compromised.

Issues for Indigenous researchers

As an Indigenous researcher working with Indigenous participants (an 'insider' researcher), you are often likely to relate closely to what research participants say – to their experiences, feelings and worldviews. That is a strength and part of the value you add to the research. At the same time it's a challenge, because what is being said or observed might seem so obvious that it's easy to assume meaning and not document detailed information. However, data need to be collected, documented and analysed in rigorous ways to ensure your personal experience or knowledge does not impact on the processes.

Aboriginal researchers say, 'Well, I understand a lot of the cross-cultural issues that are going on… and Aboriginal issues, and they're very similar in our communities'. They know what the issues are because they've either seen it in their own community or in some cases may be living it. They are able to relate [to] what is being said, 'Oh, yeah, I know exactly what he's saying here, I know what it is'. Because of this, some emerging Aboriginal researchers may not document what is being said very well, rather than saying, 'Well, okay, I've written down what you said. I'll transcribe the information and send a draft copy back to you to ensure I've captured exactly what you said'.

So that's probably the challenge for emerging Aboriginal researchers, whereas a non Aboriginal person is not confronted by the same issue. At the end of the day, there is a bit of a difference between them – but I think a robust methodology and a good supervisor should be able to help with that (Alwin Chong, Senior Research and Ethics Officer, AHCSA).

Working with an Indigenous language interpreter

Valma Banks doing phone interpreting from Broome for a client in Perth. **Photo: Kimberley Interpreting Service**

There is more to interpreting language than being bilingual. When you need a language interpreter in data collection, try to use a person who is trained, and pay recommended fees. It is risky to use family members or friends to interpret for a participant. They may lack expertise in your area of work and are not trained to seek clarification when language or terms are unfamiliar. They may (without meaning to) prompt, give advice or speak for the person. Participants may be reluctant to share personal information if they know the interpreter, fearing lack of confidentiality. These risks also apply when getting interviews transcribed. A kinship relationship may make it inappropriate for a person to interpret or transcribe, so take local advice.

When using an interpreter:

- have a pre-interview briefing, especially if you need to use technical terms and research language

- use a triangular seating arrangement

- at the start of the interview, explain the role of the interpreter: many Aboriginal people have never been provided with an interpreter and need to understand that the interpreter is there only to interpret what you are saying, not to take sides, give advice, make judgments or tell anyone outside the meeting what was said

- speak directly to the participant and address them as *you*: the interpreter will interpret for you and the client in the first person

- use plain English: use short statements and pause often so the interpreter can remember and interpret accurately

- Ensure eye contact and non-verbal communication are with the participant, not the interpreter (adapted from KIS n.d.).

Check with local service providers to find out what interpreter services and resources are available to support data collection. Some services have guidelines and resources that can help researchers. For example:

Northern Territory government's Aboriginal Interpreter Service:

- Guidelines to Determine if an Aboriginal Interpreter Is Required: **<www. dlgh.nt.gov.au/ais/__data/assets/pdf_file/0019/6544/Guidlines.pdf>**.

- Useful Hints on Working with an Aboriginal Language Interpreter: **<www.dhlgrs.nt.gov.au/__data/assets/pdf_file/0017/6542/Useful_Hints.pdf>**.

Kimberley Interpreting Service:

- How to Work with Aboriginal Interpreters: **<www.kimberleyinterpreting.org.au/i_workwith.html>**.

CRCAH & Charles Darwin University:

- Sharing the True Stories: Improving Communication in Indigenous Health Care –Working with Interpreters: **<www.cdu.edu.au/centres/stts/guidlines_strategies_interp.html>**.

Protecting records of Indigenous knowledge

When data are important to cultural heritage, family and community history, they need safekeeping. Information can be archived (e.g. in a community library or at AIATSIS), with the custodians deciding both where and the terms of access. They need control over how stories, art and knowledge might be used in the future, as well as in the research.

People were… offered a copy of their interviews. This… enabled further questions by myself and clarifications by those interviewed, but it also demonstrated the progress of the research and the recognition of people's contributions. The return of interviews also enabled me to confirm whether, when the research was completed, they wanted their interviews archived (at AIATSIS in Canberra) and, if they did, whether under particular restrictions (McCoy 2004:264).

Indigenous cultures often record knowledge or information in forms such as paintings, dance and song. Researchers need to consider protection for the safekeeping of these types of data (e.g. artworks, film footage, tools).

part c: designing and managing a successful research project

Working safely with culturally restricted information

Information that is secret and sacred under customary laws may 'be made available only to the initiated, used at a particular time and purpose. It may be information that can only be seen and heard by particular clan members (such as men or women or people with certain knowledge)' (Janke 2009a:7).

Meticulous care is needed when doing research that involves culturally restricted information. There is risk of causing great distress, shame and/or offence when mistakes are made. Transparency reduces the risk of causing worry and making mistakes. Work with participants to ensure that protocols and laws for culturally restricted information are observed and are appropriate to the community. If you are privileged with private information, take care to honour the custodians with that trust.

You need to be aware of culturally restricted information at each stage of the data collection process:

- **before you collect data:** be clear about what is expected of you – include your obligations in the written research consent agreements (e.g. an agreement that you won't tell the wrong people if you find out secret or sacred information)

- **when you are collecting data:** if you are collecting data that may be sensitive, always check, up front, what can be talked about and recorded – clarify what is and isn't restricted as you go; read or play back information you have recorded (stories that are transcribed should be read back through an interpreter). These processes can verify content and confirm permission for use. If you are an Indigenous researcher recording Indigenous knowledge with your own people, you may be given access to some of this knowledge because of your cultural connection. Make sure you, and all contributors, are clear about what should happen to the data and what can or cannot be publicly shared

- **when you store data:** take care to ensure that only the right people have access to stored data – this also applies to findings and reports: materials should be archived according to local Indigenous laws and practices, in places and under access restrictions determined by the knowledge owners

- **before you publish:** take the proposed publication back to contributors to check that you haven't included inappropriate information or images. People must be clear about the meaning and scope of publication. For example, don't take for granted that all contributors have experience with Internet technology – explain if necessary. All involved must have the opportunity and time to raise concerns, consult others in authority, negotiate and impose conditions to protect against unauthorised use.

Placing culturally sensitive information in a public domain such as the internet was the basis of many discussions over the life of the project [about childbirth beliefs and practices in the Maningrida area]. A session at the Women's Centre demonstrated the internet using a data projector and was well attended. Participants commented how pleased they were that women all over the world would be able to read their stories. They did suggest that sections could be clearly marked with a warning 'Women's Section Only' as there are strong taboos about men sharing some of this knowledge. However, women were mostly concerned about Aboriginal men but commented that they would not look at it as they know the law… Molly commented 'This is Women's Business, not secret ceremony business [so] it's okay to put it there'. Women did not seem as concerned that non-Aboriginal men around the world may access the site. In fact some women stated they believed 'it would help them to understand our ways' (Kildea *et al*. 2009:154).

Within many Indigenous communities, we know it is not appropriate to show photographs of people after they have passed away. Check what should be done if a person's image is in a research product and the person passes away – it may influence decisions about publication design and film making.

Some women who shared their stories passed away during the course of the project… We had discussed this during data collection asking if they were happy to have the photos used after they were gone. All women had given consent however we asked women to talk to their families and close relatives about it so that it would be clear and agreed by the family. Although each woman consented for continued use of their photo beyond their passing, consent was also obtained from the families of the deceased.

A poster with participants' faces was also produced during the project… Over the course of production we were up to a sixth draft (each draft removing a woman who had passed away) before it was printed. This confirmed to us, in a very personal way, Molly's concern about the elders dying before their knowledge had been documented (Kildea *et al*. 2009:154).

} Chapter 10, 'Methods for Reporting and Dissemination', includes guidelines for using images, artwork, music and digital media.

Analysing and interpreting data

A main message within this guide is that research processes in Indigenous health should be collaborative. Processes should maintain the relationships that underpin successful, ethical research and involve people at the site, team members, and people who manage and support the project. Indigenous ways of seeing and knowing are essential to successful Indigenous health research. These messages apply in the analysis and interpretation phases as well.

The methods you use to analyse and interpret data will, of course, be determined by the research area or discipline, the aims and question/s, the methods used, data type and many other factors. Some data analysis tools and programs restrict involvement of non-researchers. Some methodologies rely on participatory analysis.

Within the constraints of the analysis tools you are using, maximise the expertise available. Get different perspectives on the story the data tells. Involve other researchers and community partners in interpreting the findings. Bear in mind that people who have a role in working out the findings have an interest in seeing them disseminated and used.

The importance of local knowledge

A local perspective brings knowledge that may be vital for making sense of the data. The importance of local community and cultural knowledge was highlighted when researchers interpreted the findings of a long-term study of health outcomes in the remote desert community of Utopia, which is made up of 16 Homeland communities (outstations) on Alyawarr and Anmatjerr traditional lands. The 10-year cohort study built on earlier work on the risk factors for heart disease and focused on mortality rates, hospitalisation and primary health care records. It found that mortality rates for the community of Utopia were 40 per cent better than the average outcomes for Indigenous Australians in the Northern Territory.

Only through knowledge of the community and its history could links be made between positive health outcomes and specific determinants such as land ownership, community control over the way health services are delivered, and an active lifestyle based around cultural practices.

Theo Allan RN provides a check up for Violet Petyarre during a Health Service visit at Lylentye (Mosquito) bore. **Photo: Alistair Ayto, Urapuntja Health Service**

… when we look at the standard macro indicators, employment, education and housing , there's no difference between Utopia and the average community so the results have to be partly related to what's happening in the social organisation of the community. This is a decentralised community with a long history of running its own affairs and a very well established primary health care service. So these things are very likely to be the contributing factors to explain the better outcomes… The decentralised model of outstations has benefits in physical activity, diet and less access to alcohol. The risk factor indicators show that obesity is more noticeable in communities near the store than in the remote outstations (Professor Ian Anderson, [speaking here as] Director, Onemda VicHealth Koori Health Unit and Research Director, CRCAH)*…*

This study gives hard evidence that community outstations and a community lifestyle do actually work if the primary health care is delivered properly. We're very strong on our law and culture here, bush tucker and bush medicines too, and all that empowers our community (Ricky Tilmouth, Researcher, Senior Aboriginal Health Worker, Urapuntja Health Service, Utopia)*…*

… health outcomes here show the importance of land and traditional practices but also qualitatively what we observe is the more subtle thing of people being empowered and being in charge of their own lives (Dr Karmananda Saraswati Urapuntja Health Service, Utopia) (AusSMC 2008).

Planning a group session to analyse or interpret data

If you plan to use a small group process to help interpret the data, the following steps may be helpful.

1. Work with research partners to set up the invitation list, place, date, time.

2. Organise a co-facilitator or translator if needed.

3. Prepare an initial summary of the data, avoiding jargon where possible. The summary could explain the meaning and show the significance of the information (e.g. data trends) or group the data (e.g. themes). Prepare a background summary if the group includes people who haven't been involved in doing the research.

4. Prepare the resources you need (e.g. key comments on cards if asking the group to help categorise qualitative data, graphs on posters or PowerPoint slides).

5. Plan the session, allowing adequate time for presentation and discussion.

6. Rehearse the presentation of data with team members/mentor.

7. Organise resources such as butcher's paper, whiteboard, projector.

8. Organise refreshments, confirm who will attend and organise transport if needed.

… maximise the expertise available. Get different perspectives on the story the data tells. Involve other researchers and community partners in interpreting the findings.

Interpreting data from collections

Earlier chapters raise the problem of health data collections about Indigenous people being incomplete and inconsistent. This poses problems when comparing and interpreting this data. **Jane Freemantle** is an Associate Professor at Onemda VicHealth Koori Health Unit, where she is conducting research to address the critical issue of lack of data to describe Indigenous (particularly child) health. She offers the following advice.

> *… data inconsistencies, incompleteness and inaccuracies are a common theme in the Indigenous health data of colonised countries. So often we are comparing 'apples with fruit salad' when comparing data collections, which means we are not able to accurately interpret the data within a broader context. I would advise researchers, who are using data… collected through statutory and administrative data collections, surveys and other population data collections, to explore the data thoroughly before interpreting it. Be clear about who or what populations are included in and, importantly, excluded from the collections. This knowledge is crucial for an accurate understanding of what the information represents, in the context of the whole population.*

Reading and interpreting data from collections as an 'insider' researcher poses further challenges for Indigenous researchers. Additional layers of meaning can often be read into the data. The process can become an emotional and confronting experience, as explained by **Bronwyn Fredericks**, who is a Senior Research Fellow at Queensland University of Technology, and has an adjunct position at Monash University.

> *For us as Indigenous researchers, interpreting data from collections can bring with it unexpected feelings and emotions, such as sadness and anger, happiness and excitement. Reading over and interpreting information about us as Indigenous people reveals how the collectors of the data thought about us or understood us at the time of the collection. Sometimes it also reveals how we, as Indigenous people, participated in that data collection willingly or how we actively worked against it and used resistance strategies. It is the sheer weight of the illness and death data that at times overwhelms me as it reflects my family, friends, community and that of all the other Aboriginal people I know, love and cherish. It reflects our lives.*

Key messages for researchers

- Put time into understanding Indigenous cultural and intellectual rights in research.

- The principles of ethical data collection, management and interpretation are universal. Each Indigenous research setting is unique. Materials and processes need to be designed to suit the setting and the participants if they are to uphold research ethics and result in valid, useable findings.

- The more you involve community in research design, resource development and processes, the more likely you are to get robust data and accurate, meaningful interpretation.

- Data storage should protect confidentiality and respect cultural and intellectual property rights. Arrangements should include short-term and long-term storage and access.

chapter 10:

methods for reporting and dissemination

This chapter looks at different ways to report and disseminate research findings in Indigenous health research.

The CRC for Aboriginal Health invested time and effort in developing research processes and products appropriate to the Indigenous health research environment. The Lowitja Institute, which now administers the CRCAH's successor CRCATSIH, aims to produce the knowledge, tools and resources to use research, so that health interventions are embedded within health systems and services. This puts even more emphasis on reporting and disseminating research findings in real and practical ways that are of use to those working to improve Indigenous health.

The chapter describes the type of knowledge sharing that has been found to work best for different user groups. It offers practical tips for producing a variety of knowledge exchange products. And it emphasises how much easier you will find it to plan processes and produce products that reach your audience if you have developed relationships with research user groups during the life of the project.

Different research users and ways to exchange knowledge

In Indigenous health research the main user groups are Indigenous communities and organisations, politicians and policy makers, Indigenous and mainstream health care providers and practitioners, other researchers or academics, the media and the general public (including opinion leaders).

When it comes to disseminating research findings, one size does not fit all. Table 1 provides suggestions about how health researchers can report information to different groups in different ways.

Table 1: Ways in which health researchers can report information to different groups

Research user group	Methods to exchange research information
Indigenous communities and organisations People who have 'championed' the project	Plain language reports and summaries Local language information Fact sheets on project outcomes Workshops Stories Art Dance Music DVDs and videos on research findings Flip charts and posters Presentations at community meetings and events (festivals, open days, health expos) Community radio Stories on National Indigenous Television Stories on research in local newspapers Articles in Indigenous media Community and organisation websites Personal contact with community leaders Social media Mobile telephone alerts
Politicians	Personal briefings and meetings Enlist 'champions' to deliver message Overview in brief memo Evidence briefings
Health policy makers, planners, managers	Policy briefs Short plain language reports Electronic updates/email alerts Advocacy Discussion papers Fact sheets on research outcomes Video linkup Evidence briefings Seminars/workshops Personal networking

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Health care providers and practitioners	Standard treatment manuals/guidelines
	Professional education
	Conference presentations
	Reports and discussions papers
	Video linkup (e.g. education sessions)
	Personal networking
	Professional networks and newsletters
	Professional journals
	Specialist e-lists
	Systematic reviews
	Care plans
	Treatment schedules
	Continuous quality improvement processes
Other researchers and academics	Research reports
	Academic journals
	Academic networks and newsletters
	Specialist e-lists
	Conference presentations
	Seminars and professional forums
	Theses
General public (including opinion leaders)	Media – radio, television, newspapers, magazines
	Internet – including clearinghouses
	Regional and community planning events, seminars (e.g. University of the Third Age)

How to turn research findings into messages for research users

You've done the research. You've talked to stakeholders throughout the project and know who your target groups are. You've got the findings. This is your chance to convince your audience that the research findings are important to their work. They need to be presented in ways that show research users what lessons they can take from the research, and how to action them (CHSRF 2007:1).

Turning your summary of findings into main messages goes one step further than simply answering the question, 'what did we find out?', and tells your audience what you think the findings mean for them. The main messages are then disseminated using methods that suit each audience.

The process starts with three questions:

1   **What did we learn from the research?** Set aside your academic report and ask, 'what did we learn from the research?' Focus on how to express clear conclusions based on what you've learned.

2   **Who is this important for?** What do they most need to know about what you've learned? Consider your audience/s, the context they work in or problems they need to solve.

3   **What does it mean for them?** Spell it out in a brief statement that suggests what needs to be done. Use terms that are used in the work of the target audience.

A fourth question, **'what is the best way of getting the message across?'**, will help you decide the most suitable methods for presenting messages to each audience. This chapter helps you to make those decisions and develop effective strategies and products.

Applying the three questions – an example

In Chapter 5 is a case story called 'Using evidence from a diabetes study to change local clinical guidelines'. Here is an example of how the findings from that study, conducted across health care sites in the Kimberley, could be turned into research messages.

1   **What did we learn from the research?**

The study found that when laboratory glucose samples were compared with POC glucose samples, the results were quite similar. Earlier research had shown POC testing helped patients to understand and follow through on treatments for diabetes, but it was not recognised by health authorities as a reliable test.

This study showed that POC blood glucose testing was reliable for excluding diabetes, and could be used as part of the test for diabetes.

2   **Who is this important for?**

It is important for policy makers who determine resources, clinical leaders who determine guidelines and practitioner training, practitioners at remote health care sites, and patients in rural and remote communities.

They need to know that POC testing can be used to help improve health outcomes for patients with diabetes

3 **What does it mean for them?**

Key message for policy makers:

Diagnosis and management of diabetes among Aboriginal patients can be improved through POC testing for diabetes. The POC tests are a low-cost investment that give immediate results and increase the relevance of the results for the patient, and follow-up for treatment. Resources will need to be allocated for the provision of blood glucose meters at each remote health service site in the region, but savings will be made through reduced transport costs and off-site testing.

Key message for clinical leaders/managers:

Local clinical guidelines need to include POC testing as a reliable test to exclude and initially diagnose diabetes. Successful adoption of POC testing will require all clinical staff in remote areas to be competent in use of blood glucose meters. A training plan will be needed.

Key message for practitioners:

POC testing using a blood glucose meter is reliable for diagnosing or excluding diabetes. It enables you to give a patient immediate feedback and advice about diabetes management, and improves patient follow-through with treatment.

Key message for patients:

If you have diabetes, it is important to start managing it as soon as possible. The local health service can do a test that tells you straight away if you have diabetes or not.

4 **'What is the best way of getting the message across?**

The case story in Chapter 5 'Using Research for Change' explains how the researchers got the messages across to different audiences (see p.127).

Questions to guide dissemination/knowledge exchange

The CRCAH drew upon work of the Institute for Work & Health, Canada to put together questions to guide researchers who are planning dissemination. Use these questions to help maximise the impact of your research findings.

Key messages

What are the key messages from your project?

What are the new learnings/knowledge that can be gained?

Are there any actionable ideas/recommendations?

Has the environment changed since your final report was written?

What is the magnitude of the messages/changes suggested?

What do you want to change as a result of your findings (e.g. behaviour, policy, programs, practice, research, teaching etc.)?

What do you expect to change?

What is the quality of the work?

What reaction do you want from the users? What is the likely reaction you will get?

Will your project:

- inform curriculum development?
- influence practitioners?
- inform thinking in policy?
- change behaviour?
- inform future research agendas? If so, how?

What is the expected impact?

In what ways, and at what levels (policy, service delivery, behaviour) do you want your research to be used to achieve the change desired (e.g. increasing awareness and understanding, concepts, lobbying)?

To whom (audience)?

Who are the users or individual messengers who will be interested and should know about your project findings?

Are there specific audiences for specific messages?

What are the relationships of the target audiences to the key messages?

Are there any audiences we don't already have an established relationship with, in whom we may need to invest more energy (time, money)?

Is the current environment receptive to the messages?

What is the size of the audience?

Are the findings in line with the ideology of the users/audiences?

By whom (messenger)?

Who is best placed to deliver the key messages? Where possible, build the capacity of an Indigenous researcher on the team to write up and deliver presentation/s on your research findings.

How?

Should there be a media release?

Should there be a launch of your findings?

Should you use social media (e.g. Twitter, facebook) to promote findings?

Should there be presentations/interviews/media linked to findings?

Are there other project findings or evidence that supports your project findings?

How to package/transfer the messages?

Should you use a policy brief/community report/journal article/CD–Rom/executive summary/electronic format/media/website?

What are the barriers/challenges to getting the key messages out?

What other activity is needed (e.g. meetings, presentations), and who should be involved?

(Adapted from Reardon, Lavis & Gibson 2006).

Writing workshop underway at Indigenous Postgraduate Summer School, The University of Melbourne

Case story – Planning and writing for dissemination

Jane Yule is Research Communications Manager for the Lowitja Institute. Jane talks about writing for publication and the importance of planning for knowledge exchange.

Plan ahead for knowledge exchange

Think about the end of your research cycle, right at the beginning. In the past people have got to the end of a project and then realised they're not sure how to get the knowledge out to a wider audience. They might have peer-reviewed journal articles, conference presentations or key note lectures – a very traditional approach to knowledge exchange – but they haven't got any funding left to implement wider dissemination.

If you want to do good research you have to engage with communities, so… you need to give a lot of thought as to how you are going to transfer or exchange that knowledge. If you're a student writing up a thesis, for example, you will need to think about how you're going to feed your research back to the community. They're probably not that interested in a journal article, but may be interested in a community report or a website that explains what's going on, or facts sheets, or brochures, or a video project.

part c: designing and managing a successful research project

Writing community reports

When you want to feedback information to a community audience there is not much point writing an academic report… [Look] at much shorter sections and summaries, key messages, and standalone quotes that… summarise the research. Where possible, use photos and diagrams.

Community reports shouldn't be very long – 5000 to 10,000 words maximum. Your thesis or major research report is there in the background if people want more details… The best thing is to look at some community reports. There are some good examples around and they tend to follow a structure (see below).

Other ways of publishing and exchanging information

You don't have to publish your research in the traditional sense; you could have a summary on the website, or make your own website. You could have flyers or posters. If you think your research is important for policy, then put together a two- to four-page policy brief for government.

If it's a project involving young people, a social networking site may be a better way of disseminating your research – Facebook or Twitter. You could do it through video or photo voice. But it will all be a bit wasted if you don't start with the community first and negotiate that reporting back process. Talk to people as you go along about different methods and what might work, and give them regular updates.

Being smart…

You want your research to make a difference. Translating research into plain words is not dumbing it down. It's actually really smart to write something so other people can understand it, and so that the research gets to a wider audience.

Think about the end of your research cycle, right at the beginning.

} For best practice case studies that illustrate some innovative ways of disseminating research, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Reporting to community and Indigenous organisations

Reporting throughout the project

A high level of community engagement is a feature of many successful Indigenous health research projects. Regular reporting throughout the project is important for keeping the community engaged, especially if a project is long term and/or researchers are based off-site. Giving back in this way is expected. This is one way that Indigenous research tends to differ from mainstream research.

Use different strategies to reach more people. Set up efficient systems to update different groups with an interest in the research. For example, part of your regular reports to the project advisory group could be in the form of a project update in a staff newsletter, a poster in a service waiting room or a meeting presentation to managers.

Negotiate with community partners what is reported, the preferred formats, and the people you report to and how often. Allocate adequate time and resources.

People in communities are realistic about what is possible. We have given feedback in person at community meetings, but that is not always possible. In a tobacco project which has trialled monitoring tobacco consumption, using store sales in 24 remote NT Aboriginal communities, we knew that feedback in person would not be sustainable after the project. So we said up front, 'What we can do is send you a poster that shows your community's results every six months.' And that was ok. We identified a person in each community who would put the posters up, and we send him or her six laminated posters that show the community's tobacco sales for the previous six months. That has worked out well for everyone (David Thomas and Joseph Fitz, Menzies School of Health Research).

Interim reporting may be integral to the methodology (e.g. when it is part of an action research cycle). Above all, don't wait until the end of the research project to report to community. And if you can't meet a reporting obligation, make sure you let the right people know.

Reporting at the end of the project

When you report at the end of the project, the same reporting strategies may be suitable. However, your final report needs to signal the end of the research and the start of the next phase – putting the findings to use. How these are presented, and who presents them, influences whether the research finding are seen as useable. One thing is certain – if you write an academic-style report and send it to a busy organisation it is unlikely to make a difference to anything except filing space.

...don't wait until the end of the research project to report to community.

Where possible, build the capacity of an Indigenous researcher on the team to write up and deliver presentation/s on your research findings – to all target audiences. Strategies for good community reporting are to:

- regularly update the list of community members and Indigenous organisations you report to

- ask the advice of the target audience about format and language

- use clear headings and plain words: use visual images such as artwork, diagrams and photographs; highlight key facts and figures (e.g. large font, boxes, shading) – get help from an editor and a graphic designer if you don't have these skills

- keep graphs simple and self-explanatory

- consider final reports in a variety of formats to reach a varied audience (e.g. written report, personal presentation, DVD, website)

- summarise main elements of a large report on a brochure or factsheet – this will reach more people

- test the presentation/product with a community audience

- make sure presentations are led by community-based researchers where possible – they should include opportunities to talk about 'where to from here'.

Structure of a community report

Summary – one or two pages that might include key messages.

Introduction – two to five pages and background, how the research came about.

What happened – 10 pages about what you did and how you did it, rather than explaining your methodology in-depth. People might want to know, for example, that the research was done in partnership with the local Aboriginal community, and respected and listened to community ideas.

What was learned – five pages on the lessons from this research and what improvements can be made.

References – (minimal) and signposts for where people can find out more information.

Acknowledgments – Be aware that major funders and the people – communities, organisations and other researchers – involved in your research need to be acknowledged properly in publications. You can really damage relationships if you leave off a logo! (Jane Yule, Research Communications Manager, The Lowitja Institute)

} For advice about structuring and presenting reports, ask the Communications Manager in your university or research organisation.

A final report needs to acknowledge the input that community members have had during the life of the project. Take care that no one is left out of the acknowledgments, and respect the wishes of people who want to be anonymous.

} Examples of community reports are available on various websites (**www.lowitja.org.au/publications/;
www.onemda.unimelb.edu.au/publications/reports.html;
www.ichr.uwa.edu.au/waachs/publications/booklets**).

The Lowitja Institute has collected some great case stories about best practice in knowledge exchange – stories that show innovative ways of reporting and sharing research information with communities.

Case story – Community-directed knowledge exchange

Peter Thomsen worked for several years as Culture and Multimedia Officer in the Multimedia Unit at the Menzies School of Health Research. He also chaired the Aboriginal subcommittee of the Top End Human Research Ethics Committee. Peter explains how video productions can be used to help make health research more effective.

The idea for the video was initiated from the community members who had been involved in the project, and who wanted to find the best way to communicate the story of the project and its outcomes back to the central Arnhem Land community. The video production could be broadcast on the local community television service, shown to the community council and at the health clinic, and also used to help convince funding bodies as part of a campaign for additional resources. (One of the outcomes of this research project was a plan to build a family centre in the community, which needed funding) (Thomsen 2003:7).

One member of the research team, Paul Wunungmurra, had some previous experience with film production as an actor, and was keen to learn more about the production side…Paul's role was central to the production process, as he acted as a connection point of understanding between the community, the research project, and the video production….(Thomsen 2003:7)

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

The idea for the video was initiated from the community members who had been involved in the project, and who wanted to find the best way to communicate the story … back to the central Arnhem Land community.

Case Story – Sharing evidence and planning change through storytelling

Bernadette Shields is the Senior Aboriginal Health Promotion Coordinator for the Chronic Diseases Program in the NT Department of Health and Families. She talks about using a storyboard and storytelling to share health research evidence.

In our health promotion program we use Aboriginal ways, both visual and storytelling, to share information that comes from research about preventable chronic diseases. I usually start a session by talking about how we hear some old stories, but also some new stories now that we didn't know before, as to why some of us are getting sick. I say that it's a good story, because it has come out of research evidence and can help us make positive changes that can keep our families, communities and culture strong. I compare the old days – when physical activity was part of everyday life, when families were moving around with the seasons – with now, when we don't move around much and sometimes eat unhealthy foods…

We use a storyboard with felt symbols because it's visual and interactive, and it's portable. We can pick this storyboard up and go and sit with family groups wherever they feel comfortable. That could be sitting under the tree, or down at the beach – wherever they choose…

} For the full case story, see the Lowitja Institute website (www.lowitja.org. au/case-stories-researchers).

We use Aboriginal ways, both visual and storytelling, to share information that comes from research…

Information technology and multimedia have the potential to help a wide community audience to access research messages; for example, the National Health Interactive Technology Network (HITnet) Program, led by the University of Queensland in Cairns, shares health information through a network of centrally supported touch-screen kiosks. Indigenous communities buy their own kiosks and control the information that is displayed. People can work through health education modules using the touch-screens. The kiosks collect statistics about the modules people choose to see, and their gender and age group. Keep looking for new ways and opportunities to share research information, and share them with others via the Lowitja Institute website.

Reporting to policy makers and service managers

Policy makers and service managers have many competing priorities and will generally be much less interested in your research than you are. As a consequence, reports about your research that you want them to take notice of need to be brief and written in non-academic language, with policy implications highlighted, so that it is clear the research is relevant and can be used to improve the service. Presentations should follow the same principles.

A report sent 'cold' to a manager or policy maker is unlikely to have an impact unless it is about an issue of current concern. Personal contact usually works best (e.g. from a community leader in the advisory group). Presentation opportunities include special briefings, planning meetings and seminars. Video linkup may increase access to managers across regions.

Government policy makers who advise politicians also need targeted material and strong advocacy, as **Alastair Harris**, former Communications Manager at the CRCAH and now a Health Communications Consultant, explains.

Don't be ashamed of being political. If you work in the context of Aboriginal health in Australia… the work is going to be political. I'm not saying that researchers should project themselves into party political debate, but there's almost a sort of embarrassment about advocating in a strongly political way for research outcomes to be taken up. And given the state of Aboriginal health and our lack of success in building health equity in this country, the days for feeling shamed about political advocacy should be gone.

> *Researchers can avoid getting directly involved in politics. For example, when there is a political debate going on [that involves Indigenous wellbeing], you might not be able to intervene, but you might time the release of some relevant research… other people can draw the connections…*
>
> *I've heard journalists ask researchers, 'Well, what does this research mean for [policy change]?' The answer to that is, 'Well, that's a question you should be directing to the politicians. We're simply providing the evidence of what works and what doesn't.'*

A policy brief

A policy brief focuses on a defined problem or issue. It aims to convince policy makers that the problem is urgent, and the proposed action or policy alternative is necessary. A policy brief is strategic. It builds on what the audience already knows and reflects their values with convincing language and evidence. It is professional rather than academic. It uses simple language to focus on evidence-based, feasible solutions, not research methodology (Young & Quinn 2004:1–2).

A policy brief needs to be well laid out and eye-catching. Figure 6 shows a policy brief, 'Targetting Indigenous Australians' Smoking Rates', produced by the Centre for Excellence in Indigenous Tobacco Control at the University of Melbourne.

When there is a political debate going on [that involves Indigenous wellbeing], you might not be able to intervene, but you might time the release of some relevant research… other people can draw the connections…

Figure 6: An example of a policy brief

Starts with a clear statement of the policy problem.

This section uses evidence to explain why the issue is important. No academic jargon or specialised abbreviations.

Title explains what the policy brief is about in clear concise and active language.

Contact details stand out clearly. A highly respected and credible contact person, as in this example, adds to likely success.

This section explains what might be done.

Lots of space on the page, headings and dot points make it user friendly. Graphics are attractive but low key.

Headings are clear.

This section explains work and research that needs to be done about the issue.

These sections give background information about the organisation, backed up with recognisable logos.

Sources are identified – adds credibility.

Strategies used by tobacco control organisations have not as yet had the impact they've had on Australians in general

There has been no decrease in the daily smoking rates for Indigenous people for 16 years and the rate has remained static at 51%. This is in contrast to the steady decline of smoking rates in the broader Australian population that are down to 17%.

Current Indigenous tobacco control programs need to be assessed to find out what is working and increase the capacity of health services to deliver effective programs

- An assessment of the current Indigenous tobacco control-related workforce is required and more Indigenous tobacco control positions within all sectors—Community, Government and NGOs—need to be created.
- Culturally appropriate programs developed specifically for Indigenous communities need to be evaluated to establish what has worked, what hasn't worked and what can be improved upon. Adequate support mechanisms need to be available to those wanting to quit.
- An improvement in employment, education, income, home ownership would contribute to a decline in smoking rates. Currently 39% of wealthier Aboriginal and Torres Strait Islanders smoke.
- The Cooperative Research Centre for Aboriginal Health is funding a project that will make it easier to assess the impact of anti-smoking interventions in Aboriginal communities by monitoring tobacco sales at community stores.

ABOUT THE CENTRE FOR EXCELLENCE IN INDIGENOUS TOBACCO CONTROL

The Centre for Excellence in Indigenous Tobacco Control (CEITC) is a national organisation, funded by the Australian Government Department of Health and Ageing until 2010, which aims to increase knowledge about Indigenous tobacco control. CEITC began in September 2003 and is based within the Onemda VicHealth Koori Health Unit at The University of Melbourne.

There are currently four staff members who work in a variety of ways to boost the profile of Indigenous tobacco control and encourage others to undertake activities in this area. Some of this work serves a clearing house function where the Centre brings together knowledge from Aboriginal and Torres Strait Islander and tobacco control organisations from around the country and ensures that such knowledge is processed and disseminated appropriately.

CEITC will begin several research projects, the largest of which will focus on Health Worker capacity to run tobacco control projects and on developing a national Indigenous tobacco control research network to oversee and assist progress in this field.

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CEITC   Onemda   THE UNIVERSITY OF MELBOURNE

Tips for writing a policy brief

- Think about the current policy context (local/State/Territory/national/international; and relevant policies, Commonwealth–State relations, place in election cycle and so on). Can you line up your research findings with policy directions? If so, make the connection explicit.

- Write in the reverse order that you would use in an academic paper. Start with the conclusion, put the most important message in the first paragraph, then go back to your findings. Avoid an academic writing style. Sound certain (rather than trying to qualify statements).

- Write as if you were the person responsible for implementing the proposed solution. (Is it concrete? Is it responsible? Is it technically feasible? Will it win support from important individuals/groups? Is it economically justified – what are the costs and savings?).

- Remember – the key word is brief. Many researchers use the 1:3:25 model (one-page summary for decision makers; three-page detailed summary for advisors to decision makers; 25-page detailed report for whoever needs to back up the argument with the research).

- Get others outside your specialist area to read it for clarity. Be prepared to do a lot of re-drafting to get it right (adapted from Lewis 2006).

} For varied examples of policy briefs, see the 'Publications' lists on the websites of research organisations.

Disseminating research to health practitioners and the research community

Health practitioners and other researchers access research findings through published reports, professional journals and newsletters. Media articles/reports that target the general community are a good way of making people aware of research that may be relevant to practice. Conference presentations reach professional audiences. However, these methods depend on practitioners seeking out the research information. You reach more of the target audience by delivering findings to workplaces in useable formats and messages.

How you report will be influenced by the area of practice and type of research, education backgrounds and cultural perspectives of the audience. Another factor to consider is that practitioners' experience of research varies. Avoid making assumptions about attitudes to, or experience of, research. Many have qualifications and/or extensive experience as researchers – you may be a practitioner–researcher yourself. Many have limited or even negative experiences of research. These factors impact on how receptive people are to the findings.

Practical, ready-to-use information

Service providers and practitioners are more likely to use research findings when it is clear that they are relevant, and when they are easy to access and apply. Practical, easy-to-use research messages are especially important in Indigenous health, where the need for improved service delivery and better individual health is so urgent, and where many frontline workers are over-stretched and under-resourced.

Research dissemination is most successful to practitioners when:

- information is available in the workplace

- reports/presentations use plain language and familiar health care terms

- the focus is on practical ways to benefit clients

- there is a clear link between the findings/messages and their own practice

- there is support from managers and workplace systems to change practices, based on evidence (e.g. through policy and professional development)

- changes in practice are backed up with practical resources and training.

Clinical research evidence is often disseminated to practitioners through standard treatment manuals/guidelines and skills training. It is incorporated into care plans and treatment schedules. Evidence about what does and doesn't work is used to shape health promotion programs and health interventions. It is used as a benchmark for service reviews and continuous quality improvement processes.

} An example of a national product is *National Alcohol Treatment Guidelines for Indigenous Australians* (Department of Health and Ageing 2007).

Local projects can produce resources for local practitioners. A good example of this is the *Alcohol Handbook for Frontline Workers* (Laycock 2004).

When frontline workers in Far West NSW asked for alcohol intervention resources, focus groups were conducted to collect data from workers about the alcohol-related issues that affected their work, and the type of information and resource they needed. This data, experts' input and evidence-based guidelines for safe drinking and brief interventions were used to develop an Alcohol Handbook for Frontline Workers. When the handbook was launched, workers attended sessions where they got their own copy and learned how to make use of it when working with clients (Kate Gooden, Project Manager and Alison Laycock, writer).

Guidelines or standard treatment manuals alone are not enough to bring about improved practice. They must be integrated into the daily routines and systems of a health centre or practice.

} The Audit and Best Practice for Chronic Disease Project, an action research project that resulted in tools, processes, resources and infrastructure for continuous quality improvement, is a good example of how evidence-based guidelines for best practice can be integrated into routine health care. Details are available on the One21seventy website (**www.one21seventy.org.au**).

Research can reach practitioners in low-cost and creative ways.

To help demystify research and its applicability to work practices, an Evidence Based Practice Interest Group was established at Casuarina Community Health Centre in Darwin. It has been meeting four times a year for the last three years and is mainly attended by Child and Family Nurses.

A research article, relevant to practice, is circulated prior to the session illustrating a particular research methodology. This is then discussed and critically appraised. These sessions are informal and generate much discussion and sometimes lead to the review of the evidence used by current local guidelines… The Group… aims to raise awareness of why evidence is crucial in providing quality care and practice, and [to] provide an opportunity for analytical discussion (Karen Piper, PHCRED group facilitator, Centre for Remote Health).

Face-to-face dissemination usually works best. For example, after they completed a study to look at whether point-of-care (POC) capillary blood glucose meters were sufficiently accurate to be used to diagnose diabetes in Kimberley health centres, the researchers travelled to some of the study sites and presented the findings to the community and clinic staff, used

videoconference to present to the Kimberley Health Research Network, and presented at a scientific meeting and a conference (see case story in Chapter 5). One researcher was a member of the group that reviews the regional clinical guidelines for chronic disease management. Dissemination was proactive and designed to reach practitioners and policy makers in remote locations.

Some ways of disseminating to practitioners and other researchers are to:

*   ask to present the research to workplace or student groups

*   use your professional networks and word-of-mouth

*   be opportunistic – talk about the research when you meet Elders, leaders, managers, health service board members and other relevant people with influence

*   write about the research in professional and workplace newsletters, and for journals in the relevant area of practice

*   present at conferences and at in-service education programs

*   access specialist e-lists

*   set up a blog and contribute to other people's blogs

*   put the research report on a relevant professional website

*   send the research report to the Australian Indigenous Health*InfoNet*, which is widely accessed by people who work in Indigenous health

*   look for opportunities to talk about the research in video linkup and online chat rooms, especially when practitioners (or you) work in rural and remote settings.

Conference presentations

Presenting your research at a conference can involve giving a paper, taking part in a panel discussion, or presenting a poster or other form of presentation (e.g. performance). Find a conference that lines up with your research and area of study and make the most of the opportunity for networking and information exchange.

Large conferences usually have websites with information on how to submit abstracts about your research presentation. The websites often publish PowerPoint presentations and abstracts after the conference, which means your research work can reach a wider community of interest.

Kylie Stothers

Case story – Creating a poster to share research information

Kylie Stothers is a Jawoyn woman and a Primary Health Care Research, Evaluation and Development Research Associate at the Centre for Remote Health (CRH), based in Katherine, NT. Kylie presented a poster titled 'Evaluation of the Mental Health Seminar Series' at the 2009 Primary Health Care Research, Evaluation and Development Tri-State Conference in Alice Springs.

I developed the poster as part of my learning plan. My manager Melissa Lindeman and I discussed taking that next step in research professional development and presenting at a conference. I chose a poster because I am not confident in public speaking, so I thought this would be an easy step into presenting research information in public…

My manager in Alice Springs gave me guidance about what was in a poster, and where to go for assistance. Being in a small satellite office in Katherine, I had to be resourceful. I found the PHCRIS [Primary Health Care Research and Information Service] website the most useful place. It had practical advice and really easy-to-follow steps.

Doing the layout and design was time consuming work. I learnt computer skills I didn't have before simply because I had no on-site assistance – support from colleagues was done via email… I asked two allied health professionals… to give me feedback on the different poster drafts. I also asked family and friends, to make sure the poster made sense to people outside the health field. I needed to allow for this time in the process and the finished product ended up looking quite different from the early drafts.

I got positive feedback about the poster at the conference. Many people talked about how fiddly the process is and how it takes a real skill to be able to put findings onto a poster that is catchy, visual and informative… Because it is visual and it gives an insight into one of the activities that CRH is involved with, the poster might be used in the future to help showcase CRH activities.

Academic thesis writing

A thesis is a type of research report. It is a large document that reveals the results of a long period of research and the intellectual effort engaged in by the scholar. It may be quite narrowly focused or of broader public interest, but it must have intellectual substance and display academic rigour. A thesis shows the reader not simply the journey the student has gone through but also the skills and knowledge acquired along the way (UMPA 2011).

A thesis is ultimately written for examiners, who will use it to assess you. It is too long and too academic in writing style for an audience outside the academic domain. This is an important message to take on if you want your research to make a difference. Most postgraduate candidates need guidance from others to translate their research findings for other audiences. This is to be expected, given that you will have spent several years immersed in academia. There are sometimes exceptions to this rule, such as when audiences are involved as co-researchers.

In order to make ethics and values real, and for this research to be trustworthy, transparent and accessible, I needed to write a readable thesis.

Case story – One thesis for two audiences

Janet Kelly is a non-Indigenous nurse researcher who submitted a PhD thesis in 2008. She explains why she wrote one thesis for two audiences and how she approached the writing.

Within the university, I was advised to write two documents about the research – one a community document and the other an academic thesis for examination. However, the Aboriginal Women's Reference Group were adamant that for me to write two different documents was to continue a colonising trend of taking Aboriginal knowledge and repackaging it, so that it was no longer accessible to, or co-owned by community.

One Elder woman said: 'If you write two documents then how do we know what you have written and how can we give cultural approval for it. No – you write a readable document and we'll read it.' They also discussed issues of trust, saying, 'we have been betrayed by governments and organisations before. We know you and we trust you. We don't know or trust the university.'

I listened to what the Aboriginal women were saying. In order to make ethics and values real, and for this research to be trustworthy, transparent and accessible, I needed to write a readable thesis. In order to do this, I needed to place community and Aboriginal women's needs alongside, and sometimes higher, than the needs of the university. I invited Aboriginal women (community members and health professionals) to form an Aboriginal Women's Reference Group to guide the research and the thesis report. Some of my peers at university had difficulty accepting that a community group would define the parameters of my/our research, but my supervisors were very supportive. When I said, 'This is the Aboriginal Reference Group's bottom line', they worked with me/us to make it fit within the necessary academic standards.

Janet's supervisors at Flinders University were Professor Charlotte de Crespigny, Associate Professors Eileen Willis and Sheryl de Lacey, and Dr Yoni Luxford. **Eileen Willis** explains how Janet's thesis met the requirements of examiners.

Perhaps this thesis' most important contribution is that it keeps alive the ideas of community development/action research in a time when welfare programs are focused on measurable outcomes in line with bureaucratic formula and the delivery of services…

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

Writing a journal article

Reporting in peer-reviewed journals is a traditional way of establishing the academic and professional credibility of your research. Peer review means that your article is reviewed by a few research peers, who give feedback and judge whether or not the article is worthy of publication in that journal. Reviewers look for originality, scientific or methodological merit, whether it is suitable for the journal's audience and so on.

In recent years, more academic journals have become open access, which means they are published online and can be accessed free of charge.

Careful timing is important. Many journals do not want to publish research that's already been covered by other journals – and they can take up to a year to actually publish an article. This can delay the feedback of findings to a community audience, so try to get a research peer-reviewed article accepted as early as possible.

Writing guidelines are available for different types of articles and include:

- CONSORT (CONsolidated Standards of Reporting Trials) Statement (**www.consort-statement.org/index.aspx?o=1011**)

- Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for Reporting Observational Studies (**www.strobe-statement.org/Checklist.html**)

- SQUIRE (Standards for Quality Improvement Reporting Excellence) guidelines for quality improvement reporting: explanation and elaboration (**http://qshc.bmj.com/content/17/Suppl_1/i13.full**).

Other useful resources to guide writing include:

- the Cochrane Collaboration website, which contains useful guidelines on conducting and reporting systematic reviews (**www.cochrane.org/information-researchers-and-authors**)

- peer-reviewed journals and other professional health publications (e.g. Aboriginal and Islander Health Worker Journal), which offer up-to-date research information

- open access journals such as BioMed Central (**www.biomedcentral.com/browse/journals/**).

Don't overlook opportunities to 'publish' grey literature, such as discussion papers. They can be published more quickly than a peer-reviewed journal article but do not have the same academic validation as a journal article.

Ross Bailie

Case story – Writing an article for a peer-reviewed journal

Ross Bailie is a professor and researcher, and a Program Leader with the Lowitja Institute. Ross is an experienced writer and a peer reviewer for a number of international and Australian scientific journals. Here he talks about the peer review process and where to find guidance on structuring your article.

When you get to the stage of writing a journal article… you are usually confident that you have a good understanding of the issues and something important to say. All the same, it's important to treat it as a learning process. Expect to get critical feedback from reviewers when you submit the article. Feedback is not always gentle and it is easy to feel affronted and defensive. Try to see through that, to understand what the editors and reviewers are saying and to respond in a non-defensive way. Take it as a learning experience and recognise that peer review is not a perfect process.

There are two kinds of peer review processes: blind review, where the authors' and reviewers' names are not known; and open review, where authors' and reviewers' names are put to articles and responses. Blind review is the more traditional approach used by scientific journals. Some online journals post reviewers' comments and authors' responses on the web, as well as the article, so it is a fully transparent process. I am in favour of open review because it requires reviewers and authors to justify their comments and think carefully about whether they have any possible conflict of interest. Ideology can influence comments – we shouldn't be able to hide behind anonymity.

To get published, you need to follow the writing guidelines for the particular journal and the article type. I would suggest writers look at resources such as the British Medical Journal *module: 'How to write a research paper and get it published (http://learning.bmj.com/learning/search-result. html?moduleId=5001079).*

Bronwyn Fredericks

Case story – Working on the art of writing

Bronwyn Fredericks is a Murri woman from south-east Queensland (Ipswich/ Brisbane region). She is a Senior Research Fellow with the Faculty of Health, Queensland University of Technology, and has an adjunct position at Monash University. Bronwyn's work has appeared in academic and community publications in health and other disciplines. She sits on several editorial boards and is a peer reviewer for a number of journals. Bronwyn writes about the craft of writing and shares some of her tips as an Aboriginal writer.

We can use writing as a vehicle to document what we think, how we do things and what matters to us. We can also leave writing for the generations that follow us so that they can quote Aboriginal and Torres Strait Islander scholars and writers, politicians, activists and community members about our business. Collectively we can all make a difference to the struggle and rehistory our history and what is known about us as Indigenous peoples…

For me the hardest part of writing used to be getting down that first sentence or paragraph. Now what I do is:

- *create a document*
- *start to write down dot points around the first idea for a paper or the theme of the paper*
- *build on the dot points with more dot points*
- *make sentences from the dot points*

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- *group the sentences with common ideas*

- *start forming paragraphs*

- *reflect on the order of what is written and maybe move the paragraphs around*

- *develop linking sentences between the paragraphs*

- *create sections as this helps clarify ideas and later helps the reader when scanning the article*

- *keep references up to date and add in as required, noting page numbers for direct quotes.*

Over time I keep coming back to the document. In the beginning I don't worry too much about word length or grammar. I really just focus on getting my thoughts and ideas or a description down on paper… Sometimes I even write my feelings down because I might want to capture those within the feel of the paper and I can work the words in a suitable way later.

When writing a journal article or chapter I find that I really need to be well organised. I go through my books and articles and put aside anything I absolutely want to reference. It doesn't matter if they are hard copies or electronic versions. I always sort alphabetically because I find it avoids multiple checking of references. I use the same font and size for the first draft. There is plenty of time for stylising later and writing guidelines can vary depending on the journal. If you want to get published you need to follow the writing guidelines set by the journal you are going to send the article to. Don't forget to always proof read your work and do spell checks….

} For the full case story, see the Lowitja Institute website (www.lowitja.org.au/case-stories-researchers).

We can use writing as a vehicle to document what we think, how we do things and what matters to us. We can also leave writing for the generations that follow us so that they can quote Aboriginal and Torres Strait Islander scholars and writers, politicians, activists and community members about our business.

Reporting to the general public

Information in the public domain is available to all relevant groups – Indigenous communities and organisations, health care providers and practitioners, politicians, policy makers and managers, other researcher and academics. You can target the general community through open media, such as press, radio and networking websites. People with an interest in your research topic can choose to follow it up.

You can target communities of interest by sending your reports to open access sites such as the Australian Indigenous Health*InfoNet* and health information clearinghouses.

Blogging

Blogs are a simple and cost-effective way to share information with a wide audience. Many blogs can be set up without cost, for example, Blogger (www.blogger.com/) or WordPress (http://wordpress.com/). Personal blogs are web-based journals that can be accessed by Internet users. They are used as a digital diary to record your thoughts or to put your view across. Images and graphics can be uploaded. Set up you own blog or write about your research on other people's blogs.

Some services, organisations and interest groups have blogs. Explore whether you can post research reports, and access other people's research, on organisation and library blogs. Do a simple web search using the key word 'blog', with 'Indigenous', 'Aboriginal', 'health' etc.

Using the media

You can use the media to get your research into the public domain. Disseminating research through the media raises public awareness of issues and findings, which in turn can make politicians and policy makers more likely to pick it up.

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Case story – Disseminating research through the media

Alastair Harris worked as the Communications Manager at the CRCAH, has a background in radio journalism and has provided media training and advice for grassroots campaigns. Alastair offers some tips about using the media.

Universities have media units. Most have regularly updated news pages. My message is to push the importance of your research to your supervisors and then to your institution's media people. Approach your university media team to get your work promoted.

Never discount the importance of media… The broader your audience, generally the less defined your message. If your research is in cardiac health and you're writing… for the cardiac health journal… you can really get down to the complex detail of your research. But if it's going to be published in the newspaper, for instance, then you know you're not going to be afforded that same level of detail. Now even if half a dozen [people] follow up an interest sparked by that article, then there's great potential for research uptake and for greater dissemination of your work. So don't discount the use of 'crass advocacy', as one researcher described it to me.

Remember, even a local media release gets transmitted across the length and breadth of the country. We have found that if it's got something that people are interested in, there's massive response to it.

Never forget that when working in Aboriginal health, your key audience has to be Aboriginal people. The main media I use are Aboriginal… Koori Mail, community radio stations, networked organisations like the National Indigenous Radio Service who do news bulletins. If people hear that there's good work going on, then they will track it down – and they do regularly. Because there's no one more desperate to find solutions to Aboriginal health than those people who happen to be Aboriginal themselves and live in communities where it has such a huge impact on their lives and their families' lives.

Preparing for a media interview

For many researchers there will be employer regulations about talking to the media or to politicians. Find out what they are. There are two critical things in communication, one is what you key messages are, and the other is your audiences. Have those two sorted in your head. Before the interview, write some dot points of what your key messages are. Get down to ten points, at the most.

One of the ways of making research really relevant and easily accessible to people is to try and personalise it, talk about the impact on a hypothetical patient or a hypothetical community. Because like all professionals, researchers often tend to speak in jargon and assume a lot of prior knowledge. I think historically people have been fairly intimidated by academics and researchers – and certainly many Aboriginal people have been.

Writing a media release

… in terms of media you don't need to necessarily have the entire story in there, every last detail, because it's not like getting it published in a peer-review journal. It's about trying to get it on the front page of a newspaper and the news bulletin on the ABC, and then if people are interested they will chase that research up. And there are some good impacts in that – working in this way there's a much greater likelihood of the research being taken up.

If media are reporting in a negative way it can be detrimental, especially if journalists don't really understand the bigger issues that inform the research.

Using images, artwork, music and digital media

The beauty of film is that once it's produced and you're confident in the end product, it can be played for years and years in a variety of forums. It reaches a wide audience. It doesn't matter if it's kids or Elders – everyone loves to see a film (Paul Stewart, Research and Community Development Officer, Onemda VicHealth Koori Health Unit).

Research findings can reach wide audiences when visual images, artwork, music, film and digital media are used. These are good mediums for letting the communities know more about what you found in your research. However, these formats can present dilemmas around cultural and intellectual property, privacy and ownership. For this reason, they often need to be factored into ethics approval processes. There are pitfalls for the unaware that can compromise trust, jeopardise people's rights and put you in a difficult ethical position.

Tips for researchers using images, artwork, music and digital media

When preparing to use people's images, words or music make sure you think through the questions that follow.

What do people need to know?

Consider:

- Who else has interests in this material (e.g. the community, university, government departments, non-governmental organisations, the mainstream media etc.)?

- If you receive consent to use an image that will be 'publicly communicated' or 'published' on a website – what website? Who will see it? Will the person who gives consent be able to request that it be removed later? Will someone else will be able to take that image and use it elsewhere?

- What 'publicly communicated content' actually means (e.g. this might include printed community reports; appearances in the news and in media publications; promotional material such as brochures and posters; websites, social networking sites and YouTube).

- The advantages for you, the researcher.

- The advantages for the person being filmed/photographed or interviewed.

- The advantages for the community.

What do I need to do?

Unpack the product into stages/steps – for example:

- Making a film involves research and project development, script development, pre-production and production, editing and post-production, screening and broadcasting, and footage archiving.

- Using a photograph involves sourcing or taking the photograph, agreeing on placement and context, attribution and distributing the resource.

Prepare well:

- What needs to be done and decided at each stage?

- What are the intellectual property and Indigenous knowledge issues? How do I take care of them with respect and sensitivity?

- What resources do I need on hand (e.g. fact sheet, FAQ sheet, consent forms)?

Allow plenty of lead-time:

- Negotiate terms well in advance and before the camera rolls; make your first visit (or a number of visits) without the camera.

- Get approval for different stages (e.g. permission to be filmed, signing off edited version and final product etc.).

Example sign-off email:

'Thank you very much for agreeing to be interviewed and for providing consent to be filmed. ***[Insert key points of contact here e.g. editor's and director's names here]*** *has edited your interview and included the excerpt in a* ***[insert type of product here e.g. promotional video]*** *for the purposes of* ***[insert purpose here e.g. website(s) URLs; brochures]****. We would like to give you an opportunity to comment on whether you are happy with the way you have been portrayed in* ***[name project and product here]****. You can read the transcript (attached) or view the video at the following private website* ***[insert website URL here]*** *by entering the following user name and password* ***[insert username and password here]****.'*

Set up an agreement for the management of raw material (e.g. unpublished images, sound recordings, captured footage) and final products:

- Will unused footage be destroyed, archived in a central depository or given back to the community?

- If the final product is available on a website, will the product be reviewed after two/four/six years? (Is it still relevant? Has a person in the film passed away?).

- If parental consent was given for using a child's image, what happens when he/she reaches an age to grant or withhold his/her own consent?).

Never assume anything. Always consult. If in doubt, leave it out. Always ask!

Is there material that might be sensitive?

• Review each frame or photograph for any copyright issues or the use of sensitive material. Check what appears in the foreground/ background (e.g. artwork). Is there litter, property damage or behaviour that could misrepresent the community?

• Think about how images of children, the elderly and people who are sick may be used now and into the future. If these images are handed over to the media, will they be portrayed inappropriately?

• Negotiate what should be done in the event that an individual appearing in the footage passes away.

• How do you decide what's public and what's private when people are sharing stories about their personal health (e.g. in a video recording)?

You need to include a statement about sensitivities and Indigenous viewer advice on all videos and websites, and on some printed material. For example, the ABC states on websites and at the start of programs: *'Advice: Aboriginal and Torres Strait Islander viewers are advised that this website/film may contain images and voices of people who have died.'*

} The 'Sensitivity' page on the AIATSIS website provides warnings about sensitive materials in relation to language and deceased persons (www.aiatsis.gov.au/sensitivity.html).

Table 2: Guide to using images, artwork, music and digital media (overleaf) lists issues to be considered and resources needed at various stages when negotiating and using images, artwork, music and digital media in research products.

Table 2: Guide to using images, artwork, music and digital media

Formats	Examples	Things to consider	Useful resources
1. Asking permission and negotiating terms of use			
Photographs	Sourcing a photograph taken by someone else, or for another purpose.	Has the photographer given permission? Have subjects given permission for use in this context? How can you obtain consent for use for this purpose?	Australia Council for the Arts Protocols for Producing Indigenous Australian:
Artworks			
Video/film	Requesting permission to take or use a photograph for a report.	How will the image/interview/recording be used (e.g. websites, social networking)? Will it be released to the media?	Visual arts
Audio recordings			Media art
Music	Seeking permission from a community to film for a university project.	Include all possible uses you may have when asking permission (e.g. in report, newsletter, poster, website).	Music
		How will it be edited? Will it be given to a third party? Will protocols get passed on in the handover?	Performing arts
			Writing.
	Buying artwork from an artist to illustrate a research report.	Do community members being filmed understand the purpose of the film and how their images will be used? Have you prepared a plain English statement? If needed, do you have an interpreter? Do you have suitable consent forms/processes (e.g. spoken consent on film)?	Australian Copyright Council.
	Using an Indigenous artist's song to back a film you are making to report findings.		National Association for the Visual Arts.
		Do people want to be identified or to be anonymous?	(See Bibliography on p.279)
	Using free downloadable music in films and presentations.	Buying an artwork does not mean you can reproduce and publish it: the artist needs to grant permission, which may involve a fee.	
		Licensing agreements often apply to music. Check conditions and costs.	
		Check if third-party permission is needed when using open access software.	

2. Collecting material on the ground

Photographs Video/film Audio recordings Artworks	Taking photographs of people in community and work settings. Shooting film footage of health workers in the field. Filming a musician while performing.	Images in foreground and background may be sensitive. Are people and place identifiable? Are there sensitive images? Who needs to give consent? Use of language in film: what is being said? Who are the contacts (name, address, telephone number etc.) in the community? Who is the next of kin? Who is the researcher/point of contact, now and in future? The musician may be happy to perform for the film, but is there a contract with a record company that prohibits it? Are there royalty fees?	FAQ sheet to answer questions (e.g. what does putting it on a website really mean? How is wider coverage managed?). Plain language statements. Consent forms for photography/film etc. Written agreement to avoid problems later.

3. Negotiating Memoranda of Understanding, licensing agreements, IP ownership

Video/film Audio recordings	A community organisation teams up with a research institution to make a DVD about a project in the community. A non-government organisation wants to show a film not produced by them on their website in order to raise funds for those portrayed in the film.	Who owns the material? Has sharing of benefits and ownership been considered? Shared IP means shared copyright: it is important to put your name to it to take responsibility for future use and contact with community. Reproduction: copyright relates to downloading from the Internet, using others' work in PowerPoint presentations, showing artworks etc. Permission is needed. Who is the community contact? Who is the university/organisation contact? Has appropriate research ethics clearance for communications products and outcomes been factored in?	Research ethics committees. Community consent processes. Copyright agreements. Reciprocal agreements. Plain English statements.

Formats	Examples	Things to consider	Useful resources
3. Negotiating Memoranda of Understanding, licensing agreements, IP ownership *Continued…*			
		What is the subject agreeing to by signing a consent deed?	
		How are differences in language, interpretation and understanding managed?	
		Western concepts of ownership and law versus traditional concepts of collective ownership.	
		Culture, language, stories, dance, artwork are locally specific, and need case-by-case agreement. You need to respect authenticity when putting material together.	
4. Deciding how a product is used			
Editing video footage	Website, annual reports, community reports, television, radio etc.	Has the edit been approved by participants?	Copyright advice.
Altering and inserting image into a report		Films and videos could end up on YouTube as part of a university or organisation marketing strategy. Are participants aware of this and ok with it?	Sign-off process/forms.
Editing a song			
5. Storage and archiving			
Locally stored	Need to archive the product coming from the research.	Who takes responsibility for storage and where does the raw footage/audio get stored?	Some research organisations may offer secure storage on a server.
Stored on accessible shared drive	Often need to archive unedited raw footage or tapes.	Has the community/individual been given copies?	Individual back-up options are available, e.g. mass storage memory sticks.
		Who takes responsibility for telling the community where the content is stored?	

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5. Storage and archiving *Continued...*

Archived with organisations and libraries (e.g. AIATSIS)	Who can access it? For what purpose? Is there an agreed date on which the archived footage should be destroyed?	Central depositories (e.g. AIATSIS, National Library of Australia) can archive and/or respectfully caretake finished product.

6. Review and follow-up (ongoing and impartial)

Is there an ongoing contact between the community and the research organisation?	Who is the community contact if circumstances change (e.g. death of contact)?	Record-keeping systems.

For more advice about using images, artwork, music and digital media see the 'Useful Resources and Websites' section on the Lowitja Institute website (www.lowitja.org.au/resources-researchers).

Key messages for researchers

- Plan for reporting and dissemination when you plan the project.

- There are many ways to share research findings. They need to be tailored to meet the needs and preferences of each research user group.

- Research findings and research messages are not the same thing. Findings need to be turned into messages that have meaning for the research user group.

- Decisions about the way you share research findings and messages will be easier if you have developed relationships with research user groups before/during the project.

- Skills and knowledge needed for reporting and dissemination are varied, and often specialised. Working in partnership with others is usually critical to success.

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