

# Indigenous Research: A Commitment to Walking the Talk. The Gudaga Study—an Australian Case Study

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**Abstract** Increasingly, the role of health research in improving the discrepancies in health outcomes between Indigenous and non-Indigenous populations in developed countries is being recognised. Along with this comes the recognition that health research must be conducted in a manner that is culturally appropriate and ethically sound. Two key documents have been produced in Australia, known as The Road Map and The Guidelines, to provide theoretical and philosophical direction to the ethics of Indigenous health research. These documents identify research themes considered critical to improving the health of the nation's Indigenous peoples. They also provide values that, from an Indigenous perspective, are foundational to an ethical research process. This paper examines these research themes and values within the context of a current longitudinal birth cohort study of Indigenous infants and children in south-west Sydney: the Gudaga Study. Considerable time and effort have been invested in being true to the

values stated in these documents: reciprocity; respect; equality; responsibility; survival and protection; and spirit and integrity. We have learnt that it is vital to be true to these values when conducting Indigenous health research—to quite literally “walk the talk”.

**Keywords** Indigenous populations

## Introduction

Discrepancies in life expectancies between the Indigenous and non-Indigenous populations of developed countries are well acknowledged. In Australia the health of the nation's Indigenous population has repeatedly been shown to be poor compared to the general Australian population, with lower life expectancy, a greater burden of disease and higher hospital separation rates (Australian Institute of Health and Welfare 2008). These poor health outcomes commence prenatally and continue across the lifespan. Of particular relevance to this paper is the health and development of Indigenous infants and children. When compared to non-Indigenous infants aged less than 12 months, these children have: lower birth weights (Sayers and Powers 1993; Australian Institute of Health and Welfare 2002; Leeds et al. 2007; Australian Institute of Health and Welfare 2009); higher rates of premature births (Leeds et al. 2007); slower growth (Rousham and Gracey 1997); greater morbidity (Leeds et al. 2007; Australian Institute of Health and Welfare 2009); and higher rates of hospital admissions (Read et al. 1994) and Sudden Infant

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Death Syndrome (Australian Institute of Health and Welfare 2009).

Countries such as Australia, New Zealand and Canada are increasingly recognizing the role of health research in improving the health outcomes for Indigenous populations (Cunningham et al. 2003). However, the way these three countries fund Indigenous health research differs. Australia and New Zealand direct funding for Indigenous health research through their respective national research funding organisations (the National Health and Medical Research Council [NHMRC] and the Health Research Council of New Zealand respectively). Canada has gone a step further and established a dedicated Indigenous health research centre, the Institute of Aboriginal Peoples' Health (Canadian Institutes of Health Research 2007). This Institute is responsible for setting and overseeing that country's Indigenous health research agenda.

Historically, research with Indigenous people in Australia has a chequered history. There are perceptions among Indigenous groups that research has been undertaken out of “curiosity”; has not respected Indigenous culture and practices; has not benefited the communities where it was conducted or Indigenous communities in general; and that Indigenous people will, as a result of these past practices, not participate in research. A realization that research evidence documenting health and health needs of Indigenous people is necessary to support interventions to “close the gap”—as one Australian government policy termed it—in the life expectancies of Indigenous populations has led to a renewed commitment in Australia to Indigenous health research by the NHMRC. The NHMRC has established specific Indigenous research committees to oversee research funding and other related activities in Indigenous communities. Specific strategies to promote the ethical conduct of research among Indigenous people have been lead by these committees and have resulted in the development and implementation of consensus statements and guidelines to support research in Indigenous communities (National Health and Medical Research Council 2002, 2003). Similar documents have been produced by other countries with significant Indigenous populations: for example, New Zealand (Health Research Council of New Zealand 1998) and Canada (Canadian Institutes of Health Research 2007).

In Australia, the NHMRC has increased funding for Indigenous research and supported the production of guidelines to ensure its ethical conduct. These guidelines

include the *Strategic framework for improving Aboriginal and Torres Strait Islander health through research* (known as the Road Map) (National Health and Medical Research Council 2002) and the *Values and Ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research* (known as the Guidelines) (National Health and Medical Research Council 2003).

The Road Map was published by the Aboriginal and Torres Strait Islander Research Agenda Working Group of the NHMRC and is currently under review (National Health and Medical Research Council 2008). This document identifies six research themes considered critical to improving the health of Indigenous people (see Box 1). The Road Map identifies a need for research that is descriptive in nature and longitudinal in design. In particular the Road Map calls for descriptive research that outlines patterns of (amongst other matters) health risk as well as cohort studies that consider infancy and childhood. The Road Map specifically identifies the paucity of information on the health needs of urban communities and the “significant research gap” on issues faced by urban and urban fringe Indigenous populations (National Health and Medical Research Council 2002, 13).

#### Box 1

##### Research themes identified in the Road Map

1. descriptive research outlining patterns of health risk, disease and death over time (including longitudinal studies);
2. a research focus on factors and processes that promote resilience and wellbeing such as cohort studies;
3. a focus on health services research which describes the optimum means of delivering services and interventions to Aboriginal peoples;
4. a focus on the link between health status and policy and programs lying outside the direct influence of the health sector;
5. research in under-researched Aboriginal communities including urban areas;
6. health research capacity building.

The second document, the Guidelines, identifies six values that, from an Indigenous perspective, are fundamental to an ethical research process (National Health and Medical Research Council 2003).

The process of developing these guidelines, described as “lengthy and sometimes difficult”, has been reviewed by a number of commentators including Humphery (2003, 14), Dunbar and Scrimgeour (2003) and Gillam and Pyett (2003). A companion publication to the Guidelines is the NHMRC document *Keeping research on track. A guide for Aboriginal and Torres Strait Islander peoples about health research ethics* (National Health and Medical Research Council 2005). This document provides an explanation of ethical health research and the values and principles found in the Guidelines. These values include:

1. reciprocity
2. respect
3. equality
4. responsibility
5. survival and protection
6. spirit and integrity.

While the Road Map and Guidelines identify the constituents of “ethical research” from an Indigenous perspective, there is limited information in the published literature on their implementation into new research programs. Two papers, based on research conducted in Western Australian, do consider the values identified in the Guidelines: Gower’s school based research project (Gower 2003); and the Kalgoorlie otitis media project (Lehmann et al. 2008). Gower’s paper draws upon his fieldwork experience rather than identification of the strategies he used to implement the Guidelines. His work is both urban and rural based but within the educational rather than health domain. Lehmann et al.’s study goes a step further than Gower, in that it identifies and discusses the strategies they used in their commitment to adhere to the Guidelines. Their work, while health oriented, is within a remote setting. To date, we have been unable to identify any papers describing the implementation of the type of research called for in the Road Map and the values identified in the Guidelines to Indigenous child health research within an urban context.

### Aim

The aim of this paper is to describe our approach to implementing the recommendations of the Road Map

and the Guidelines into the development and implementation of a longitudinal birth cohort study, the Gudaga Study, among urban Indigenous infants. It is not our intention to review the process of developing the Road Map or Guidelines or to evaluate critically the role of the documents in Indigenous health research as these have been done by others including Humphery (2003); McKendrick and Aratukutuku Bennett (2003); Dunbar and Scrimgeour (2005); and Anderson et al. (2003). Our intention is to demonstrate how we have operationalised the principles found in these two documents—how we “walk the talk”.

The Gudaga Study is an eight-year, NHMRC funded, longitudinal birth cohort study of Indigenous children and their mothers, living in an outer urban area of south-west Sydney. The study is describing the birth outcomes, health, development and health services use of children and their mothers. The cohort was recruited using a maternity ward survey of mothers between October 2005 and May 2007 (Comino et al. 2009). All mothers participating in the study gave their informed written consent. A strong feature of the study is the employment of Indigenous Project Officers who are themselves mothers of young children and members of the local Indigenous community. They visit the Gudaga mothers in their homes every 6 months. At each home visit a structured questionnaire is completed which seeks age-appropriate information on a range of health-related issues. At three intervals the children receive a full health and development assessment conducted by a paediatric registrar.

The study was approved by the NSW Aboriginal Health and Medical Research Council and Sydney South West Area Health Service Human Research Ethics Committees. At the local level, approval for the study was given by the board of Tharawal Aboriginal Corporation (hereafter referred to as Tharawal), our local Aboriginal Community Controlled Health Service.

### Implementing the Indigenous Health Research Guidelines

In implementing this research we were committed to developing “best practice” protocols that incorporated the key recommendations of the Road Map and Guidelines.

Many features of the Gudaga Study are in keeping with research recommendations called for in the Road Map, including the longitudinal and descriptive nature of the study, and the use of a birth cohort in an urban setting. Within Australian Indigenous child health research, few studies have sought to combine all of these recommended elements. Yet study designs of this nature are very appropriate to Indigenous health research. These studies are sensitive to history (personal or community), allow the investigation of relatively complex health-related issues and may contribute valuable information towards a “big picture” understanding of health and health outcomes in Indigenous communities (Grove et al. 2003, 638).

The Guidelines consider the values it identifies to be as important as scientific rigor (National Health and Medical Research Council 2003). While most researchers believe that these values underlie their research, the experience of many Indigenous communities suggests these values have been hard to incorporate systematically into practice. In designing and implementing the Gudaga Study considerable investment of time and resources was made to ensure implementation of the values. Our approach is described below.

### Reciprocity

The Guidelines define reciprocity as “mutual obligation” (National Health and Medical Research Council 2003, 10) which, within the research context, means inclusion and recognition of the contribution of all research partners (National Health and Medical Research Council 2003). This value calls for research outcomes that provide equitable benefits of value to Indigenous communities or individuals—benefits that must be valued by the participating Indigenous communities and be defined by those communities according to their own values and priorities.

Reciprocity involves exchange. Within the Gudaga project, exchange occurs within the four Indigenous groups that make up the study (see Table 1). This Table identifies the qualities each of the Indigenous groups brings to the study. It also identifies the attributes the study exchanges with each group. The items vary from the abstract (wisdom and knowledge) to the concrete (baby photos).

In this community, the giving of photos is not as trite as it may seem. This is a community where

ownership of a camera is a luxury beyond the reach of some families and many of our mothers place great value upon the receipt of these photos. This is probably what the Guidelines meant when it suggested Indigenous peoples may place “greater or lesser value on the various returns than the researchers” (National Health and Medical Research Council 2003, 10). The photos also demonstrate our commitment to reciprocity even if there is no opportunity for anything to be returned. Unfortunately, several of the babies in the study have died. Each death effectively means the family is no longer involved in the study. However, in each instance, our Project Officers have given the mothers photos taken before the death of each baby. This simple gesture to mothers who are no longer part of the study means so much to families who have very few photos. Wherever possible, photos are also given to mothers whose babies have been removed from their home by the state’s welfare agency, the Department of Community Services.

### Respect

The second identified value is respect. As the Guidelines acknowledge, this value is “fundamental” (National Health and Medical Research Council 2003, 11) to not only a functioning moral society, but also health research that has integrity and ethical standing. It is from a basis of respect that trust is nurtured. We have come to value trust as pivotal to the success of our study.

Of all the values identified in the Guidelines, respect has attracted the most attention within the literature. In addition to the Guidelines it is the emphasis of the *Cultural Respect Framework for Aboriginal and Torres Strait Islander health* (hereafter, the Framework) (Australian Health Ministers’ Advisory Council’s Standing Committee on Aboriginal and Torres Strait Islander Health Working Party 2004) and, at a more general level, the *Guidelines for ethical research in Indigenous studies* (Australian Institute of Aboriginal and Torres Strait Islander Studies 2000). Others such as Thomson (Thomson 2005) have also stressed the need for cultural respect in Indigenous health research.

While the primary aim of the Framework is to influence corporate health governance and organisational management many of the Framework’s principles provide valuable direction for studies such as

**Table 1** Reciprocity within the Gudaga Project

Indigenous groups involved in the Gudaga project	What the project gives to the Indigenous groups	What the Indigenous groups give to the project
Indigenous health organisations	Feedback	Expertise Experience
Local Indigenous healthcare professional	Capacity building Feedback	Expertise Local knowledge
Local Indigenous community (including the study's Indigenous project officers)	Opportunity for input Capacity building Training	Expertise Wisdom Local knowledge Encouragement to project mothers
Project mothers	Thank-you health packs Photos of baby/child Paediatric assessments at 1, 3 and 5 yrs	Access to babies/toddlers Willingness to answer survey questions honestly and openly

Gudaga. Table 2 identifies the Framework's principles and identifies examples of Gudaga's response to each principle.

Building respect and engaging with the participating communities takes time. This research has its genesis many years before the Gudaga Study was funded. Researchers from University of New South

Wales have worked with Tharawal and with Indigenous health workers over many years to advocate for additional health services for Indigenous infants, mothers and their families. The time spent "yarning" to support community identified initiatives earned the researchers community respect and trust. In Australia, the role of yarning in Indigenous health research process

**Table 2** Gudaga's response to the value of "respect"

Principle	Gudaga's response
Holistic approach	Questions in surveys (see Table Two)
Health sector responsibility	Describing health, development and health services use to better inform policy and resource allocation
Community control of primary health care services	Support Tharawal—long record of advocacy—roots of the study
Working together	Active partnerships with government, non-government and private organisations
Localized decision-making	Local Indigenous community determined issues to be investigated (otitis media and SIDS)
Building capacity	Training of Indigenous staff Opportunities to build capacity of Indigenous Associate Investigators
Accountability	Regular reporting to Tharawal Management Board Community forums will be held as results become available

is not new. It was, for example, pivotal to the success of the 2001 Cooperative Research Centre for Aboriginal and Tropical Health's *Yarning about research with Indigenous peoples* workshop (Cooperative Research Centre for Aboriginal and Tropical Health 2001).

We have also nurtured and developed active partnerships with a number of other organisations including the regional health service, non-government organisations and private companies. These partnerships have provided the study with everything from postage and accommodation to the small "thank you" gifts we give to participating infants and their mothers. The participation of a wide cross-section of the community speaks of the respect held by many of the local Indigenous community.

The Framework suggests a holistic approach that acknowledges the relationship between physical, spiritual, cultural, emotional and social wellbeing, and community capacity (Australian Institute of Aboriginal and Torres Strait Islander Studies 2000). We incorporate this principle in the questions we ask the mothers at each contact point. A sample of the questions pertaining to each domain is found in Table 3.

Closely tied to respect is the value of trust. It has been suggested (see for example Pyett (2002)) that the issue of trust is pivotal to Indigenous health research. Some Indigenous researchers such as McKendrick and Aratukutuku Bennett have contended trust has been "forever violated" (2003, 22) by past research conducted in Indigenous communities. This has not been our experience. We are constantly astounded at the level to which participating mothers will confide in the Project Officers; the level to which they will disclose information over and above that which is

sought through the structured questions asked of each mother. We originally decided against asking about drug-taking habits fearing this would be seen as intrusive to the mothers and we may not obtain accurate information. During the first few months of conducting the first round of interviews we found many mothers volunteered the information. On the basis of this experience we subsequently included some questions on illicit drug-use. Similarly, mothers freely talk to the Project Officers of their experiences with domestic violence and financial stress. We consider the trust, openness and engagement of the mothers to be as important as the scientific rigor of the study's investigation.

### Equality

Equality, and the equal value of all people, is the Guidelines' third value (National Health and Medical Research Council 2003). The lack of equality within Indigenous communities is well documented. So too is the correlation between social and economic inequality and poor health. The Guidelines identify three components of equality: valuing knowledge and wisdom; equality of partners; and the distribution of benefit (National Health and Medical Research Council 2003). Gudaga is attempting to incorporate each of these components in its work.

We place a strong emphasis on the knowledge and wisdom of the various groups within our local Indigenous community. The mothers and Indigenous Health Workers of the local community, for example, identified the issues to be included in the research design. Our Project Officers were selected on the

**Table 3** Dimensions of wellbeing addressed in survey questions

Dimensions of wellbeing	Questions asked of mothers
Spiritual	How important is Indigenous ceremonial business to you (or your partner)?
Cultural	Do you (or your partner) speak an Indigenous language?
	Do any of your children speak an Indigenous language?
	Do any of your children understand this language?
Emotional	Is being a mother what you expected?
Social wellbeing	What positive things have happened to you and your family as a result of having this baby?
	If something went wrong, no one would help me?
	I have family and friends who make me feel safe, secure and happy?
	There are people I can count on in an emergency?
	Who do you go to for most of your support?

basis of their local knowledge rather than, as is standard practice, academic qualifications and formal research experience. Every Indigenous Health Worker in the immediate geographic area (including the area health service) is given the opportunity to contribute their knowledge and wisdom through a variety of forums. We meet regularly with the board of Tharawal Aboriginal Corporation to seek their input.

Our commitment to the equality of all partners is seen within the research team. If the research team was chosen on the basis of traditional research expertise measures, we would not have the team we needed any more than if we had a team comprising exclusively of great wisdom and experience in Indigenous cultures and health. The challenge and achievement has been a team of equals who provide all the skill sets required. We therefore explicitly recognise the knowledge base and cultural understanding our Indigenous investigators bring to the research team and the study. These attributes are valued just as much as formal qualifications and academic experience.

The Guidelines recognise the distribution of benefit to be “a fundamental test of equality” (National Health and Medical Research Council 2003, 15). Though the study’s results are still some way off, thought has already been given to ways the study’s benefits will be shared with the Indigenous community and our other Indigenous partners. It is anticipated a mix of aural and written formats ranging from easy-to-read factsheets to community forums will be used to ensure as broad a cross-section of the community as possible are able to access the results arising from the study.

### Responsibility

The fourth value identified in the Guidelines is responsibility (National Health and Medical Research Council 2003). A key responsibility is to do no harm (National Health and Medical Research Council 2003). For those of us who work on Gudaga this means we carry certain responsibilities. These responsibilities are in addition to the science of our inquiry and they are based on the recognition of past wrongs: **ALL RESEARCHERS SHOULD DO NO HARM.**

Gudaga researchers have a responsibility to do no harm to the Gudaga babies, mothers, or their immediate and extended families. The study’s proto-

col stipulates that one of the Indigenous Project Officers must be present at each contact point. Other researchers, students and paediatricians may need to be present but they can only do so in the presence of the Project Officer. This safeguard is in place to ensure that the research is being undertaken in a culturally safe environment.

The Guidelines also require researchers to establish processes to ensure accountability to individuals, families and communities (National Health and Medical Research Council 2003). Gudaga has set in place a number of accountability components. All participating mothers are given the contact details of our area health service’s ethics committee which they can contact at any stage should they have concerns. Confidentiality is assured. It is also well known amongst participating mothers that we have strong links with Tharawal and they know they could speak with Tharawal staff should they have any accountability concerns or if there are any other problems or issues.

### Survival and Protection


This value is based on past practices which saw Indigenous cultures eroded and marginalized. There is, understandably, a strong priority amongst Indigenous peoples to protect their culture and identity (National Health and Medical Research Council 2003). This value recognises that, for many Indigenous peoples, health research is “inextricably linked with colonisation and its ongoing consequences” (McKendrick and Aratukutuku Bennett 2003, 20). The value also acknowledges Australia’s past research history of Indigenous communities. At best, many of these communities were over-researched and under-compensated. At worst, as Grove, Brough, Canuto and Dobson point out, they were “exploited, stigmatised, disrespected and misrepresented” (Grove et al. 2003, 638). For many Indigenous communities, past research practices influence the participation in research today.

While the Gudaga team appreciates the ways in which some past research exploited both communities and individuals, we do not sense this to be the experience of the mothers participating in this study. For many, if not all, of the project mothers, this is the first time they (or their extended family) have been involved in a research study. The

mothers generally view their involvement as a positive step toward the provision of better health services for their children.

Whether or not the study mothers feel exploited, we still have a commitment to incorporating the values of survival and protection. One way we have done this is through the recognition and incorporation of the distinctiveness of Indigenous cultures, in particular language and art. For us, the inclusion of Indigenous language and art is recognition of the cultural distinctiveness of Indigenous peoples and their right to enjoy that distinctiveness. The study's

name, "Gudaga", means "healthy baby" and comes from the local Tharawal language. It was suggested to us by local Indigenous health workers. Indigenous art has also been incorporated into the study. Our commitment to including Indigenous art was somewhat tested when the community's senior women elders insisted any artwork concerning mothers and babies had to be designed by a woman. This was not an easy request but we finally found a local Indigenous mother who created a wonderful logo featuring Indigenous art that is rich in maternal/child symbolism (see Box 2).

	<p style="text-align: center;"><b>Box 2</b></p> <p>The project's logo was designed by Tracey Skinner, a young Gumbaiyngar Yaegal mother living, at the time, in our local Indigenous community. The logo is rich in maternal-child symbolism:</p> <ul style="list-style-type: none"> <li>• the four squares are the four services connected to the project;</li> <li>• the four heavy wavy lines are the pathways that lead the women into the project;</li> <li>• the outer circle is the hospital</li> <li>• the wavy line within the circle is the emotional journey of having a baby;</li> <li>• the dots are the 12 months the babies will be involved in the project;</li> <li>• the inner circle is the womb and the kidney shape is the foetus;</li> <li>• the circle is purple and this colour was chosen to symbolise women.</li> </ul>
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The logo is used extensively throughout the study. It is, for example, featured on all promotional material that informs the community of the study. The logo is also featured on the shirts worn by staff and many of the gifts we give the mothers and babies. These gifts include screen printed "I'm a Gudaga baby" and "I'm a Gudaga kid" t-shirts and bright yellow sunhats with the same wording. Mothers receive a coffee mug featuring the logo. Gifts such as these have been specifically designed to engender a sense of involvement in the study.

### Spirit and Integrity

This value, acknowledging the links that bind the generations together, is considered to be the "overarching value" that connects the other five into a coherent whole (National Health and Medical Research Council 2003, 19). It is made up of two components: continuity between past, current and future generations; and behaviour that maintains coherence of Indigenous values and cultures. The Guidelines are not the only publication to recognise the importance of this value.



Smith (1999), for example, suggests it is a Western assumption that the individual is the basic social unit. She questions methodologies that assume the individual is the appropriate unit of analysis (Smith 1999). Grove et al. (2003) build on this view and suggest public health questions, framed in a Western paradigm, that appear to require individual-based investigation may need to be reconsidered when working in an Indigenous context.

The Gudaga Study has a strong focus on not only the child, but the child's mother and the extended family that supports the mother/child dyad. The questions asked at each home visit, for example, include questions not only of the child's and mother's health and health service use but also the involvement of the extended family, friends and community.

We have a small number of toddlers who, through the intervention of the Department of Community Services, live with their grandmothers. In each case the grandmothers have agreed to their grandchild remaining in the study. In working with two, and occasionally three, generations Gudaga acknowledges past, current and future generations and the links, within Indigenous culture, that bind the generations together.

## Conclusion

What began as a yarn under gum trees over ten years ago has resulted in the first longitudinal birth cohort study of Indigenous infants and children to be conducted on the east coast of Australia—the Gudaga Study.

Underpinning the development and implementation of this research has been the recommendations of two key NHMRC documents known as the Road Map and the Guidelines. These two documents have broad implications for the conduct of Indigenous health research by identifying values and principles to consider and demonstrate at each stage of the research process. In many instances Indigenous health research is strong on rhetoric but short on application. Much of current research fails to be bound by the philosophical and ethical foundation called for in these documents. Gudaga demonstrates that it is possible to adhere to the research themes of the Road Map and the values of the Guidelines: to do considerably more than “talk the talk” but to go the next step and actually “walk the talk”.

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