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CHAPTER 1: BACKGROUND TO THE STUDY AND LITERATURE REVIEW

1.1 Indigenous Health in Australia

By all accepted indicators of health status, Indigenous Australians have poorer health than non-Indigenous Australians. The disparities in health outcomes for Indigenous Australians have been well documented in a large number of government reports (eg ABS & AIHW 2005, AIHW 2004, AIHW 2006, AIHW 2007, Shannon et al 2003) and other reviews (eg Australian Medical Association 2007, Oxfam Australia & National Aboriginal Community Controlled Health Organisation 2007, National Rural Health Alliance 2006). Inequitable disparities between Indigenous and non-Indigenous populations are seen across virtually all accepted measurements of health status including birth weight, perinatal mortality, vaccination rates, infant hospitalisation rates, rates of infectious and chronic diseases, dietary indicators, obesity, self-assessed health, and life expectancy (AIHW 2004, ABS & AIHW 2005, AIHW 2006). Indigenous Australians have lower life expectancy, higher infant mortality, higher hospitalisation rates, and higher rates of adult mortality from all major causes of death (Dwyer et al 2004, ABS & AIHW 2005, AIHW 2006). The life expectancy at birth for Indigenous Australians born between 1996 and 2001 is estimated to be approximately 17 years less than their non-Indigenous counterparts (HREOC 3 2005). Differences in life expectancy between Indigenous and non-Indigenous Australians by gender are illustrated in Table 1-1 below.

Table 1-1: Average life span for Indigenous Australians and total Australian population

<table>
<thead>
<tr>
<th>Population</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous Australians, 1996-2001</td>
<td>59.4</td>
<td>64.8</td>
</tr>
<tr>
<td>Total Australian population, 1998-2000</td>
<td>76.6</td>
<td>82.0</td>
</tr>
</tbody>
</table>


---

1 Australian Bureau of Statistics (ABS)  
2 Australian Institute of Health and Welfare (AIHW)  
3 Human Rights and Equal Opportunity Commission (HREOC)
Trends in mortality among Indigenous populations indicate that mortality rates have not improved in Australia over time. Figure 1-1 indicates crude death rates over a decade among Indigenous people in Western Australia, South Australia, and the Northern Territory. Crude death rates are calculated by dividing the number of deaths in a given year by the total population, then multiplying by 100,000. The figure indicates little or no improvement in death rates across all three states/territories over the ten year period.

**Figure 1-1:** Indigenous crude death rates (a) for Western Australia, South Australia, and Northern Territory: 1991-2002*

![Indigenous crude death rates graph](image_url)

(a) Deaths are based on year of occurrence of death and state of usual residence.
(b) Deaths per 100,000 population.

* Reproduced from: ABS & AIHW (2005). *The health and welfare of Australia’s Aboriginal and Torres Strait Islander peoples*. Canberra: Commonwealth of Australia: Figure 9.31.

Ring et al have compared trends in life expectancies for Indigenous populations across developed nations. His research (Figure 1-2) demonstrates again that mortality rates among Indigenous Australians have not improved over time; however, Indigenous populations in countries such as Canada and New Zealand have enjoyed marked improvements in life expectancy over twenty years. These trends suggest that rapid reductions in mortality rates are feasible (Ring et al 1998).
**Figure 1-2:** Trends in annual all-cause mortality rates* across Indigenous Australians, Maori, Native Americans, and All Australians: 1974-1995**

* standardised to the World’s Standard Population, 1960

** Reproduced from: Ring I & Firman D. Reducing Indigenous Mortality in Australia: lessons from other countries. *MJA* 1998; 169: 530, Figure 1.

Figure 1-3 illustrates age-standardised mortality rates across four developed nations—Australia, New Zealand, USA, and Canada. The discrepancy in mortality rates between Indigenous and total populations is greatest in Australia.
Figure 1-3: Age-standardised mortality rates of people in Australia, New Zealand, the United States and Canada, by Indigenous status*


Data from the Australian Bureau of Statistics and Australian Institute of Health and Welfare report the main reasons for hospitalisation of Indigenous Australians are circulatory diseases, diabetes, respiratory diseases, musculoskeletal conditions, kidney disease, eye and ear problems, and mental and behavioural disorders (ABS & AIHW 2005). These diseases make a considerable contribution to the morbidity and mortality experienced by Indigenous populations in Australia. The three leading causes of mortality are circulatory diseases, external causes of death (predominantly accidents, suicide, and assault), and cancer (ABS & AIHW 2005).

In comparison to non-Indigenous Australians, Aboriginal and Torres Strait Islanders suffer proportionally greater rates of diabetes, cancers, ischaemic heart disease, liver disease, intentional self-harm, mental and behavioural disorders due to psychoactive substance use, car accidents, and other forms of heart and circulatory diseases. Table 1-2 compares the prevalence of selected conditions among Indigenous and non-Indigenous populations, while Table 1-3 compares causes of death between these populations.
Table 1-2: Age-standardised prevalence of selected conditions (a,b,c) for Indigenous vs. Non-Indigenous Australians: 2001*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Indigenous</th>
<th>Non-Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye/sight problems</td>
<td>46</td>
<td>51</td>
</tr>
<tr>
<td>Musculoskeletal diseases</td>
<td>35</td>
<td>32</td>
</tr>
<tr>
<td>Arthritis</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Diseases of the respiratory system</td>
<td>33</td>
<td>30</td>
</tr>
<tr>
<td>Asthma</td>
<td>17</td>
<td>12</td>
</tr>
<tr>
<td>Circulatory problems/diseases</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td>Ear/hearing problems</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td>Endocrine, nutritional and metabolic diseases</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Diseases of the nervous system</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Digestive diseases</td>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

(a) Proportions have been age standardised using the 2001 estimated resident population of Australia.
(b) Total numbers have been weighted using ABS population estimates.
(c) Sum of components may exceed 100% as persons may have reported more than one type of condition.

Source: ABS, 2001 National Health Survey

* Reproduced from: ABS & AIHW (2005). The health and welfare of Australia’s Aboriginal and Torres Strait Islander peoples. Canberra: Commonwealth of Australia: Figure 7.7. Available online at:
Table 1-3:  Age-specific death rates for Indigenous vs. Non-Indigenous Australians aged 35-54: 1999-2003*

<table>
<thead>
<tr>
<th>Condition</th>
<th>INDIGENOUS</th>
<th>NON-INDIGENOUS</th>
<th>RATE RATIO (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
<td>Males</td>
</tr>
<tr>
<td>Ischaemic heart disease (I20–I25)</td>
<td>237.5</td>
<td>102.7</td>
<td>33.1</td>
</tr>
<tr>
<td>Diabetes (E10–E14)</td>
<td>73.6</td>
<td>56.7</td>
<td>3.5</td>
</tr>
<tr>
<td>Disease of liver (K70–K77)</td>
<td>69.0</td>
<td>45.3</td>
<td>8.3</td>
</tr>
<tr>
<td>Other forms of heart disease (I30–I52)</td>
<td>45.2</td>
<td>18.4</td>
<td>5.4</td>
</tr>
<tr>
<td>Intentional self harm (X60–X84)</td>
<td>45.2</td>
<td>7.8</td>
<td>7.8</td>
</tr>
<tr>
<td>Mental and behavioural disorders due to psychoactive substance use (F10–F19)</td>
<td>40.6</td>
<td>7.8</td>
<td>3.0</td>
</tr>
<tr>
<td>Malignant neoplasm of digestive organs (C15–C26)</td>
<td>36.8</td>
<td>15.6</td>
<td>2.4</td>
</tr>
<tr>
<td>Chronic lower respiratory disease (J40–J47)</td>
<td>35.2</td>
<td>26.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Influenza and pneumonia (J10–J18)</td>
<td>32.2</td>
<td>12.0</td>
<td>2.6</td>
</tr>
<tr>
<td>Assault (X85–Y09)</td>
<td>31.4</td>
<td>12.7</td>
<td>2.5</td>
</tr>
<tr>
<td>Cerebrovascular disease (I60–I69)</td>
<td>30.6</td>
<td>27.6</td>
<td>1.1</td>
</tr>
<tr>
<td>Malignant neoplasm of respiratory and intrathoracic organs (C30–C39)</td>
<td>30.6</td>
<td>19.1</td>
<td>1.6</td>
</tr>
<tr>
<td>Ill-defined and unknown causes of mortality (R95–R99)</td>
<td>26.1</td>
<td>10.6</td>
<td>2.4</td>
</tr>
<tr>
<td>Car occupant injured in transport accident (V40–V49)</td>
<td>25.3</td>
<td>11.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Pedestrian injured in transport accident (V01–V09)</td>
<td>20.7</td>
<td>12.0</td>
<td>1.7</td>
</tr>
</tbody>
</table>

a) Per 100,000 population.

(b) Data for Queensland, South Australia, Western Australia and the Northern Territory combined. Deaths are based on year of occurrence of death for 1999–2002 and year of registration of death for 2003. Disease groupings are based on three-digit groupings of ICD–10.

(c) Rate for Indigenous Australians divided by the rate for non-Indigenous Australians.

Source: AIHW, National Mortality Database


The social, environmental, and economic conditions of Indigenous people are regarded as significant contributors to the differences observed in health status (ABS & AIHW 2005, Carson et al 2007). There is considerable evidence that cultural and social disadvantage are key determinants of ill health (Marmot 2005). Regional analyses of Indigenous populations in Canada suggest that there is a correlation between poor health outcomes and living in neighbourhoods with lower socioeconomic status (Martens et al 2002, Martens et al 2006). Education, housing and infrastructure, employment, a history of dispossession, incarceration, and contact with the criminal justice system are other dimensions of social disadvantage that are believed to be associated with poorer health outcomes (Couzos et al 2005a, Durie 2003, Acheson 1998, Desai et al 1998, Pena et al 2000).
Overall, Indigenous Australians have lower incomes, educational attainment, and employment rates than non-Indigenous Australians (SCRGSP\(^1\) 2003, ABS & AIHW 2005).

It is evident that Indigenous people have poorer health than non-Indigenous people in Australia and that there are likely to be complex social and economic factors contributing to their health status. The continued lack of improvement in health outcomes for Indigenous Australians (Ring et al 2002, Ring et al 1998) indicates that currently, there are gaps in our knowledge base, and suggests that more research is needed to develop successful policies and programs capable of addressing health inequalities (Sanson-Fisher et al 2006, Acheson 1998, RAWG\(^2\) 2004).

1.2 Research to Improve Indigenous Health

1.2.1 The value of research in improving health for disadvantaged populations

There is considerable evidence that research can underpin substantial health gains. Health research that is priority-driven has the potential to contribute research evidence that directly influences and improves population health. Furthermore, health research that is characterised as priority-driven and intervention-based has the capacity to influence policy, shape practice, and impact health outcomes (HMRSRC\(^3\) 1998, IRHMRC\(^4\) 2004)

Information from research into Indigenous health can play a critical role in describing health, analysing the determinants of health and ill health, and in contributing to the development of effective policy and programs (Sanson-Fisher et al 2006, Anderson 2003, Thomson 2003). To improve health outcomes for disadvantaged populations, accurate information is needed about the causes of ill health and the relative effectiveness to improve health of different treatments, interventions, and programs (Acheson, RAWG). In Indigenous health, it is particularly important to understand the impact of policy changes, and to evaluate the impact of health interventions in improving population health outcomes (Grol et al 2003, Acheson 1998). To inform initiatives in this area, accurate demographic and health-specific information about these populations is necessary (Stephens et al 2006, Bramley et al 2004). A strong and detailed

\(^1\) Steering Committee for the Review of Government Service Provision

\(^2\) Indigenous Research Agenda Working Group of the NHMRC

\(^3\) Health and Medical Research Strategic Review Committee

\(^4\) Investment Review of Health and Medical Research Committee
evidence base specific to disadvantaged populations facilitates the development of cost-efficient policies and programs (Anderson 2003).

As shown in Figure 1-2 and Figure 1-3, the decrease in Indigenous mortality rates experienced elsewhere in the world has not occurred in Australia (Ring et al 1998, Ring et al 2002, Bramley et al 2004). Many authors have noted the need in Australia for more and better research targeting the major causes of death, relevant risk factors, and effective programs in Indigenous health to form the basis of better policy and programs (Thomson 2003, Anderson 2003, Ring et al 2002, Sanson-Fisher et al 2006, Bramley et al 2004, Couzos et al 2005a).

1.2.2 The characteristics of research most likely to improve health in disadvantaged populations


An international workshop organised between UN and UNESCO in 2004, concluded that “Indigenous peoples should fully participate as equal partners, in all stages of data collection, including planning, implementing, analysing and dissemination, access and return, with appropriate resourcing and capacity building to do so.” Research must also “respond to the priorities and aims of the Indigenous communities themselves” (Stephens et al 2006). These conclusions resound throughout the international literature—Indigenous inclusion and engagement are essential to conducting research that is significant, and capable of improving health outcomes and services (Schnarch 2004, Tuhiwai-Smith 1999). While it must be acknowledged there is little empirical evidence to support these principles, they make intuitive sense and there is considerable agreement internationally that these characteristics of research are most likely to improve health for disadvantaged populations.

1 Collaborative Research Centre for Aboriginal Health
2 Investment Review of Health and Medical Research Committee
3 Australian Bureau of Statistics & Australian Institute of Health and Welfare
4 Commonwealth Department of Health and Ageing
In the Australian context, there very little published research about how to ensure Indigenous research has the characteristics most likely to improve health. A search of medical databases for published articles since 2000 including the terms “Aboriginal health research AND Australia” located 273 studies, of which 15 were pertinent to building research capacity (Table 1-4). Each of these publications was classified by “type of article.” *Literature Review* is an article that summarises and critiques work in the field. *Empirical Review* is an empirical survey that summarises evidence from the literature. *Program Description* is an article that describes a health intervention, but does not include an empirical evaluation. *Methods for Research* refers to a paper that describes how a research study was conducted, and methodological considerations including Indigenous consultation and participation. *Case Report (empirical research)* refers to an article which describes empirical evidence from a research study. *Discussion Paper* is a publication that does not present original data or describe a specific research project or intervention, but discusses methodological considerations, theoretical frameworks, and historical perspectives.

As shown in Table 1-4, the majority of publications addressed ethical issues for research in Indigenous populations. Empirical data that was presented in these studies was used to demonstrate the challenges of informed consent in clinical trials (Russell et al 2005), the prevalence and nature of Indigenous health research publications (Sanson-Fisher et al 2006), and the capacity of ethics committees to consult Indigenous people in review processes (Stewart et al 2006). None of the papers were empirical studies evaluating strategies to build research capacity. The studies outlined in Table 1-4 are referred to throughout this thesis.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title of Paper</th>
<th>Year Published</th>
<th>Type of Article</th>
<th>Focus of Article</th>
<th>Description of Contents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson I, Griew R, McAullay D</td>
<td>Ethics guidelines, health research and Indigenous Australians</td>
<td>2003</td>
<td>Literature Review</td>
<td>Ethical guidelines for research</td>
<td>review of key ethical issues for Indigenous health research; particularly processes for consultation, negotiation of collective consent, and assessment of relevant and beneficial research</td>
</tr>
<tr>
<td>Bailey J, Veitch C, Crossland L, Preston R</td>
<td>Developing research capacity building for Aboriginal &amp; Torres Strait Islander health workers in health service settings</td>
<td>2006</td>
<td>Methods for Research</td>
<td>Framework for research capacity building program</td>
<td>documents theoretical framework and structure of community-based research training modules for Aboriginal &amp; Torres Strait Islander Health Workers in Queensland</td>
</tr>
<tr>
<td>Couzos S, Lea T, Murray R, Culbong M</td>
<td>We are not just participants—we are in charge': the NACCHO ear trial and the process for Aboriginal community-controlled health research</td>
<td>2005</td>
<td>Methods for Research</td>
<td>Ethical framework for conducting community-controlled research</td>
<td>documents ethical and methodological issues underpinning clinical RCT study undertaken by National Aboriginal Community Controlled Health Organisation</td>
</tr>
<tr>
<td>Field P, Wakeman J</td>
<td>A case study in strategic change: developing a strategic research program to address cardiovascular disease and related disorders in Aboriginal and Torres Strait Islander peoples and rural and remote settings</td>
<td>2002</td>
<td>Discussion Paper</td>
<td>National Heart Foundation research funding for intervention and evaluation studies in Aboriginal &amp; Torres Strait Islander health</td>
<td>description of critical factors for strategic change process in funding Indigenous health research; particularly identifying research priorities, advocacy, and ear-marking funding for Indigenous health research</td>
</tr>
<tr>
<td>Holmes W, Stewart P, Garrow A, Anderson I, Thorpe L</td>
<td>Researching Aboriginal health: experience from a study of urban young people's health and well-being</td>
<td>2002</td>
<td>Methods for Research</td>
<td>Ethical framework for conducting community-controlled research</td>
<td>documents ethical and methodological issues underpinning public health study undertaken by Victorian Aboriginal Health Service</td>
</tr>
<tr>
<td>Humphery K</td>
<td>Dirty questions: Indigenous health and 'Western research'</td>
<td>2001</td>
<td>Literature Review</td>
<td>Ethical guidelines for research</td>
<td>reviews the development of ethical guidelines for Indigenous health research</td>
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<td>Author(s)</td>
<td>Title of Paper</td>
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<td>Focus of Article</td>
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<tr>
<td>Humphery K</td>
<td>Setting the rules: the development of the NHMRC guidelines on ethical matters in Aboriginal and Torres Strait Islander health research</td>
<td>2003</td>
<td>Discussion Paper</td>
<td>Ethical guidelines for research</td>
<td>describes the actions and events that led to NHMRC Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research in 1991</td>
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<td>Kelly J</td>
<td>Is it Aboriginal friendly? Searching for ways of working in research and practice that support Aboriginal women</td>
<td>2006</td>
<td>Methods for Research</td>
<td>Participatory research processes</td>
<td>describes personal learning experiences and methodology used for participatory action research of Aboriginal women's health</td>
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<td>Kowal E, Anderson I, Bailie R</td>
<td>Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research</td>
<td>2005</td>
<td>Discussion Paper</td>
<td>Indigenous participation in health research</td>
<td>identifies four rationales for Indigenous participation in health research, and implications for implementation and evaluation of participation</td>
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<td>McDonald MI, Benger N, Brown A, Currie BJ, Carapetis JR</td>
<td>Practical challenges of conducting research into rheumatic fever in remote Aboriginal communities</td>
<td>2006</td>
<td>Program Description</td>
<td>Challenges of consultation and consent for research in Aboriginal communities</td>
<td>processes of consultation and consent with Aboriginal communities require considerable investments of time which may not be compatible with time constraints of funding bodies</td>
</tr>
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<td>Prior D</td>
<td>Decolonising research: a shift toward reconciliation</td>
<td>2007</td>
<td>Discussion Paper</td>
<td>Indigenous participation in health research</td>
<td>describes colonising effects of traditional research methods and an alternative approach focused on Indigenous cultural values and methods of inquiry</td>
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<td>Russell FM, Carapetis JR, Liddle H, Edwards T, Ruff TA, Devitt J</td>
<td>A pilot study of the quality of informed consent materials for Aboriginal participants in clinical trials</td>
<td>2005</td>
<td>Case Report (measurement research)</td>
<td>Challenges of informed consent for research in Aboriginal communities</td>
<td>results of a cross-sectional qualitative and quantitative survey suggest that one-off presentations of research objectives to study participants are unlikely to produce informed consent</td>
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<th>Author(s)</th>
<th>Title of Paper</th>
<th>Year Published</th>
<th>Type of Article</th>
<th>Focus of Article</th>
<th>Description of Contents</th>
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<tr>
<td>Sanson-Fisher RW, Campbell EM, Perkins JJ, Blunden SV, Davis BB</td>
<td>Indigenous health research: a critical review of outputs over time</td>
<td>2006</td>
<td>Empirical Review</td>
<td>Kinds of studies conducted in Indigenous health research over time</td>
<td>quantitative review of Indigenous health research publications in Australia, Canada, New Zealand, and USA; describes distribution of Original Research (measurement, descriptive, and intervention), Reviews, Program Descriptions, and Discussion Papers</td>
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<td>Stewart P, Shibasaki S, Anderson I, Pyett P, Dunbar T, Devitt J</td>
<td>Aboriginal and Torres Strait Islander participation on ethical review of health research</td>
<td>2006</td>
<td>Empirical Review</td>
<td>Indigenous participation in ethical review process</td>
<td>a survey of Australian human research ethics committees about key review processes and mechanisms used to consult Indigenous people; more formal mechanisms for Indigenous input are needed to ensure relevant and beneficial research</td>
</tr>
<tr>
<td>Todd AL, Frommer MS, Bailey S, Daniels JL</td>
<td>Collecting and using Aboriginal health information in New South Wales</td>
<td>2000</td>
<td>Discussion Paper</td>
<td>Ethical guidelines for research</td>
<td>describes the development of NSW Aboriginal Health Information Guidelines</td>
</tr>
</tbody>
</table>
1.2.2.1 Indigenous Research: the Australian experience

Aboriginal populations in Australia have been the subject of research since the 19th Century. While early research was primarily of an anthropological nature, the earliest health research published was in 1870—an article describing the application of Indigenous medicines in healing an Aboriginal man (Thomas).

A historical analysis of early Indigenous health research suggests that “research often focused on accumulating information before Aboriginal people were ‘lost to science’ rather than on how best to address Indigenous health problems.” (Thomas 2001: 3). For example, physicians described the physiology and transmission of disease by classifying research subjects according to “quotients of Aboriginal blood” (Thomas 2001: 17). Aboriginal Australians feel that they have been exploited by disrespectful experimentation—subjected to invasive examinations and procedures, objectified, scrutinised, and inaccurately represented—without conferring any health benefits to Aboriginal populations (Humphrey 2001, Bailey et al 2006, Holmes et al 2002). This process of ‘colonisation through research’ has been recognised across Indigenous populations worldwide, and Maori scholar Linda Tuhiwai-Smith notes “the word itself, ‘research’, is probably one of the dirtiest words in the indigenous world’s vocabulary” (Tuhiwai-Smith 1999). A catch phrase often used to summarise this sentiment is “Aboriginal people have been researched to death.”

While Indigenous people have long been critical of research done on their communities and cultures, it was not until the 1970s that Indigenous intellectuals and community members began to debate research in the political arena. The debate focused around issues of control—from community consultation and consent, to intellectual ownership and application of research findings (Humphrey 2003, Anderson 2007, Russell et al 2005).

In the 1980s, these debates culminated in the articulation of ethical guidelines for research in Indigenous populations. Two themes emerged from these debates:

- For Aboriginal communities to have ultimate ownership and control of research, a concerted effort to train Indigenous researchers will be required. Using Indigenous frameworks for research methodology and analysis, this approach constitutes what Linda Tuhiwai-Smith calls “researching back” to acquire, express, and apply knowledge in a beneficial manner (Tuhiwai-Smith 1999). In this approach, the research is undertaken by Indigenous people.
To enable “useful research” to be conducted, Indigenous communities need to help identify and define research questions (Humphrey 2000, Anderson 2007). Historically, most research in Australia has been undertaken by non-Indigenous researchers, and not necessarily informed by the priorities of Indigenous people. However, to identify high-priority health issues and discover how to address them requires close consultation with Indigenous community members and organisations (RAWG 2002, Dunbar et al 2005, Elias et al 2001).

These two approaches are recognised and supported in both the Australian and international literature as good practice for Indigenous health research (Dunbar et al 2005, Humphery 2000, Tuhiwai-Smith 1999, Schnarch 2004, Elias et al 2001, CoRE 2006). These criteria are also supported by the NHMRC Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (NHMRC 2003a); they describe the kind of research that is needed to improve Indigenous health in contemporary Australia. This debate also led to the six criteria generally referred to as the Darwin Criteria:

- **Community engagement:** The proposal demonstrates how the project has had and will have relevant community engagement by individuals, communities and/or organisations in conceptualisation, development and approval, data collection and management, analysis, report writing and dissemination of results.

- **Benefit:** The proposal demonstrates the potential health benefit of the project for Aboriginal and Torres Strait Islander peoples. Benefit need not necessarily be direct or immediate.

- **Sustainability and transferability:** The proposal demonstrates how the results of the project have the potential to lead to achievable and effective contributions to health gain for Indigenous people, beyond the life of the project. This may be through sustainability in the project setting and/or transferability to other settings. In considering this issue the proposal should address the relationship between costs and benefits.

- **Building capability:** The proposal demonstrates how Aboriginal communities, researchers and others will develop relevant capabilities through participation in the project.

- **Priority:** The research and potential outcomes are a priority for Indigenous communities either at community, regional or national levels.
**Significance:** The research addresses an important public health issue for Aboriginal and Torres Strait

These six criteria have been used by Indigenous Health Review Panels for a decade to assess applications and prioritise proposals for funding (NHMRC 1997).

In order to understand the modern context of Indigenous health research and its future directions, we need to understand the history of Indigenous health research. While the health outcomes and research practices among Indigenous populations in Australia have not been optimal, these experiences have led to advocacy for more multi-disciplinary, intervention-based and clinical research; rigorous evaluation of existing policy and programs; and a deeper understanding knowledge translation—the application of research findings into policy and practice (Anderson 2003, Anderson 1997, Bowen et al 2005). This kind of research evidence is more likely to inform the development and delivery of effective health policies and services, and create meaningful health gains for Indigenous Australians. This kind of evidence will require increased research capacity.

1.2.2.2 Principles of good practice for Indigenous health research based on the international and Australian experience

The principles outlined below are derived from the international literature about Indigenous health research principles, and lessons learned from the Australian research experience. They are embodied within the six NHMRC criteria for health and medical research of Indigenous Australians, discussed extensively within the studies outlined by Table 1-4, and the topic of extensive international literature. Based on these considerations, there is growing consensus that research that meets the following particular criteria is more likely to improve Indigenous health:

1. **Intervention research has the capacity to improve health outcomes.** This is especially true in the context of health services research, where clinical staff, health workers, and other service providers have the opportunity to use research skills in the applied setting to test optimum means for delivering preventive, diagnostic, and treatment based health services (RAWG 2004, Bailey et al 2006, Couzos et al 2005a, Elias 2001). Research evidence collected within clinical and policy-making settings enables pertinent information to be collected about interventions and services that are cost-effective and

Intervention research will require multi-disciplinary teams with a broad base of skills in planning and implementation of health programs, evaluation of services that are effective and sustainable, and translation of research findings into policy and the development of better interventions and health services (RAWG 2004, Anderson 2003). A skilled, multi-disciplinary research workforce will also play a critical role in improving advocacy for Indigenous health and the application of research findings (Stephens et al 2006, Ried et al 2005).


i) Indigenous engagement in research design ensures that culturally appropriate research questions and data collection methods are shaped by Indigenous knowledge (including beliefs, perceptions, and attitudes that may be specific to an Indigenous community) (Kowal et al 2005). Indigenous participation in setting the research agenda ensures that pertinent research questions are asked, and research is designed to strategically address the needs prioritised by Indigenous communities and organisations (NHMRC 2003a, Humphery 2003, RAWG 2004). For example, the authors of an epidemiological study on acute rheumatic fever in remote Aboriginal communities described an extensive community consultation that was led by a senior Aboriginal researcher and conferred with community councils, traditional landowners, health boards, health centre staff, community women’s centres, and senior staff at regional schools. The authors indicated that the research question was constantly reshaped throughout consultation process as community concerns came into focus. Defining the research question required “a considerable investment of time and local engagement…before the project proceeded with local support” (McDonald et al 2006: 511).
For non-Indigenous researchers to negotiate community consultations, it is important to develop skills based on cultural respect that enable stronger partnerships to be formed between Indigenous communities and academics (Bowen et al 2006). These consultation and communication skills will ensure all research projects address priority areas of concern, and that Indigenous participants are well informed about the purpose and benefit of a study (Prior 2007, Tuhiwai-Smith 1999, Russell et al 2005).

In the case of consulting Indigenous community members, it is especially important that Indigenous people are engaged in the process of ethical review. Registered human research ethics committees (HRECs) are the formal mechanism nation-wide for consideration and formal approval of all health and medical research. However, a survey of all registered human research ethics committees in Australia indicates that 44% of ethical boards “had no processes or protocols to include Indigenous people,” and only 21% “have formal mechanisms for Indigenous input in decision-making around the ethics of health research involving Indigenous people” (Stewart et al 2006). “Formal mechanisms” were defined as registered Indigenous HRECs, permanent Indigenous representation on a HREC, or a mandated process of review by an Indigenous subcommittee. This evidence indicates that better standards for Indigenous representation on Australian human research ethics committees are required (Stewart et al 2006). Indigenous input is a control mechanism for ethical review panels to ensure good, morally sound research practices are implemented. Mechanisms for indigenous input will improve the relevance, appropriateness, applicability, and benefits of Indigenous health research (Kowal et al 2005, Anderson et al 2003).

ii) Indigenous participation and control of data collection and analyses enables relevant evidence to be collected in a culturally-appropriate fashion, community empowerment, and also more accurate interpretations of research findings (Schnarch 2004, Tuhiwai-Smith 1999).

iii) Dissemination and application of research findings is facilitated by Indigenous engagement (Bowen et al 2005). There is further need to define and implement dissemination strategies that are appropriate for Aboriginal & Torres Strait Islander populations.
3. Building research capacity among Indigenous people provides a culturally appropriate, long-term, and sustainable approach to improving Indigenous health through research (Tuhiwai-Smith 1999, RAWG 2004, Couzos et al 2005, AHRNETS 2006, Bailey et al 2006, CRCAH 2006, Elias et al 2001, Schnarch 2004). Research that is community-controlled and conducted by Indigenous researchers “can be of a high scientific standard without compromising the values and principles of those being researched” (Couzos et al 2005b: 107). For example, in a clinical ear trial investigating ototopical treatments for chronic suppurative otitis media, all the principles described in this section were applied to conduct a landmark Aboriginal community-controlled, double-blind randomised control trial study. A clinical setting for the research project allowed for the examination of practical solutions to Aboriginal health problems. The authors suggest that Aboriginal control of all research facets “prevented potential conflicts around design of the study, ownership of the data, funding or other priorities, which have been common problems for community-research body affiliations” (Couzos et al 2005b: 107). The success of this trial demonstrates not only the quality and scope of research design, but also the social benefit and untapped potential for Aboriginal community-controlled health services to undertake research projects (Couzos et al 2005b, CRCAH 2006, Bailey et al 2006).

1.3 Australian research to improve Indigenous Health: Does it meet the principles?

As shown in Table 1-4, there has been surprisingly little empirical analysis of Indigenous health research in Australia, and the extent to which it meets the principles outlined above.

There are a number of discussion papers and opinion pieces by Indigenous scholars that note a continuing lack of engagement with Indigenous people, and a need for more focus on intervention research (Couzos et al 2005, Anderson 2003, Holmes et al 2002, Kowal et al 2005). It is particularly important to both consult Indigenous people about all aspects of research design, and to train greater numbers of Indigenous community members and organisations to conduct health research (Stewart et al 2006, Anderson et al 2003, Bailey et al 2006, Couzos et al 2005, Prior 2007, Kelly 2006, Tuhiwai-Smith 1999, RAWG 2004). As discussed in the previous section, it is thought that greater investments of time and financial support in the research projects that meet the principles described above will generate more research evidence capable of improving health services and outcomes for disadvantaged populations such as Indigenous Australians.
The review outlined in Table 1-4 located one empirical paper that reviewed the quantity and kind of research conducted over the last two decades in Indigenous health. Sanson-Fisher et al (2006) analysed the number and nature of Australian Indigenous health research publications in peer-reviewed journals. Publications were classified as original research, reviews, program descriptions, discussion papers or commentaries, or case reports. Original research publications were further classified as either measurement, descriptive, or intervention studies. A cross-sectional sample of publications from three years between 1987 and 2003 was used to track changes over time. The same methodology was applied to assess and compare Indigenous health research outputs across Australia, Canada, New Zealand, and the United States. The results of this study are summarised in Table 1-2.

**Table 1-5: Indigenous health research outputs over time in Australia, Canada, New Zealand, and the United States**

<table>
<thead>
<tr>
<th></th>
<th>Australia</th>
<th>Canada</th>
<th>New Zealand</th>
<th>United States</th>
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<tbody>
<tr>
<td></td>
<td>All</td>
<td>Measure</td>
<td>Descriptive</td>
<td>Intervention</td>
</tr>
<tr>
<td><strong>Australia</strong></td>
<td>19</td>
<td>2 (11%)</td>
<td>17 (89%)</td>
<td>0</td>
</tr>
<tr>
<td>1987–1998</td>
<td>19</td>
<td>2 (11%)</td>
<td>17 (89%)</td>
<td>0</td>
</tr>
<tr>
<td>1997–1998</td>
<td>60</td>
<td>6 (7%)</td>
<td>54 (75%)</td>
<td>0</td>
</tr>
<tr>
<td>2001–2003</td>
<td>101</td>
<td>9 (9%)</td>
<td>92 (73%)</td>
<td>13 (13%)</td>
</tr>
<tr>
<td><strong>Canada</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1987–1998</td>
<td>53</td>
<td>2 (4%)</td>
<td>51 (92%)</td>
<td>4 (8%)</td>
</tr>
<tr>
<td>1997–1998</td>
<td>65</td>
<td>0</td>
<td>65 (100%)</td>
<td>4 (6%)</td>
</tr>
<tr>
<td>2001–2003</td>
<td>51</td>
<td>5 (10%)</td>
<td>46 (88%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>New Zealand</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1987–1998</td>
<td>22</td>
<td>1 (5%)</td>
<td>21 (95%)</td>
<td>0</td>
</tr>
<tr>
<td>1997–1998</td>
<td>51</td>
<td>2 (4%)</td>
<td>49 (98%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>2001–2003</td>
<td>32</td>
<td>3 (9%)</td>
<td>29 (84%)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td><strong>United States</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1987–1998</td>
<td>123</td>
<td>6 (5%)</td>
<td>110 (89%)</td>
<td>7 (4%)</td>
</tr>
<tr>
<td>1997–1998</td>
<td>274</td>
<td>12 (4%)</td>
<td>262 (96%)</td>
<td>16 (6%)</td>
</tr>
<tr>
<td>2001–2003</td>
<td>298</td>
<td>24 (9%)</td>
<td>274 (85%)</td>
<td>15 (6%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1131</td>
<td>72 (6%)</td>
<td>993 (87%)</td>
<td>76 (7%)</td>
</tr>
</tbody>
</table>


Among original research publications in Australia, there has been a substantial increase in the total number of publications and in the numbers of both descriptive and intervention-based studies. The number of
descriptive studies increased more than three-fold from 1987-1988 to 1997-1998. Over the same decade, the number of publications for intervention-based studies increased from zero to fourteen. Nonetheless, 78% of all original research publications in 2001-2003 were descriptive, 9% were measurement, and only 13% were intervention-based. This evidence suggests that health research of Indigenous Australians is still predominantly descriptive, which will not maximise the benefits of research in improving health. The dominance of descriptive research is not optimal (Sanson-Fisher et al 2006); more intervention research is required to describe the best means of delivering preventive, diagnostic, and treatment-based health services and interventions to Indigenous Australians (RAWG 2004).

It is evident that there is limited information about the extent to which Australian research in Indigenous health meets the principles for best practice; however, based on the available information, it appears that there are considerable gaps in the research currently undertaken.

1.4 Building capacity for Indigenous health research to meet the principles of good practice

1.4.1 Building research capacity: the international experience

Building research capacity involves both strengthening research practices and increasing the number of skilled researchers in the field of Indigenous health. There has been considerable experience in building research capacity for Indigenous health overseas, particularly in Canada and New Zealand.1 The framework for international knowledge exchange between comparable Indigenous populations has already been established between Australia, Canada, and New Zealand. In 2002, the research funding agencies for these three nations endorsed a tri-partite agreement for Indigenous health research (see Illustration 1-1). The intention of this agreement is “to share expertise on the “purchase” (funding) of health research and to develop policy for collaborative research between the three countries, including sponsoring placements of individuals, funding international research projects, and supporting other collaborative research relationships” (Cunningham et al 2003: 445).

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1 Specific international examples of policy frameworks for research funding and programs for building research capacity will be discussed in greater detail in Section 6.5.3 and Section 6.5.4.
Indigenous scholars from around the globe have grappled with comparable issues of how to increase funding for high-impact research substantially and quickly, as well as how to engage Indigenous community members and organisations throughout the research process (Schnarch 2004). As a result, many interesting examples of strategies to improve Indigenous health through research have emerged internationally. There is a consensus that building research capacity will require efforts to:

- Increase the amount of money spent on Indigenous health research.
- Ensure resources are allocated and targets are met in a timely fashion.
- Encourage research to be done in a way more closely allied to the needs of communities.
- Address priority health issues to facilitate high-impact research and maximise benefits

Some of the best examples come from the work undertaken by the Canadian Institute for Health Research (CIHR) and the New Zealand Centre of Research Excellence (CoRE).

In 2001, the Canadian Institute for Health Research launched the ACADRE (Aboriginal Capacity and Development Research Environments) centres as a capacity building initiative in health research. The eight ACADRE centres located across the nation, each has a different research focus. For example, the
Centre for Aboriginal Health Research (CAHR) in Manitoba has focused on building capacity in applied population health research for First Nation people. To advance self-governance over health and health research, they advocate for shared leadership, power, and decision-making from design to dissemination. To facilitate population health research that is owned, controlled, and accessible to First Nation communities, they have developed the Manitoba First Nations Summer Institute in Applied Population Health Research. The program provides basic research training in epidemiology, how to conduct community need assessments, ethical protocols, quantitative data analysis techniques, and hands-on experience using data from surveys, health services, and mortality databases. The innovative training program is unique in that the curriculum can be delivered over a one-week period and taught on-site within communities. This enables greater access to educational resources and training (Elias et al 2001).

In 2002, the New Zealand CoRE transformed its research program to encompass a Capability Building Programme. Within five years, it aims to produce a new generation of 500 high quality Maori researchers across all disciplines that will be capable of contributing to constructive social change throughout their careers. To encourage development of a research culture that fosters Maori leadership, large investments were made to develop infrastructure within Maori research centres. These research centres are now accredited to deliver PhD programs, significantly increasing the flow of students into postgraduate study and accelerating PhD completions. To bridge the transition from graduate study to research leadership, an extensive mentoring program is provided to researchers and students. Bringing students together in a collegial, multi-disciplinary environment, with everyone participating in the mentoring process, has had a tremendous impact on increasing university enrolments. For example, growth rates at one university were as much as five-fold in 18 months (CoRE 2006). This flourishing and quickly expanding Maori research community has the potential to play a critical role in developing healthy research partnerships with communities, and actively engaging these partners in constructive social change through research.

The potential relevance of these programs for Australia will be discussed in greater detail in Chapter 6. Most notably, these programs are built upon principles of Indigenous engagement and empowerment. They enrol high numbers of Indigenous participants each year, and design their investments, support networks, resources, and infrastructure to support their graduation. These programs illustrate capacity building principles in practice.
1.4.2 Building research capacity: the Australian experience

The need to address Indigenous health issues has been acknowledged across Australian state and federal governments. The Commonwealth Department of Health and Ageing has in recent years recognised the importance of policies designed to support capacity building and monitor the skill development and growth of health professionals working in Indigenous health, especially among Indigenous community members and organisations. These policies also recognise the importance of building capacity across community, organisational, academic, and policy contexts. (AHMAC 2002, AHMAC 2006, DoHA 2005).

Few of these Indigenous health policies include strategies to build capacity for research. Even when federal policy documents do include recommendations about building research capacity, they fail to include specific plans for implementation and indicators for assessment. For example, the National Strategic Framework for Indigenous Health outlines the Commonwealth’s financial commitment to allocate adequate health research funding and implement the NHMRC Road Map, but does not set forth an implementation plan (DoHA 2005). Both the five year implementation plan that is set forth within the AHMAC-endorsed policy document, and the framework for action by governments outline workforce development as a priority area; neither specifies a plan of action for developing or funding research capacity (DoHA 2005, DoHA 2003). In the two most recent reports assessing implementation of the National Strategic Framework for Indigenous Health, neither evaluation framework includes indicators to monitor the numerical strength or capability of the Indigenous health research workforce (AHMAC 2006, SCRGSP 2003). It is virtually impossible to measure progress or assess policy implementation without indicators to benchmark research capacity, or a national framework that is assessable. Furthermore, the scope and impact for policies and programs to build research capacity in Australia seems limited when compared with initiatives underway in Canada and New Zealand.

Likewise, in the peer review literature, there is relatively little information about strategies to build research capacity (as shown in Table 1-4). The existing studies have largely focused on the value of experience in Aboriginal communities for non-Indigenous researchers. For example, an evaluation for a prevocational medical training program in remote Australia indicated that students gained applied medical knowledge and research skills in public health by participating in a four-week training program, and twenty-week work experience in community and remote area health clinics (Mak et al 2006). Another example is a community-based, Aboriginal-controlled research training module that has recently been piloted among Indigenous health workers in Queensland. Guided by principles of Indigenous engagement, the program utilises an applied framework for building research capacity—integrating culturally appropriate service
delivery with training in monitoring and evaluation methods. While a full evaluation of program outcomes has not yet been published, preliminary findings affirm the importance of both the “researching back” and “Indigenous engagement” approaches; the utility of training researchers in a community health services setting; and the effectiveness of improving health outcomes by building research capacity among employees at Indigenous community-controlled organisations (Bailey et al 2006).

While there remains limited information about strategies to increase capacity in Aboriginal health research, or empirical evidence to demonstrate their impact, there is agreement that this will require:

- **an increase in the number of skilled researchers in the field of Indigenous health.** A critical mass of researchers is needed to establish a highly trained, multi-disciplinary cadre of experts in Indigenous health. This cadre should have expertise in a diversity of social, scientific, technological, and organisational abilities; and work across an array of research settings—including community-controlled health organisations, health research institutes, community organisations, universities, and clinical settings. It is especially important that Indigenous community members and organisations are among those trained to conduct this kind of research (CRCAH 2006). Development of this critical mass is contingent upon allocation of adequate training resources across a diversity of disciplines, thereby ensuring a wealth of applicable research evidence is being collected from policy-making, clinical, laboratory, and service settings.

- **strengthening research practices for all researchers working in the field of Indigenous health.** In this sense, capacity building refers to the formal education and training opportunities that strengthen the knowledge, skills, and expertise of individual researchers working in the field of Indigenous health. To generate research evidence that is going to benefit Indigenous communities requires skills in cultural competency, engaging Indigenous community members and organisations, collaborative partnerships between institutional campuses and communities, and a focus on high-impact, intervention-based research.
1.5 The role of NHMRC in building Indigenous health research capacity

1.5.1 Overview of NHMRC research funding

The National Health and Medical Research Council (NHMRC) was established in 1936 as a national funding body for health and medical research. NHMRC remains the peak funding agency for health and medical research in Australia. By 2006, the annual budget for NHMRC was $434.7 million. The majority of NHMRC’s funds are allocated to investigator-initiated proposals selected through competitive peer review mechanisms. The main categories of grants awarded are for Research Support (including program and project grants), People Support (to pay stipends to individual researchers from PhD students to senior fellowships), and Infrastructure Support (e.g., for equipment and database repositories). As part of the Research Support stream, NHMRC has funded Strategic Awards to address areas of critical need. Figure 1-3 illustrates the distribution of agency expenditure in 2006.

Figure 1-5: Distribution of 2006 NHMRC expenditure*


As is evident from Figure 1-5, the majority of funds are expended through Research Support, and this constitutes approximately three-quarters of the annual budget. People Support is also a key component of the NHMRC budget, and constitutes about a fifth of total annual funds.
In addition to the distribution of awards, the distribution of broad research areas is also a good approximation for evaluating the current pool of researchers being supported by NHMRC. Figure 1-4 illustrates roughly half the money allocated by NHMRC in a given year is for biomedical research, clinical research receives around 30% of funds, and a relatively smaller proportion is allocated to public health (14%) and health services (4%) research.

**Figure 1-6:** Distribution of all NHMRC research funding by Broad Research Area: 2006*

![Pie chart showing distribution of NHMRC funding by research area: 49% Basic Science, 30% Clinical Medicine and Science, 14% Public Health, 2% Preventive Medicine and Science, 1% Health Services Research, 2% Not Applicable, 1% Not Applicable.](image)


### 1.5.2 The role of NHMRC research funding in improving Indigenous health

The NHMRC has a special responsibility to improve Indigenous health through research by supporting research that creates meaningful health gains by targeting the major causes of death and relevant risk factors, and informing effective policy and programming to improve the delivery of health services. Innovative research initiatives can smooth the road to equitable health outcomes for Indigenous Australians.

The agency is governed by the principles outlined within its legislation, the National Health and Medical Research Council Act 1992 (NHMRC 1992), and as an independent statutory body, the Commonwealth does
not have legal jurisdiction to mandate how NHMRC allocates research funding (NHMRC 2000c, NHMRC 2001a, NHMRC 2001b).

NHMRC has for the most part expended funds on Indigenous health research through regular investigator-initiated funding rounds (Lonsdale 2007, Anderson 2007).

As described elsewhere in this thesis, in the 1990s NHMRC recognised that it was not providing sufficient support for Indigenous health research, and made a policy commitment to greater levels of expenditure. In October 2002, the NHMRC made a commitment to allocate 5% of agency expenditure toward Indigenous health research—embracing for the first time a fiscal target that earmarked funds for Indigenous health research.

Three strategies have been used to increase expenditure and implement the 5% policy through the research support schemes.

i) **The first strategy employed by NHMRC is to provide additional pools of money for Indigenous health within regular funding rounds.** As an example, there were four additional allocations of $2.5 million earmarked for Indigenous health research in Capacity Building Grant Rounds funded between 2002 and 2006; these awards were provided for grants that were fundable, but not one of the top four applications in that funding round.

ii) **The second strategy is to create Strategic Awards for areas of high need.** However, only one funding round of Strategic Awards specific to Indigenous health—*Healthy Start to Life*—has ever been announced over the past decade. No previously announced funding rounds have ever been earmarked for building research capacity in Indigenous health.

iii) **The third strategy used is to lower the cut-off mark for successful project proposals.** This strategy has been used by NHMRC for over a decade, but there is little evidence to suggest that this strategy is effective in building research capacity, or at encouraging other sectors and health professionals to engage in research.
1.5.3 People Support

This thesis explores People Support funding for Indigenous health research over a decade—from 1996 to 2006. People Support Awards were selected as a lens for analysis because they provide a pathway for career development and capacity building. Within the People Support schemes, it is also possible to examine the proportion of funding expended on researchers who self-identify as Indigenous.

The People Support schemes are particularly important for growing research capacity in historically under-funded areas such as Indigenous health because they offer an opportunity to increase the number and quality of researchers, and develop the skill base for the research workforce (RAWG 2004, NHMRC 2006). While representing only a quarter of agency expenditure, investment here will lead to a stronger pool of researchers in the future. The People Support scheme provides a suitable lens for applications to be compared—awards are allocated to individual researchers rather than research teams.

1.5.4 Overview of NHMRC People Support pathways and programs to improve Indigenous health

As the leading national agency for health and medical research, NHMRC provides People Support as a career pathway of awards to support the development of individual health researchers. Four principle types of awards are made within this pathway; and the value of these awards increases to correspond with the level of expertise: NHMRC Scholarships are typically awarded to post-graduate students; NHMRC Training Awards are post-doctoral awards; Career Development Awards are usually awarded three to five years post-doc; and Career Awards are usually awarded to established researchers 10 or more years post-doc (NHMRC 2005a). A fifth type of award—Capacity Building Grants in Population Health Research—was also examined due to the capacity building nature of this funding mechanism. As Strategic Awards, Capacity Building Grants in Population Health Research technically classify within NHMRC Research Support, but they provide a framework for career development to early career health researchers. In 2002, Capacity Building Grants in Population Health Research were introduced to support individual researchers within research teams with a disciplinary focus on public health and health services. This innovative model provides both financial support and a mentoring framework for career development. Within each research team, senior researchers, or lead applicants, are matched with more junior team investigators as “skill mentors,” providing expertise and guidance in research design, quantitative and qualitative methods, presentation of research findings, writing for publication, and other aspects of skill development (NHMRC 2006).
Figure 1-7 below illustrates NHMRC People Support pathways, and the five types of awards allocated (in purple).

**Figure 1-7:** People Support Career Pathways

- **Traditional People Support**
- **Scholarships**
- **(Post-Doc) Training Awards**
- **Career Development Awards**
- **Career Awards**

- 5-year salaries
- Career & skill development
- Mentoring framework
Figure 1-8 below illustrates the numerical distribution of all awards from the traditional stream of People Support over the past seven years.

**Figure 1-8:** Numerical distribution of All* NHMRC People Support Awards: 2000-2006

* n = 2788


The distribution of award allocations indicates the proportion of awards that are scholarships (45%), Training Awards (28%), Career Development Awards (7%), and Career Awards (20%)

### 1.6 Summary

In summary, building research capacity is paramount to the development and testing of better interventions and health services that will result in meaningful health gains for Indigenous people. There is a growing international consensus—founded on experience—that the characteristics of research that is most likely to lead to improvements in Indigenous health are:

- Intervention-based studies of preventive, diagnostic, and treatment based health services, as well as evaluations of policy implementation and impact
- Research projects that engage Indigenous people in all stages and aspects of research (including consultation, development of research design, ethical review, data collection and monitoring, interpretation of results, report writing, dissemination and application of research findings)
Research programs that increase the number and skill base of health professionals conducting research in Indigenous health.

In this thesis, these three principles of good practice for Indigenous health research will be used to assess the allocation of NHMRC research over the past decade.

While there are limited reports of strategies for building health research capacity for Indigenous health in Australia and no empirical evidence to demonstrate their impact (Table 1-4), there is an international framework for sharing Indigenous health research expertise with New Zealand and Canada. Research training models trialled by the New Zealand Centre of Research Excellence and Canadian Institute of Aboriginal Health provide valuable examples of successful capacity building strategies that uphold the three principles of good research practice for Indigenous health.

In Australia, NHMRC has made a policy commitment to uphold these principles of good research practice by funding research to improve Indigenous health. As the agency’s current funding mechanism for building capacity among individual researchers, the People Support pathways and programs are the lens for evaluation in this thesis. This thesis aims to understand both the evolution and impact of NHMRC’s policy commitment to Indigenous health research.
CHAPTER 2 STUDY AIMS

The goal of this thesis is to examine NHMRC’s contribution to building capacity in Indigenous health research. The thesis examines the policy changes occurring at NHMRC over the past decade, and their impact on the approach to research and expenditure through the People Support scheme. It focuses on People Support as it is the most direct method for building research capacity. It evaluates current funding practices and provides information to assist in planning for the future.

The specific objectives of the research are:

1. To understand and describe the factors that led to the policy changes in Indigenous health research. An analysis of NHMRC’s evolving policy response was undertaken, and the impact of these policy changes evaluated. Specifically, a number of key informants were interviewed to investigate the catalysts for change, and to describe the NHMRC policy response between 1997 and 2002.

2. To describe the extent to which research approaches used by People Support recipients meet the principles of good practice. A case study of successful People Support applications in 2005 and 2006 was undertaken to assess current research practices, and demonstrate the impact of policies adopted in 1997 and 2002. Original application forms and Operational Definitions (Appendices D & E) for a series of indicators were used to evaluate the quality of research proposals. A selection of these indicators was used to evaluate the prevalence of intervention research, engagement of Indigenous community members and organisations, and the extent to which Indigenous people are being trained or employed as part of the research team.

3. To describe the impact of policy change on funding allocations for Indigenous health research. NHMRC People Support funding for Indigenous health research between 1996 and 2006 was examined as an approximation of the national investment to build research capacity. This study examines a decade of awards allocated through the People Support scheme to advance the work, training, and development of researchers who study Indigenous health in Australia. The study examines annual expenditure and the distribution of awards; the characteristics of successful
research applications and applicants; and the efficacy of funding mechanisms to implement policy decisions. Specifically, this part of the study aims:

a. To identify how many and what proportion of People Support awards were made to researchers who study Indigenous health

b. Evaluate the distribution of People Support funding for Indigenous health by Broad Research Area

c. To determine if People Support for researchers who study Indigenous health has increased over time

d. To estimate what proportion of People Support funding is awarded to researchers who self-identify as Aboriginal or Torres Strait Islander

e. To assess the impact of Capacity Building Grants for Health Research on expenditure for building research capacity in Indigenous health, particularly among Indigenous scholars

f. To evaluate the distribution of researchers who self-identify as Indigenous by academic institution and State/Territory

g. To evaluate the distribution of People Support funding for Indigenous health by State or Territory
CHAPTER 3  STUDY ONE: EXAMINATION OF NHMRC POLICY CHANGES

3.1 Introduction
As reviewed in Chapter 1, there is wide agreement about the principles of good practice for research that contributes to improving Indigenous health. Existing evidence in the literature suggests that research practices in Australia have not been optimal (Sanson-Fisher et al 2006, Couzos et al 2005b).

As the major funding body for health and medical research in Australia, NHMRC has a responsibility to fund research projects that contribute to improvements in Indigenous health. In the late 1990s, there was mounting pressure on NHMRC to increase both the sum amount of support for Indigenous health, and the number of research projects that meet the principles outlined above.

This chapter provides an analysis of NHMRC’s policy response to these pressures.

3.2 Aim of Study One
To understand and describe the influential factors that led to the policy changes in NHMRC for Indigenous health research.

3.3 Methods
3.3.1 Study design
Semi-structured interviews were conducted with a selected sample of people who played a leading role in NHMRC. The author and her supervisors identified seven potential study participants through key informants and NHMRC documentation. Key informants were selected for their role in spearheading policy changes, and those interviewed are detailed in Section 3.3.2 below. Each interview was conducted in person and digitally recorded by the author. Both the transcribed interviews and notes taken during the interviews were used to conduct the analysis. Also, the author referred to key documents from NHMRC minutes and correspondence for the analysis.
3.3.2 Data Collection

All key informants who were identified agreed to participate in this study. The author conducted a total of seven semi-structured interviews with individuals who held the following positions in 2002:

1. Chair of NHMRC Research Committee & member of Council
2. Chair of Research Agenda Working Group (RAWG) & Indigenous Member of Council
3. Indigenous Member of Council and previous (1997-2000) member of RAWG
4. Indigenous Member of RAWG & author of *Road Map*
5. Indigenous Member of RAWG & current Member of Aboriginal and Torres Strait Islander Health Forum
6. Member of RAWG & Strategic Research Development Committee
7. Secretariat for Office of Aboriginal and Torres Strait Islander Health (OATSIH)

At the commencement of each interview, participants were provided with a summary sheet, briefly outlining the policy decisions adopted by NHMRC in 2002 (Appendix A). The author used an interview schedule with the following open-ended questions to identify influential factors in driving the 2002 NHMRC policy changes:

1. From your perspective, what drove the changes in policy?
2. Was there any key evidence that was used? If so, what impact did it have?
3. Who drove this change in policy? How?
4. Did anyone resist the policy changes? If so, who and why?
5. In retrospect, is there anything that should have been done differently in the policy process?
6. If you were wanting to change Indigenous health policy in the future, what do you think might be the key issues to consider?
7. How would you like to see the 2002 policy decisions continue to evolve over the next triennium (2007-2010)?

The interviewer used open-ended questions so as not to limit the breadth and accuracy of responses by key informants.
3.3.3 Data Analysis

The interviews were transcribed and content analysed according to major thematic areas and trends identified in current policy-making literature. Interviewee responses for factors driving policy change were classified within five domains—key evidence, influential individuals, determining circumstances, policy climate, and timing for policy changes. Similarly, if any barriers to changing policy were identified, they were also classified within these spheres of influence.

Study participants were also asked to identify approaches and strategies used to encourage policy change; future directions for policy implementation and development; and key issues for consideration in making future policy changes.

3.4 Results

3.4.1 What were the external catalysts for policy change?

All participants identified the following four factors as influential in reshaping the NHMRC’s policy approach to Indigenous health research

(i) Mounting evidence of the urgent health needs for Indigenous communities

Several participants identified the 1994 evaluation of the National Aboriginal Health Strategy (NAHS) as influential in shaping the policy climate. The evaluation of the strategy indicated that it had little impact in improving the state of health for Aboriginal people, and had not been adequately implemented (NAHS Evaluation Committee 1994). Interviewees also cited The Virtuous Cycle: Working Together for Health and Medical Research—Health and Medical Research Strategic Review Discussion Document as influential; the evaluation (referred to as the Wills Review in this thesis) acknowledged health equity issues were of growing concern in Australia, and the need for skilled Indigenous professionals in the workforce (HMRSRC 1998). Participants reported that these evaluations not only benchmarked the ongoing poor state of Aboriginal health, but also articulated the challenge of effectively implementing policy to create health gains among Indigenous populations. One informant said that, upon scrutinising the national investment approach to Aboriginal health issues, it became apparent that “there is no evidence of where that money’s been spent.”
These two documents—the 1994 National Aboriginal Health Strategy Evaluation and Wills Review (NAHS Evaluation Committee 1994, HMRSRC 1998)—stressed the importance of research outcomes and created pressure for the NHMRC to focus on Indigenous health research.

(ii) Increasing pressure from Indigenous communities to ensure research maximises health gains

Participants thought that the key to the policy change was growing pressure from Indigenous communities for research that leads to health gains. There was a growing awareness of inappropriate research practices being used within Indigenous communities. Over two centuries, research had become a ‘dirty word.’ Much of the research that had been conducted was considered to be self-serving, and beneficial only to the researcher who had collected data, acquired a degree, and written publications. With the emergence of self-determination and community-controlled services, Aboriginal people began to demand that “research evidence be fed back to the community…. because there was nothing coming back to us and we knew there was nothing happening on the ground.”

Participants cited a growing body of reviews and personal experience to describe the response of Indigenous communities to research initiatives. Aboriginal community members expressed exasperation about being scrutinised as a population for research, but having little or no benefit conferred. As one participant put it, “we’ve been researched to death.” A host of issues were identified as impediments including little funding, lack of community engagement in project consultation and implementation, minimal collaboration with Indigenous communities and organisations, and the proliferation of research that investigates health needs but does not contribute to improving them. Participants reported that Aboriginal community members, academics and organisations emphasised the need for a new approach to research; to ensure real health gains, community engagement in all stages of the research process was emphasised—including consultation, data collection and storage, interpretation of research evidence, and the dissemination and application of findings. As one senior informant explained, “they (non-Indigenous researchers) keep researching Blacks, but there’s still Blacks sitting there with the same illnesses as when I was a kid! Building Aboriginal research capacity is the way forward…”

As one participant explained, “high impact” and “intervention based” research has emerged as the result of two parallel and influential movements among health professionals. These terms refer to research evidence that is likely to create meaningful health gains for Indigenous Australians (eg
intervention studies). The debate about ethics that produced the Darwin Criteria (NHMRC 1997)—described earlier in Section 1.2.2—played an integral role in raising awareness about the historical context of research in Indigenous communities. It also developed a series of principles to focus and guide research that engages Indigenous community members and organisations, builds community capacity, and addresses health needs as prioritised by Indigenous people.

(iii) Increasing pressure to consider gains from investments in research

The majority of interviewees nominated the Wills Review (HMRSRC 1998) as a key catalyst for policy change at NHMRC. As one participant explained, the review stemmed from “an underlying principle that we don’t just need to do research for the interest of research… we should really try to address some of the gaps in our understanding or knowledge that may actually lead to improved outcomes and to better ways to deliver resources.” The Wills Review emphasised the importance of evidence-based healthcare, and of examining the outcomes of research funding, be that in wealth creation through commercialisation or in health gains. Participants felt that this review created a “desire to be seen to do something” within NHMRC. One participant noted that it “articulated the voice of a growing movement in economic rationalism, putting the onus on research investments to produce an evidence-base for cost-efficient and efficacious health services.” The 1998 Wills Review reiterated the importance of efficient grant allocation mechanisms and “research that contributes direction to population health and evidence-based health care.”

(iv) Increasing pressure from government to earmark funding for research in Indigenous health

Participants nominated the House of Representatives Standing Committee on Family and Community Affairs Inquiry into Indigenous health commencing in 1997 as a key catalyst. Written submissions and committee deliberations culminated in the Health is Life report (HRSCFCA 2000), which issued a series of 35 recommendations to improve the state of Indigenous health. The final recommendation of the report was that “the National Health and Medical Research Council allocate at least five per cent of total annual research funding for Indigenous health research.” Several study participants cited this recommendation as one of the decisive turning points in driving policy change.

One study participant provided the author with extensive internal documentation detailing the NHMRC’s response to this recommendation in committee minutes and ministerial correspondence. This written material indicated that Dr. Michael Wooldridge, Minister for Health and Aged Care brought recommendation #35 to the attention of NHMRC. In his letter to the chairperson of NHMRC, he noted that “under existing Legislation, the National Health and Medical Research
Council Act 1992, the Government cannot direct the National Health and Medical Research Council to allocate any percentage of funding for specific purposes.” The issue was in turn tabled at the next meeting for both the Indigenous Research Agenda Working Group (RAWG) and the Strategic Research Development Committee, and a response paper was prepared. In 2001, the Strategic Research Development Committee recommended increasing funding of Indigenous health research, but declined the 5% commitment. At the time of the decision, it was agreed RAWG would develop a Road Map to guide and focus the development of an Indigenous health research agenda. The committee response noted “encouraging Indigenous researchers is an important step in capacity building within the Indigenous community.”

Respondents perceived the recommendations of the Health is Life report were consistent with the Wills Review in pressing NHMRC to improve its approach to Indigenous health issues.

3.4.2 What was NHMRC’s policy response to pressure for change?

Respondents nominated seven changes to NHMRC policy over a five year period; the evolution and sequence of these policy decisions is illustrated in Figure 3-1 below, and further outlined in Appendix B.
Increasing pressure to consider gains from investments in research

Mounting evidence of the urgent health needs for Indigenous communities

Increasing pressure from Indigenous communities to ensure research maximises health gains

Growing internal recognition of NHMRC’s responsibility to generate more high-impact research in Indigenous health

Leadership by key NHMRC council and committee members

Greater representation of Indigenous people within NHMRC

NHMRC adopts Darwin Criteria

NHMRC establishes Indigenous Health Review Panels

Formal acknowledgement of Indigenous health research as a priority area for development

Road Map endorsed by NHMRC

RAWG established

1st triennium

2nd triennium

RAWG dissolved & Aboriginal & Torres Strait Islander Health Forum established

Adopt Capacity Building Strategy

LEGEND:
- External reports
- External catalysts for policy change
- Internal catalysts for policy change
- NHMRC policy decisions

**Figure 3-1** Catalysts for change: NHMRC policy timeline
3.4.2.1 The 1997 NHMRC policy decisions

Listed below are the 1997 policy decisions nominated by interview participants:

(i) Adoption of the Darwin Criteria

Most participants nominated the adoption of the Darwin Criteria in 1997 as the first key policy change. This was important because the Darwin Criteria were introduced to assess researchers’ commitment to engage Indigenous communities in beneficial research projects, and prioritise projects for funding. The six Darwin Criteria for health and medical research of Indigenous Australians are community engagement, benefit, sustainability and transferability, building capability, priority, and significance. Funding applicants are required to detail in two pages of their research proposal how their work will address each of these criteria. These guidelines, also known as the Criteria for Health and Medical Research of Indigenous Australians, outline the principles of conduct for researchers who study Indigenous health. They were agreed upon as a series of consolidated guidelines for Indigenous health research after two national gatherings in 1986 and 1987.

In 1986, more than two hundred researchers, health professionals, and Aboriginal community representatives gathered for the first time to debate a wide range of health issues in a forum convened by the NHMRC and the Menzies Foundation. The gathering brought together professionals with both biomedical and socio-cultural research training to debate ethics, funding mechanisms, the collection of health statistics and the evaluation of services, and priority areas for research. A year later, a further workshop was convened to focus on methodological and ethical research issues. As a result of this consultation, a series of research principles known as the Darwin Criteria were first drafted in 1987 to guide appropriate research practices in Indigenous health. In 1997, the Darwin Criteria, also known as the Intervention Based Criteria, were adopted by NHMRC to assess grant applications for health research of Indigenous Australians (Appendix C). These six criteria were previously described in Section 1.2.2.1.

(ii) Establishment of the Indigenous Health Review Panels

Several respondents cited the 1997 decision to establish Indigenous Health Review Panels to guide the assessment process for project proposals in Indigenous health. Indigenous Health Review Panels enabled representatives of Indigenous communities to contribute to determining whether research applications are suitable for funding.
The Darwin Criteria are the cornerstone of the application assessment process used by the Indigenous Health Review Panels (IHRP); all NHMRC applicants who wish to conduct health and medical research of Indigenous Australians are required to address these criteria in their applications. IHRP were established as a type of ‘gateway’ process for reviewing ethical issues of proposed research programs, and prioritising applications for funding. With representation of Indigenous community members, organisations, and academics, IHRP play an important role in developing individual members’ knowledge and application of ethical guidelines. They also provide a quality control mechanism for Indigenous health research funded by NHMRC.

(iii) Establishment of the Indigenous Research Agenda Working Group (RAWG)

The Indigenous Research Agenda Working Group (RAWG) was established in 1997 as a joint initiative of the NHMRC and the Office for Indigenous Health (OATSIH). As an advisory body, RAWG was established to provide guidance about Indigenous health issues, and develop a strategic research agenda for NHMRC to prioritise better research practices and health issues for funding (RAWG 2002, NHMRC 2002b, RAWG 2004). All interview participants cited the formation and activity of this group as a spearhead for the 2002 policy decisions.

3.4.2.2 The 2002 NHMRC policy decisions

At the 144th council session of NHMRC in October 2002, RAWG tabled a document outlining the agency’s policy options. Interviewees reported that policy documents prepared by RAWG were received by “a high degree of vocal support” on Council. The following policy decisions were endorsed at that time:

(iv) Endorsement of the NHMRC Road Map: A Strategic Framework for Improving Indigenous Health through Research

All participants acknowledged the extensive work and comprehensive consultation process used by RAWG to develop the Road Map, and identified the Road Map as a compelling policy document to guide future NHMRC investments. The Road Map describes a framework for prioritising the health research needs of Indigenous communities; these priorities are used to guide NHMRC investments. The Road Map also emphasises the need to build health research capacity—both by increasing the numbers of researchers in Indigenous health, and by improving research practices.
Interview participants acknowledged RAWG was responsible for drafting this key document in 2001, and NHMRC endorsement in 2002. One informant described her role in facilitating an extensive consultation with key stakeholders across Australia before drafting the NHMRC Road Map: a strategic framework for improving Indigenous health through research. The document articulates six thematic areas that should be prioritised for research development and funding to create meaningful health gain for Indigenous people.

The six thematic areas are briefly outlined below (as written in the Road Map)

1. Descriptive research which outlines patterns of health risk, disease and death. This information should be utilised to inform the development of sound preventive, early diagnosis and treatment based interventions which are likely to result in meaningful health gain for Indigenous peoples
2. A research focus on the factors and process that promote resilience and wellness; in particular but not exclusively, during periods of pregnancy, infancy, childhood and adolescence and which form a basis for good health throughout the lifespan
3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Indigenous peoples
4. A focus on the association between health status and health gain and policy and programs that lie outside the direct influence of the health sector
5. A focus on engaging with research and action in previously under-researched Indigenous populations and communities
6. Development of the nation’s Indigenous health research capacity (including Indigenous researchers) and health research practice in relation to Indigenous communities

To increase the accountability and responsiveness of council to Indigenous health issues, RAWG was dissolved and re-established as the Indigenous Health Forum, reporting directly to Council (NHMRC 2002b). Since its inception in 2003, the Indigenous Health Forum has been responsible for monitoring and evaluating implementation of the Road Map. All participants described the Road Map as a living document, and expressed a desire to see the Road Map reviewed and revised to reflect current circumstances and priorities.
(v) **Formal acknowledgement of Indigenous health research as a priority area for development**

Several participants highlighted the importance of this acknowledgement in improving expenditure and Indigenous representation within the agency (see points below). One respondent reported that this acknowledgement enabled NHMRC to reinterpret existing NHMRC legislation, and allow funds to be earmarked for Indigenous health research. In practice, this meant allocating a designated proportion of the NHMRC annual budget to Indigenous health.

(vi) **Commitment to 5% target of annual expenditure**

All participants acknowledged this funding commitment as a landmark decision by NHMRC. The recommendation to allocate 5% of agency expenditure to Indigenous health was first tabled in 2000 as a mandate from the Commonwealth, as put forward in the Health is Life report (House of Representatives Standing Committee on Family and Community Affairs 2000). The decision was not adopted as agency policy until the 144th meeting of Council in October 2002 (NHMRC 2002b), after careful consideration of agency legislation, and lobbying by influential members of Roadmap Working Group. The decision to adopt a funding quota was a landmark change in agency policy, and reflects an organisational commitment to improve Indigenous health and restore equity.

(vii) **Increase Indigenous representation across all NHMRC Principal Committees and Council**

Congruent with ethical principles that Indigenous people should be engaged at all levels of decision-making in research, representation within the NHMRC is imperative. In accordance with the principle to engage Indigenous community members in all stages of research, all participants emphasised the importance of Indigenous participation in decision-making within NHMRC.

Since 1997, there has always been Indigenous representation on Indigenous Health Review Panels, but not always on NHMRC Council and Principal Committees. One informant explained that in 1997, the Strategic Research Development Committee formed a sub-committee called RAWG (Research Agenda Working Group) to advise NHMRC on Indigenous health issues. The main responsibility of RAWG was to develop a Road Map that prioritised thematic areas for funding. All interview participants agreed that over two trienniums, RAWG had played an influential role in rearticulating the NHMRC’s approach to investing in Indigenous health.

All participants reported that over the last decade, the Indigenous voice within Council had gained strength as Aboriginal representation increased across NHMRC. The first Aboriginal chair of
RAWG said he considered himself the first Black representative to hold a position within NHMRC that was not purely tokenistic. The informant explained that predecessors had not realised NHMRC’s potential; research practice and policy remained stagnant during their tenure. Three informants believed that with an Aboriginal representative on the Strategic Research Development Committee and chairing RAWG, Aboriginal representation in RAWG transformed from token minority representation to constituting a Black majority—increasing the committee’s punch power and influence.

Most informants reported that at the conclusion of RAWG’s second triennium in October 2002, a series of policy changes were tabled and adopted by NHMRC thanks to the advocacy and contributions of influential Aboriginal committee representatives. Among these changes was the decision to have Indigenous representation across all NHMRC Principal Committees and Council.

3.4.3 What drove the NHMRC policy response?

In addition to the external catalysts for change (Section 3.4.1), interview participants also cited internal catalysts of policy change. All interviewees identified the following three factors as influential in bringing about change within NHMRC.

(i) Growing internal recognition of NHMRC’s responsibility to generate more high-impact Indigenous health research

Participants felt that external evaluations of Indigenous health such as the Senate Inquiry and Wills Report created a “desire to be seen to do something” within NHMRC. As an evaluation of research investments, the Wills Review was particularly influential in prioritising the poor state of Aboriginal health as a NHMRC policy issue. Interviewees describe a shared acknowledgement across Principal Committees at NHMRC that high quality research supported by efficient funding mechanisms could improve health outcomes for Indigenous Australians.

(ii) Greater representation of Indigenous people within NHMRC

All interviewees emphasised the key role played by Indigenous members of Council and Principal Committees in driving the policy changes. From 1997 to 2002, the Indigenous voice within NHMRC gained strength as the number of Aboriginal representatives increased across the agency. By 2000, there was an Aboriginal chair of RAWG and 9 Indigenous members. There was also an Aboriginal
member of Council. A few participants reported the importance of Indigenous people constituting a majority within RAWG during its second triennium.

(iii) Leadership by key NHMRC Council and Committee members

Interviewees said that as external pressure to address Indigenous health issues mounted, key committee members and Council encouraged NHMRC to be responsive, and develop a strategy to address priority health issues.

3.4.4 What were the main barriers that had to be overcome?

When asked to identify obstacles to the policy change, all interviewees responded that there was no resistance from within Council beyond “mutterings behind the scene.” Some participants, however, identified a changing view of the NHMRC Act within the agency. It was reported that in the early part of the period, NHMRC argued that its legislation prevented the agency adopting a 5% funding target. Indeed this was outlined in NHMRC’s deliberations over the Health is Life report (NHMRC 2000a, 2000b, 2000c, 2001a, 2001b, 2001c), but not in the formal response provided to the Minister for Health and Ageing (2001d). This view shifted over time, so that by 2002 it was possible to agree a 5% funding target without modification to the legislation (NHMRC 2002c). The first draft prepared in response to the Minister of Health in August 2001 primarily cited “under existing legislation, the National Health and Medical Research Council Act 1992, the government cannot direct the National Health and Medical Council to allocate any percentage of funding for specific purposes” (NHMRC 2001a).

After two more deliberations, the reply to the Minister in June 2002 did not cite this legislation at all; rather, the reply focused on drawing attention to the range of initiatives developed and supported by NHMRC to improve Indigenous health over the last three years. While the reply acknowledged the difficulty in identifying research explicitly related to Indigenous health versus research that provides evidence pertinent to Indigenous communities, it estimated that in 2001, 2.1% of total NHMRC research funding (over $4.6 million) funded Indigenous health research, and over 5% funded research of diseases pertinent to Indigenous communities. The formal reply noted, “while the objective of the Health is Life report’s recommendation is commendable, the focus on an arbitrary floor such as 5% may, of itself, offer little in the way of improving the health status of Indigenous people through research. Such a focus may also obscure the positive impact of a range of initiatives that may not involve an increase in expenditure” (NHMRC 2002a).
3.4.5 What challenges will Indigenous health research policy face in the future?

Interviewees identified five issues that need to be addressed in the next triennium and beyond. Interviewees suggested that NHMRC should:

(i) Develop an action plan to ensure existing policy is implemented

All participants emphasised the importance of revisiting existing policies to evaluate implementation, and adjust policies to reflect current priorities. Informants identified the need to review and plan for actualisation of the following initiatives: reaching the 5% funding target, evaluation of the Road Map, and evaluation of the Strategy for Building Capacity in Indigenous Health Research.

The Strategy for Building Capacity in Indigenous Health Research was endorsed by NHMRC at its 159th Session in December 2005. In the strategic plan the 2006-2009 triennium, NHMRC outlines the following six objectives for Indigenous health research: to create internationally competitive knowledge in Indigenous health, to develop research capacity and capability within Australia, to improve utilisation of research findings, to capture and utilise research findings to improve health outcomes, to maintain and promulgate high ethical standards, to engage with the Indigenous community, and to improve governance and accountability within NHMRC (NHMRC 2005b). While this document outlines the principle issues for consideration in building research capacity for Indigenous health, the “outcomes” are not measurable indices. Participants noted that this makes evaluation of this policy virtually impossible.

(ii) Revisit the Road Map

All interview participants emphasised the Road Map should be revisited to reflect current priorities, and an evaluation needs to be conducted to assess the short and medium term impact of recent investments.

(iii) Develop innovative funding mechanisms

Participants reported that current funding mechanisms within NHMRC need to be reshaped to ensure research capacity is being developed among Indigenous people. The current career pathway offered through People Support remains largely inaccessible to Indigenous researchers. Interviewees suggested NHMRC and academic institutions collaborate in promoting scholarship opportunities and facilitating the application process. Also, one participant advocated the NHMRC support and fund research models that “bring together an extended network of multi-disciplinary researchers.” Most
Interviewees acknowledged that the value of scholarships would have to increase to attract professionals currently working in other fields. Many participants acknowledged the innovative nature of funding models like the Population Health Capacity Building Grants, and believed the mentor model was more appropriate to support and train Indigenous researchers.

(iv) Amend NHMRC legislation to make provisions for Indigenous health

One participant advocated the amendment of the 1992 NHMRC Act to make provisions for Indigenous health inequalities, and reflect the agency’s priorities and strategies. Examples of concessions for Indigenous health research include the adoption of funding and workforce targets.

(v) Continue to improve Indigenous representation

All participants emphasised the importance of ongoing Indigenous representation within Council and across all Principal Committees.
3.5 **Summary of Results**

A series of landmark policy changes were adopted by NHMRC in 1997 and 2002, including the decisions:

- to establish criteria for assessing health and medical research of Indigenous Australians
- to establish Indigenous Health Review Panels
- to establish the NHMRC Road Map Working Group (RAWG)
- to develop and endorse the Road Map, a strategic research agenda for prioritising Indigenous health research funding
- to formally acknowledge Indigenous health as a priority area of development
- to commit 5% of annual NHMRC expenditure to Indigenous health
- to increase Indigenous representation across all NHMRC Principal Committees and Council

Interview participants cited the catalysts for these policy changes were:

- mounting evidence for the urgent health needs of Indigenous communities
- increasing pressure from Indigenous communities to ensure research maximises health gains
- increasing pressure to consider gains from investments in research
- increasing pressure from government to earmark funding for research in Indigenous health

Key informants reported that these external catalysts created a growing internal recognition of NHMRC’s responsibility to generate more high-impact Indigenous health research. The NHMRC deliberated for two years over the Health is Life report’s recommendation to allocate 5% of the annual budget to Indigenous health before endorsing the decision. Interviewees credit the role of Indigenous representation and leadership by key NHMRC Council and Committee members as influential factors in bringing about the policy change. In other words, key informants highlighted the importance of engaging Indigenous people in the policy process, and building their capacity as NHMRC Committee members as keys to reaching these policy decisions.
CHAPTER 4 STUDY TWO: THE EXTENT TO WHICH PEOPLE SUPPORT AWARDS SUPPORT PRINCIPLES OF GOOD PRACTICE FOR INDIGENOUS HEALTH RESEARCH

4.1 Introduction

Study One described in Chapter 3 outlines the evolution of a broad reaching policy agenda within NHMRC—designed both to encourage more research focused directly on improving health outcomes of Aboriginal people, and on increasing the total amount of funding provided for Aboriginal health research. In the late 1990s, there was mounting pressure on NHMRC to consider the principles for practice described by researchers when applying for funding to study Indigenous health.

As discussed in Chapter 1, there has been substantial debate about the types of research that are more likely to result in health gains. However, there is little research of an empirical nature about building research capacity for Indigenous health in Australia (Table 1-4), the existing evidence base suggests that the characteristics of Indigenous health research have not been optimal historically. Kowal et al (2005) and Anderson et al (2003) suggest that there is still a lack of consultation with community members and organisations in Indigenous health research. Sanson-Fisher et al (2006) demonstrate the lack of intervention research studies in Australian publications about Indigenous health. There is no empirical evidence about the impact of strategies to build research capacity, or to demonstrate their impact. The lack of research evidence to inform improvements in health and health services, and the evidence that does exist suggest that, in Australia, more research that meets the principles of good practice for Indigenous health research needs to be conducted, and adequately resourced by NHMRC research funding.

As detailed in the literature review (Chapter 1), and highlighted by interview participants in Chapter 3, the following characteristics in research are likely to be important for creating meaningful health gains:

1. Focus on intervention research that examines whether policy, services, or programs have the capacity to improve health outcomes.
2. Engagement of Indigenous community members and organisations in all stages of research including consultation, development of research design, ethical review, data collection and monitoring, interpretation of results, report writing, dissemination and application of research findings.

3. Research programs that increase the number and skill base of health professionals conducting research in Indigenous health. These programs include multi-disciplinary training in a broad base of skills in both clinical and policy settings (including negotiation of community consultations and consent, planning and implementation of health programs, evaluation of services that are effective and sustainable, and translation of research findings into policy and the development of better interventions and health services). Building research capacity among Indigenous people provides a culturally appropriate, long term, and sustainable approach to improving Indigenous health through research.

These key principles will be used in this study to benchmark research practices among current NHMRC People Support recipients. People Support pathways and programs are the key funding mechanism for NHMRC to build research capacity. Evaluation of research practices for successful applicants in 2005 and 2006—by assessing good practice against the three principles described above—allows us to assess the impact of policy changes on current research practice three years after policy changes.

4.2 Aim of Study Two
To describe the extent to which research approaches used by People Support recipients meet the principles of good practice for Indigenous health research.

4.3 Methods
4.3.1 Study design
We conducted a case study evaluating the extent to which projects undertaken by People Support recipients were in accord with the three principles of good research practice outlined above. We examined researchers funded through the four types of awards offered in the NHMRC People Support stream—a career pathway for researchers with increasing experience: Scholarships, Training Awards, Career Development Awards, and Career Awards (NHMRC 2005a). We also examined a second funding vehicle,
which is a new funding model; NHMRC Capacity Building Grants in Population Health Research were introduced in 2002 to support research teams with a disciplinary focus on public health and health services. Within each research team, senior researchers, or lead applicants, are identified as skill mentors for more junior team investigators (NHMRC 2006).

Researchers were classified as (a) all those who study Indigenous health, referred to as “researchers who study Indigenous health,” and (b) a subset of these applicants—those who indicated on their application forms that they were Aboriginal and/or Torres Strait Islander--referred to as “researchers who self-identify as Indigenous.”

### 4.3.2 Data sources and data extraction

A keyword search of the NHMRC Research Management Information System (RMIS) was used to identify researchers who study Indigenous health and received NHMRC People Support funding. Grant awards with the following terms in either the title, lay summary, keywords, or fields of research were included for review: Aborigines or Aboriginal; Torres Strait Islander; Indigenous; Koori.

While Capacity Building Grants in Population Health Research are classified by NHMRC as Strategic Awards, and not part of the People Support scheme, they do encompass a framework for the educational and financial support of health researchers in training, and were included for analysis. For Capacity Building Grants in Population Health Research, a standardised question on the application form (section 1.3 on the form) was used to identify “research involving Indigenous Peoples.” Applications that marked ‘yes’ were included.

For the purposes of this case study, only awards commencing in 2005 or 2006 were examined. This was because the author wanted to examine successful applicants at a time when the policy impact was likely to be greatest; the last two years should be a period where we could see whether People Support was being awarded in line with the intent of the new policy.

The author was granted access to original application forms for review, and all applications were coded for 14 items including information about thematic areas of the Road Map, project design, and research practices. All applications were double-coded, meaning the author and a research assistant coded all items for each case independently; in case of disagreement, the application was jointly reviewed for consideration until the coders could agree on how the item should be coded. Operational Definitions
(Appendices D & E) for coding the data were developed, reviewed, and agreed upon by the author, her supervisors, and the director for Strategic Research Initiatives at NHMRC.

4.3.2.1 Classification of Indigenous status
NHMRC People Support applicants were classified as researchers who self-identify as ‘Indigenous’ or ‘non-Indigenous’ according to the application forms. Applicants that indicated they were Aboriginal and/or Torres Strait Islander were classified as ‘Indigenous,’ while applicants who indicated they were neither were classified as ‘non-Indigenous.’

4.3.3 Data analysis
The grants were assessed against the three criteria outlined above using the following operational definitions:

- **Focus on intervention research**—the proportion of successful award recipients reporting that they intended to conduct intervention-based research programs that include the development or implementation of interventions and health services.

- **Engagement of Indigenous community members and organisations**—the proportion of successful applications that (a) describe an advisory group with Indigenous membership in project design; and (b) complete the special section of their application form designed for review by the Indigenous Health Review Panels. This section asks applicants conducting health and medical research of Indigenous Australians to explain how their research project addresses the Darwin Criteria, and outline their commitment to Indigenous engagement.

- **Building research capacity among Indigenous people**—the proportion of award recipients who (a) self-identify as Indigenous; and (b) employ or train an Indigenous person as part of their research team.

---

1 All NHMRC applicants for Indigenous health research have been required to complete this section since 1997.
4.4 Results

The keyword search identified 38 People Support recipients in 2005 or 2006 who study Indigenous health. However, upon closer review of these applications, 7 were excluded because no component of the outlined research project mentioned or included the study of an Indigenous population. In 2005 and 2006, NHMRC awarded 31 People Support Awards and 7 Capacity Building Grants in Population Health Research to support Indigenous health research.

4.4.1 Focus on intervention research

As Table 4-1 illustrates, only 8 of 31 successful applications to People Support for Aboriginal health research were intervention-based studies. Less than one-third (26%) of People Support recipients included an intervention-based component in their research program. The majority of funded applications focused on descriptive research.

In contrast, nearly all successful applications for Capacity Building Grants in Population Health Research included intervention-based studies. Almost all (86%) successful Capacity Building Grants in Population Health Research included the development or implementation of a health intervention; however, since multiple researchers are included in each grant, this does not mean that 86% of researchers conduct intervention-based research, and it is not possible to extract this information.

The two kinds of awards are not directly comparable because People Support Awards are to individuals, and Capacity Building Grants in Population Health Research are to teams of researchers. However, the evidence suggests that Capacity Building Grants are conducive to supporting intervention-based research programs.

Table 4-1  Distribution of People Support Awards and Capacity Building Grants in Population Health Research awarded 2005-2006: Intervention-based vs. Descriptive Studies

<table>
<thead>
<tr>
<th></th>
<th>People Support Awards</th>
<th>Capacity Building Grants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Descriptive</td>
<td>23</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>31</td>
<td>7</td>
</tr>
</tbody>
</table>
4.4.2 Engagement of Indigenous community members and organisations

Tables 4-2 and 4-3 illustrate respectively the distribution of successful People Support recipients who a) completed the special section of their application based on the Darwin Criteria for the Indigenous Health Review Panels to assess, and b) described a project advisory group with Indigenous membership in research design. As discussed in Chapter 1, addressing the Darwin Criteria is important because it is required by NHMRC for research of Indigenous Australians, and because it is a means for applicants to demonstrate that their research will be conducted in a culturally-appropriate manner and to the benefit of Indigenous communities. If applicants do not complete this section, that does not necessarily mean they are not engaging Indigenous communities; however, we have used this as a proxy to indicate the extent to which applicants take the principles of good practice for Indigenous health research seriously in their application.

Table 4-2  Distribution of People Support Awards and Capacity Building Grants in Population Health Research awarded 2005-2006: Completion of Darwin Criteria among successful funding applications

<table>
<thead>
<tr>
<th></th>
<th>People Support Awards</th>
<th>Capacity Building Grants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>31</td>
<td>7</td>
</tr>
</tbody>
</table>

Approximately two-thirds of People Support recipients addressed the Darwin Criteria in their application forms. Completion rates were much higher among Scholarship and Training Award recipients; no recipients of Career Development Awards or Career Awards completed this section of their application. Just over half of successful Capacity Building Grant applications completed this section.
Table 4-3  Distribution of People Support Awards and Capacity Building Grants in Population Health Research awarded 2005-2006: Inclusion of Indigenous advisory group among successful funding applications

<table>
<thead>
<tr>
<th></th>
<th>People Support Awards</th>
<th>Capacity Building Grants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>31</td>
<td>7</td>
</tr>
</tbody>
</table>

Less than half of successful People Support recipients described a project advisory group with Indigenous membership. NHMRC Scholarship holders were the most likely to include an Indigenous project advisory group in their proposed research program. The majority (86%) of Capacity Building Grants in Population Health Research described the inclusion of an Indigenous project advisory group in project design.

4.4.3  Building research capacity among Indigenous peoples

4.4.3.1  Indigenous Applicants

In 2005 and 2006, NHMRC People Support awarded researchers studying Indigenous health a total of 31 financial awards (16 Scholarships, 9 Post-doc Training Awards, 3 Career Development Awards, and 3 Career Awards). Most of these were awarded to people from non-Indigenous backgrounds; only two Scholarships were awarded to applicants who self-identified as Indigenous.

In 2005 and 2006, 7 Capacity Building Grants in Population Health Research were awarded to support Indigenous health research; a total of 58 team investigators were allocated funding. Twenty-four self-identified as non-Indigenous and 34 as Indigenous. The issue of support for researchers who self-identify as Indigenous is given further consideration in the next chapter.

4.4.3.2  Indigenous Employees

Among 31 People Support recipients, just over half (54.8%) are training or employing an Indigenous person who is not the recipient of a training award as part of the research team. This does not include recipients who self-identify as Indigenous. Since Capacity Building Grants in Population Health Research only support researchers included on the application, they were not considered for this criterion.
4.5 Summary of Results

- The study examined the extent to which recipients of People Support awards and Capacity Building Grants in Population Health Research in 2005 and 2006 who study Indigenous health met three principles of best practice in Aboriginal health research: focus on intervention research; engagement of Indigenous community members and organisations; building research capacity among Aboriginal people.

- Among recipients of People Support Awards, less than one third included an intervention component, two thirds addressed the Darwin Criteria, and about half included an Indigenous advisory group or employed an Indigenous person as part of the research team. More could be done to encourage recipients of People Support Awards to undertake research in a way that is regarded as best practice in Aboriginal health. This is particularly true of the more senior award recipients.

- Among recipients of Capacity Building Grants in Population Health Research, most included an intervention component and had an Indigenous advisory group. The Capacity Building Grants in Population Health Research appear to be a more effective method in stimulating best practice for Indigenous health research.

- There is opportunity to improve allocation of People Support funding to support principles for good practice in Indigenous health research.
CHAPTER 5    STUDY THREE: DID THE POLICY CHANGES IMPACT THE AMOUNT OF PEOPLE SUPPORT FUNDING FOR INDIGENOUS HEALTH AND HOW IT WAS SPENT?

5.1 Introduction
As demonstrated by Chapters 1 and 3, there was growing recognition throughout the 1990s that NHMC needed to fund more research for Indigenous health, and prioritise projects that uphold the principles of good practice for Indigenous health research. In response to these mounting pressures, NHMRC endorsed seven inter-linking policy changes (Section 3.4.2): adoption of the Darwin Criteria, establishment of Indigenous Health Review Panels, establishment of RAWG, endorsement of the Road Map, formal acknowledgement of Indigenous health research as a priority area for development, a commitment to allocate 5% of the annual NHMRC budget to Indigenous health, and an increase in Indigenous representatives across all NHMRC Principal Committees and Council.

Chapter 4 describes the ways in which Indigenous health research is funded through People Support and Capacity Building Grants in Population Health Research to support research that upholds the principles of good practice for Indigenous health research. However, the 2002 NHMRC policy changes were also designed to increase the sum amount of funding allocated to support Indigenous health research. In 2002, NHMRC endorsed the financial commitment to allocate 5% of the annual research budget to Indigenous health.

Chapter 5 describes how funding for building research capacity in Indigenous health is currently allocated. It assesses the impact of the 5% policy decision on the allocation of money, using People Support as a lens for research funding.
5.2 **Aim of Study Three**

To describe the impact of policy change on funding allocations by NHMRC for Indigenous health research. More specifically:

- h. To identify how many and what proportion of People Support awards were made to researchers who study Indigenous health
- i. Evaluate the distribution of People Support funding for Indigenous health by Broad Research Area
- j. To determine if People Support for researchers who study Indigenous health has increased over time
- k. To estimate what proportion of People Support funding is awarded to researchers who self-identify as Aboriginal or Torres Strait Islander
- l. To assess the impact of Capacity Building Grants for Health Research on expenditure for building research capacity in Indigenous health, particularly among Indigenous scholars
- m. To evaluate the distribution of researchers who self-identify as Indigenous by academic institution and State/Territory
- n. To evaluate the distribution of People Support funding for Indigenous health by State or Territory

5.3 **Methods**

5.3.1 **Study design**

This paper examines a decade of awards allocated through the People Support scheme to advance the work, training, and development of researchers who study Indigenous health in Australia. This study examine changes in NHMRC funding over time among (i) researchers studying Indigenous health and (ii) researchers who self-identify as Aboriginal or Torres Strait Islander to evaluate the impact of policy changes adopted by the NHMRC in 2002. It examines the annual distribution of People Support awards and expenditure by broad research area, state/territory, administering institution, and Indigenous status (as self-identified by award recipients in their applications).
5.3.2 Data sources and data extraction

The NHMRC Research Management Information System (RMIS) was used to capture information about the distribution of People Support Awards for Indigenous health research between 1996 and 2006. To identify researchers who study Indigenous health, a keyword search was used to generate a relevant database; grant awards with the following terms in either the title, lay summary, keywords, or fields of research were included: Aborigines or Aboriginal; Torres Strait Islander; Indigenous; Koori. These databases provided the authors with the following information: Grant ID #, applicant name, name and state of administering institution, project title, broad research area and fields of interest, type of award, and financial allocation per calendar year.

For Capacity Building Grants in Population Health Research, data for the same fields of information were recorded from standardised application forms. A standardised question from the application form was used to identify “research involving Indigenous Peoples” (Section 1.3). Applications that checked ‘yes’ or used the following keywords to describe the field of research were included: Aborigines or Aboriginal; Torres Strait Islander; Indigenous; Koori.

5.3.2.1 Classification of Indigenous Status

NHMRC People Support applicants were classified as researchers who self-identify as ‘Indigenous’ or ‘non-Indigenous’ according to the application forms. Applicants that indicated they were Aboriginal and/or Torres Strait Islander were classified as ‘Indigenous,’ while applicants who indicated they were neither were classified as ‘non-Indigenous.’

5.3.3 Data analysis

The database described above was used to examine changes in annual NHMRC People Support grants and expenditure over time. Financial allocations were analysed by type of award, broad research area, state/territory, administering institution, and Indigenous status. The distribution of awards was examined both by the number of awards made and by the financial value of awards.
5.4 Results

5.4.1 People Support Awards for researchers studying Indigenous health

From 1996 to 2006, a total of 134 awards (96 Scholarships, 23 Training Awards, 7 Career Development Awards, and 8 Career Awards) were awarded to researchers who study Indigenous health. Over a decade of People Support, a total of $11.2 million was allocated to researchers studying Indigenous health.

Figure 5-1 illustrates the numerical distribution of awards from the traditional stream of People Support. It compares the distribution of awards between all recipients of People support and recipients who study Indigenous health.

**Figure 5-1** Numerical distribution of NHMRC People Support Awards:

All Awards vs. Indigenous Health Research Awards, 2000-2006

The distribution of award allocations for Indigenous health research indicates that a larger proportion of awards are for scholarships when compared with the distribution of all People Support Awards. Figure 5-1 suggests that there are more high-level awards (Training Awards, Career Development Awards & Career Awards) allocated among all People Support recipients than are allocated to researchers who study Indigenous health. As the skill-base and pool of researchers in Indigenous health expands over the upcoming years, it may be that greater numbers of researchers progress along the People Support career pathway (Figure 1-7) to receive more high-level awards.

* n = 2788

** n = 116
Figure 5-2 illustrates the distribution of expenditure by award within People Support, for the same time frame. Again, the distribution of financial allocations suggests that Indigenous health research is being awarded comparatively fewer high-level awards such as Career Awards and Training Awards.

**Figure 5-2** Financial Distribution of NHMRC People Support by award:

All People Support Awards vs. Indigenous Health Research Awards, 2000-2006

Broad Research Areas for People Support Awards in Indigenous health research

Broad Research Areas allow us to classify the type of research being conducted by People Support recipients. Researchers in Basic Science are primarily conducting biomedical research of a descriptive nature. Studies in Clinical Medicine and Science, Public Health, Health Services Research, and Preventive Medicine and Science tend to be intervention-based, and focus both on the design and delivery of treatments and services, and impact evaluation on population health outcomes. Figure 5-3 on the following page illustrates the distribution of annual NHMRC People Support expenditure by broad research area. It compares the distribution of research funding by broad research area for 2006 People Support recipients who study Indigenous health and those who do not.
Among all 2006 NHMRC People Support recipients, the majority of research funding was allocated to training in Basic Sciences (65%) and Clinical Medicine and Science (23%). Comparatively, far fewer researchers who study Indigenous health were financially supported to pursue training in these fields (20% in Basic Sciences and 10% in Clinical Medicine and Science). The majority of People Support expenditure for recipients studying Indigenous health was in Public Health (60%).

The distribution of funding by broad research area suggests that the majority of non-Indigenous research supported by the NHMRC is in Basic Science, while the majority of Indigenous health research is in Public Health.
5.4.3 Have People Support financial allocations for Indigenous health research increased over time?

Annual People Support allocations to support Indigenous health research increased from $495,000 in 1997, to $864,400 in 2003, and to $3,207,300 in 2006. A three-fold increase in People Support expenditure followed the 2002 policy changes (Figure 5-4). As shown in Figure 5-5, $3.2 million in 2006 represents 3.3% of all funds awarded for People Support.

Figure 5-4 Annual NHMRC People Support Expenditure for Indigenous Health Research: 1996-2006

While the financial allocations for Indigenous health research through People Support increased substantially since 2002, the financial allocations for all research through People Support were also increasing over this time. Therefore, to accurately gauge NHMRC expenditure for Indigenous health, it is important for us to examine both of these trends (illustrated in Figure 5-5). In 2003, Indigenous health research represented 1.4% of all People Support expenditure. In 2006, Indigenous health research represented 3.3% of all People Support expenditure, indicating a 2% increase in expenditure. The financial allocation for Indigenous health research and the proportion of People Support flowing to Indigenous health research has increased.

This study is unable to evaluate NHMRC expenditure on Indigenous health across all its schemes, and therefore unable to assess if the 5% target has been met overall. While NHMRC never made a commitment to reach the 5% target on a scheme-by-scheme basis, increased expenditure in People Support...
Support is of most relevance to building research capacity. NHMRC expenditure through People Support has not reached the 5% funding target five years after the policy change (Figure 5-5).

**Figure 5-5** Annual Distribution of Research Funding for Indigenous Health People Support and All People Support: 2000-2006.

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5.4.4 *Is NHMRC People Support building research capacity among Indigenous peoples?*

Over a decade of NHMRC People Support, only 9.2% of financial allocations for researchers who study Indigenous health through People Support were to researchers who self-identify as Indigenous (or 0.08% of total expenditure on People Support). From 1996 to 2006, 27 NHMRC Scholarships worth $1.1 million were awarded to researchers who self-identified as Indigenous—all receiving the most junior of the four types of People Support.

For researchers who self-identify as Indigenous, People Support funding has not increased over time. In 2006, only two Aboriginal scholars were awarded funding through the People Support pathway. Over a decade of NHMRC People Support, financial awards only increased for researchers who self-identify as non-Indigenous (Figure 5-6).
5.4.5 What funds have been provided through the Capacity Building Grants in Population Health Research program?

While NHMRC Capacity Building Grants in Population Health Research are categorised by NHMRC as Strategic Awards, and not part of the People Support scheme, they do encompass a framework for the educational and financial support of health researchers in training. Since the scheme began in 2002, twenty-five Capacity Building Grants in Population Health Research have been awarded; eight of these were awarded to support Indigenous health research. These awards supported a total of 70 team investigators (34 self-identify as non-Indigenous and 36 self-identify as Indigenous).

Since 2002, the majority of funding (78%) provided for the support of researchers who self-identify as Indigenous was administered through Capacity Building Grants in Population Health Research. Figure 5-7 illustrates the distribution of funding to researchers who self-identify as Indigenous over the last decade. Within People Support, Indigenous scholars have only received NHMRC Scholarships, and expenditure levels have remained stagnant over time. The Capacity Building Grants in Population Health Research have boosted the financial allocations to Indigenous scholars substantially over just a couple years.
Over the past 5 years, $56.6 million has been awarded for 25 Capacity Building Grants in Population Health Research. Of these funds, 33% were provided to support Indigenous health research. These eight grants supported 70 researchers (36 of whom self-identify as Indigenous), and were worth a total of $18.6 million. This is substantially more than the sum allocated to researchers who study Indigenous health through People Support over the last decade ($\$11.2$ million).

Since this study does not include total expenditure for Strategic Awards, it is subsequently difficult to determine how Capacity Building Grants in Population Health Research contribute to meeting the 5% target. Also, because these awards have only been funded for a limited amount of time, it is difficult to assess their impact over time. However, the evidence in this chapter and an excellent track record for meeting the principles of good research practice for Indigenous health (Section 4.4) suggest that this is a good model for building research capacity, particularly among Indigenous scholars.

5.4.6 Where are we training researchers who self-identify as Indigenous?

Among People Support recipients, administering institutions with the largest number of Aboriginal or Torres Strait Islander scholars were Curtin University of Technology (17), James Cook University (12), and University of Sydney (8). When team investigators of Capacity Building Grants in Population Health Research are included in analyses, states training the greatest number of researchers who self-identify as...
Aboriginal or Torres Strait Islander are: Queensland (20), Western Australia (18), and New South Wales (11).

5.4.7 Where are we training researchers who study Indigenous health?

The distribution of awards by state/territory is reported in Table 5-1 below. States training the greatest number of researchers who study Indigenous health were Queensland (45), the Northern Territory (41), New South Wales (36), and Victoria (35).

Table 5-1: Distribution of NHMRC award recipients for Indigenous health research by award and state/territory: 1996-2006

<table>
<thead>
<tr>
<th></th>
<th>NHMRC Scholarships</th>
<th>NHMRC Training Awards</th>
<th>NHMRC Career Development Awards</th>
<th>NHMRC Career Awards</th>
<th>People Support Total</th>
<th>NHMRC Capacity Building Grants</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>2</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>22</td>
<td>14</td>
<td>36</td>
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<tr>
<td>VIC</td>
<td>1</td>
<td>3</td>
<td>16</td>
<td>6</td>
<td>26</td>
<td>9</td>
<td>35</td>
</tr>
<tr>
<td>QLD</td>
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<td>1</td>
<td>20</td>
<td>3</td>
<td>27</td>
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<td>NT</td>
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<td>ACT</td>
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<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Total Australia</td>
<td>8</td>
<td>7</td>
<td>96</td>
<td>23</td>
<td>134</td>
<td>70</td>
<td>204</td>
</tr>
</tbody>
</table>

Within the People Support stream, states training the greatest number of researchers who study Indigenous health were the Northern Territory (31), Queensland (27), and Victoria (26).
Figure 5-8: Comparative Distribution of NHMRC People Support Awards* and Indigenous Australians**

![Graph showing the distribution of People Support expenditure on Indigenous Health compared to the proportion of the Indigenous population in Australia by state/territory.]

* n = 134    ** n = 516,800


When compared with the distribution by state/territory of Indigenous Australians, there are greater relative numbers of researchers who study Indigenous health in Victoria and the Northern Territory, but relatively fewer in New South Wales and Queensland (Figure 5-8).

5.5 Summary of Results

- This study examined how People Support expenditure was distributed and the extent to which policy changes impacted expenditure. The distribution of expenditure over time was examined by broad research area, researchers who self-identify as Indigenous, academic institution, and state or territory. The study also examined the impact of Capacity Building Grants in Population Health Research on funding for researchers who study Indigenous health, particularly those who self-Identify as Indigenous.
• Within People Support, the allocation of funding for Indigenous health has increased from 1.4% to 3.3% since the 2002 policy changes. The distribution of financial awards only increased for researchers who self-identify as non-Indigenous.

• The majority of People Support recipients studying Indigenous health identified Public Health (70%) as their broad research area.

• Capacity Building Grants in Population Health Research made a huge impact on capacity building expenditure for Indigenous health research, particularly among scholars who self-identify as Indigenous. The total value of capacity building grants allocated over four years ($18.6 million) to support Indigenous health research exceeded the amount allocated through People Support over a decade ($11.2 million). Among 70 team investigators supported, 36 self-identified as Indigenous. When considered in conjunction with the findings in Chapter 4, this evidence suggests Capacity Building Grants in Population Health Research are a good model for building research capacity in Indigenous health.

• Including both People Support Awards and Capacity Building Grants in Population Health Research, states training the greatest number of researchers who study Indigenous health are: Northern Territory (45), Queensland (41), New South Wales (36), and Victoria (35).

• As greater investments are made to develop research capacity for Indigenous health, increasing efforts will be required to train researchers across a diversity of research disciplines, methodologies, and clinical settings. The People Support schemes are particularly important for growing research capacity in historically under-funded areas such as Indigenous Health because they offer an opportunity to increase the number and skill base of researchers across all research disciplines. As the evidence from Chapter 1 (Tables 1-4 and 1-5) and Chapter 5 (Figures 5-2 and 5-3) suggests, more capacity building is needed in fields of measurement and intervention-based research for Indigenous health, such as Clinical Medicine and Science, and Health Services Research.
Chapter 6  DISCUSSION OF MAJOR FINDINGS

6.1 Summary of major findings

This thesis has addressed the question of funding for Indigenous health research. It has examined the policy changes at NHMRC in the late 1990s through to 2002 and the reasons that these occurred. It has explored the impact of these changes on the types of research undertaken and the amount of funding provided—using the People Support scheme as a lens for evaluation.

The major findings from this work are summarised here and their implications explored in the following sections of the discussion:

• Since 1997, NHMRC endorsed and began implementing seven inter-linked policy changes: adoption of the Darwin Criteria, establishment of Indigenous Health Review Panels, establishment of RAWG, endorsement of the Road Map, formal acknowledgement of Indigenous health research as a priority area for development, a commitment to allocate 5% of the annual NHMRC budget to Indigenous health, and an increase in Indigenous representatives across all NHMRC Principal Committees and Council.

The series of policies adopted by NHMRC in 2002 endorsed a financial commitment to improve Indigenous health through research, and also a commitment to fund research that is more likely to create meaningful health gains for Indigenous Australians. As discussed in Chapter 4, the 2002 NHMRC policy changes were stimulated primarily by increasing pressure from government, the community, and Indigenous scholars to consider gains from investments in research, and formal acknowledgement within NHMRC of its role in improving Indigenous health through research. The external catalysts for change included mounting evidence from external reports. A Government Inquiry into Indigenous health sparked debate about earmarking NHMRC funds for Indigenous health, and the outcomes of public investment in research. Strong leadership from members of RAWG, Principal Committees and Council within NHMRC was an important internal catalyst for policy change.

• This study also examined the impact of policy changes on what kinds of research received funding allocations. There is widespread acknowledgement that research funding agencies have historically focused on investigator initiated research—a conservative approach that may not focus research
efforts in areas of greatest health need (Cooksey 2005, Rix et al 2005). As discussed in the literature, there is a need to develop the evidence-base for interventions and treatments, and so, a growing demand for research that informs the delivery of health services in a clinical setting (Anderson 2003, Thomson 2003). The study in Chapter 4 evaluates successful research applications from 2005 and 2006 to determine if they uphold the following three principles of good practice for Indigenous health research: intervention-based research likely to contribute to meaningful health gains among Indigenous Australians, consultation and engagement with Indigenous community members and organisations throughout all stages of research, and training & employment of Indigenous people as part of the research team.

The results of Study Two and Sanson-Fisher et al (2006) indicate similar results: few studies of Indigenous health are intervention-based. Among successful People Support recipients, roughly half engage Indigenous community members and organisations in project advisory groups and as members of the research team. Among Capacity Building Grants in Population Health Research, nearly all applications described one or more intervention-based components and an Indigenous project advisory group as part of their study design. In 2005 and 2006, Capacity Building Grants in Population Health supported 34 students who self-identified as Indigenous; only 2 Indigenous scholars were funded by People Support. This evidence suggests that Capacity Building Grants in Population Health Research are a good model for supporting the principles of good practice, and building greater research capacity for Indigenous health.

- Evidence in Chapter 5 suggests there is an uneven distribution of People Support recipients across research disciplines, with a concentration of 70% in Public Health, 5% in Basic Science, 11% in Clinical Medicine, 11% in Health Services Research, and 3% in Preventative Medicine. While evidence from Chapter 4 suggests Capacity Building Grants in Population Health are a good way to build research capacity in clinical and multi-disciplinary settings, particularly among researchers who self-identify as Indigenous, Chapter 5 considers the efficacy of People Support as a mechanism for increasing research expenditure for Indigenous health. At a policy level, NHMRC has not made a commitment to fund 5% to Indigenous health on a scheme-by-scheme basis; however, the value of People Support as a mechanism for building research capacity suggests that investment through these schemes will help build capacity for the future. Since the 2002 NHMRC policy changes, the amount of People Support funding for Indigenous health has increased from 1.4% to 3.3% of all awards. In the same timeframe, financial allocations to researchers who self-identify as non-Indigenous have increased through People Support, but support to researchers
who self-identify as Indigenous has not increased. While the 5% commitment to fund Indigenous health research was not quarantined to People Support, progress toward this target can be observed; this study indicates that the policy changes were influential in raising the sum and proportion of annual People Support expenditure for Indigenous health research. However, development of the research workforce has primarily been among researchers who self-identify as non-Indigenous, indicating a need for innovative strategies to build greater research capacity among Indigenous community members and organisations, particularly in multi-disciplinary, clinical and policy settings.

Is People Support the best-practice approach to building research capacity for Indigenous health? The second part of Chapter 5 evaluates the impact of Capacity Building Grants on (a) expenditure for Indigenous health, and (b) the value of annual awards allocated to researchers who self-identify as Indigenous. The capacity building model was successful in boosting investments for both. As a mechanism for funding Indigenous health research, People Support allocated $11.2 million over a decade and Capacity Building Grants in Population Health Research awarded $18.6 million over five years. People Support trained 27 researchers who self-identify as Indigenous over a decade; Capacity Building Grants in Population Health Research have supported 36 researchers who self-identify as Indigenous since 2004. When considered in conjunction with the findings in Chapter 4, this evidence suggests the capacity building model is an effective way of building research capacity for Indigenous health and supporting the kind of research that creates meaningful health gains.

- The future of building research capacity is paramount to the development and testing of better interventions and health services that will result in meaningful health gains for Indigenous Australians. This study indicates that policy has been influential in shaping the NHMRC’s approach to funding research that improves Indigenous health. Capacity Building Grants in Population Health Research have been successful at increasing numbers of researchers who self-identify as Indigenous, and supporting good research practices for Indigenous health. The evaluation presented in this thesis uses programs with a focus on building research capacity as a tool for assessment of research investments for Indigenous health over time. While funding for Indigenous health has increased over time through People Support and Capacity Building Grants in Population Health Research, this evaluation indicates policy implementation requires a detailed plan, time for execution, and regular monitoring.
6.2 Why did the policy change occur?

Interview participants and internal NHMRC documentation indicate that the series of policies adopted by NHMRC between 1997 and 2002 were landmark decisions in articulating Indigenous health issues for priority research development, reaffirming the NHMRC’s role, stating NHMRC’s financial commitment, and enabling new funding approaches. It was interesting that all of the key informants reported little resistance from the research community or within the agency. The Road Map and policy options drafted by RAWG received a high degree of support, and were endorsed by a receptive Council. External catalysts and internal leadership were dynamic agents in driving policy change. These findings are consistent with previous analyses of policy processes (Field et al 2002, Hogwood et al 1984, Sabatier 1993).

External catalysts such as reports, investment reviews, and pressure from Indigenous communities contributed to increasing pressure for NHMRC to formally acknowledge its role in improving Indigenous health through research. Deliberations over key evidence from external investment reviews and a House of Representatives Inquiry into Indigenous health were important catalysts for influencing the policy and practice of research funding to maximise health gains for Indigenous Australians. Of notable importance, NHMRC committed to a purpose-specific funding quota for the first time. Recent reviews of research funding agencies such as the review of UK health research funding conducted by Sir David Cooksey and the Health and Medical Research Strategic Review in Australia have recommended substantial changes to funding organisations and development of innovative funding mechanisms, so as to increase the likelihood that research benefits health services and outcomes (Cooksey 2006, IRHMRC 2004).

Internal leadership by Indigenous representatives and other senior individuals within NHMRC’s Council and Principal Committees was also influential in driving policy change. It was clearly significant that these leaders were able to identify responsive and feasible funding mechanisms, and that NHMRC could adopt decisions to bring about change. Respondents emphasised the importance of Indigenous members in RAWG and Council in bringing about these changes.

Good quality policy making depends upon evidence from a variety of sources including experts, stakeholder consultation, existing research internationally, and evaluation of previous policies. Intervention-based research is particularly important for improving the quality of evidence that informs policy (Nutbeam 2003, Dobrow et al 2004, Cooksey 2006). Cooksey recommends that research funding
agencies should do more to increase the investment in applied research, and accelerate the uptake and application of new technologies and research findings (Cooksey 2005). To ensure policy makes a substantial contribution to Indigenous health gains, there will be a continued need to monitor implementation and review outcomes of existing policies (Thomson 2003, Walt 1994).

6.3 Health research of Indigenous Australians: Does it use a best-practice approach?

Indigenous Australians perceive that they have been the subject of exploitative research for over a century (Humphery 2001, Thomas 2001). Both in Australia and internationally, it is widely recognised that Indigenous control, ownership, and power in research matters is very important (Schnarch 2004); ultimately, Indigenous communities and organisations have to “research back” to ensure the evidence will be used to the benefit of Indigenous people (Tuhiwai-Smith 1999). Study Two (Chapter 4) examined the extent to which research funded through the People Support schemes and the Population Health Capacity grants addressed the three principles for good practice in Indigenous health research:

The first criterion for best-practice research is intervention research that informs policy and the development and delivery of treatment-based and preventive health. A focus on intervention research is important because testing interventions and services informs our understanding of effective policy and program approaches for creating meaningful health gains. Among People Support recipients in 2005 and 2006, one-quarter (26%) of projects included the development or implementation of an intervention. Nearly all (six of seven) Capacity Building Grants in Population Health Research that were awarded to conduct Indigenous health research during this period also included an intervention-component in the proposed research program. Research by Sanson-Fisher et al (2006) indicates that approximately 13% of published Indigenous health studies in Australia are intervention-based. This evidence suggests that the field of studies in Indigenous health is predominantly descriptive in nature, and there is a need for more intervention studies.

The second criterion for good research practice relates to engaging Indigenous community members and organisations in research; this is important because it ensures research questions are priority-driven and research methodologies are culturally appropriate. A survey of human ethics committees in Australia suggested that more work needs to be done to consult Indigenous people about research. Forty-four percent of Australian health research ethics committees have no processes or protocols to include Indigenous people and only 21% have formal mechanisms for Indigenous consultation in the review
process (McDonald et al. 2006). Among People Support recipients, approximately two-thirds addressed the Darwin Criteria for working with Indigenous communities in their applications; roughly half of all current People Support recipients are successfully engaging Indigenous community members and organisations in consultation, and as partners in research. They are doing this by including Indigenous project advisory groups in research design, and by employing Indigenous people as part of the research team. This is one of the first studies in Australia to conduct an empirical review of research practices for engaging Indigenous community members and organisations.

The third criterion relates to research programs that build the number and skill base of health professionals conducting research for Indigenous health. Building research capacity includes training researchers across a broad base of disciplines, and developing skills in both clinical and policy settings. Building research capacity among Indigenous people is particularly important because it provides a culturally appropriate, long-term, and sustainable approach to improving Indigenous health through research. Among 31 People Support recipients, only two Indigenous researchers were directly supported. Among 70 team investigators supported through Capacity Building Grants in Population Health Research, 36 (51%) self-identified as Indigenous.

Capacity Building Grants in Population Health Research appear to be better in stimulating best-practice across most of the criteria. This might be for several reasons: first, the Capacity Building Grants in Population Health Research provide a supportive research environment (e.g., collaborative approaches to research and guidance from more experienced researchers in the field) to develop good research practices for Indigenous health such as consultation skills. These awards were allocated to groups with excellent track records of collaborative and intervention-based research in Indigenous health. Second, it provides a more long-term funding approach to developing researchers by providing five-year awards, and supporting high numbers of researchers who self-identify as Indigenous. The program may be more attractive to researchers who self-identify as Indigenous because of the flexible pay scale for current professionals and the program framework for collaborative research and skill mentoring. Third, it is a more responsive funding mechanism that allows for current Indigenous professionals to be adequately compensated, thereby increasing possibilities for clinicians and health professionals to acquire research skills. Finally, the framework for Capacity Building Grants in Population Health Research encourages the development of collaborative research initiatives that integrate multi-disciplinary research teams and service providers, increasing opportunities for health services research of preventive, treatment, and intervention-based services. The collaborative research model and longer-term funding mean that
partnerships with Indigenous communities are either already established or have adequate time and capacity to develop.

In summary, the case study of 2005-2006 recipients for People Support and Capacity Building Grants in Population Health Research demonstrates that applicants were meeting the criteria for good practice to some extent, but there is room for improvement. It should be acknowledged that proxy measures were used to do this evaluation and that the sample size of the case study was relatively small. However, this evaluation was done more than three years after policy changes, allowing adequate time for the impact of policy to be observed. NHMRC is well placed to encourage future change in Australian policy and research; however, interview participants cited two issues for consideration when developing policy for Indigenous health. First, it is unlikely that policy change alone will be sufficient without a detailed plan for implementation. For example, completion of the Darwin Criteria has been endorsed as a standard practice for NHMRC applicants since 1997; ten years later this policy is still not fully implemented. Second, policy outcomes need to be defined and monitored regularly to ensure Indigenous health research is funded and conducted in a way that is responsive to the health needs of Indigenous Australians.

The case study conducted in Chapter 4 cannot demonstrate change over time; it does benchmark the extent to which current research is consistent with NHMRC policy and the principles of good practice for Indigenous health research. There have been no previous empirical investigations of this type (Table 1-4).

6.4 The impact of policy change on research funding allocation

Study Three (Chapter 5) examined the impact of the policy changes on funding for Indigenous health through the People Support scheme. Following the 2002 policy decision to increase expenditure for Indigenous health, funding for researchers who study Indigenous health has increased from less than $500,000 annually to $2.7 million in 2006, or 3.3% of total NHMRC People Support allocations. However, this falls short of the target to spend 5% of the agency budget.

There has been no increase in People Support for those applicants who self-identify as Indigenous. Over a decade of People Support, less than 1% has been awarded to researchers who self-identify as Indigenous and less than 10% of the researchers who study Indigenous health self-identify as Indigenous. However, the Capacity Building Grants for Population Health Research have been very successful, and have increased funding for researchers who self-identify as Indigenous twenty-fold.
Several lessons can be drawn from this analysis to strengthen Australia’s research effort in Indigenous health in the future.

First, the 2002 decision to increase funding for Indigenous health research appears to have had some impact on the allocation of resources through People Support. While an implementation plan was never explicitly articulated, NHMRC has increased expenditure by utilising the Road Map to guide the development of Strategic Award initiatives, and lowering quality cut-off points for robust proposals of Indigenous health research. It is evident that more targeted implementation strategies based on a better understanding of the barriers to Indigenous health will be required to meet NHMRC’s goal of a 5% funding allocation through the People Support scheme.

Second, although there have been increases in funding through People Support; these have been for health researchers who self-identify as non-Indigenous. People Support funds for people who self-identify as Indigenous have remained low over time, and only the lowest level of People support (Scholarships) have been awarded to these applicants. We need to better understand the barriers for Indigenous applicants in accessing People Support, especially among post-doctoral awards. NHMRC will need to consider taking a more active role in the growth and skill development of Indigenous scholars by facilitating the application process—actively seeking and mentoring potential applicants, and consideration of higher value awards to attract skilled individuals with many other career options. It is evident that a much more substantial strategy will be required if the numbers of people who self identify as Indigenous is to increase.

In addition to the Canadian Institutes of Health Research, and Centre of Research Excellence in New Zealand, some Australian institutions have been particularly successful in building research capacity. Collaborative research centres such as Onemda Koori Health Unit in Victoria and the Menzies School of Health Research in the Northern Territory have been influential in augmenting the number of researchers who study Indigenous health. Curtin University and James Cook University have trained a large number of researchers who self-identify as Indigenous. These institutions should be examined in further research to identify the resources and mechanisms that facilitate their success.

Third, it is evident that the majority of People Support for Indigenous health research has been to scholars working in public health research. However, there is also a need to better understand the physical basis of diseases that affect Aboriginal people in greater numbers (eg otitis media, lupus) and to improve the quality of health care provided to Indigenous people. It might therefore be anticipated that we would see
the development of funding mechanisms or processes that promote an increase in People Support for Indigenous health researchers working in biomedical and clinical disciplines.

6.5 What is the future of building Indigenous health research capacity?

It is evident that the policy decisions made in 2002 were a landmark for the prioritisation and funding of Indigenous health research in Australia. This analysis suggests though, that after five years, it may be timely for NHMRC to review its approach to building capacity in Indigenous health research, particularly among individuals who self-identify as Indigenous, and to articulate a new strategy for the future based on what has been learned. This will ensure endorsed policies are implemented in a timely fashion.

Based on the findings discussed above, four major strategies might be considered in further developing Indigenous health research in Australia: strengthen engagement with Indigenous communities; learn from international experience; develop a strategic approach to capacity among researchers who self-identify as Indigenous; review implementation and evaluation of policy.

6.5.1 Strengthen Indigenous engagement in research

As reviewed in Chapter 1, it is widely agreed that Indigenous community members and organisations should be engaged in consultation, and as members of the research team (eg Kowal et al 2005, Stewart et al 2006, Couzos et al 2005). As described above, the data reported in Chapter 4 indicate that more could be done to improve engagement with Indigenous community members and organisations.

First, the ways in which NHMRC might best encourage such approaches will need to be carefully considered. The Indigenous Social Justice Commissioner has noted the potential value of building upon existing resources and capacity within the Aboriginal community-controlled health sector, saying that Aboriginal Health Services are well positioned to facilitate community consultation, and “Aboriginal primary health care providers would also be able to identify strategies and processes that are complementary and additional to the delivery of health services… the types of activities that would be amenable to local level agreements” (HREOC 2005: 89). NHMRC could consider forging closer working relationships with the community-controlled health sector.

Second, more work needs to be done by NHMRC to ensure completion of the Darwin Criteria by award applicants. This section allows applicants to address issues of working with Indigenous communities, and demonstrate that they are successfully engaging Indigenous community members and organisations in
consultation, and as partners in research. This has been endorsed as a standard practice for NHMRC applicants since 1997; ten years later this policy is still not fully implemented.

Third, NHMRC might seek to ensure Indigenous involvement in all aspects of its own work, including Indigenous representation across all Principal Committees and Council. To expand on the expertise of Indigenous leadership already available for consultation, the NHMRC may wish to consider increasing student representation within the Indigenous Health Forum. The importance of Indigenous representation was highlighted by interviews in Chapter 3.

6.5.2 Learn from overseas experience in building research capacity among Indigenous people

Australia could draw on considerable international experience in developing capacity in indigenous research. In 2002, Australia entered into a tripartite agreement with Canada and New Zealand to facilitate this learning process by sharing research expertise and working collaboratively to generate a stronger evidence base through research. This collaborative research effort provides the framework for exchange and learning between nations with comparable population health inequities (Cunningham et al 2003).

New Zealand

The New Zealand Centre of Research Excellence provides us with a practical model for establishing a critical mass of researchers. In 2002, a five-year target was set to graduate a total of 500 Maori PhD scholars across all academic disciplines. In addition to active recruiting and extensive student support services, all students were provided with a mentor to guide their academic development and provide social support throughout the duration of their PhD program. The initiative has been highly successful, and New Zealand is on track to establish a critical mass of Maori scholars in disciplines including health, history, social sciences, and education (CoRE 2006). By articulating a target with a timeframe, the New Zealand Centre of Research Excellence made the implementation and monitoring of a critical mass a feasible endeavour.

Australia might consider a similar approach to identifying goals for capacity development in Indigenous health research. This should be done in consultation with Australian Indigenous health researchers, and might include for example, identifying a target number of people to be supported from Indigenous
backgrounds, or defining the distribution of funding for particular health or research priorities. This would enable NHMRC to develop appropriate implementation strategies, and ensure these goals are achieved over the next five years.

**Canada**

The Canadian Institutes for Health Research and the Institute for Aboriginal Peoples Health have clearly articulated in their current five-year strategic plan a “commitment to building research capacity and infrastructure in Aboriginal health research, working regionally, nationally, and internationally to create partnerships, and developing an advanced health research agenda that includes Aboriginal cultural values, models, and culturally specific knowledge translation strategies” (CIHR 2005).

The eight Aboriginal Capacity and Developmental Research Environments (ACADRE) centres are an initiative supported by the Canadian Institutes of Health Research and the Institute of Aboriginal Peoples Health. Each of these centres offers an array of awards to undergraduate and graduate students, as well as to community members and organisations interested in conducting health research. Each centre also provides a collaborative environment that links research partners including academic institutions, local Aboriginal Nations, and Aboriginal organisations and health centres (AHRNETS 2006).

The ACADRE model is recognised as a successful model in Canada for helping to achieve these objectives, and “sustaining and growing the ACADRE network is viewed as being an important long-term goal and investment” (CIHR 2005). Strategies to enhance research capacity and infrastructure for Aboriginal health within Canada include not only the sustained growth of ACADRE, but also a commitment to engage researchers from across disciplines and various educational and career levels. In addition to the traditional academic model, the ACADRE model aims to support community-based research as a new category of investigators, “cross-pillar initiatives with senior Aboriginal mentorship for new and junior researchers,” and to develop exchanges between academic or government institutions, and community-based organisations so as to facilitate a better understanding of the health needs and issues faced by Aboriginal communities (CIHR 2005).
The success of the ACADRE model is demonstrated, not only in the number of Indigenous and non-Indigenous researchers trained, but also by the programs and support provided to students. In addition to guidelines for grant writing and publication (CIHR 2006), students are provided support and feedback by faculty members for scholarship and ethics applications. Most ACADRE centres report high graduation rates. Another noteworthy resource provided to students is the annual national gathering that is held each summer for all ACADRE participants. At this forum, students present their work and network with their peers, providing additional social and academic support.

**Figure 6-1**  Distribution of Canadian Indigenous health research students supported through ACADRE in two provinces: Manitoba and Ontario**

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<thead>
<tr>
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<tbody>
<tr>
<td></td>
<td>Undergraduate</td>
<td>Masters</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>25</td>
<td>14</td>
</tr>
<tr>
<td>Non-Aboriginal</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>31</td>
<td>19</td>
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** Data provided by ACADRE centres

As Figure 6-1 illustrates, the ACADRE centres have been highly successful in supporting great numbers of Aboriginal scholars. In fact, about three-quarters of awards in both Manitoba and Ontario are to Aboriginal scholars.
Training and development of early career researchers and students is paramount to establishing a pool of highly-skilled researchers. To develop workforce capacity and equip researchers with all the necessary skills typically requires resourcing for a career pathway through academic institutions of higher learning. In Australia, these institutions often struggle to enrol Indigenous students in their post-graduate research programs. The admission process is often contingent upon prior qualifications or experience in the field, and financial ability to leave the workforce for study. There will not be adequate numbers of health professionals who self-identify as Indigenous until greater numbers are completing high school, until greater numbers are entering university, and until greater numbers are supported to obtain their diplomas. It should be acknowledged that this kind of capacity building is well beyond the scope of NHMRC; however, it important for continued development of research capacity in the long term.

A good example of how this might be achieved is provided by Boston Public Schools in partnership with Northeastern University who in 1995 founded a charter school dedicated to development of diverse future health professionals. Since some of the greatest gaps in the American healthcare workforce are due to the lack of professionals from minority backgrounds (Yager et al 2007, Srinivasan et al 2005). Health Careers Academy selects students from diverse cultural, socio-economic, and educational backgrounds. The freshman class in 2006 was 50% African American and 19% Hispanic.

The school is embedded within a university campus and so, has access to necessary facilities such as science labs. While science and maths are an important part of the coursework, the curriculum also integrates daily lessons in Spanish, weekly contact with a diverse range of health professionals as guest lecturers, and work experience in health care settings.

Through internships and community service in health care settings, students can gain hands-on exposure to nearly every field of medicine from health services or HMOs to health law or nursing. These kinds of innovative avenues are exposing high school students from disadvantaged backgrounds to health careers. The experiential education is often what encourages these students to go on and pursue careers in health, for their results on standardised tests for science and maths are often not as encouraging.

As many as a third of students in any given class may fail that year’s standardised test in Math Performance; however, 100% may go on to complete high school and 95% to attain higher education either through a two-year or four-year college. Graduates from Health Careers Academy may have below-
average scores on their SATs—standardised entrance examinations for universities—but are hitting well above the average of their counterparts when it comes to enrolling in higher education.

Across the last five years of high school students at Boston’s Health Careers Academy, CALD (culturally and linguistically diverse) students of colour have succeeded in graduating at a 98% success rate and continuing on to higher education at a 95% success rate. Comparatively, the state-wide graduation rates are 70% for African Americans and 51% for Latinos (Greene 2002); the nation-wide rate (27.6%) for attaining a postsecondary degree is 17.6% among African Americans and 12% for Hispanics (US Census Bureau 2007). While no follow-up studies have been conducted to find out what proportion of graduating students have gone on to pursue careers in health sciences, these figures clearly indicate a successful model for supporting the training and development of young health professionals from minority and disadvantaged backgrounds.

6.5.3 Develop a more systematic and strategic approach to capacity building among researchers who self-identify as Indigenous

The preceding section outlined some of the international experiences in building research capacity. As well as drawing on these experiences, NHMRC should consider taking a more systematic and strategic approach to increasing the numbers of researchers who self-identify as Indigenous. The current approach to building research capacity is to fund Indigenous research through existing support schemes. As described above and demonstrated in Chapters 4 & 5, there is evidence to suggest this approach is not optimally effective and that there will be a need for a more systematic and strategic approach, perhaps drawing on the international experience outlined above.

In Study One, most interview participants reported that the NHMRC career pathways needed to be strengthened to support greater numbers of Indigenous researchers. Key informants recommended strategies such as increasing the value of scholarships for current professionals, and improving the feedback and support mechanisms for grant applicants. Many participants highlighted inadequate training in grantsmanship as a barrier to accessing NHMRC support; participants identified mentoring, collaborative research teams, and workshops as appropriate avenues for learning grantsmanship skills. Finally, one informant suggested the NHMRC adopt a funding target for the number of Indigenous scholars trained in health research over the next decade.

It appears from that NHMRC has not developed a systematic approach to ensuring the implementation of its policies. Some informants in Chapter 2 characterise particular initiatives that spawned from NHMRC
policy changes as “thrown together at the time.” It is evident that these changes were based on a ‘best
guess’ about what might work rather than a careful analysis of barriers among Indigenous researchers or
among NHMRC funding policy. For example, it is likely that there will be a need for strategies to develop
leaders in Aboriginal health research, to provide mentoring for Aboriginal scholars, and to develop centres
of excellence. Likewise, there was no consideration of existing barriers within current funding mechanisms
like salary levels or time frames for project grants.

6.5.4 Review, implementation, and evaluation of policy

It seems likely that if there is to be a real increase in research to improve Indigenous health, there will be a
need for long term action and commitment, adequate intellectual, technical, and financial resources, and
measurable benchmarks and targets which enable the community to determine whether progress is
sufficient (Walt 1994, HREOC 2005: 67). It is important that policy outcomes are identified, that
monitoring against these outcomes is undertaken and that the policy is regularly reviewed in the light of
progress against the outcomes (Bridgman et al 2004, Sutton 1999). Figure 6-1 illustrates the role of
monitoring and evaluation in the policy cycle. Policy evaluations “ensure that lessons learned are fed back
into the decision-making process” (HM Treasury 2003: 45).

Effective policy implementation requires a detailed plan, a time frame for execution, and regular
monitoring of measurable outcomes. None of the current NHMRC policies for Indigenous health
research outline targets with measurable outcomes and an explicit timeframe such as the following:

- Commit X% of People Support awards for Indigenous health research to researchers who self-
  identify as Indigenous within five years.
- Commit X# of PhD scholars who study Indigenous health and self-identify as Indigenous over the next ten years.
- Commit X% of financial support for Indigenous health to intervention-based research projects by
ten years time.
Participants in Study One emphasised the need for implementation and monitoring plans if Indigenous health research capacity is to continue improving. For example, several interviewees cited the importance of revisiting the Road Map to reflect current research priorities, assess implementation, and evaluate medium and long-term impacts of research investments. Participants also reported that the Strategy for Building Capacity in Indigenous Health Research and the 5% funding target would require more detailed implementation plans to ensure these policies are fully realised.
6.6 Conclusions

The ongoing need to invest in building capacity for Indigenous health research has been formally acknowledged by NHMRC; the agency supports the view that greater research capacity will enable research that contributes to improving the health of Indigenous Australians.

The work reported in this thesis indicates that some progress has been made in building capacity in Indigenous health following the policy changes by NHMRC. However, it also indicates that more could be done to improve both the amount and type of research that is supported.

In the future, there will be a need for NHMRC to adopt more systematic approaches to building research capacity based on overseas experience, and adapted to the Australian context. Based on analyses in this thesis, some of the more important things to act on in the short term might include: strengthening Indigenous engagement and research capacity, developing strategies for building research capacity based on overseas experiences, particularly among researchers who self-identify as Indigenous, and monitoring and evaluating policy outcomes regularly.
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Appendices

A Summary sheet for interview participants

At the 144th session of NHMRC, the landmark decision was made:

- To adopt Indigenous health research as a strategic priority area
- To allocate 5% of total annual research funding to Indigenous health research
- To adopt and implement the *Road Map: A Strategic Framework for Improving Indigenous Health Through Research*
- To increase representation of Indigenous across NHMRC Council and Principal Committees
- To establish the Indigenous Health Forum as a committee reporting directly to council, and responsible for monitoring and evaluating implementation of the Road Map

B Key NHMRC policy developments for Indigenous health research

B.1 Establishment of the Indigenous Research Agenda Working Group
The Indigenous Research Agenda Working Group (RAWG) was established in 1997 as a joint initiative of the NHMRC and the Office for Indigenous Health (OATSIH). As an advisory body, RAWG was established to provide guidance about Indigenous health issues that should be prioritised for research funding. The *Road Map* articulates these areas of need, and emphasises the need to build health research capacity—both by increasing the numbers of researchers in Indigenous health, and by improving research practices (3,4).

B.2 The Darwin Criteria: principles for good research practice
In 1986, more than two hundred researchers, health professionals, and Aboriginal community representatives gathered for the first time to debate a wide range of health issues in a forum convened by the NHMRC and the Menzies Foundation. The gathering brought together professionals with both biomedical and socio-cultural research training to debate ethics, funding mechanisms, the collection of health statistics and the evaluation of services, and priority areas for research. A year later, a further workshop was convened to focus on methodological and ethical research issues. As a result of this consultation, a series of research principles known as the Darwin Criteria were first drafted in 1987 to guide appropriate research practices in Indigenous health. In 1997, the Darwin Criteria, also known as the
Intervention Based Criteria, were adopted by NHMRC to assess grant applications for health research of Indigenous Australians (Appendix B).

The six Darwin criteria are listed and briefly outlined below

1 **Community engagement**—community members and organisations should be involved in all stages of research: conceptualisation and design of the research project, data collection and management, analysis and interpretation of results, report writing, and dissemination of research evidence

2 **Benefit**—projects should demonstrate the potential health benefit that the research will have for Indigenous peoples

3 **Sustainability and transferability**—project proposals should demonstrate how research will contribute to health gain for Indigenous peoples extending beyond the life of the project. The research initiative should be either sustainable in the project setting, or transferable to other settings, and explain the relationship between costs and benefits.

4 **Building capability**—community members and organisations should develop relevant skills and capabilities through participation in the research project. This may include training or employment of Indigenous as part of the research team, or the implementation of a capacity building initiative.

5 **Priority**—the research evidence generated by the proposed project should address health issues that have been identified and prioritised by Indigenous communities either at a community, regional, or national level.

6 **Significance**—the proposed research program should demonstrate that it will contribute to substantial health gains for Indigenous peoples.

**B.3 Establishment of the Indigenous Health Review Panels**

The Darwin Criteria outlined above are the cornerstone of the application assessment process used by the Indigenous Health Review Panels (IHRP); all NHMRC applicants who wish to conduct health and medical research of Indigenous Australians are required to address these criteria in their applications. IHRP were established as a type of ‘gateway’ process for reviewing ethical issues of proposed research programs, and prioritising applications for funding. With representation of Indigenous community members, organisations, and academics, IHRP play an important role in developing individual members’ knowledge and application of ethical guidelines. They also provide a quality control mechanism for Indigenous health research funded by NHMRC.
B.4 Indigenous representation at NHMRC

Congruent with ethical principles that Indigenous people should be engaged at all levels of decision-making in research, representation within the NHMRC is imperative. Since 1997, there has always been Indigenous representation on IHRP, but not always on NHMRC Council and Principal Committees.

In 1997, the Strategic Research Development Committee formed a sub-committee called RAWG (Research Agenda Working Group) to advise NHMRC on Indigenous health issues. The main responsibility of RAWG was to develop a Road Map that prioritised thematic areas for funding. Over two trienniums, RAWG played an influential role in rearticulating the NHMRC’s approach to investing in Indigenous health.

Over the last decade, the Indigenous voice within council has gained strength as Aboriginal representation increased across NHMRC. The first Aboriginal chair of RAWG considers himself the first Black representative to hold a position within NHMRC that was not purely tokenistic. Predecessors had not realised NHMRC’s potential; research practice and policy remained stagnant during their tenure. With an Aboriginal representative on SRDC and chairing RAWG, Aboriginal representation in RAWG quickly transformed from token minority representation to constituting a Black majority—increasing the committee’s punch power and influence.

In October 2002, at the conclusion of RAWG’s second triennium, a series of policy changes were tabled and adopted by NHMRC thanks to the advocacy and contributions of influential Aboriginal committee representatives. Among these changes was the decision to have Indigenous representation across all NHMRC Principal Committees and Council. To increase the accountability and responsiveness of council to Indigenous health issues, RAWG was dissolved and re-established as the Indigenous Health Forum, reporting directly to Council.
B.5  NHMRC Road Map: a strategic framework for improving Indigenous health through research

RAWG was responsible for drafting this key document in 2001, and NHMRC endorsement in 2002. The NHMRC Road Map: a strategic framework for improving Indigenous health through research was drafted after an extensive consultation with key stakeholders across Australia. The document articulates six thematic areas that should be prioritised for research development and funding to create meaningful health gain for Indigenous people.

The six thematic areas are briefly outlined below (as written in the Road Map)

1. Descriptive research which outlines patterns of health risk, disease and death. This information should be utilised to inform the development of sound preventive, early diagnosis and treatment based interventions which are likely to result in meaningful health gain for Indigenous peoples.

2. A research focus on the factors and process that promote resilience and wellness; in particular but not exclusively, during periods of pregnancy, infancy, childhood and adolescence and which form a basis for good health throughout the lifespan.

3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Indigenous peoples.

4. A focus on the association between health status and health gain and policy and programs that lie outside the direct influence of the health sector.

5. A focus on engaging with research and action in previously under-researched Indigenous populations and communities.

6. Development of the nation’s Indigenous health research capacity (including Indigenous researchers) and health research practice in relation to Indigenous communities.

Since its inception in 2003, the Indigenous Health Forum (Section 4.3) has been responsible for monitoring and evaluating implementation of the Road Map. As a living document, we might expect to see the Road Map reviewed and revised to reflect current circumstances and priorities.

B.6  The 5% funding commitment

The recommendation to allocate 5% of agency expenditure to Indigenous health was first tabled in 2000 as a mandate from the Commonwealth—as put forward in the Health is Life report (Section 4.2) (Senate
Inquiry). The decision was not adopted as agency policy until October 2002, after careful consideration of agency legislation, and lobbying by influential members of Roadmap Working Group AWG. The decision to adopt a funding quota was a landmark change in agency policy, and reflects an organisational commitment to improve Indigenous health and restore equity.

B.7 The Strategy for Building Capacity in Indigenous Health Research 5% funding commitment

This document was developed to articulate strategic directions for building capacity in Indigenous health research over the 2006-2009 triennium. It was endorsed by Council at its 159th Session in December 2005. In its strategic plan, it outlines the following six objectives and outcomes:

- **Objective 1:** create internationally competitive knowledge in Indigenous health
  - **Outcome 1:** new knowledge is created leading to innovation and improvement in Indigenous health

- **Objective 2:** develop Indigenous research capacity and capability within Australia
  - **Outcome 2:** highly trained health and medical research workforce in Indigenous health, who have access to high quality research equipment and facilities

- **Objective 3:** improve utilisation of research findings in Indigenous health
  - **Outcome 3:** research findings in Indigenous health are captured and utilised to improve health outcomes

- **Objective 4:** maintain and promulgate high ethical standards in Indigenous health
  - **Outcome 4:** maintain an efficient and effective system of review for Indigenous health research and ensure high ethical standards are adopted and maintained

- **Objective 5:** engage with the Indigenous community
  - **Outcome 5:** increased awareness in the Indigenous community about the benefits of research and ownership of health advice provided by NHMRC

- **Objective 6:** improve governance and accountability
Outcome 6: effective and high quality governance that support the implementation of NHMRC strategies in Indigenous health, monitors and reports outcomes, promotes Indigenous leadership and the inclusion of Indigenous people in NHMRC processes

While this document outlines the principle issues for consideration in building research capacity for Indigenous health, the “outcomes” are not measurable indices. This makes evaluation of this policy virtually impossible.

C Darwin Criteria (also known as NHMRC Criteria for Health and Medical Research of Indigenous Australians)

Applicants are required to address the extent to which their application fulfils these criteria in relation to research into the health of Indigenous Australians including documentation and other relevant written evidence where appropriate.

The criteria are:
• Community engagement
• Benefit
• Sustainability and transferability
• Building capability
• Priority
• Significance

Community engagement
The proposal demonstrates how the project has had and will have relevant community engagement by individuals, communities and/or organisations in conceptualisation, development and approval, data collection and management, analysis, report writing and dissemination of results.

Benefit
The proposal demonstrates the potential health benefit of the project for Aboriginal and Torres Strait Islander peoples. Benefit need not necessarily be direct or immediate.

Sustainability and transferability
The proposal demonstrates how the results of the project have the potential to lead to achievable and effective contributions to health gain for Indigenous people, beyond the life of the project. This may be through sustainability in the project setting and/or transferability to other settings. In considering this issue the proposal should address the relationship between costs and benefits.

Building capability
The proposal demonstrates how Aboriginal communities, researchers and others will develop relevant capabilities through participation in the project.
Priority
The research and potential outcomes are a priority for Indigenous communities either at community, regional or national levels.

Significance
The research addresses an important public health issue for Aboriginal and Torres Strait Islander people.

D Operational definitions for Case Study: Part One

Selected Cases of NHMRC People Support Awards were marked according to the coding scheme outlined below

ITEM 1: Indigenous status: self-reported ‘YES’ or ‘NO’ by applicant on Appendix 3 of NHMRC application as

- An **Aboriginal** is a person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he or she lives.
- A **Torres Strait Islander** is a person of Torres Strait Islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he or she lives.

- Anyone who self-identified ‘YES’ as Aboriginal and/or Torres Strait Islander was coded as “yes” for Indigenous
- Those who marked ‘NO’ as Aboriginal and/or Torres Strait Islander were coded as “no” for non-Indigenous
- Anyone who failed to complete Appendix 3 was coded “TH2C”

ITEM 2: Classification of Descriptive and/or Intervention research:

- **Project was coded as D for descriptive if:**
  2. qualitative or quantitative research methods (survey, interview, observation, numerical data collection) are outlined in proposed research program

  OR

  3. **Broad Research Area** is “Basic Science”

- **Project was coded as I for intervention-based if:**
  5. development or implementation of a service/program is described in aims/objectives or proposed research program

    § signalled by keywords such as “program(§)” or “intervention(§)” either developed or implemented as part of the research program
• If the project proposal outlined both descriptive and intervention-based research techniques, it was coded as DI for descriptive and intervention-based research.

§ For the purpose of later analyses, these cases were later classified as “intervention-based”

ITEM 3: Comparison of State of Origin for Researcher, State of Administering Institution & State Where Research is Conducted

b. State of Origin for Researcher:
• Coded according to state/territory of birth (as provided by proof of citizenship)
• Anyone who failed to submit a copy of birth certificate or passport was coded “TH2C”

a. State of Administering Institution:
• Coded according to state/territory of administering institution identified by researcher in application

a. State Where Research is Conducted:
• Coded according to state/territory in which the study population is located as identified in:
  o proposed research program
  OR
  o community engagement section of 6 Criteria for Health and Medical Research of Indigenous Australians
• Coded “NATL” if data was captured from every state/territory in research
• Coded “TH2C” if it was too difficult to determine the location of study population according to these criteria

ITEM 4: Completion of 6 Criteria for Health and Medical Research of Indigenous Australians
• Coded ‘yes’ if it was completed and in applicant’s file
• Coded ‘no’ if it was not found in applicant’s file

ITEM 5: Community Engagement

a. Indigenous Project Advisory Group
• Coded ‘yes’ IF
  1. Explicit mention of research advisory group formation in the following section of project proposal
§ aims/objectives
§ background OR
§ proposed research program

OR

5. Describes composition and membership of an advisory group from local community within community engagement section of 6 Criteria for Health & Medical Research of Indigenous Australia

AND

7. Indigenous representation is outlined on said advisory panel

• Coded ‘no’ if case did not fulfil the above criteria
• Coded ‘TH2C’ if too difficult to determine using criteria outlined above

b. Participatory Research Model

• Coded ‘yes’ IF
  1. Use keywords “participatory research,” “action research,” or “participatory action research” in:
     § aims/objectives AND/OR
     § proposed research program
  OR

  2. Mention training or collaboration of community members as part of research team in 6 Criteria for Health & Medical Research of Indigenous Australia section:
     § building capability AND/OR
     § community engagement

• Coded ‘no’ if case did not fulfil the above criteria
• Coded ‘TH2C’ if too difficult to determine using criteria outlined above

ITEM 6: Research Proposal Addresses 6 Road Map Priority Areas for Indigenous health research

a. Priority Area 1

• Coded ‘yes’ IF researcher outlines in aims/objectives, proposed research program, or significance sections of project summary:
  1. Implementation of treatment based interventions or preventive services as part of the research program

OR
2. Descriptive research that will inform the delivery of sound preventive, early
diagnosis or treatment based interventions

OR

3. Secondary analysis of existing datasets to identify successful interventions and
programs

• Coded ‘no’ if they were believed not to fulfil the required criteria
• Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

b. **Priority Area 2**

• Coded ‘yes’ IF:
  1. Keywords “wellbeing” “wellness” or “resilience” are used explicity in
     • **aims/objectives** section of project summary
     • **proposed research program** OR
     • **keywords** identified by researcher

OR

2. researcher identifies “healthy start to life” within **national priority areas** section

OR

3. **proposed research program** or **significance** sections address foundations of good
health

• Coded ‘no’ if they were believed not to fulfil the required criteria
• Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

c. **Priority Area 3**

• Coded ‘yes’ IF research describes within **aims/objectives** or **proposed research program** of
project summary:
  1. Link between health investment, health services, and health outcomes

OR

2. Descriptive research of barriers to accessing or delivering health services

OR

3. Examination of health policy for prevention and treatment of disease within
   Indigenous populations

OR

4. Broad Research Area is “Health Services Research”
d. **Priority Area 5**

- Coded ‘yes’ IF researcher:
  1. refers to study population using keywords “urban community”, “Torres Strait Islander community”, “young adults”, “adolescents”, “elderly” or “grandparents” in *aims/objectives* or *proposed research program*
    
  OR
  2. demonstrates that research program addresses under-researched areas in connective tissue disease (ie. lupus), otitis media, mental health, dental health, suicide, masculinity, sexual assault, child abuse, or incarceration within the *background* and *significance* sections of project proposal

- Coded ‘no’ if they were believed not to fulfil the required criteria
- Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

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e. **Priority Area 6a**

- Coded ‘yes’ IF research outlines within *proposed research program* or *community engagement* section of Criteria for Health and Medical Research of Indigenous Australians:
  1. Integration and active membership of community members in consultation and implementation process

- Coded ‘no’ if they were believed not to fulfil the required criteria
- Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

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f. **Priority Area 6b**

- Coded ‘yes’ IF researcher
  1. Self-identifies as Aboriginal and/or Torres Strait Islander in Appendix 3 of application

  OR
  2. outlines plans to train an Indigenous person as part of the research team in *proposed research program* AND/OR

  § *building capability* section of Criteria for Health and Medical Research of Indigenous Australians

- Coded ‘no’ if they were believed not to fulfil the required criteria
- Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information
E  Operational Definitions for Case Study: Part Two

Selected Cases of NHMRC Capacity Building Grants in Population Health Research were marked according to the coding scheme outlined below

ITEM 1: Indigenous status: self-reported ‘YES’ or ‘NO’ by applicant in Section C of Lead Applicant/Team Investigator Details within NHMRC Capacity Building Grant for Population Health Research application as

- An Aboriginal is a person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he or she lives.
- A Torres Strait Islander is a person of Torres Strait Islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he or she lives.

- Anyone who self-identified ‘YES’ as Aboriginal and/or Torres Strait Islander was coded as “yes” for Indigenous
- Those who marked ‘NO’ as Aboriginal and/or Torres Strait Islander were coded as “no” for non-Indigenous

ITEM 2: Number of relevant publications (refereed journal articles, book chapters, conference papers, government reports, technical/commissioned reports, reviews, or best practice guidelines):

The number of relevant publications was recorded as identified by:
- Lead applicants in Section 4: Lead Applicant Details of the application
- Team investigators in Section 5: Team Investigator Details

ITEM 3: Classification of Descriptive and/or Intervention research:

- Capacity Building Grant was coded as D for descriptive if:
  9. qualitative or quantitative research methods (survey, interview, observation, numerical data collection) are outlined in project summary (Section 1.2) or aims in Section 7 of application
  OR
  10. signalled by keywords “qualitative research” and “quantitative research” in Section 2.3

- Project was coded as I for intervention-based if:
  12. development or implementation of a service/program is described in project summary (Section 1.2 or 7)
§ signalled by keywords such as “program(s)” or “intervention(s)” either developed or implemented as part of the research program

OR

13. grant application indicated in Section 1.5 “yes” to conducting a clinical trial

• If the project proposal outlined both descriptive and intervention-based research techniques, it was coded as DI for descriptive and intervention-based research.
  § For the purpose of later analyses, these cases were later classified as “intervention-based”

ITEM 4: Comparison of State of Origin for Researcher, State of Administering Institution & State Where Research is Conducted

b. State of Origin for Researcher:
• Submission of birth certificate or passport was not required for this application, and therefore data was not recorded

a. State of Administering Institution:
• Coded according to state/territory of administering institution identified by researcher in application

a. State Where Research is Conducted:
• Coded according to state/territory in which the study population is located as identified in:
  o Project summary
OR
  o 6 Criteria for Health and Medical Research of Indigenous Australians
  • Coded “NATL” if data was captured from every state/territory in research
  • Coded “TH2C” if it was too difficult to determine the location of study population according to these criteria

ITEM 5: Identification of research involving Aboriginal or Torres Strait Islander Peoples

• Coded ‘yes’ if checked ‘yes’ box in Section 1.3 of application
• Coded ‘no’ if checked ‘no’ box in Section 1.3 of application
ITEM 6: Completion of 6 Criteria for Health and Medical Research of Indigenous Australians

- Coded ‘yes’ if it was completed and in applicant’s file
- Coded ‘no’ if it was not found in applicant’s file

ITEM 7: Community Engagement

a. Indigenous Project Advisory Group

- Coded ‘yes’ IF
  1. Explicit mention of research advisory group formation in the following section of project proposal
     § Consumer and Community Participation (Section 2.8)
     § Ethical Implications of Research Involving Humans (3.4) OR
     § Project summary (Sections 1.2 or 7 in application)
  OR
  11. Describes composition and membership of an advisory group from local community within community engagement or benefit sections of
      6 Criteria for Health & Medical Research of Indigenous Australia

AND

  15. Indigenous representation is outlined on said advisory panel

- Coded ‘no’ if case did not fulfil the above criteria
- Coded ‘TH2C’ if too difficult to determine using criteria outlined above

b. Participatory Research Model

- Coded ‘yes’ IF
  1. Mention collaboration of community members as part of research team in 6 Criteria for Health & Medical Research of Indigenous Australians section:
     § building capability AND/OR
     § benefit

OR
2. Mention training or collaboration of employees within community organisations as part of research team in 6 Criteria for Health & Medical Research of Indigenous Australia section:

§ building capability AND/OR
§ benefit

• Coded ‘no’ if case did not fulfil the above criteria
• Coded ‘TH2C’ if too difficult to determine using criteria outlined above

ITEM 8: Research Proposal Addresses 6 Road Map Priority Areas for Indigenous health research

a. Priority Area 1
• Coded ‘yes’ IF researcher outlines in project summary (Section 1.2), significance (Section 1.3) or proposed research program (Section 7):
  1. Implementation of treatment based interventions or preventive services as part of the research program
  OR
  2. Descriptive research that will inform the delivery of sound preventive, early diagnosis or treatment based interventions
  OR
  3. Secondary analysis of existing datasets to identify successful interventions and programs
• Coded ‘no’ if they were believed not to fulfil the required criteria
• Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

g. Priority Area 2
• Coded ‘yes’ IF:
  1. Keywords “wellbeing” “wellness” or “resilience” are used explicitly in
    • Project summary (Section 1.2)
    • Keywords describing field of research (Section 2.3)
  OR
  2. researcher identifies “healthy start to life” within national priority areas section
  OR
  3. benefit or significance (Section 1.3) addresses foundations of good health
• Coded ‘no’ if they were believed not to fulfil the required criteria
• Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

h. **Priority Area 3**

• Coded ‘yes’ IF research describes within **project summary** (Section 1.2), **proposed research program** (Section 7), or **significance/benefit** sections of 6 Criteria for Health & Medical Research of Indigenous Australians:
  1. Link between health investment, health services, and health outcomes
  OR
  2. A focus on health services research, and the optimum means for delivering preventive, diagnostic and treatment-based health services and interventions to Indigenous people
  OR
  3. Examination of health policy for prevention and treatment of disease within Indigenous populations
  OR
  4. Broad Research Area is “Health Services Research”

• Coded ‘no’ if they were believed not to fulfil the required criteria
• Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

i. **Priority Area 5**

• Coded ‘yes’ IF researcher:
  1. Refers to study population using keywords “urban community”, “Torres Strait Islander community”, “young adults”, “adolescents”, “elderly” or “grandparents” in **project summary**
  OR
  2. Demonstrates that research program addresses under-researched areas in connective tissue disease (ie. lupus), otitis media, mental health, dental health, suicide, masculinity, sexual assault, child abuse, or incarceration within the **significance** section (1.3) of project proposal

• Coded ‘no’ if they were believed not to fulfil the required criteria
• Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information
j. **Priority Area 6a**
- Coded ‘yes’ IF application outlines within *sustainability and transferability, benefit* or *building capability* section of Criteria for Health and Medical Research of Indigenous Australians (Section 1.3):
  1. Integration and active membership of community members in consultation and implementation process
- Coded ‘no’ if they were believed not to fulfil the required criteria
- Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

k. **Priority Area 6b**
- Coded ‘yes’ IF application
  1. Includes team investigators who self-identify as Aboriginal and/or Torres Strait Islander in Section C of applicant details
  OR
  2. outlines plans to train an Indigenous person as part of the research team in *building capability* section (1.3) of Criteria for Health and Medical Research of Indigenous Australians
- Coded ‘no’ if they were believed not to fulfil the required criteria
- Coded ‘TH2C’ or ‘unknown’ if it was determined too difficult to code with available information

(Footnotes)
* A copy of the Operational Definitions is available upon request.
1 From beginning of ACADRE funding (April 1, 2004) to March 31, 2006