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A Descriptive Study of Ethical Procedures That Maintain Cultural Security When Conducting Health Research With Aboriginal and Torres Strait Islander School Children in Western Australia

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A DESCRIPTIVE STUDY OF ETHICAL PROCEDURES THAT MAINTAIN CULTURAL SECURITY WHEN CONDUCTING HEALTH RESEARCH WITH ABORIGINAL AND TORRES STRAIT ISLANDER SCHOOL CHILDREN IN WESTERN AUSTRALIA

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This thesis is presented in fulfilment of the requirements for the degree of Bachelor of Health Science with Honours

Faculty of Computing Health & Science
Edith Cowan University

December 2005

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

ABSTRACT

Cultural security is the maintenance of values and beliefs and the celebration of diversity unique to different cultures. This honours thesis developed a proposed framework to guide collaborative ethics procedures that demonstrate the Aboriginal values relevant to health research for use in Western Australia (WA). These values of reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity have been identified in the National Health and Medical Research Council's *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. Ethical procedures for maintaining cultural security when conducting health research among Aboriginal people throughout Australia were investigated.

Current practices in international and national Indigenous health research were reviewed to gain a better understanding of an Australian Aboriginal context. The literature confirmed that a community development approach aimed at empowering a community through involvement, consultation and ownership would assist in maintaining the cultural security of Aboriginal health research participants. As a descriptive study, the attitudes and experiences of Aboriginal researchers and Aboriginal health workers in the demonstration of these values in Aboriginal child health research were also investigated.

Data were gathered using two questionnaires. The first questionnaire collected practice-based evidence (in a face-to-face interview) from two Aboriginal researchers with extensive experience in Aboriginal child health research to create case studies of the procedures they employed to demonstrate the values listed above. The literature review and the case studies were used to develop a proposed framework for demonstrating the values. Expert consultation was sought for content validation of the proposed framework. A panel of health promotion practitioners and researchers were asked to complete a semi-structured questionnaire about the proposed framework.

Nineteen participants were recruited for the expert panel and seven completed questionnaires were returned. On a continuous scale of 1-5 for maintaining cultural

security (where a higher score indicates cultural security would be maintained) all 29 proposed framework examples received a mean rating of >3.5.

The 29 framework examples were then matched to the values of reciprocity, respect, equality, responsibility, survival and protection and spirit and integrity. An additional 87 items were presented to the expert panel members to explore group consensus that the examples demonstrate the Aboriginal values relevant to health research. Seventy nine items received a mean rating >4.0.

Unexpectedly, consensus among the panel members that framework examples demonstrated the Aboriginal values relevant to health research was not reached for 27 of the 87 examples. These examples were related to: participant recruitment; capacity building; community involvement; committee involvement; potential use of project information; project agreements; and complaints processes. A more indepth expert consultation on these examples was outside the scope of this thesis project.

The overall feedback from the expert panel indicated that a revised framework would assist researchers achieve two things: demonstrate the Aboriginal values relevant to health research; and maintain the cultural security of project participants. Mean scores and comments by the expert panel were used to review the proposed framework. The revised framework will be used to guide the ethics application for a school-based Aboriginal bullying prevention and reduction project to be conducted in a Midwest, Murchison community in WA.

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Chapter One

Introduction

The purpose of this honours thesis was to develop a proposed framework that would inform the maintenance of cultural security for Aboriginal school children who participate in health research in Western Australia (WA). Further to the ethical standards established by the National Health and Medical Research Council (NHMRC) for all Australians who participate in health research, a specific set of guidelines have also been created for health research that involves Aboriginal or Torres Strait Islander people. The proposed framework in this thesis was developed on the premise that the values and principles within the guidelines set by the NHMRC (National Health and Medical Research Council, 2003) can assist health researchers to maintain the cultural security of Aboriginal research participants.

Additionally, this project provided preliminary work for a study to be conducted by Edith Cowan University's (ECU) Child Health Promotion Research Unit (CHPRU). The CHPRU study will investigate bullying prevention and reduction among Aboriginal school children in the Midwest, Murchison region of WA. A literature review was conducted to identify and explore ethical practices for health research among the Aboriginal people of Australia. This information was then used to guide the development of a series of semi-structured questionnaires for administration to Aboriginal health researchers and health workers in WA. Data gathered were used to guide the development of a proposed framework for collaborative ethics processes that more effectively align ethical procedures with Western Australia's Aboriginal people in health research.

1.1 Research question

The research question for this thesis project was taken from the recommendations of the NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* and is -

"How can the Aboriginal values relevant to health research be demonstrated when conducting research that targets Aboriginal and Torres Strait Islander school children in Western Australia?"

1.2 Sub questions

The sub-questions for this project are organised thematically according to the NHMRC (2003) guidelines in the above mentioned document and are as follows:

1. What do researchers need to do to demonstrate the value of **reciprocity** when conducting health research among Aboriginal school children in WA?
2. What do researchers need to do to demonstrate the value of **respect** when conducting health research among Aboriginal school children in WA?
3. What do researchers need to do to demonstrate the value of **equality** when conducting health research among Aboriginal school children in WA?
4. What do researchers need to do to demonstrate the value of **responsibility** when conducting health research among Aboriginal school children in WA?
5. What do researchers need to do to demonstrate the value of **survival and protection** when conducting health research among Aboriginal school children in WA?
6. What do researchers need to do to demonstrate the value of **spirit and integrity** when conducting health research among Aboriginal school children in WA?

1.3 Definition of Terms

Definitions particular to understanding this thesis project are outlined below.

1.3.1 Aboriginal

Although it is more common to refer to the native inhabitants and land carers of Australia as either Indigenous Australians (Anderson & Thomson, 2002; Australian Indigenous Health*InfoNet*, 2004) or as Aboriginal and Torres Strait Islander (Office for Aboriginal and Torres Strait Islander Health, 2004) for the remainder of this thesis potential research participants will be referred to collectively as Aboriginal (Donovan & Spark, 1997). This is justified in as much as the Torres Strait Islands are off the North and East Coasts of Australia and consequently relatively few Torres Strait Islanders live in WA (Australian

Bureau of Statistics, 2005). Having made such a generalisation, it is also recognised that within the umbrella of an Aboriginal reference different groups and sub-groups exist throughout Australia and within Western Australia; unique in their own traditions, customs, laws and cultural idiosyncrasies (McMurray, 2003; National Health and Medical Research Council, 2003). However, when considering the native inhabitants of other countries for the purpose of comparison, the term Indigenous will be used (Castellano, 2004).

1.3.2 Aboriginal values relevant to health research (NHMRC, 2003)

The NHMRC has set ethics standards for health research that is conducted in Australia. Further to these standards, the NHMRC (2003) has also prescribed the values of **reciprocity, respect, equality, responsibility, survival and protection,** and **spirit and integrity** as essential in the practice of ethical Aboriginal health research. These values form the foundation for this thesis as set out in the sub-questions and will be described in greater detail within the literature review.

1.3.3 Community

A community is a group of people who collectively identify sameness in one or all of the following: geography, culture or personal characteristics such as age or gender, ethnicity, and spirituality (McMurray, 2003; National Health and Medical Research Council, 2003). In regard to the Aboriginal people of Australia, it is recognised that further to defining communities of 'Aboriginal' or 'Torres Strait Islander', differences exist between groups according to geography and that health issues facing those living in urban, rural and remote areas are also different (Manderson, Kelaher, Williams, & Shannon, 1998). Morgan, Slade and Morgan (1997, p. 598) describe the sense of community that is experienced by Aboriginal people as more than an expression of social cohesion, it is an "expression of life itself".

1.3.4 Cultural security

The Western Australian Department of Health (no date) suggests that cultural security is more than the possession of a 'cultural awareness' or a tokenistic knowledge of the existence of differences between Aboriginal and non-Aboriginal cultures. Rather, the concept of cultural security recognises that cultural differences between Aboriginal and

non-Aboriginal people may require specific attitudes and practices in order to keep these differences intact (Western Australian Health Department, no date). In the context of this thesis, cultural security refers to the ethical procedures that must occur throughout the research process in order to maintain the "legitimate cultural rights, values and expectations of Aboriginal people" who participate in research (Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Western Australian Health Department, no date p. 2). In short, it means that the Aboriginal values relevant to health research of: reciprocity, respect, equality, survival and protection, responsibility, and spirit and integrity are demonstrated through the principles prescribed by the NHMRC during and after any participation in a research project (NHMRC, 2004; Western Australian Health Department, no date).

1.3.5 Empowerment

For the purpose of this paper empowerment will be used in reference to any "process that enables disadvantaged people to increase control over events that determine their lives" (Hecker, 1997, p. 784). The principles that assist in the actualisation of empowerment will be described in more detail in the literature review.

1.3.6 Ethics process

Meeting ethical requirements for conducting health research involves the process of: gaining informed consent; respecting the rights of participants to withdraw from involvement in the research project; maintaining confidentiality and privacy of data collected through the research; respecting cultural values of research participants; ensuring publication of data respectfully represents research participants; and conducting research in a manner that qualifies for the trust of participants, individually and as a community (Edith Cowan University, 1999). Aboriginal health research requires that ethics processes are determined by the dynamic moral standards of Aboriginal people (Shibasaki & Stewart, 2005). Furthermore, "ethical research is research which not only 'does not harm', but also has positive outcomes (in the short and long term) for the communities in which the research is conducted..." (McKendrick & Bennett, 2003, p. 20).

1.4 Significance

> Instead of considering Indigenous health research guidelines in isolation from practice, commentators are calling for evidence-based research that considers what ethical processes are being supported by institutions and in turn, being implemented by researchers.
>
> (Henry, Dunbar, Arnott, Scrimgeour, & Murakami-Gold, 2004, p. 21)

The NHMRC (2003) has established guidelines for the ethical conduct of Aboriginal health research; within these guidelines six specific values have been identified and detailed. The absence of these values in previous research among Aboriginal communities necessitates their articulation and promotion in Aboriginal health research practices (Gillam & Pyett, 2003). Observance and application of these values in research is designed to safeguard all aspects of Aboriginal health be it physical, cultural, spiritual, emotional, mental or social wellbeing. The aim of this thesis was to develop a framework that assists researchers in demonstrating the Aboriginal values relevant to health research in maintaining the cultural security of Aboriginal health research participants.

Establishing partnerships between researchers and communities is crucial to conducting ethical research that is also culturally appropriate among Aboriginal people (Henderson, Simmons, Bourke, & Muir, 2002; Shibasaki & Stewart, 2005). Community consultation that is guided by collaborative ethics processes will increase the ability of researchers to align their project with the way Aboriginal people view their health and wellbeing (Australian Health Ministers' Advisory Council, 2004; Dressendorfer et al., 2005). This type of community consultation could also assist in the development of health promotion interventions that are more effective in improving the health and wellbeing of Aboriginal children in Western Australia (Australian Health Ministers' Advisory Council, 2004; Dressendorfer et al., 2005; Shibasaki & Stewart, 2005). Moreover, this form of consultation in research demonstrates true partnerships with Aboriginal communities and facilitates opportunities for the researchers to uphold Aboriginal values relevant to health research throughout the project (NHMRC, 2003). In turn, it is anticipated that an increased sense of ownership would cause the following positive outcomes: community support and participation for the research project; stronger community interest in project outcomes; and faster acceptance and adoption of resultant intervention programs (Hearn & Wise, 2004;

Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Rowley, Daniel, Skinner, & Skinner, 2000; Shibasaki & Stewart, 2005).

Chapter Two

Literature Review

2.1 Introduction

The purpose of this literature review is to explore the processes of ethical practices within Aboriginal health research in Australia. This literature review will start with an international comparative of Indigenous and non-Indigenous health that leads to a history of Aboriginal health research and a national analysis of literature for ethical research strategies. The Aboriginal values relevant to health research will be examined to identify the most culturally appropriate approach for maintaining cultural security. This literature review will also explore how researchers can empower research participants through community involvement, collaborative consultation and participant ownership in an effort to bridge the distances between researchers and Aboriginal research participants.

2.2 An overview of Indigenous and Aboriginal health

2.2.1 Indigenous health: land and identity

> Next to shooting indigenous peoples, the surest way to kill us is to separate us from our part of the Earth. Once separated, we will either perish in body or our minds and spirits will be altered so that we end up mimicking foreign ways, adopt foreign languages, accept foreign thoughts and build a foreign prison around our indigenous spirits, a prison which suffocates rather than nourishes as our traditional territories of the Earth do. Over time, we lose our identity and eventually die or are crippled as we are stuffed under the name of 'assimilation' into another society.
>
> (Independent Commission on International Humanitarian Issues, 1987 cited in Reid & Lupton, 1991, p. xi)

The above quote aptly describes the relationship of land, culture and identity for many Indigenous peoples throughout the world (Reid & Lupton, 1991). Essentially, it is a poetic description of the inextricable link, held by many people, of health and wellbeing to the land. For Indigenous people, this relationship to their home or tribal lands is brought about by the belief that generations are connected through the land itself (Durie, 2004). In this

sense a connection to tribal land perpetuates spiritual bonds to ancestors and to posterity within the same moment (Durie, 2004).

Although the above quote was made almost 20 years ago, the contemporary condition of health among Indigenous people worldwide continues to give rise for grave concerns at domestic and international levels (McMurray, 2003). Uniquely, two hundred years after colonisation, Australia's Aboriginal people fare worse in every measurable category for health and wellbeing when compared against other Indigenous peoples in similarly developed nations (Canadian Institutes Health Research, no date; Jackson & Ward, 1999; McMurray, 2003; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002). McMurray (2003, p. 281) points out that embarrassingly "Australia is the only industrialised country in the world to have a section of its population face a shrinking life expectancy".

So why is the above quote relevant to this literature review? Aboriginal people in Australia were denied the freedom to express their cultural identity through assimilation actions that failed to recognise their cultural uniqueness and left them ostracized as a people. Aboriginal history, post-European colonisation, is filled with racist practices such as: the dispossession of Aboriginal people from their tribal lands that resulted in a loss in cultural identity; the forced removal of Aboriginal children from their families that resulted in a loss in family identity; isolation from non-Aboriginal society and general disempowerment through the lack of opportunity for Western progress that resulted in a loss in individual and community identity (Angus & Lea, 1998; Hearn & Wise, 2004; Henderson et al., 2002; Holmes, Stewart, Garrow, Anderson, & Thorpe, 2002; Saggers & Gray, 1991). Marginalisation of Aboriginal Australians was further perpetuated through discriminatory health and social policies that reinforced and nurtured intolerance and bigotry (Angus & Lea, 1998; National Health and Medical Research Council, 2003; Palmer & Short, 2000; Saggers & Gray, 1991).

2.2.2 Indigenous health disparities and health philosophies

Needless to say, the long term ramifications of the above policies and practices have had disastrous effects on the health and life outcomes for Australia's Aboriginal people

(Anderson & Thomson, 2002; Australian Indigenous Health*InfoNet*, 2004; Hearn & Wise, 2004; National Health and Medical Research Council, 2003; Palmer & Short, 2000; Saggers & Gray, 1991). The Australian Bureau of Statistics (ABS, 2005) reported that from 1991–2002 Aboriginal people in WA experienced significant declines in morbidity and mortality, however death rates among adults aged between 35 and 54 years were up to five times higher than non-Aboriginal Australians (ABS, 2004). The ABS (2004) attributes these negative health outcomes to social disadvantages that result in increased levels of violence-related death and injury; tobacco smoking; and hazardous levels of alcohol consumption. Aboriginal people also experience higher rates of preventable illnesses such as: "infectious disease, obesity, diabetes, heart disease, kidney disease and cancer" when compared against non-Aboriginal Australians (ABS, 2004, p. 5).

Cultural misconceptions and 'difference blindness', the term used by the NHMRC (2003) to describe prejudice towards cultural diversity, were the dominant attitudes of many non-Aboriginal Australians (Palmer & Short, 2000; Saggers & Gray, 1991). Morgan et al. (1997) suggest that in order to develop appropriate health interventions and improved outcomes, the world view or health and life philosophy as seen by Aboriginal people must be acknowledged and implemented into Aboriginal health programs. The removal of difference blindness requires the working recognition that differences existing between Aboriginal and non-Aboriginal cultures extend into health philosophies; hence, non-Aboriginal researchers need to see and understand health in the same way that Aboriginal people see and live health (Baillie & Paradies, 2005; Matthews et al., 2002).

Aboriginal people measure their health and wellbeing in terms of collective community wellness – this is contrary to the individualistic measure that non-Aboriginal, namely European/Western people use to gauge health (Jackson & Ward, 1999; National Aboriginal Community Controlled Health Organisation, no date). The attainment of 'health' is assessed by different measures for Aboriginal people; the welfare of 'everyone and everything' is taken into consideration before 'good health and wellbeing' can be claimed (NAACHO, no date; NHMRC, 1997b). In essence, the health and wellbeing of everything else, be it land, sky, animals, or other people determines the health and wellbeing of an individual in a community cycle of life-death-life (NAACHO, no date; NHMRC, 1997b). This health philosophy of life-death-life is holistic in the truest sense because it includes

environmental, social, emotional, spiritual and cultural wellness (NAACHO, no date; NHMRC, 1997b). It acknowledges the connection that each member of the community has to each other creating a fundamental cultural obligation for the wellbeing of all things (NACCHO, no date; Wilkes, Houston, & Mooney, 2002).

Morgan, Slade and Morgan (1997) also attribute poor health and the poor utilisation of existing health services by Aboriginal people, to the failure of non-Aboriginal institutions and governments in understanding this holistic belief and lifestyle. Programs that are inconsistent with an Aboriginal perspective of health, or rather life-death-life threaten cultural security (NACCHO, no date). As such when health services, health research, or health promotion interventions do not validate or encourage Aboriginal values, Aboriginal people do not use them; thus a negative cycle of the utilisation of health services has further compounded Aboriginal health discrepancies (Rowley et al., 2000). Much of the research into the health of Aboriginal people in Australia has produced irrelevant and ineffective health messages for Aboriginal people and disappointingly Aboriginal health research has not been able to ameliorate the discrepancies in Aboriginal health (Baillie & Paradies, 2005; Humphrey, 2001; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Sheehan, Ridge, & Marshall, 2002).

2.2.3 Indigenous health research

On a global level, an increased focus over the last two decades on Indigenous cultural recognition has contributed to improvements in health and social conditions for Indigenous people in other countries (McMurray, 2003; Menzies, 2001; O'Neil, Reading, & Leader, 1998). In particular, the localised successes experienced by the New Zealand Maori and Canadian First Nations people have contributed to global cultural renaissance movements among Indigenous peoples through the capitalisation of cultural empowerment (McMurray, 2003; O'Neil et al., 1998). Today, both Indigenous and non-Indigenous researchers and health workers in the above mentioned countries strongly advocate on behalf of Indigenous people for respectful representation in research and promote the need for cultural values to drive research practice and research themes (Buetow, 2004; Durie, 2004; Golds, King, Meiklejohn, Campion, & Wise, 1997; Menzies, 2001; Ten Fingers, 2005).

In New Zealand, culturally secure health research practices have proved beneficial for both researchers and their participants. Durie (2004) provides examples in the form of case studies that describe how changes in attitudes among non-Maori health researchers occurred as they came to a deeper understanding and acceptance of Maori health philosophies. In one of the case studies, Durie (2004) describes the initial resistance by some non-Maori researchers to suggestions for project changes that were inline with Maori cultural requirements. As the researchers came to an understanding of Maori health philosophies, this resistance was short lived and a collective expression of support ensured that the changes went ahead smoothly (Durie, 2004). Further to facilitating tolerance and respect among the researchers, the case study reported that after the changes were made, Maori communities responded to the project with greater levels of enthusiasm and participation (Durie, 2004).

In a positive move forward and in recognition of the existing health differences between Indigenous and non-Indigenous people, a Tripartite Cooperation Agreement was signed in 2002 by the Australian, Canadian, and New Zealand national health research agencies (Canadian Institutes Health Research, no date; Cunningham, Reading, & Eades, 2003). The agreement primarily aims to protect the cultural values of Indigenous people in research within those three nations and to encourage increased participation and leadership within Indigenous research (Canadian Institutes Health Research, no date; Cunningham et al., 2003). In 2003, Australia and New Zealand published modified guidelines for ethics in Indigenous health research; both countries new guidelines fall inline with the general statements of the Agreement (Health Research Council, 2002; National Health and Medical Research Council, 2003).

2.3 A history of Aboriginal health research

2.3.1 The Aboriginal health research experience

The mistreatment of Aboriginal people in Australia over the past two centuries has culminated in a general mistrust toward the intentions of European institutions or the integrity of European authority (Holmes et al., 2002; Humphrey, 2001). Humphrey (2001) provides an extensive history of the evolution of Aboriginal health research in Australia from the 1970s through to the 1990s; much of the research of the 20th century among

Aboriginal people proved beneficial only to those collecting data, leaving little if any reward for research participants. Despite the bestowal of academic accolades for health research conducted by institutions during this period, the health of the researched communities remained the same, or worse, deteriorated (Henry et al., 2004; Manderson et al., 1998; Shibasaki & Stewart, 2005). By the early 1980s research practices in some regions resulted in a considerable level of resistance among Aboriginal people to participate in research (Henry et al., 2004; Humphrey, 2001). On completion of their study of an Aboriginal mental health promotion intervention, Sheehan, Ridge and Marshall (2002) acknowledged the inseparable influence of past research practices on the current state of Aboriginal health and wellbeing. Sheehan, et al. (2002) recommended that researchers must respect the fact that for some communities, reluctance and mistrust towards research projects is the natural consequence of historical mistreatment (Sheehan et al., 2002). As such, acknowledgment of and contrition for Aboriginal history is considered to be a primary step towards improving Aboriginal health and the conduct of Aboriginal health research (Jackson & Ward, 1999).

2.3.2 Evidence of ethical conduct in Aboriginal health research

The number of peer-reviewed publications on Aboriginal health research is substantial and the annotated bibliography compiled by McAullay, Griew and Anderson (2002) provides an extensive reference of examples on this topic. Additionally, the Cooperative Research Centre of Aboriginal and Tropical Health, located in the Northern Territory, has also published numerous reports including a monograph series on Indigenous Research Reform (Henry et al., 2002; Henry et al., 2004; Matthews et al., 2002). One of the major themes acknowledged within the literature is the need for Aboriginal people to be empowered in both health intervention programs and research projects. Strategies for empowering research participants will be discussed in more detail later within this literature review.

Notwithstanding the volume of literature on Aboriginal health research, specific examples that demonstrate Aboriginal values relevant to health research (NHMRC, 2003) are inadequately addressed. Only a few studies described how the research project maintained ethical conduct to support Aboriginal participants and their community (Henderson et al., 2002; Manderson et al., 1998; Pyett & VicHealth Koori Health Research and Community

Development Unit, 2002). This may be due in part to the fact that the first set of guidelines for conducting ethical health research in Australia was not published until 1991 (Gillam & Pyett, 2003; Humphrey, 2001) and that the follow-up document identifying Aboriginal values relevant for health research (NHMRC, 2003), which this thesis is based on, is only two years old. This considerably narrows the timeframe for the availability of published articles describing research processes against the standards set in the NHMRC (2003) guidelines. Consequently, it is difficult to ascertain what has worked well in demonstrating the Aboriginal values relevant to health research.

2.3.3 Evidence of ethics frameworks for Aboriginal health research

Examples of ethical procedures prior to 2003 can be found in reports such as that provided by Manderson et al. (1998). In describing the formative stages of their longitudinal study on women's health in Australia, Manderson et al. (1998) convincingly describe the consequences of underestimating the importance of early community inclusion. Failure to have community partnerships established in the early stages of a study further lengthen project delays naturally associated with community negotiation and consultation (Manderson et al., 1998).

Another example of support for the establishment of community partnerships in research can be found in the Indigenous Research Framework (IRF) developed by the Department of Rural Health at the University of Melbourne (Henderson et al., 2002). The IRF was designed to assist non-Aboriginal health researchers develop partnerships with the Koori (local Aboriginal) people of north-eastern Victoria (Henderson et al., 2002). Guidelines for conducting research under the IRF framework include:

- early, ongoing community consultation;
- community involvement to ensure community relevance and benefits;
- ethical review for research to be conducted by a committee that has at least two Koori representatives;
- cultural supervision of non-Aboriginal researchers; and
- community ownership of data, including community approval of any project material prior to publication (Henderson et al., 2002).

The IRF is loosely structured to accommodate for the varying needs of different Aboriginal communities within the Shepparton, Victoria region and for the flexible application of its principles in other regions throughout Australia (Henderson et al., 2002). This recognition of the need for flexibility of the framework is consistent with Gillam and Pyett's (2003) Aboriginal health research recommendations to avoid dogmatic compliance with ethics guidelines that fail to provide culturally secure research to the participating community. The Indigenous research framework offers an example of how the Aboriginal values relevant to health research could be demonstrated.

Additionally, Pyett and the VicHealth Research and Community Development Unit (2002) promote for the use of three principles to guide Aboriginal health research:

- project accountability to the community;
- regard for the cultural safety of participants; and
- project ownership by the community.

Further to the above principles, Pyett and the VicHealth Research and Community Development Unit also advocate for the use of a cultural sponsor, who whilst being an Aboriginal co-researcher acts as a cultural advisor and interpreter. The recommendation for the use of a cultural advisor is applicable to all researchers (including those that are Aboriginal from different regions) who are either not known by the participating community or not familiar with local customs and traditions (Henderson et al., 2002; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002). As the relationship of trust between researcher and project participants is crucial to practicing ethical research and maintaining cultural security the use of an Aboriginal co-researcher/cultural advisor would appear to be essential. However, in line with capacity building possibilities for participating communities, it would be negligent of researchers to limit the role of the Aboriginal co-researcher to that of a 'recruiting agent' (Pyett & VicHealth Koori Health Research and Community Development Unit, 2002). Maximising the benefits of this role to both the project and the community could be achieved if inclusive to the primary responsibilities of the Aboriginal co-researcher are: "informing, supporting, empowering and caring for participants" (Pyett & VicHealth Koori Health Research and Community Development Unit, 2002, p. 61).

Also in Victoria, a Memorandum of Understanding (MOU) was developed for an Aboriginal blood borne virus training program conducted in 2003 (Waples-Crowe & Pyett, 2005). The MOU was essentially a mission statement that was used to facilitate the program's goals and helped to maintain the integrity and transparency of the organisations involved in the program (Waples-Crowe & Pyett, 2005). Within the program review Waples-Crowe and Pyett (2005) explain the steps necessary for successful cross-cultural collaboration between what they differentiate as 'mainstream' and Aboriginal health organisations. Although not devised for use in research processes as such, the ten steps listed below (Waples-Crowe & Pyett, 2005, p. 14-15), could easily be applied to relationships between Aboriginal participants and non-Aboriginal researchers in a health research setting –

1. A long time frame
2. Building trust
3. Valuing each other
4. Get educated
5. Good planning
6. Useful product
7. Community initiated
8. Identifying the partners and formalising partnerships
9. Supportive work environments
10. Cultural awareness

Effectively, these steps are specific examples of principles for empowerment which will be explained in more detail later in this literature review. It is noteworthy however that some of the feedback included within the program review was extremely positive for the additional efforts taken within the program to develop cross-cultural relationships of trust (Waples-Crowe & Pyett, 2005). Primarily, the use of overnight training sessions were credited for the strength of the relationships developed throughout the program; this was a beneficial strategy because it provided informal opportunities for interaction to occur between trainers and participants such as talking during meal times and evening socialising sessions (Waples-Crowe & Pyett, 2005).

2.4 Aboriginal values relevant to health research

2.4.1 National ethics guidelines for Aboriginal health research

> ... Guidelines for ethical conduct ... [have] not been enough to ensure that the rights and interests of Indigenous participants in research activity are adequately represented. There is evidence to suggest that these guidelines do not mandate for substantial changes to the way researchers operate and that currently, inadequate institutional mechanisms are in place to monitor the activity of researchers once formal human research ethics committee (HREC) approval has been granted.
>
> (Henry et al., 2002, p. 12)

As pointed out in the above quote, the 'interim' NHMRC ethical guidelines for Aboriginal health research were inadequate for maintaining the cultural security of research participants and their communities. Hence, it was necessary for the NHMRC to modify the then existing guidelines to more effectively assist Aboriginal health researchers to conduct ethical research (Adams, 2002; Henry et al., 2004). Maintaining Aboriginal values that are relevant to health research throughout the entirety of a research project is intrinsic to the cultural security of the participating Aboriginal community (NHMRC, 2003; National Health and Medical Research Council, 2003; Western Australian Health Department, no date).

The latest version of the NHMRC (2003) guidelines for conducting ethical health research among Aboriginal people is the result of a workshop held in Ballarat, Victoria in June 2002 (NHMRC, 2003). The guidelines aim to "reconcile the interests of research and researchers with the values, expectations and cultures of Aboriginal... communities"(NHMRC, 2003, p. 5). Within the guidelines, the NHMRC (2003) asserts that a sincere effort to investigate possibilities for improving Aboriginal health means that researchers must respect the distinct and different cultural values of Aboriginal people and their communities. Individually and collectively the cultural values of: **reciprocity**, **respect**, **equality**, **responsibility**, **survival and protection**, and **spirit and integrity** must be active throughout a research project in order for it to be conducted in an ethical manner (NHMRC, 2003). As illustrated in Figure 1 these values are timeless to Aboriginal people and as such the past, the present and the future are interwoven into the importance and reality of each value (NHMRC, 2003).

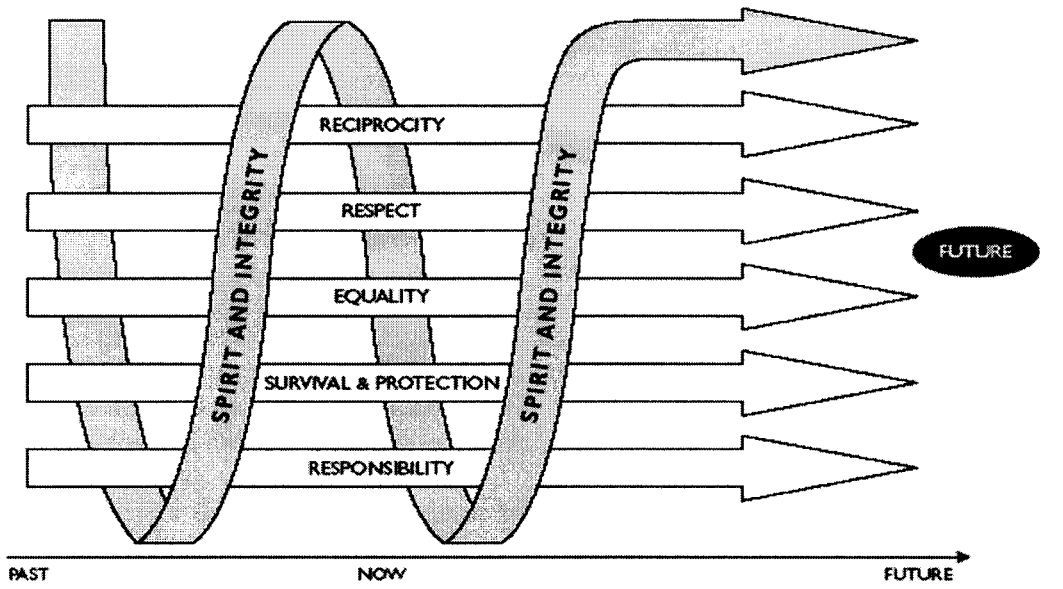

Figure 1. Aboriginal values relevant to health research ethics (Source: NHMRC, 2003, p. 9)

The observance and application of these values in research are intertwined in their design for safeguarding all aspects of Aboriginal culture; as such there is the possibility for the values to overlap in their demonstration (NHMRC, 2003).

2.4.2 Reciprocity

The value of reciprocity aims to ensure that there are equitable benefits for researcher and participant alike to be gained from the research project, and includes recognition of the contribution made by participants to the study. Unfortunately, as the NHMRC (2003, p. 10) points out, it appears that the nature of research "involves unequal power relationships" between those who research and those who are researched. For an equal partnership to occur, the 'benefits' of participation must be defined by the values of the participating community not the researcher or the project (NHMRC, 2003). The NHMRC (2003) suggests that one of the ways this value can be demonstrated is through the establishment of research objectives that are able to positively contribute to the overall health and wellbeing of the participating community.

The NHMRC (2003) guidelines provide five principles for demonstrating the value of **reciprocity**, they are:

- "How the proposed research demonstrates intent to contribute to the advancement of the health and wellbeing of participants and communities" (NHMRC, 2003, p. 11).

- "Whether the proposal links clearly to community, regional, jurisdictional or international Indigenous health priorities and/or responds to existing or emerging needs articulated by Aboriginal and Torres Strait Islander Peoples" (NHMRC, 2003, p. 11).

- "The nature of benefits for participants or other Aboriginal and Torres Strait Islander communities, and whether there is evidence of clear and truthful discussions about the potential benefit of the research proposal prior to approval" (NHMRC, 2003, p. 11).

- "Whether the researcher has demonstrated willingness to modify research in accordance with participating community values and aspirations" (NHMRC, 2003, p. 11).

- "Whether the proposed research will enhance the capacity of communities to draw benefit beyond the project, e.g. through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level" (NHMRC, 2003, p. 11).

2.4.3 Respect

The value of respect aims to acknowledge the contribution of participants in a cooperative and sensitive way, and ensures full community consultation throughout the entire research process (NHMRC, 2003). One way this value can be demonstrated by researchers is through the recognition of potential differences in values; researchers must accept that participant priorities may compete with the research project, thus project timeframes must be flexible and adjusted accordingly (Miller & Rainow, 1997).

The NHMRC (2003) guidelines provide eight principles for demonstrating the value of **respect**, they are:

- "Whether the proposal responds to the diversity of Aboriginal and Torres Strait Islander Peoples and communities, including the way decisions are made" (NHMRC, 2003, p. 12).

- "How the proposal acknowledges the individual and collective contribution of Aboriginal and Torres Strait Islander Peoples" (NHMRC, 2003, p. 13).

- "How the researchers propose to minimise the effects of difference blindness on and in the research process" (NHMRC, 2003, p. 13).

- "How the research proposal engages with Aboriginal and Torres Strait Islander People's knowledge and experience" (NHMRC, 2003, p. 13).
- "Whether appropriate agreements have been negotiated about ownership and rights of access to Aboriginal and Torres Strait Islander People's intellectual and cultural property" (NHMRC, 2003, p. 13).
- "Whether the processes of reaching agreement demonstrate engagement with the values and processes of participating communities" (NHMRC, 2003, p. 13).
- "Whether the participating communities have expressed satisfaction with the research agreement and decision making processes" (NHMRC, 2003, p. 13).
- "Whether in reaching agreement with participating communities all relevant issues including management of data, publication arrangements and the protection of individual and community identity have been adequately addressed" (NHMRC, 2003, p. 13).

2.4.4 Equality

The value of equality aims to ensure that differences in Aboriginal values and culture remain intact throughout the entire research process; a particular emphasis of this value is placed on ensuring that Aboriginal people have a right to be different to non-Aboriginal people and that any level of participation (individual or community) has no negative cultural ramifications (NHMRC, 2003). Additionally, this value can be demonstrated through appropriate information dissemination, meaning that all information, i.e. reports and data are presented to the community in a format that is understood by both the research participants and the community as a whole (NHMRC, 2003).

The NHMRC (2003) guidelines provide three principles for demonstrating the value of **equality**, they are:

- "Whether the ways that participating communities are included in the research processes demonstrate equality" (NHMRC, 2003, p. 15).
- "Whether the research agreements have the strength necessary to sustain equality" (NHMRC, 2003, p. 15).
- "Whether participating communities have understood and expressed satisfaction with the proposed research, its potential benefits and their distribution. Researchers therefore have a responsibility to ensure that the information that they provide is understood and usable in decision making by participating communities" (NHMRC, 2003, p. 15).

2.4.5 Responsibility

The value of responsibility aims to do no harm to research participants (NHMRC, 2003). The aims of this value can be achieved, in part, through collaboration that consists of constant consultation/feedback sessions with the participating community. Consultation sessions throughout the entirety of the research project provide forums for expression of community concerns, values and expectations enabling researchers to address potential problems as they arise (NHMRC, 2003; National Health and Medical Research Council, 2003).

The NHMRC (2003) guidelines provide five principles for demonstrating the value of **responsibility**, they are:

- "What measures are identified to demonstrate transparency in the exchange of ideas and in negotiations about the purpose, methodology, conduct, dissemination of results, and potential outcomes/benefits of research?" (NHMRC, 2003, p. 17).
- "How provision is made for appropriate ongoing advice and review from the participating community, including mechanisms to monitor ethics standards and to minimise the likelihood of any unintended consequences arising from or after the research project" (NHMRC, 2003, p. 17).
- "What does the proposal say about timely feedback obligations to communities and whether that feedback is relevant to the expressed concerns, values and expectations of research participants and communities?" (NHMRC, 2003, p. 17).
- "How the proposal demonstrates agreed arrangements regarding publication of the research results, including clear provisions relating to joint sign off for publication and the protection of individual and community identity if appropriate" (NHMRC, 2003, p. 17).
- "Whether there is clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it" (NHMRC, 2003, p. 17).

2.4.6 Survival and Protection

The value of survival and protection aims to eliminate even the subtlest practice of colonisation or assimilation in research by establishing an attitude of celebration in the diversity of the Australian Aboriginal culture (NHMRC, 2003). In turn, the NHMRC (2003) suggests that this will strengthen individual identity and ultimately family and community cohesion. This value can be demonstrated by ensuring that in addition to positive health outcomes, the research project has social relevance that provides

opportunities for individuals and communities to enjoy their cultural distinctiveness (NHMRC, 2003).

The NHMRC (2003) guidelines provide five principles for demonstrating the value of **survival and protection**, they are:

- "Whether the research project contributes to or erodes the social and cultural bonds among and between Aboriginal and Torres Strait Islander families and communities" (NHMRC, 2003, p. 19).
- "What safeguards are in place against the research project contributing to discrimination or derision of Aboriginal and Torres Strait Islander individuals or cultures?" (NHMRC, 2003, p. 19).
- "Whether the proposal respects the intrinsic values based expectations and identity of Aboriginal and Torres Strait Islander Peoples and communities including the balance between collective and individual identity" (NHMRC, 2003, p. 19).
- "How the proposal contributes to the opportunity for Aboriginal and Torres Strait Islander Peoples to better advocate for or enjoy their cultural distinctiveness" (NHMRC, 2003, p. 19).
- "What strategies have been identified to eliminate any threats to Aboriginal and Torres Strait Peoples ability to enjoy their cultural distinctiveness?" (NHMRC, 2003, p. 19).

2.4.7 Spirit and Integrity

The value of spirit and integrity aims to ensure that all of the above values are practiced (NHMRC, 2003). Importantly, the value of spirit and integrity cannot be realised if reciprocity, respect, equality, responsibility, and survival and protection are compromised in any degree. This value can be demonstrated by researchers when acceptance of the participating community's social, spiritual and cultural values are revered throughout the entire research process (NHMRC, 2003).

The NHMRC (2003) guidelines provide four principles for demonstrating the value of **spirit and integrity**, they are:

- "How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's cultural, spiritual and social cohesion, including workable timeframes" (NHMRC, 2003, p. 20).

- "Whether the proposal recognises in the conduct and reporting of research the diversity of Australian Aboriginal and Torres Strait Islander People's cultures, including the mechanisms through which communities may make decisions" (NHMRC, 2003, p. 20).

- "Whether the proponents of the proposal are able clearly to demonstrate personal integrity, specifically in the development of their proposal" (NHMRC, 2003, p. 20).

- "Does the proposal demonstrate a commitment to working within the spirit and integrity of Aboriginal and Torres Strait Islander Peoples?" (NHMRC, 2003, p. 20).

2.4.8 Reviewing the guidelines

Prior to the publication of the NHMRC (2003) guidelines a draft of the document was circulated for academic and professional feedback. In response, Gillam and Pyett (2003) point out that the values in and of themselves are not new concepts to what constitutes ethical research practice. Rather, it is a history of the absence of these values in Aboriginal research that necessitates their articulation and consequent zealous promotion for the application and practice of reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity (Adams, 2002; Gillam & Pyett, 2003). The Aboriginal values relevant to health research as set out by the NHMRC (2003) identifies that an explicit demonstration of each value and its principles must take place in order for research to remain ethical (Gillam & Pyett, 2003) and maintain the cultural security of the participating community.

However, McKendrick and Bennett (2003) suggest that the guidelines fail to do more than identify the presence of complexities in Aboriginal health research. They suggest that the NHMRC (2003) guidelines are restricted to being an introductory platform to ethical Aboriginal health research, rather than the vehicle that can assist in a power shift for Aboriginal people in the ownership of project and health outcomes (McKendrick & Bennett, 2003). As such, evidence is needed for the demonstration of how the Aboriginal values relevant to health research can be employed in research practice. Accordingly, this thesis aims to act on the above criticisms and limitations. Case studies and expert consultation will be employed to explore consensus among Aboriginal health researchers and practitioners for a framework to guide how a research project may demonstrate the Aboriginal values for health research in future projects.

The values and principles outlined above are designed to protect Aboriginal research participants and assist researchers in conducting ethical research with integrity. Further to this mandate for ethical health research and addressing Henry, et al's (2002) criticism of HRECs, in WA the Western Australian Aboriginal Health and Information Ethics Committee (WAAHIEC) is the local organisation that monitors ethical standards in Aboriginal health research. In addition to standard institutional ethics applications, approval to conduct a research project among Aboriginal people in Western Australia must also be granted from the WAAHIEC. Moreover, to ensure that the cultural security of participants is maintained in health research, the WAAHIEC (no date) criteria demands an extensive explanation on how each of the NHMRC (2003) values (and their correlating principles) for Aboriginal health research will be demonstrated throughout the research process.

2.5 Empowerment in Aboriginal health research

> Health promotion is carried out *by* and *with* people, not *on* or *to* people. It improves both the ability of individuals to take action, and the capacity of ... communities ... [and it] requires practical education, leadership training and access to resources.
>
> (World Health Organisation, 1997, p. 263)

In 1997 the World Health Organisation (WHO) published the Jakarta Declaration (WHO, 1997). Whilst the Bangkok Charter of 2005 (WHO, 2005) supersedes the Jakarta Declaration, the Bangkok Charter (WHO, 2005) concentrates on globalising health issues. The five priorities of the Jakarta Declaration (WHO, 1997) are more relevant to this literature review as it aims to further health promotion efforts in addressing the determinants of health (WHO, 1997). The above quote is taken from the fourth priority of the Jakarta Declaration (WHO, 1997) which focuses on empowering individuals, organisations and communities and although the Declaration refers to health promotion in general, the fourth priority can be applied to this thesis topic. From the values and principles identified in the NHMRC (2003) guidelines Aboriginal health research should also be carried out ***by*** and ***with*** Aboriginal people, not *on* or *to* them (WHO, 1997).

Empowerment of Aboriginal communities that participate in health research is a necessary action for cultural security to be maintained (Shibasaki & Stewart, 2005). As illustrated earlier in Figure 1, the Aboriginal values relevant to health research are constant and as such the empowerment of participants and their communities can not be limited to occurring within a specific event within the timeframe of the research project. To be sustainable and effective, empowerment must be active prior to the commencement of the research project, during data collection and after the project's completion.

The DRH framework (Henderson et al., 2002) mentioned earlier, also identified that the participating community in the study were empowered because of the level of their project involvement throughout the entirety of the research process. Hence, empowerment in Aboriginal health research is more likely to be achieved through the demonstration of the following principles: **involvement** in the development of the project; **consultation** as to the appropriateness and relevance of the project; and shared **ownership** in project outcomes (Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Holmes et al., 2002; Miller & Rainow, 1997; Sheehan et al., 2002; Shibasaki & Stewart, 2005). As with the values in the NHMRC (2003) guidelines, involvement, consultation and ownership are interrelated and overlap in their objectives, hence it would be difficult for researchers to empower participants in one aspect without doing so in another.

2.5.1 Involvement

Community involvement in the research process can not be limited to the role of participant under investigation, rather partnerships such as those formed for participatory action research are an effective way of empowering participants (Hecker, 1997). It is difficult for the community values and priorities to be truly represented in a project unless they are actively involved in planning, action, reflection and evaluation (Hecker, 1997). Miller and Rainow (1997) suggest that community resistance to research participation may be due, in part, to the lack of apparent research relevance or the delay of positive health improvements. As previously mentioned, relevance to community health needs are more likely to be achieved with community involvement in the decision making process of the research project (Miller & Rainow, 1997).

Furthermore, a partnership between the community and an institution is beneficial as exchanges in resources and knowledge can be advantageous to both parties. Research institutions have access to resources that assist in the development of effective health interventions which are usually unavailable to the community (Pyett, 2002; Shibasaki & Stewart, 2005). In turn, community knowledge in project design, data collection and analysis, and dissemination of findings increases the validity of the institute's project (Durie, 2004; Pyett, 2002).

Community involvement can not be limited to the identification of local health issues to ensure project relevancy, it must continue through all stages of the research process. Therefore all communication, especially research results, must be relevant to the participating community. In addition to avoiding jargon, reports should be written in the community's language, increasing relevance and potential benefits through intervention application to the participating community (Hecker, 1997). The issue of the format or the style used to present results to the community is of particular importance in remote areas as English is usually the third or fourth language spoken (Donovan & Spark, 1997).

Miller and Rainow (1997) encourage feedback of research data to the community as it is collected, they suggest that 21st century technology such as laptop computers make it possible for data entry and analysis to be conducted while researchers are still in the community. Meyer (2000) refers to this approach as 'democratic' research in as much as it assists in the creation of equality between those conducting the research and those being researched. A democratic research approach empowers the participating community and also increases the level of community trust towards the project. Additionally, when data analysis and interpretation is conducted by the community two outcomes are achieved: firstly, employment opportunities are made available to community members throughout the project; and secondly, community members are empowered as their role expands from one who is 'researched' to one who assists in the project as a 'research consultant' (Hearn & Wise, 2004; Miller & Rainow, 1997). The use of an Aboriginal co-researcher/cultural advisor as previously described is an example of how the redefining of participant roles can occur.

Community **involvement** as described above demonstrates the following principles of the Aboriginal values relevant to health research in accordance with the NHMRC (2003) guidelines through:

- **reciprocity** "as the project enhances the capacity of the participating community through the development of skills" (NHMRC, 2003, p. 11);
- **respect** "as the project responds to the diversity of the participating community, including the way decisions are made" (NHMRC, 2003, p. 12);
- **equality** "as the project agreements have the strength necessary to sustain equality" (NHMRC, 2003, p. 15);
- **responsibility** "as the project feedback is timely and relevant to the expressed concerns, values and expectations of the participating community" (NHMRC, 2003, p. 17);
- **survival and protection** "as the community involvement ensures that safeguards are in place against discrimination and derision" (NHMRC, 2003, p. 19); and
- **spirit and integrity** "as the project demonstrates an understanding of and an agreement about the relationship of the community's cultural, spiritual and social cohesion, including workable time frames" (NHMRC, 2003, p. 20).

2.5.2 Consultation

Collaborative consultation is essential throughout the entirety of a project. Again this means during formative planning and data collection, prior to data publication and at intervention. Consultation that occurs between researchers and the community at these stages is considered to be an effective vehicle for the actualisation of empowerment (Hearn & Wise, 2004; Henderson et al., 2002). It is not enough to merely engage in consultation sessions, rather constructive collaboration needs to take place; working partnerships that develop trust and respect are most likely to facilitate collaborative consultation (Hearn & Wise, 2004). Thomsen (2003) supports the need for relationships of trust and points out that when research involves people it must accommodate for the dynamic requirements of human diversity. Consultation is insufficient if it is made up of well meaning, but empty 'good intentions'; genuine negotiation must occur.

> Part of blackfella way of doing things is to sit down and talk: people develop stories to identify problems, discuss courses of action and negotiate agreement on what needs to be done. Everyone gets heard, no matter how long it takes everyone has ... a say and everyone is satisfied.
> (Thomsen, 2003, p. 4)

This is the type of negotiation that contributes to positive health changes taking place within the community (Hearn & Wise, 2004). Community consultation and feedback is essential throughout the research project to maintain project integrity. Further to the 'sharing' process, consultation provides a forum for the community to determine that the Aboriginal values relevant to health research are being honoured by researchers (Hearn & Wise, 2004; Miller & Rainow, 1997). In this environment of open communication, researchers are made aware of any concerns or issues that need addressing as they arise and can therefore respond promptly and appropriately in accordance with community values (Meyer, 2000; Sheehan et al., 2002). In the development of their guidelines for health research in remote communities, Donovan and Spark (1997, p. 94) suggest that, "as far as possible, the community should be involved in the objectives, design and implementation of the study. Most importantly, a formal feedback of the results to the community should be arranged".

The format of feeding back information to the community is also an important facet of the consultation process. Mak, McDermott, Plant and Scrimgeour (1998) point out that any written communication (whether preliminary information or ready-to-publish results) needs to be presented to the community in an appropriate language and style. To motivate researchers to do what would seem to be common decency, the NHMRC (2003) suggests that to provide feedback any other way would compromise the ethical conduct of the project and therefore threaten the cultural security of research participants. An excellent example of clarity in reporting back to the community can be found in the story boards produced for the *Western Australian Aboriginal Child Health Survey* (Telethon Institute for Child Health Research & Kulunga Research Network, 2004). In these story boards a narrative provided a clear and simple description of: the background to the study; the community values; an explanation of the survey; information about survey participants; regional statistics for population, family and culture, housing, children at birth, physical health; and future plans for the survey data (Telethon Institute for Child Health Research & Kulunga Research Network, 2004).

Furthermore, it is important that the spirit of sharing continues when the project information is presented back to the community. Sharing is more likely to occur when the

information is presented in an environment conducive to open discussion and reflection (Brown, Hunter, & Whiteside, 2002). Brown et al. (2002, p. 38) suggest "using a local neutral Indigenous venue, providing tea, coffee and food where possible, and encouraging and assisting Indigenous workers involved in the initial research to present the findings". In addition to this, Shibasaki and Stewart (2005, pg. 7) encourage the use of practical research processes that are fun, inviting and educational for the community in "creating an awareness of good research practices". Only consultation with the community will reveal what is appropriate for meeting the above recommendations.

Collaborative **consultation** as described above demonstrates the following principles of the Aboriginal values relevant to health research in accordance with the NHMRC (2003) guidelines through:

- **reciprocity** "as researchers demonstrate clear and truthful discussions about the potential benefits of the project to the community" (NHMRC, 2003, p. 11);
- **respect** "as the project minimises the effects of difference blindness on and in the research process" (NHMRC, 2003, p. 13);
- **equality** "as the ways that the participating community are included in the project demonstrates equality" (NHMRC, 2003, p. 15);
- **responsibility** "as the project demonstrates transparency in the exchange of ideas and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of the project" (NHMRC, 2003, p. 17);
- **survival and protection** "as the projects contributes to the opportunity of the participating community to better advocate for or enjoy their cultural distinctiveness" (NHMRC, 2003, p. 19); and
- **spirit and integrity** "as the project recognises in the conduct and reporting of research the diversity of Aboriginal culture, including the mechanisms through which the participating community may make decisions" (NHMRC, 2003, p. 20).

2.5.3 Ownership

Ownership of the research project by the participating community can be achieved if a participatory or democratic approach is used. A responsibility shift or power transfer from research institutions back to the community increases the level of ownership and empowerment that can be achieved by the participating community (Hearn & Wise, 2004; Shibasaki & Stewart, 2005). Hecker's (1997, p. 788) study of Aboriginal health workers

found "that when the 'researched' become the researchers and are given a genuine opportunity to set the agenda for the research, the process can develop initiative, strengthen decision making and, in so doing, increase self-reliance". In this way consultation sessions become meetings that assist Aboriginal communities to take ownership of the research project in achieving their goals in health research, interventions and ultimately health outcomes. Again, an Aboriginal co-researcher/cultural advisor would be a useful assistant in achieving this.

Donovan and Spark (1997) suggest that in addition to ensuring relevancy of a study by involving the community in the research process, inclusion in evaluation and interpretation of the data also increases the level of project ownership by the community. This is because the research agenda is set by the community and is therefore consistent with local health and life values rather than a project that meets the interest of researchers (Henderson et al., 2002). Rowley et al. (2000) attributed part of the success of their study to early inclusion in the project through community control and ownership of the project. Results of their healthy lifestyle program targeting diabetes in a remote Kimberley community showed sustainable health behaviour changes among the Aboriginal people of that area (Rowley et al., 2000). In line with the above sentiments from Donovan and Spark (1997), Rowley et al. (2000) suggest that being a part of the ownership process, meaning project initiation, development and implementation in and of itself had positive health benefits for the participating community.

In relation to health research that targets Aboriginal children, an attitude of reservation towards institution-based research must be taken into consideration when inviting communities to participate in a project.

> It is very important to understand the depth of feeling associated with privacy breaches in relation to identity or address. This can only be understood with a good knowledge of the policy of removal of children and the discrimination experienced by Aboriginal people for generations.
>
> (Holmes et al., 2002, p. 1271)

The above quote highlights some of the issues regarding the importance of safe storage practices of records unique to Aboriginal people who participate in health research.

Holmes et al.'s (2002) caution adds further support for community ownership that ensures involvement in the initiation, design, implementation and evaluation of a research project.

Participant **ownership** as described above demonstrates the following principles of the Aboriginal values relevant to health research in accordance with the NHMRC (2003) guidelines through:

- **reciprocity** "as the project links clearly to community health priorities and responds to existing or emerging needs articulated by Aboriginal people" (NHMRC, 2003, p. 11);
- **respect** "as the appropriate agreements are negotiated about ownership and rights of access to Aboriginal intellectual and cultural property" (NHMRC, 2003, p. 13);
- **equality** "as researchers ensure that the participating community has understood and expressed satisfaction with the potential benefits of the project" (NHMRC, 2003, p. 15; National Health and Medical Research Council, 2003);
- **responsibility** "as researchers enter agreements regarding publication of the project results, including clear provisions relating to joint sign off for publication and the protection of individual and community identity" (NHMRC, 2003, p. 17);
- **survival and protection** "as researchers ensure that the project contributes to the social and cultural bonds among Aboriginal families and communities" (NHMRC, 2003, p. 19); and
- **spirit and integrity** "as the project demonstrates a commitment to working within the spirit and integrity of the Aboriginal people" (NHMRC, 2003, p. 20).

2.5.4 Community development

Community development is the paradigm that is being used to guide this thesis project and justify early inclusion of Aboriginal people, committees or communities in the research process, i.e. involvement and consultation for the ethics process. Community development promotes collaborative consultation, participant involvement and community ownership (McMurray, 2003). Tokenistic measures for inclusion and collaboration generates mistrust within the community towards the research project (Manderson et al., 1998). If a true community development attitude is to be adopted in Aboriginal health research, then the role of research institutions needs to shift to that of research facilitator allowing the community to have true ownership of the project as suggested earlier by Meyer (2000) and Miller and Rainow (1997).

Furthermore, a community development approach of genuine consultation nurtures trust. Both the WA Health Department (no date) and the NHMRC (2003) emphatically state that trust is crucial for maintaining cultural security and conducting ethical research that can contribute to positive changes occurring in Aboriginal health. As identified earlier, only when the Aboriginal values relevant to health research of: reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity are present in the research process will trust be achieved and the cultural security of the participating community be maintained (NHMRC, 2003).

2.6 Recommendations

> While the development of ethical guidelines – along with the exploration of models of consultative, empowering and culturally sensitive research – has brought about concrete, if limited, changes in research practice, it is all too easy for the broad health research community to exaggerate this transformation.
>
> (Humphrey, 2001, p. 201)

In line with Humphrey's sentiments in the above quote, careful attention is required for monitoring the improvements of Aboriginal health research practices. Gillam and Pyett (2003) suggest that 'loose' guidelines for conducting research are sufficient to maintaining cultural security. However, McKendrick and Bennett (2003) refute this with the claim that specific guidelines would force health researchers to be more accountable for their research conduct with Aboriginal people. In support of this opinion, Holmes et al. (2002) offer that in their study of urban Aboriginal youth, it was not so much the methodology of the study that was important to participants, rather it was the attitude with which researchers and project officers conducted the study that made a difference to participants. The development of a framework to assist in monitoring research practice, perhaps similar to the DRH guidelines, is required for a Western Australian context. Furthermore, as mentioned earlier, the criteria for WAAHIEC approval necessitates a more local and relevant framework for the demonstration of the NHMRC (2003) values in Western Australian Aboriginal health research.

2.7 Conclusion

The cultural identity of Aboriginal Australians was threatened by European colonisation and Aboriginal health has been compromised as a result. Poor research practices have in part contributed to the limited improvements in Aboriginal health over the last century. The needs of Aboriginal people individually and collectively as research or intervention participants clearly demands research conduct that is ethical. Cultural security is when the cultural rights, values and expectations of Aboriginal people who participate in health research remain intact. Maintaining cultural security is more than recognising the difference between Aboriginal and non-Aboriginal cultures, in health research it involves positive action through the celebration of the collective health and wellbeing of the 'whole' community.

The purpose of this literature review was to show that cultural security of Aboriginal health research participants can be maintained through the demonstration of the following Aboriginal values relevant to health research: reciprocity, respect, equality, responsibility, survival and protection and spirit and integrity (NHMRC, 2003; National Health and Medical Research Council, 2003). The NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* is the prominent Australia document that describes these values and how they can be applied in health research with Aboriginal people.

The literature review also supported that for the cultural security of Aboriginal health research participants to be maintained empowerment must occur at a community level in the form of - involvement, consultation and ownership within the research project. Trust is a crucial element to the integrity of a project. Health researchers must prove to the communities that they wish to work in such a way that they qualify for the trust invested by the community into the project. Ultimately, cultural respect must be the motivating force behind the development of a culturally secure health research project.

The literature used for this review provided an extensive history and argument supporting the need for a framework that informs ethical practices in Aboriginal health research and this is largely based on the NHMRC (2003) guidelines. However, the literature is lacking

in the number of studies that report the practical demonstration of the six values outlined in the NHMRC guidelines for ethical conduct in Aboriginal health research .

Chapter Three

Theoretical framework

The theoretical framework for this thesis project is summarised visually in Figure 2. The diagram was developed from sources used for the literature review of this thesis and illustrates the overall concept of the importance of the Aboriginal values relevant to health research in maintaining cultural security. Furthermore, this diagram uses a community development perspective in the form of a 'bottom-up' approach to justify collaboration and consultation in the development of a culturally secure ethics process (Ife, 2002). The ultimate outcome of the diagram is a health promotion intervention that is culturally secure and contributes to improving the overall health and wellbeing of an Aboriginal community.

As a descriptive research project, this thesis will not measure any specific variables and will only focus on the lower portion of the diagram found in Figure 2. Within the lower portion of Figure 2 the following can be found:

- cultural security;
- involvement, consultation and ownership;
- reciprocity, equality, survival and protection, spirit and integrity, responsibility, and respect (NHMRC, 2003);
- community identifies the health issue for the project; and
- consultation and guidance from the community prior to the commencement of the project.

The diagram follows Henderson et al.'s (2002) suggestion that a successful intervention is more likely to be achieved if the initiative for researching local health issues is generated and developed in collaboration with the community. In essence the diagram was designed to demonstrate the potential for positive health gains when Aboriginal people have a greater level of responsibility within research processes through involvement, consultation and ownership (Dressendorfer et al., 2005; Hecker, 1997; Ife, 2002). The bottom-up approach in Figure 2 recognises that consultation and guidance from the community prior to the commencement of the project is crucial to identifying the most appropriate health promotion intervention for local health issues (Hecker, 1997; Ife, 2002).

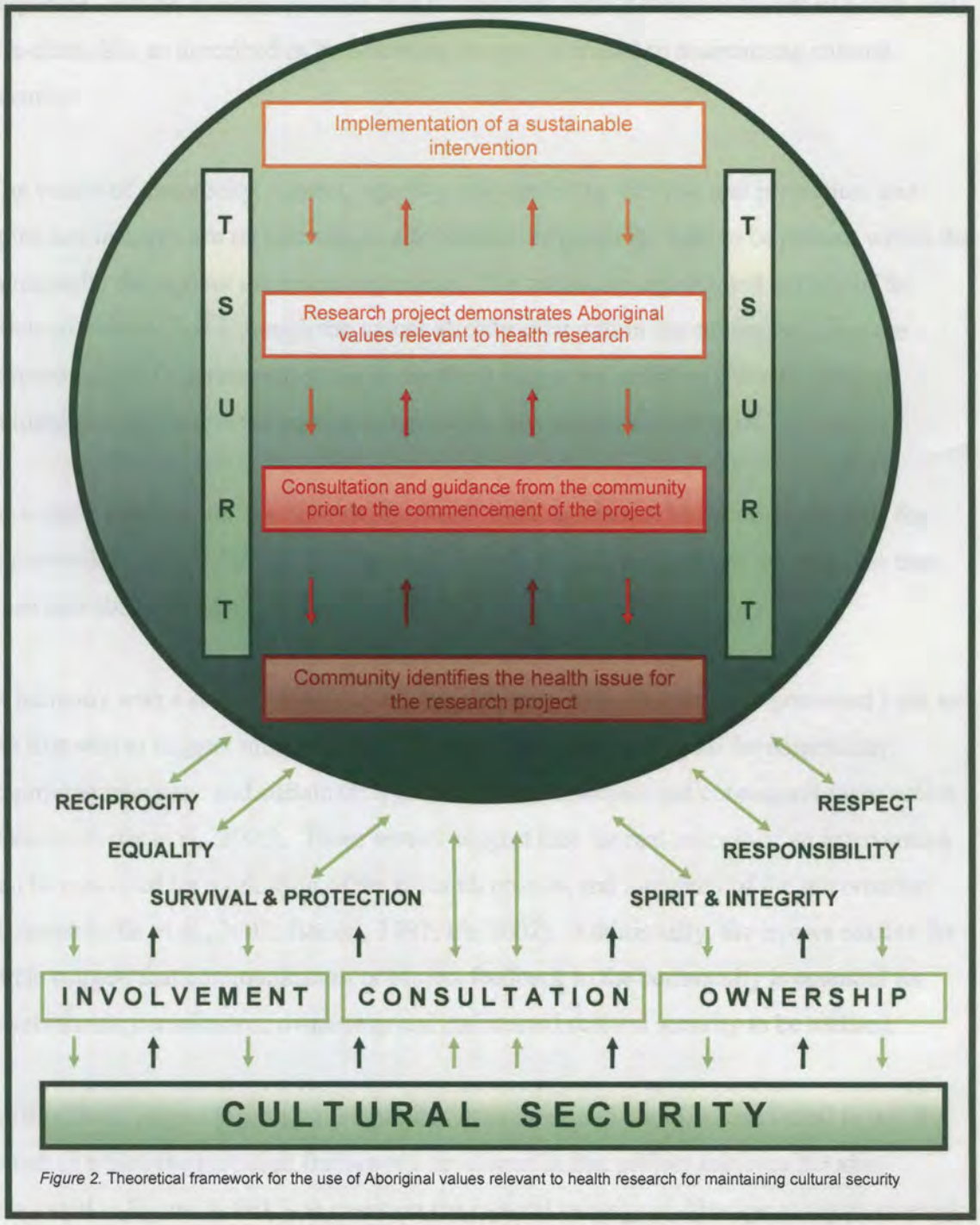

Figure 2. Theoretical framework for the use of Aboriginal values relevant to health research for maintaining cultural security

According to Ife, (2002) holism encompasses every act as an influence for the next act and this is likened to a ripple effect. Fundamentally, this ripple effect acknowledges the importance of small, seemingly insignificant acts, words or deeds and their potential for bringing about positive change (Ife, 2002). Within the visual representation of the theoretical framework for this thesis is a circle to illustrate a holistic perspective that can

create and maintain trust if Aboriginal values relevant to health research are actively respected. Hence, research practice that is consistent with Aboriginal values of health and life-death-life, as described in the literature review, is crucial to maintaining cultural security.

The values of reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity are represented as a foundation required for trust to be present within the community throughout the research process. The values are represented outside of the circle to indicate that although the values already exist within the community, it is the responsibility of the researchers to ensure these values are active in order to maintain cultural security within the participating community and to nurture trust.

At a quick glance at the framework, the word 'trust' appears to be misspelt however the framework is directional and the wording has been written to represent the path that trust must take for sustainable programs to occur.

In harmony with a socio-ecological concept, arrows within the circle are generated back to the first step to suggest multiple levels of action and interaction with the community, improving relevance and sustainability of the research project and consequent intervention (Dressendorfer et al., 2005). These arrows suggest that the real success of an intervention can be measured by replication of the research process and longevity of the intervention (Dressendorfer et al., 2005; Hecker, 1997; Ife, 2002). Additionally, the arrows outside the circle suggest that communication or project feedback to the community is essential for involvement, consultation, ownership and maintained cultural security to be realised.

As this thesis project is a formative project, future research could be conducted to test the extent to which the proposed framework developed in this project achieves the aims illustrated in Figure 2; that is to maintain the cultural security of Aboriginal health research participants and produce an intervention that contributes to health improvements for Aboriginal people.

Chapter Four

Method

The literature review and the theoretical framework of this thesis identify that:

- the cultural security of Aboriginal health research participants can be maintained through the demonstration of the following Aboriginal values relevant to health research: reciprocity, respect, equality, responsibility, survival and protection and spirit and integrity (NHMRC, 2003; National Health and Medical Research Council, 2003);
- the NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* is the prominent Australian document that describes these values and how they can be applied in health research with Aboriginal people; and
- the literature is lacking in studies that report on the practical demonstration of these six values for ethical conduct in Aboriginal health research.

Figure 3 provides an outline of the stages of this honours thesis. Gaps in the literature necessitated that practice informed evidence (eg: case studies) is needed to obtain examples of how the requirements for maintaining cultural security in Aboriginal child health research could be demonstrated. The proposed framework of examples was developed from the literature and the case studies and was then validated for its relevance for use in Western Australia (WA) by an expert panel. The expert panel was made up of: Aboriginal health workers; Aboriginal health policy officers; health researchers who are Aboriginal and non-Aboriginal; and health promotion officers who are Aboriginal and non-Aboriginal. This thesis provides a proposed framework that can be used to guide the ethics application for an Aboriginal bullying prevention and reduction project to be conducted by Edith Cowan University's (ECU) Child Health Promotion Research Unit (CHPRU) in the Midwest, Murchison region of WA.

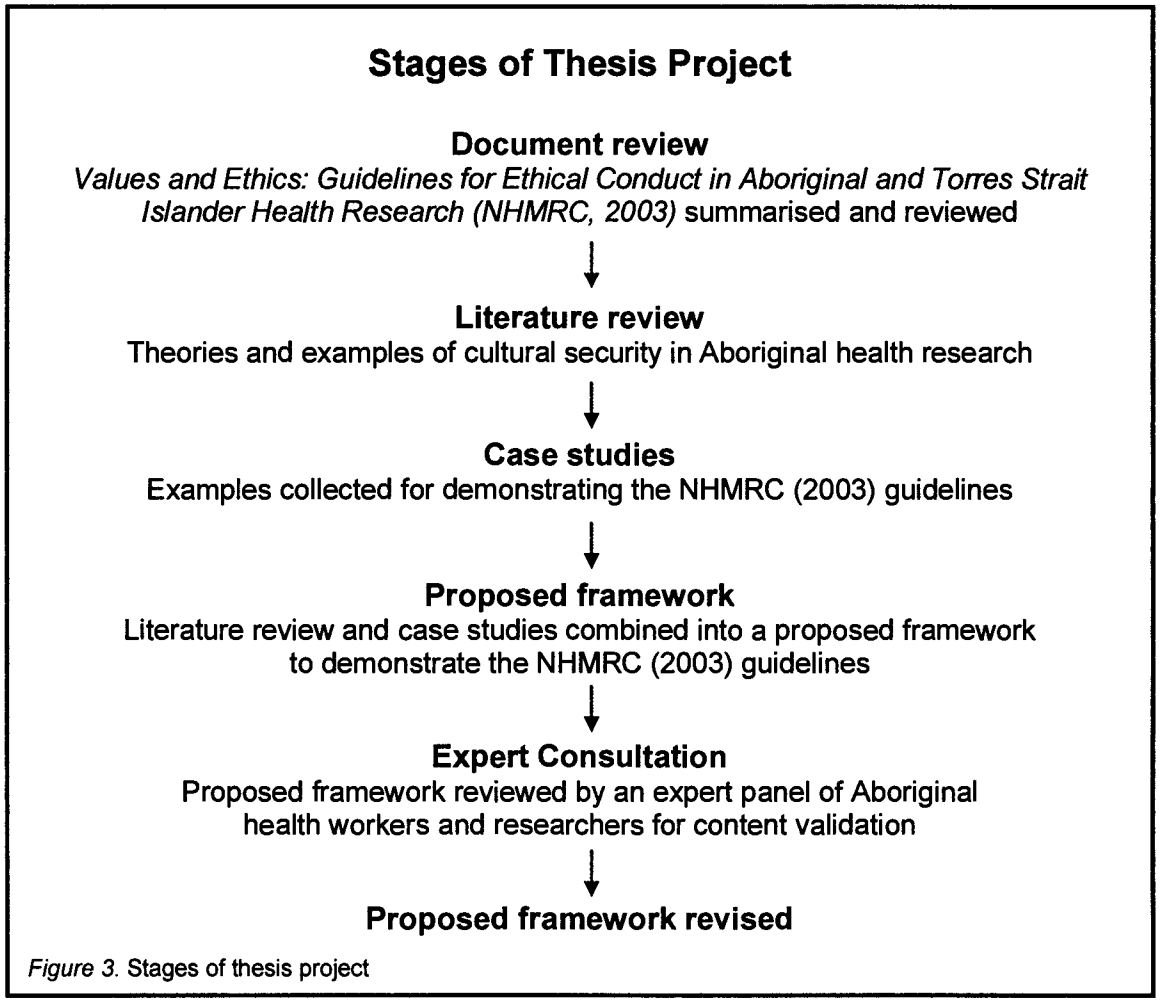

Figure 3. Stages of thesis project

4.1 Design

This thesis project is a descriptive study that aimed to describe attitudes and experiences of individuals in Aboriginal health regarding culturally secure ethical procedures and practices. The use of a descriptive study for this thesis was considered to be an efficient and economic method for gaining an insight into the most appropriate way to facilitate a collaborative ethics process with Aboriginal communities that participate in child health research in WA (Torrence, 1997). Additionally, a descriptive study provides a useful platform in providing justification for further study on the topic of this thesis project (Bowling, 2002; Torrence, 1997).

The literature review confirmed a need for a description of collaborative ethics processes for maintaining cultural security through the demonstration of Aboriginal values relevant to health research as defined by the NHMRC (2003). This finding suggested that it was necessary to collect case studies that represented practice informed evidence in order to establish current ethical procedures by Aboriginal health researchers. Based on what was identified in the literature and the creation of case studies, a proposed framework was developed as a guideline for researchers to ensure that Aboriginal values relevant to health research remain intact throughout the research process. This proposed framework was then presented to an expert panel for content validation; hence evidence collected during this project are cross-sectional data, as respondents report on their experience and knowledge at one point in time.

4.2 Sample

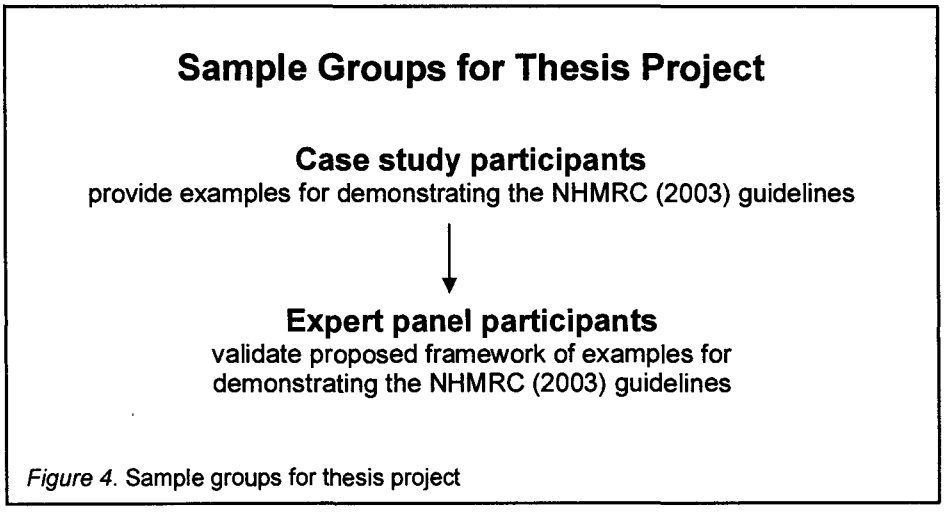

Figure 4. Sample groups for thesis project

Individuals were invited to participate in this project because their knowledge and/or experience in Aboriginal health, Aboriginal health promotion or Aboriginal health research were considered to be relevant to the topic of this thesis (Bowling, 2002). These participants were Aboriginal and non-Aboriginal men and women of different ages with varying levels of experience in Aboriginal health. Aboriginal participants were predominantly from the Nyoongar region of WA. Purposive sampling (Bowling, 2002) was used in this thesis project to obtain two case study participants and 19 expert panel participants. Further to the purposive sampling, the snowball sampling technique

(Bowling, 2002) was applied by asking initial participants to identify other individuals they felt had knowledge and/or experience relevant to Aboriginal health research and collaborative ethics processes. This technique was useful in gaining access into networks within the sample group that were unknown to the researcher. Therefore, the sample was made up of two groups; a case study group and an expert panel group.

4.2.1 Case studies

The case study participants were used to collect practical examples of how to demonstrate the Aboriginal values relevant to health research as determined by the NHMRC (2003) guidelines. Two experienced Aboriginal health researchers and health workers were identified and invited to talk about their experiences in demonstrating the values and principles relevant to Aboriginal health research (NHMRC, 2003). The case study participants had extensive experience in researching the health of Aboriginal school children and were identified by referral through: the Principal Investigator on the CHPRU Aboriginal bullying prevention and reduction project; and from the first case study participant. One participant had successfully met the ethics criteria set by the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC) in their research with Aboriginal children. The other participant worked on an Aboriginal child health project that commenced prior to the NHMRC (2003) guidelines and hence prior to the implementation of the current WAAHIEC criteria.

4.2.2 Expert panel

The expert panel was used to obtain content validation of the proposed framework that was developed from the literature review and the responses of case study participants. This panel was made up of prominent and experienced health promotion and health research professionals who commented on the proposed framework on the basis of their work with Aboriginal people in Western Australia. These participants were Aboriginal and non-Aboriginal men and women of different ages with varying levels of experience in Aboriginal health.

An informal list of potential expert panel participants was made by the student researcher with assistance from an experienced researcher on the CHPRU Aboriginal bullying

prevention and reduction project. The expert panel participants were from various regions throughout WA and were able to provide a general perspective as to whether the proposed framework would:

1. maintain the cultural security of participants in an Aboriginal child health research project; and
2. demonstrate the values and principles outlined in the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC, 2003).

An expert panel was considered to be a useful platform for drawing on current knowledge that strengthens information obtained from the literature review and the case studies (Delbecq, Van de Ven, & Gustafon, 1986). Obtaining opinions from individuals who were anonymous to each other enabled independent participation from all panel members (Goodman, 1987; Gupta & Clarke, 1996; Stahl & Stahl, 1991; Sumsion, 1998; Williams & Webb, 1994). The expert panel formed for this project consisted of individuals with a high level of knowledge and experience in Aboriginal health promotion and as such qualified as panel members (Delbecq et al., 1986; Stahl & Stahl, 1991).

4.3 Setting

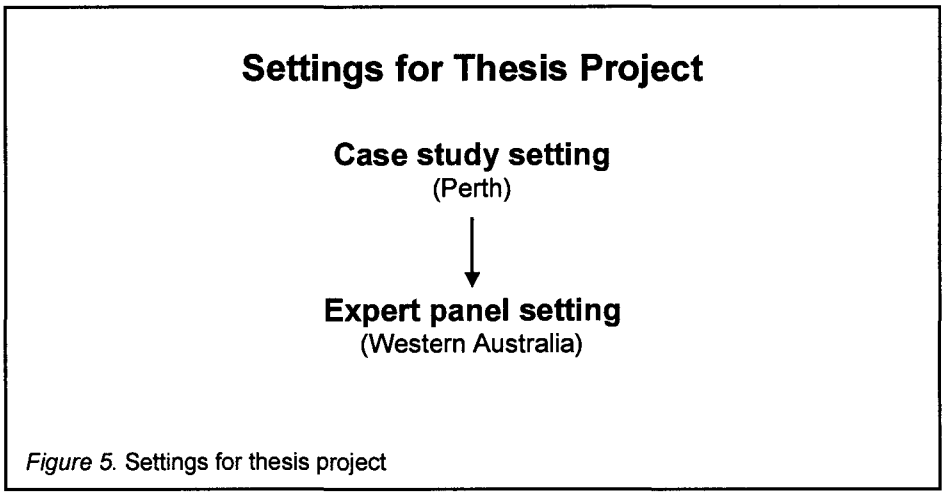

Figure 5. Settings for thesis project

The primary setting for this thesis was the Perth metropolitan area where case study participants are located. The secondary setting included various regions throughout WA;

this was determined by the geographical location of employment for the expert panel participants.

4.4 Instrument

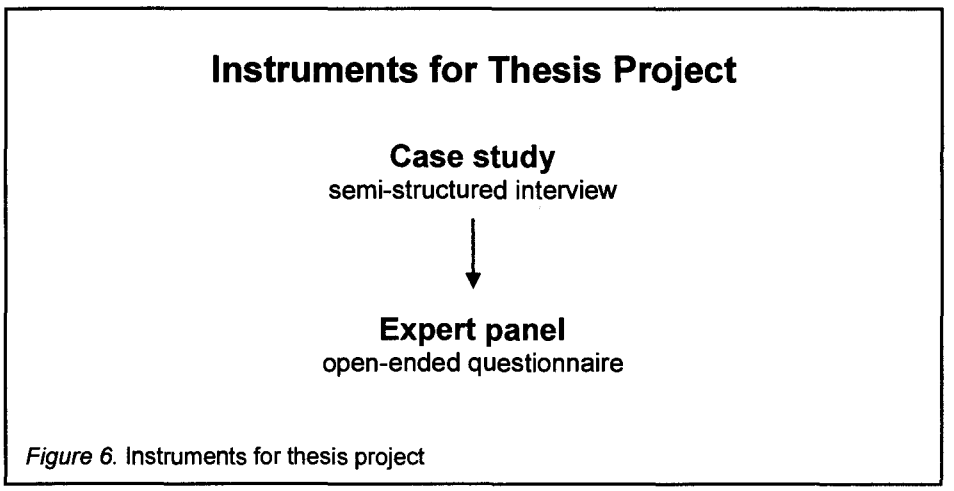

Figure 6. Instruments for thesis project

Two instruments were used for data collection in this descriptive research project: an open ended-interview for case study participants; and a semi-structured questionnaire for expert panel participants.

4.4.1 Case study instrument

The objectives of the case study instrument were to identify what Aboriginal health researchers do to demonstrate the values of: **reciprocity, respect, equality, responsibility, survival and protection** and **spirit and integrity** (NHMRC, 2003) in their health research projects with Aboriginal children in Western Australia.

The case study instrument was a semi-structured interview (Appendix 1). This instrument was derived from the research questions and the current ethics guidelines for researching Aboriginal and Torres Strait Islander people and was categorised into the value themes identified above (NHMRC, 2003). Descriptions of these values and their correlating principles were taken directly from the NHMRC (2003) guideline document. The case study instrument was administered in a face-to-face interview to two Aboriginal researchers with varying experience in Aboriginal child health research. Questions were

open-ended and one participant allowed audio recording to capture more detailed qualitative content of the interview. The responses obtained from these interviews were used to create the case studies as presented in Chapter Five.

4.4.2 Expert panel instrument

A proposed framework to identify how the Aboriginal values relevant to health research (NHMRC, 2003) could be demonstrated when conducting health research that targets Aboriginal school children in WA was developed by using:

- the NHMRC (2003) guidelines for ethical Aboriginal health research;
- a comprehensive literature review; and
- two case studies developed for this project.

The objectives for the expert panel instrument were to determine if the examples in the proposed framework would:

1. maintain the cultural security of participants in an Aboriginal child health research project; and
2. demonstrate the values and principles outlined in the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC, 2003).

The expert panel instrument was a open-ended questionnaire (Appendix 2) organised into two parts. **Part A** contained the proposed framework of 29 generic examples for how the values could be demonstrated (presented in green font in Appendix 2) with supporting references from the literature review and the case studies. **Part A** also included specific examples (presented in blue font in Appendix 2) from the case studies for the demonstration of the Aboriginal values relevant to health research as set out by the NHMRC (2003) guidelines.

In **Part B**, the NHMRC (2003) guidelines were used again to inform the thematic structure of the questionnaire. The NHMRC (2003) Aboriginal values and principles relevant to health research were paraphrased (presented in black font in Appendix 2) throughout the questionnaire. The generic examples (presented in green font in Appendix 2) presented in

Part A were matched to the NHMRC (2003) values and principles then re-presented in **Part B**. With the repetition of the 29 examples across the values and principles, **Part B** contained 87 items. In total, the questionnaire was made up of 116 items.

A Likert scale was used on the questionnaire for participants to indicate their level of agreement with the proposed framework in demonstrating the above objectives within a Western Australian context. This questionnaire was a self administered survey to allow participants privacy and time to complete the questionnaire. Responses to the questionnaire were used to revise the proposed framework developed for maintaining cultural security and demonstrating the Aboriginal values relevant to health research (NHMRC, 2003).

4.4.3 Instrument validity

Content validity of both instruments was supported by the principles of the Aboriginal values relevant to health research as set out by NHMRC (2003) and by the WAAHIEC application form for ethical approval to conduct Aboriginal health research in WA. Face and content validity of the expert panel instrument were further assessed by pilot testing the instrument on two experienced researchers. Minor changes were made to the expert panel instrument after pilot testing.

4.5 Procedures

This project was conducted using the following research procedures.

4.5.1 Recruitment of case study participants

Five participants were approached to provide case study data and were initially contacted by the student's supervisors to confirm willingness to participate in this thesis project. Following approval of the case study instrument and procedures by the ECU Ethics Sub-Committee, the research student contacted two participants by telephone and email to organise interview times. The participants were mailed confirmation information comprising the information letter and consent form (Appendix 3) with a copy of the questionnaire (Appendix 1).

4.5.2 Administration of case study questionnaire

Both face-to-face interviews with case study participants were conducted by the research student. The interviews were conducted at the interviewees' work places. With participant permission, audio recording of the interview was used to capture the qualitative detail that emerged from a semi-structured questionnaire for Interview A. The questionnaire was made up of 38 questions and each interview took approximately one and a half hours.

4.5.3 Case study descriptions

Information obtained from each respondent was compiled into transcripts (Appendix 4; Appendix 5) using: interview notes, audio recordings, and supporting documents. These supporting documents were the *Ethics Application* for the Success, Resilience and Wellbeing Project in Case Study 1; and the *Communication Strategy for the Western Australian Aboriginal Child Health Survey* (Kulunga Research Network & Telethon Institute for Child Health Research, no date) for Case Study 2. Both documents related to the research projects discussed by the respondents in their interviews.

A thematic analysis was then conducted for each transcript (Butler, 1993; Wong, 1993). This involved an examination of the transcripts to create a case study for each respondent. Participant comments were organised according to respondents' opinions or experience for how researchers of Aboriginal children's health can demonstrate: Reciprocity; Respect; Equality; Survival and Protection; Responsibility; and Sprit and Integrity. In essence the case studies for this thesis are refined transcripts and are presented in Chapter Five with the NHMRC (2003) values and principles. The use of two subjective case studies were considered the most appropriate method for retelling the stories contained in the interview transcripts (Appendix 4; Appendix 5).

Pre-testing of the case study instrument was conducted with an experienced researcher in the area of child health and modifications were made accordingly (Silverman, 1993). Both questionnaires were administered by the same interviewer to reduce inter-rater differences (Silverman, 1993).

4.5.4 Development of proposed framework

Themes within the case studies were coded and matched to the NHMRC (2003) guidelines. The thematic analysis of the case study transcripts revealed that ethical procedures employed by the Aboriginal health researchers who participated in the case study interviews were consistent with the recommendations of the literature and with the NHMRC (2003) guidelines. The literature review and the case studies were then combined to create general examples for demonstrating the Aboriginal values and principles relevant to health research (NHMRC, 2003). This process required several in-depth analyses of the interview transcripts, the literature and the NHMRC (2003) guidelines to produce several iterations of the proposed framework before the final version was achieved. This process of development and review ensured that all the values and principles were represented and that the examples could be easily understood and applied.

The outcome of this process was the development of a proposed framework (as found in Table 1 on page 74) to facilitate a collaborative ethics process for maintaining the cultural security of participants in Aboriginal child health research projects and to demonstrate the six Aboriginal values relevant to health research (NHMRC, 2003). The presentation of this information in a concise and clear manner was considered to be an important characteristic of the proposed framework. It was not the researcher's intention to replicate the NHMRC (2003) guidelines; rather, as stated in the sub-questions of this thesis project, the aim of the proposed framework was to provide examples of how the NHMRC (2003) values could be demonstrated in Aboriginal child health research in Western Australia.

4.5.5 Pilot testing

Upon ethics approval (see 4.6 *Ethics*) pilot testing of the expert panel instrument was conducted with two researchers who have considerable experience in child health and/or Indigenous research. Feedback from these participants required limited amendments. Once the recommended changes had been actioned the questionnaire was ready for administration to the expert panel.

4.5.6 Recruitment of Expert Panel

The student researcher compiled an informal list of potential expert panel participants that had been identified by case study participants and investigators on the CHPRU Aboriginal bullying prevention and reduction project. The potential expert panel participants were identified as key stakeholders or individuals with experience in Aboriginal child health research and/or practice. Expert panel participants were initially contacted by the student researcher's supervisor (Appendix 6). Immediately after telephone contact was attempted follow-up emails (Appendix 7) were sent to potential participants with the information letter and consent form (Appendix 8) and the questionnaire (Appendix 2) attached. In addition to this, hard copies of these documents were mailed or hand delivered to these participants.

The student researcher also attended the Aboriginal Health Promotion Conference in Fremantle, WA. At the Conference six more participants who met the criteria for inclusion in the expert consultation were recruited through networking. Four participants were given hard copies of the information letter, consent form and questionnaire and two participants were sent electronic copies. Further to this, all except one of the participants who received a hard copy was also sent electronic copies the next day. In total, 20 people were invited to be involved in this project as expert panel participants. One person refused due to time constraints.

4.5.7 Administration of the expert panel questionnaire

Participants were asked to individually complete and return (in the reply-paid envelope provided or by email) the questionnaire within five working days. Hard copies included two reply-paid envelopes: one for the consent form and one for the questionnaire. On receipt of completed forms, consent forms for participation in the survey were filed in a separate envelope to the completed questionnaires to ensure confidentiality. Both the questionnaire and consent forms were stored in a lockable cabinet at all times for data security. A follow-up email (Appendix 9) was sent three working days after the requested due date on the questionnaire as a final request for participation in this project.

4.5.8 Data analysis of the expert panel questionnaire

Data were de-identified by allocating code numbers to completed questionnaires. Data were then entered into SPSS Inc (2004) to tabulate group opinion on whether the proposed framework maintained cultural security and demonstrated the Aboriginal values and principles relevant to health research (NHMRC, 2003). A Likert scale was used on the questionnaire for participants to indicate their level of agreement to each item.

Two forms of agreement were sought from expert panel responses; the extent to which respondents agreed with each item (mean) and the extent to which respondents agreed with each other (standard deviation and percentage positive) for each item, or consensus (Jones & Hunter, 1995). The mean was used to assess the level of agreement with each item because for the majority of items there were no extreme values (Munro, 2001). While the median would have been a more appropriate measure of central tendency for eight items with extreme values (Munro, 2001), for consistency the mean and standard deviation (SD) were calculated for all 116 items.

Consensus between panel members was assessed in two ways. Firstly, the SD of the mean level of agreement with each item is presented. A greater SD is an indication of polar views by expert panel members. For the purpose of this project, an item with a SD of one or less indicates a good level of consensus among panel members. Secondly, the percentage of respondents agreeing (percentage positive) with the items also gives an indication of consensus and demonstration of polar views among panel members. For the purpose of this project, an item with a percentage positive of 71.4 or more indicates a good level of consensus among panel members.

Additionally, a thematic analysis was also conducted to identify common words and themes if participants chose to comment on any of the 116 items within the questionnaire.

4.5.9 Participant feedback

At the completion of this thesis project and in line with the literature review, all respondents were sent an acknowledgement letter (Appendix 10) for their contribution to this project and a copy of the revised framework (Appendix 11) for maintaining cultural security and demonstrating the Aboriginal values for health research (NHMRC, 2003).

Expert panel contributions to framework changes were identified in **bold** text (Appendix 11). Panel members were also forwarded a copy of the group opinion (Appendix 12) and respondent comments (Appendix 13) from the expert panel on the proposed framework.

4.6 Ethics

Ethical approval to conduct this thesis project was sought from the ECU Ethics Sub-Committee. Both case study participants and expert panel participants received an information letter (Appendix 3; Appendix 8) that described the project and what their involvement would require, prior to being asked to complete the consent form (Appendix 3; Appendix 8). Consent forms accompanied the information letter. Upon receipt of a signed and dated consent form it was immediately placed in a separate envelope for de-identification. At the completion of data analyses all audio tapes were destroyed. The participant questionnaires are stored in a lockable cabinet at the CHPRU for a minimum of five years, according to NHMRC requirements. Electronic data are protected by password. The research student and her supervisors are the only people with access to these data.

Chapter Five

Results

This Chapter presents the results of this descriptive study. The first section presents interview data collected to inform case studies that provide examples of how the values relevant to Aboriginal health research (NHMRC, 2003) can be demonstrated. The second section presents the proposed framework developed by matching the literature review and the case studies to the Aboriginal values and principles relevant to health research (NHMRC, 2003). The final section presents the results of content validation of the proposed framework by an expert panel.

5.1 Case Studies

Case studies were developed to inform a proposed framework for a collaborative ethics process that maintains the cultural security of Aboriginal health research participants in Western Australia. Two case studies are presented which describe how two Aboriginal child health research projects have demonstrated or will demonstrate the values of: **reciprocity, respect, equality, responsibility, survival and protection** and **spirit and integrity**. Each case study is based on interview responses from these Aboriginal researchers and supporting documents developed by their respective project.

5.1.1 Case study 1

Background

The Principal Investigator of the proposed *Success, Resilience and Wellbeing Project* (SRWP) participated in a face-to-face interview to discuss how her project would conduct culturally secure Aboriginal child health research through the demonstration of the values relevant to Aboriginal health research as established by the NHMRC (2003). The proposed SRWP will be conducted with the aim of exploring the needs of Aboriginal people in regards to their emotional and social wellbeing. Data collected from this project will then be used in the development of a training and education program to assist Aboriginal young people, aged 10-18 years, who require a support infrastructure to assist them to achieve life goals.

Italics are used in this case study to indicate direct quotes from the respondent's interview; as such the majority of this first case study is presented to read in the first person. Bolding has been used in this case study to highlight phrases and words that are key themes for demonstrating the Aboriginal values and principles relevant to health research (NHMRC, 2003); these phrases and words were then used to develop the proposed framework examples found in Table 1 (page 76). The correlating principles (NHMRC, 2003) for each of the Aboriginal values relevant to health research can be found in the boxes before the case study dialogue.

Demonstrating the value of Reciprocity

The case study interview used the following definition of Reciprocity. "In the research context, reciprocity implies inclusion and means **recognising partners' contributions**, and ensuring that **research outcomes include equitable benefits** to **Aboriginal** and Torres Strait Islander **communities or individuals**" (NHMRC, 2003, p. 10). At the time of the interview it was anticipated by this respondent that the value of Reciprocity would be demonstrated throughout the SRWP in the following ways:

1. "**Intent to contribute** to the advancement of the health and wellbeing of participants and communities" (NHMRC, 2003, p. 11).
2. "**Clear links to** community **health priorities** that **respond to existing or emerging needs** as articulated by Aboriginal people" (NHMRC, 2003, p. 11).

The whole point of doing ... [my] project is to find out what enables Aboriginal people to become successful in their chosen field ... I [also] *went back to the **national strategic framework for ATSI health**, I went back to* [the priorities] *...designated by the health department and my work fits in there.*

3. "**Evidence of clear and truthful discussions** about the **nature of benefits for participants** or other Aboriginal communities **prior to approval**" (NHMRC, 2003, p. 11).

I've ... [organised] *a **matrix** of all the groups that I think I'm going to talk to...* [and using] *a contact list... [I'll be able to check] where I'm at with those people, and whether or not I've got the right person* [and if not] *who is the next best person? ...* [Using the matrix I can inform the community what they're going to get out of participating in my project and] *where the benefits come into it.*

4. "**Willingness to modify research** in accordance with participating **community values and aspirations**" (NHMRC, 2003, p. 11).

A number of opportunities will exist [to ensure that the project remains in harmony with community values and aspirations] *like during community meetings* [and through] *phone calls and emails ...* ***all those communication levels*** **[will be kept]** ***open.***

5. "**Enhances the capacity of communities to draw benefit beyond the project** through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level" (NHMRC, 2003, p. 11).

[Its also worth recognising that benefits from participating will continue for the community] ***beyond the life of my project*** *because* [it will develop a] ... *training and education project* [for] *Aboriginal kids 10-18 years of age.* [And regarding] ***building the capacity on the project – you ... look for larger pockets of money where you can employ Aboriginal people on a longer basis in their community, so you're building their capacity.***

Demonstrating the value of Respect

The case study interview used the following definition of Respect. "Respectful research relationships acknowledge and **affirm the right of people to have different values, norms and aspirations**. Those involved in research processes should not be blind to difference" (NHMRC, 2003, p. 11). At the time of the interview it was anticipated by this respondent that the value of Respect would be demonstrated throughout the SRWP in the following ways:

1. "The project **responds to the diversity of Aboriginal** people and their communities, including the way decisions are made" (NHMRC, 2003, p. 12).

Diversity is not **[putting]** ***us in one group and saying 'Aboriginal' all the time.*** [In] *all of my papers* [I] *always have the word 'urban' on it ...* [because I'm] *biased to that group, and that's my mob ...* [This is acknowledged in my work because the] ***generalisations and limitations ...*** [are] *conveniently located in all publications so all readers are aware ...* [that the] *results* [are] *specific for that unique group.*

And ... when it says 'the way decisions are made', here ***in Perth because we've got so many different groups of people we ... call a community panel together. But in those smaller groups you might have two or three elders ...*** *In a remote community its different you probably have one or two there and they're the only people you ever speak to.*

2. **Acknowledgement** of the individual and collective **contribution** of the community to the research project (NHMRC, 2003, p. 13).

[Acknowledgement of individual and collective contribution to the project] *is done by consulting not only with participants but also groups who work with any Aboriginal network* ***that individuals not only speak for themselves but have the capacity and knowledge to represent their respective communities.*** [For] *example it is* ***the intention to ensure that individuals are personally invited to engage in open*** **[discussions]** ... *So they've got a right to say what they think about things for themselves and their family but that they can also talk for their community.*

3. The researchers **minimise the effects of difference blindness** on and in the research process" (NHMRC, 2003, p. 13).

[To minimise the effects of difference blindness] ***local community consultants will be consulted to:*** *access potential participants; to translate results for the publication of findings; and to* [confirm the] *appropriateness and use of the tool that is developed.*

4. "The project engages with **Aboriginal knowledge and experience**" (NHMRC, 2003, p. 13).

[Aboriginal knowledge and experience will be engaged through] *direct verbal communication ...* ***time*** [will also be] ***allocated for open communication about: methods; results; using findings; dissemination of results.*** [This is] *all done on a* ***regular, open and vital basis.*** [Furthermore], ***an agreement*** [will be] ***developed during regular communication*** [with the community to ensure that the project is conducted] ***in line with community protocols*** [that] ***sustain equality in Aboriginal participation.***

5. **"Appropriate agreements** have been **negotiated** about **ownership** and **rights of access to** Aboriginal **intellectual and cultural property**" (NHMRC, 2003, p. 13).

8. "Agreement with participating communities all relevant issues including **management of data, publication arrangements** and **the protection of individual and community identity**" (NHMRC, 2003, p. 13).

I'm actually going to devise a ***statement of cultural consent and participation ... in consultation with my community*** **[management]** ***group.*** *We're actually going to discuss and write up an agreement ...* ***about the ownership of the knowledge gained, like who owns that ... authorship ...*** [and] *the potential* [for] ***commercialisation.***

6. "The **processes of reaching agreement** demonstrate engagement with the **values** of the participating communities" (NHMRC, 2003, p. 13).

[With my management group] *I'm going to try for about 10* [members] *and hopefully get 7* [members] *and then it will go down to about five ... Group agreements will be made in a group statement and those statements are going to be recorded. They have to be recorded and the process by which we actually came to that, whether or not we all put our hands up, whether or not we went with the majority ...* [In my previous research,] ***these*** **[meetings]**

were facilitated in **[a]** ***non-threatening, commonly shared space... a common spot and preferably either outdoors or somewhere, where its, its home.*** [This helped to demonstrate that] ... *we weren't biased towards one group or another group, or another person* [based on where we held the meeting].

7. "Whether the participating communities have **expressed satisfaction** with the research agreement and decision making processes" (NHMRC, 2003, p. 13).

[To allow community members an opportunity to express their satisfaction with the agreement and the decision making process] *I'm actually going to have a* ***'time of reflection'.*** *I've actually called it that so that ... people can assess their satisfaction for the* [agreement and the decision making] *processes* [for the project] ... *in that meeting; whether it was 'no one had a say' or 'it was too rushed' or ... 'they weren't happy' and its all recorded – scribed in a journal ...* ***The processes have to be done separately because that goes back into your report ... It has to be reported back to the community.***

Demonstrating the value of Equality

The case study interview used the following definition of Equality. "Equality as a value may sometimes be taken to mean sameness. However, Aboriginal and Torres Strait Islander Peoples hold a strong belief that **sameness is not equality**. Aboriginal and Torres Strait Islander peoples have sought the **elimination of 'difference blindness'** so that **Aboriginal** and Torres Strait Islander **cultures can be appreciated and respected**" (NHMRC, 2003, p. 14). At the time of the interview it was anticipated by this respondent that the value of Equality would be demonstrated throughout the SRWP in the following ways:

1. "Participating **communities are included** in the research processes with equality" (NHMRC, 2003, p. 15).

[In my work I demonstrate equality by making sure that] ***genders are going to be equally represented*** *and ...* ***age ranges*** [also]. [In my proposal] ... *I've explained that in this particular project the achievement domains* [e.g. sport, music, media, academic, and politics] *are ... going to be represented.* [I've been] ***really specific*** [about equal representation of]: ***region, schools, government/non-government, Catholic, Aboriginal run schools.***

2. "The research agreements have the strength necessary to sustain equality" (NHMRC, 2003, p. 15).

[In regards to sustaining equality, well] *that's where I spoke* ***about that journal of the research processes – ... to ensure that equality with the decisions and the processes are recorded and who actually made that happen.***

3. "Participating communities have **understood and expressed satisfaction** with the proposed research, its potential benefits and their distribution. Researchers therefore have **responsibility** to ensure that the **information** that they provide is **understood and usable** in decision making by participating communities" (NHMRC, 2003, p. 15).

[To make sure that the community has understood and is satisfied with the proposed project,] ***at that first meeting I have to consult*** **[with]** ***the community as well as the potential participants and their carers,*** *all that is going to be laid on the line.* ***With the consent form*** **[and]** ***the information sheet*** [its important that] *we go through the information sheet, one by [one] ...*

I [also] *came up with a* ***results dissemination plan ...*** *so that* ***when we have our community consultations we can go point by point through it and say, "Is this the right way to do this?" But I came up with something, so that I don't go*** **[into the meeting]** ***blank ... but*** **[the results dissemination plan]** ***hasn't been ratified by the community I just did that to show that I know what I'm talking about.***

Demonstrating the value of Responsibility

The case study interview used the following definition of Responsibility. "A key responsibility within this framework is to **do no harm**, including **avoiding having an adverse impact** on others' abilities to comply with their responsibilities. Researchers and participating communities needs to establish processes to ensure **researchers' accountability** to individuals, families and communities particularly **in relation to the cultural and social dimensions** of Aboriginal and Torres Strait Islander life" (NHMRC, 2003, p. 16). At the time of the interview it was anticipated by this respondent that the value of Responsibility would be demonstrated throughout the SRWP in the following ways:

1. "Measures are identified to demonstrate **transparency in the exchange of ideas** and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research" (NMHRC, 2003, p. 17).

[To demonstrate transparency in the exchange of ideas about the project with the community] ***everything is going to be written down, any communication... like if I do an email or a phone call, it all has to be communicated, it has to be written down.*** *Not of what people have said,* [but] *if its to change a research process, then* [it is] *taken ... to the community consultation group and* [talked] *about ...* [in order to] *come up with* [new] *decisions,* [its] *all recorded.*

2. "Provision is made for appropriate **ongoing advice and review** from the participating community, including mechanisms to **monitor ethics standards** and to minimise the likelihood of any unintended consequences arising from or after the research project " (NMHRC, 2003, p. 17).

[Ongoing advice and review with the community will be facilitated through] ... *monthly reviews ...* ***any problems or issues that occur during the research process, any bits of preliminary data, or something exciting, or something not exciting or feedback from that data ... progress reports of any research outputs ... just so that people are informed.*** [Monthly reviews/newsletters will] *have pictures in it, it will be official and it will have words; and* ***on coloured paper, so it stands out.***

3. **"Timely feedback** obligations to communities and whether that feedback is **relevant to the expressed concerns, values** and **expectations** of research participants and communities" (NMHRC, 2003, p. 17).

Feedback will always be given during community meetings about research processes, expected and realised outcomes, deadlines and concerns. *A written review is going to be done at the conclusion of the project as well.* [This will be] *an overall evaluation of the things that I have spoken about, so that everybody's up to date on everything.*

4. "Agreed arrangements regarding publication of the research results, including **clear provisions relating to joint sign off for publication** and the **protection of individual and community identity** if appropriate" (NMHRC, 2003, p. 17).

5. "Clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it" (NMHRC, 2003, p. 17).

Decisions [made] *in ... those community meetings ... [are] negotiated ... You would* ***negotiate how to do*** **[everything]** ***with the community; ... getting participants ... confidentiality, ownership and rights ... how data is collected, how its published, who manages it, who stores it ... So, let the community take responsibility for that as well in negotiation.***

Demonstrating the value of Survival and Protection

The case study interview used the following definition of Survival and Protection. "Aboriginal and Torres Strait Islander Peoples continue to act to **protect their cultures and identity from erosion by colonisation** and marginalisation. A particular feature of Aboriginal and Torres Strait Islander cultures and these efforts has been the importance of a **collective identity**. This collective bond reflects and draws strength from the values base of Aboriginal and Torres Strait Islander Peoples and cultures" (NHMRC, 2003, p. 18). At the time of the interview it was anticipated

by this respondent that the value of Survival and Protection would be demonstrated throughout the SRWP in the following ways:

1. "Whether the project contributes to or erodes the **social and cultural bonds** among and between Aboriginal families and communities" (NHMRC, 2003, p. 19).

[To ensure that the project contributes to the social and cultural bonds of the participating community,] *we've got a heap of people involved ...* ***children, youth, elderly, men and women, and they'll be working together to give up information with the aim of strengthening our community*** ... [We're] ***getting people to come together from all walks of life, of all ages for a specific problem across the board, across all communities ...*** *then there's that* ***exchange of information ...*** *and* ***its not passive either, its very active, direct feedback.***

2. "What **safeguards** are in place against the research project contributing to discrimination or derision of Aboriginal culture" (NHMRC, 2003, p. 19).

[One way safeguards can be put in place against discrimination or derision of the community's culture] *is to* ***explicitly detail and define the project objectives and the findings in relationship to the characteristics of the people*** *... that we had as participants. So that* ***at all times, in all the publications ...*** **[and]** ***presentations it has to be strictly adhered to that this information works for this*** **[particular]** ***group of people.***

3. "Whether the proposal **respects the intrinsic values, expectations** and identity of Aboriginal communities including the **balance** between **collective and individual identity**" (NHMRC, 2003, p. 19).

[Furthermore], ***collective and individual identity are acknowledged in ... my proposal because my methods/tools*** **[aim]** ***to discover both those constructs ...*** **[For example, asking participants],** ***"If this is going to work for you ... how is it going to work for all the Yamatji people?"***

4. "How the proposal **contributes to** the opportunity for **Aboriginal** peoples' ability to enjoy their **cultural distinctiveness**" (NHMRC, 2003, p. 19).

For me [participants] *maintain their cultural uniqueness and sameness ...* ***in a safe and non-threatening environment that's the first and foremost thing.*** [And that's done by] ... ***ensuring that the researchers are Aboriginal themselves, the ones that collect data anyway, and they're professionally trained, they might be Aboriginal but they have to be trained to do it ...*** *so that people can participate and enjoy their cultural distinctiveness without any fear or anything.*

5. **"Elimination of threats** to Aboriginal ability to enjoy their cultural distinctiveness" (NHMRC, 2003, p. 19).

[One strategy that has been identified to eliminate any threats to the cultural distinctiveness of the community is the reporting of grievances]. ***Grievances will be reported to the Western Australian Aboriginal Health and Information Ethics Committee ...*** **[and]** ***all those complaints will have to be listed in the final review of the report itself.*** [Researchers will] ***ensure that the community, participants – kids and carers ... know that that avenue is available;*** **[and]** ***it has to be told up front, in the consent form ...*** [Its important that this grievance process is] ***always reinforced*** [throughout the project].

Demonstrating the value of Spirit and Integrity

The case study interview used the following definition of Spirit and Integrity. "This is an **overarching value that binds all others** into a coherent whole. It has two components. The first is about the **continuity between past, current and future** generations. The second is about behaviour, which maintains the **coherence of Aboriginal** and Torres Strait Islander **values and cultures**. Any behaviour that diminishes any of the previous five values could not be described as having integrity (NHMRC, 2003, p. 19). At the time of the interview it was anticipated by this respondent that the value of Spirit and Integrity would be demonstrated throughout the SRWP in the following ways:

1. How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's **cultural, spiritual and social cohesion**, including workable timeframes (NHMRC, 2003, p. 20).

I [have an understanding of the community's cultural, spiritual cohesion because I'm] ***utilising previous research and professional experiences with Aboriginal, urban Aboriginal people in local communities ... my previous experiences have told me that.*** [Additionally], ***consultation with other Aboriginal people*** *will also guide that process to ensure the partnership.*

2. Whether the proposal recognises in the conduct and reporting of research the **diversity of Australian Aboriginal** culture including the **mechanisms through which communities may make decisions** (NHMRC, 2003, p. 20).

[Responding to the diversity of the community's culture will be demonstrated because] ***all the results, particularly ... the translation*** **[of the results will be specific to the participating community] ...** *Everything* [will] *be written in such a way that the cultural diversity* [of the community is] *... recognised.*

3. Whether the proponents of the proposal are able to clearly demonstrate **personal integrity**, specifically in the development of their proposal (NHMRC, 2003, p. 20).

[The motivating force behind the integrity of those involved in my project] *is* [the] *intent for new knowledge ... basically, that's what's driving it and to capture authentic and valid information.* ***Aboriginal people must be included as participants and community consultants, so the integrity is always there.***

4. Does the proposal **demonstrate a commitment** to working within the spirit and integrity of Aboriginal people? (NHMRC, 2003, p. 20)

[Finally, a commitment to the spirit and integrity of the community will be demonstrated because] *the* ***aims and objectives will be explicitly and continually discussed with the research participants and the community and it will remain flexible to the spirit, needs and aspirations of Aboriginal people.***

Other suggestions for demonstrating the values (NHMRC, 2003)

Within each value the case study instrument (Appendix 1) asked respondents, "What else can you suggest to demonstrate these principles when conducting Aboriginal child health research?" This additional information provided by the respondent for this question can be found within the interview transcript (Appendix 4). Although these suggestions were not direct responses to demonstrating the Aboriginal values and principles for health research (NHMRC, 2003) they were considered to be relevant to the aims and objectives of this project. The additional suggestions by this respondent have been categorised into the following themes:

1. informing participants and obtaining consent;
2. recruitment of participants;
3. administration of the instrument; and
4. community feedback.

1. Informing participants and obtaining consent

A lot of our people have diabetes and they can't read so the font needs to be larger [on] ***the consent forms,*** [for example] ... *We don't just hand them out ... we do a general presentation of everything and* ***we might sit one on one or in pairs together, and go through it.*** *The thing is a lot of these families have been through this process so many times, they're over researched.*

And when it comes to photographs and video tapes *... we have to actually do a box where* ***we have to allow them to make a choice*** [on their level of recorded involvement. For

example, if they choose to participate in the project whether they want to be audio, video or photographically recorded].

[When we are working with really young children, we obtain consent] ***with the parents as well ... Sometimes those kids can't print their names so they just put a little 'x' or something, just to make them feel important*** *...* ***We explain to them that they are contributing to something that is going to make the school better.***

2. Recruitment of participants

[One project I conducted] *was about parent's perceptions of the school and how effective it was in educating their kids 'cause it was an all Aboriginal school.* ***I went out to their sports day, because that's where I*** [met] ***70% of the parents of the school, the thing was that the consent dropped, the response rate dropped to 30% when I actually started doing interviews.***

Before ***that I actually jumped on the school bus and I went to every family, because each child was picked up on the school bus, and*** [I met the] ***parents*** [that way].

3. Administration of the instrument

I wouldn't give [the kids a survey] *and get them to* [fill it in on their own] ... [On a recent project, we had] ***a school ... survey and we turned it into a questionnaire. I had the survey here and I had them there and I had the tape going just in case, and I'd ask them a question and then checked it off. But at the end of each section I would have an open response and I would ask them, "Now what do you want to say about this point?" And they ... always wanted to say something!***

[There are protocols for researching Aboriginal kids such as] ***how you talk to them; how you dress; ... how long*** [the survey will] ***take; ...*** [your] ***eye level; ... and the way you talk; ... where you sit when you actually do the survey ... like we're sitting here is a no-no, you sit under a tree...*** [Also, I think its] ***best to use a male*** [to collect the information], ***if you're dealing with boys...*** *there's so many female teachers around its probably good for* [the boys] *to have a guy* [to interact with] ... ***That personal investment that the*** [research assistant] ***gives to those kids is really important.***

4. Community feedback

[To help manage the project] *I've ... done a* ***huge flowchart*** *and I'm* [asking myself,] ***"Okay ... I'm having community consultations ... what's got to be done at this community consultation on the first ... visit?" And I have to list it all... "And what happens on the second one – what did I say in my ethics paper that I've got to actually do with the community?"*** *And that's what I'm doing now, I'm going through a* ***project management plan*** *and I'm thinking "Okay I've written that in there and where do I put that in this meeting/situation – does it come first, does it come last?"*

[Throughout the project] *we're going to do a* ***newsletter and its going to be a one-page ... with mostly photographs.*** [It will be] ***visual ... with a few things so they are always in touch so that if they don't read it, they see it in photographs. The visual things are important, and its just going to be a one pager.*** *I'll just mail it out, or I'll send it through the schools – put it in kid's bags but the problem with that is that you'll never get it to the parents ... The other thing is to* ***go to like NAIDOC week and community sporting carnivals*** [and] ***stand there ... and hand out*** [the project information or newsletters] ***to the parents*** [at events].

[For the project feedback meeting] ***we're having a barbeque luncheon – the whole school community is involved, not just the parents or the kids 'cause the report's about everybody, the school community. And we've said a 10am start but*** [it will probably start about] ***half past ten, quarter to eleven, and*** [and only be] ***probably 45 minutes, that's it. Because a lot of them have young kids and they'll be running a-muck, so with that serious stuff you've either got to get someone to watch them but they probably wouldn't like that, so we just have to get through*** [it] ***quickly.***

Conclusion

The SRWP provided informative suggestions for demonstrating how the Aboriginal values and principles relevant to health research (NHMRC, 2003) can be applied in order to maintain the cultural security of project participants and their communities. Table 1 presents the strategies that were collected from both case studies in the form of the proposed framework.

5.1.2 Case study 2

Background

The Western Australian Aboriginal Child Health Survey (WAACHS) project was a state wide study conducted from 2000 - 2001 to gain an overview of the factors that contribute to the health and wellbeing of Aboriginal children aged 0-17 in Western Australia (Kulunga Research Network & Telethon Institute for Child Health Research, no date). A *Communication Strategy for the Western Australian Aboriginal Child Health Survey* (Kulunga Research Network & Telethon Institute for Child Health Research, no date) was designed to ensure that the participants (n= >5200), their families and their communities received and understood the information collected from the WAACHS.

As the WAACHS project was conducted prior to the current NHMRC (2003) guidelines, strategies identified in the Communication Strategy (Kulunga Research Network &

Telethon Institute for Child Health Research, no date) were matched to the Aboriginal values in the NHMRC (2003) guidelines before meeting with the participant. A face-to-face questionnaire administration then took place with an Aboriginal research officer from the Kulunga Research Network who contributed to the development of the Communication Strategy (Kulunga Research Network & Telethon Institute for Child Health Research, no date) to confirm and clarify the NHMRC (2003) match ups.

Bolding has been used in this case study to highlight key aspects of the Communication Strategy (Kulunga Research Network & Telethon Institute for Child Health Research, no date) that demonstrate the Aboriginal values and principles relevant to health research (NHMRC, 2003). These phrases and words were then used to develop the proposed framework examples of this thesis project found in Table 1. Italics have been used to indicate where the respondent provided additional information from the WAACHS for demonstrating the values and principles (NHMRC, 2003). An asterisk (*) has been used to highlight excerpts from the Communication Strategy (Kulunga Research Network & Telethon Institute for Child Health Research, no date) that are repeated throughout the case study. Audio recording was not used in this interview and in contrast to Case Study 1, Case Study 2 is presented in a report format.

Demonstrating the value of Reciprocity

The case study interview used the following definition of Reciprocity. "In the research context, reciprocity implies inclusion and means **recognising partners' contributions**, and ensuring that **research outcomes include equitable benefits** to **Aboriginal** and Torres Strait Islander **communities or individuals**" (NHMRC, 2003, p. 10). The value of Reciprocity was demonstrated throughout the WAACHS through the following examples:

1. "**Intent to contribute** to the advancement of the health and wellbeing of participants and communities" (NHMRC, 2003, p. 11).
2. "**Clear links to** community **health priorities** that **respond to existing or emerging needs** as articulated by Aboriginal people" (NHMRC, 2003, p. 11).

An Aboriginal Steering Committee was formed to ensure that the survey was conducted appropriately. The Steering Committee performed several key functions that included:

- Oversaw **project development, design and implementation**
- Had **final the say on the publication of data**

- Provide **approval of written applications for access to survey data**
- **Maintained working relationships** for those involved in the survey
- Development of **employment opportunities** within the project **for Aboriginal people** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

[Additionally], the **Aboriginal Steering Committee are the gatekeepers** of the WAACHS ... data. They **provide the broader advice and direction and have the final say and decision on what happens to the information and data from the survey** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

3. **"Evidence of clear and truthful discussions** about the **nature of benefits for participants** or other Aboriginal communities **prior to approval"** (NHMRC, 2003, p. 11).

[To ensure that the project was inline with the needs and goals of Aboriginal people in Western Australia], **advice and direction** [was sought from] ... **several key Aboriginal organisations and individuals about conducting** [this] ... **survey** ... [Benefits to the participating community would come in the form of project] information [that would] be **critical to the planning and delivery of health and other ... services for Aboriginal people** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

The most critical aspect of the WAACHS has been to **develop and implement a culturally consultative and relevant communication and dissemination strategy** to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

4. **"Willingness to modify research** in accordance with participating **community values and aspirations"** (NHMRC, 2003, p. 11).

It was clearly defined in the beginning ... that ... [formal] **support would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3). ***Hence, the development and implementation of the research communication strategy was necessary.***

*At a **community level** feedback of project data gives **knowledge for decisions on the acceptance of future projects.** At a **national level data provides evidence** for the steering committee (hence, the community) to **advocate for future funding and future research projects.** In turn, this **increased** the project **accountability** for **ensuring that data contributes in a positive way to make a change within the community.***

5. "**Enhances the capacity of communities to draw benefit beyond the project** through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level" (NHMRC, 2003, p. 11).

Additionally, knowledge gained from survey data could also be used to: ***educate non-Aboriginal people about Aboriginal health issues****; provide a* ***holistic view of Aboriginal health by identifying what impacts on their social and emotional development*** *and contribute to* ***increasing the effectiveness of future health interventions*** *targeting Aboriginal people.*

Demonstrating the value of Respect

The case study interview used the following definition of Respect. "Respectful research relationships acknowledge and **affirm the right of people to have different values, norms and aspirations**. Those involved in research processes should not be blind to difference" (NHMRC, 2003, p. 11). The value of Respect was demonstrated throughout the WAACHS through the following examples:

1. "The project **responds to the diversity of Aboriginal** people and their communities, including the way decisions are made" (NHMRC, 2003, p. 12).

*[Diversity of the participating communities was protected by] the **Steering Committee** [who] **oversaw development, design, and implementation of the research project** [and] **maintain[ed] appropriate and respectful relations** with participants and communities (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

Furthermore, ***the information collected through the survey provided a snapshot of families telling their stories that represents the diversity of Aboriginal people in WA.***

2. **Acknowledgement** of the individual and collective **contribution** of the community to the research project (NHMRC, 2003, p. 13).

Consideration was given to the different needs of different communities and regions so that ***instruments and feedback were adapted according to the language groups within*** [Aboriginal and Torres Strait Island Commission] ***ATSIC boundaries. This was facilitated through community consultation on appropriate methods for feedback to communities/regions.***

3. The researchers **minimise the effects of difference blindness** on and in the research process" (NHMRC, 2003, p. 13).

A further effort to ***minimise the effects of difference blindness*** *was addressed by* ***employing Aboriginal people*** *who were education and health workers* ***to analyse the data.***

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

*Further to this **a peer review** (including non-Aboriginal professionals with extensive experience in Aboriginal health research) **was conducted of the data analysis.***

4. "The project engages with **Aboriginal knowledge and experience**" (NHMRC, 2003, p. 13).

*[Aboriginal knowledge and experience was used in the project because] **the communities and families particularly who were part of the survey, [were] ... given back information at every step of the way** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1). ***Hence, the development and implementation of the research communication strategy was necessary to facilitate open communication throughout the project.***

5. "**Appropriate agreements** have been **negotiated** about **ownership** and **rights of access to** Aboriginal **intellectual and cultural property**" (NHMRC, 2003, p. 13).

8. "Agreement with participating communities all relevant issues including **management of data, publication arrangements** and **the protection of individual and community identity**" (NHMRC, 2003, p. 13).

Protocols** were established for **data access to survey results;** permission to use any of **the WAACHS data must be applied for in writing** to the **Steering Committee.** The protocols also stipulate that **any interpretation of project data** must be made in **consultation with Aboriginal researchers.

Confidentiality was very important; the use of ATSIC regions for data collection and dissemination secured the anonymity of participating families. For example, to use one town, say Narrogin, would have made it easy for families in other towns to identify that 'so and so' doesn't do such and such with their kids, or does do such and such.

6. "The **processes of reaching agreement** demonstrate engagement with the **values** of the participating communities" (NHMRC, 2003, p. 13).

A **debriefing session** [was] ... utilised at the end of the completion of the strategy ... The aim of this [was] to see how [the communication strategy] went with **tying in the community, following protocols on Aboriginal research** and ... [providing the community with] the **opportunity to talk about the positives and the negatives** of the strategy (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 11).

7. "Whether the participating communities have **expressed satisfaction** with the research agreement and decision making processes" (NHMRC, 2003, p. 13).

Regional pre/post publication forums provided opportunities for survey results to be explained and clarified (in terms of community relevance) to participants, their families and communities. Additionally, similar forums provided an excellent platform for further consultation regarding the survey experience, appropriate

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

methods for feedback and relevance of survey results (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 12).

Demonstrating the value of Equality

The case study interview used the following definition of Equality. "Equality as a value may sometimes be taken to mean sameness. However, Aboriginal and Torres Strait Islander Peoples hold a strong belief that **sameness is not equality**. Aboriginal and Torres Strait Islander peoples have sought the **elimination of 'difference blindness'** so that **Aboriginal** and Torres Strait Islander **cultures can be appreciated and respected**" (NHMRC, 2003, p. 14). The value of Equality was demonstrated throughout the WAACHS through the following examples:

1. "Participating **communities are included** in the research processes with equality" (NHMRC, 2003, p. 15).

The **Communications Manager and [Research Officers] will visit communities** to develop a regional specific feedback plan and to determine what **regional specific information** is needed from the survey (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9). *Project feedback could then be developed according to the specific needs of ATSIC regional profiles; the use of Storyboards is an example of this.*

*A further effort to **minimise the effects of difference blindness** was addressed by **employing Aboriginal people** who were education and health workers **to analyse the data.** Further to this **a peer review** (including non-Aboriginal professionals with extensive experience in Aboriginal health research) **was conducted of the data analysis.***

2. "The research agreements have the strength necessary to sustain equality" (NHMRC, 2003, p. 15).

*It was clearly defined in the beginning ... that ... [formal] **support would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

*The most critical aspect of the WAACHS has been to develop and implement a **culturally consultative and relevant communication and dissemination strategy** to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

3. "Participating communities have **understood and expressed satisfaction** with the proposed research, its potential benefits and their distribution. Researchers therefore have **responsibility** to ensure that the **information** that they provide is **understood and usable** in decision making by participating communities" (NHMRC, 2003, p. 15).

*The Communications Manager and [Research Officers] will visit communities within each area prior to develop regional specific **information is needed from the survey. Information materials and suitable processes will be developed for community feedback** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9).

The [Research Officers] ... **assist in the development, implementation and evaluation of specific strategies** and delivery of the WAACHS findings within their area and will liaise continuously with the communities they represent and the Communications Manager involved in regards to updates, community consultations, development and delivery of strategies (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 8).

[Additionally], the **use of a plain language story board** and presentations to communities and numerous associated health, shire, sporting, policing, family and children service, cultural, disability and educational organisations [was used to ensure that participating communities understood and were satisfied with the project data] (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9).

Demonstrating the value of Responsibility

The case study interview used the following definition of Responsibility. "A key responsibility within this framework is to **do no harm**, including **avoiding having an adverse impact** on others' abilities to comply with their responsibilities. Researchers and participating communities need to establish processes to ensure **researchers' accountability** to individuals, families and communities particularly **in relation to the cultural and social dimensions** of Aboriginal and Torres Strait Islander life" (NHMRC, 2003, p. 16). The value of Responsibility was demonstrated throughout the WAACHS through the following examples:

1. "Measures are identified to demonstrate **transparency in the exchange of ideas** and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research" (NMHRC, 2003, p. 17).

***The WAACHS Steering Committee oversaw development, design, and implementation of the research project and had** the responsibility to control and maintain **appropriate and respectful relations with participants and communities** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

*The *[Research Officers]* will assist in the development, implementation and evaluation of specific strategies and delivery of the WAACHS findings within their area and will **liaise continuously with the communities** they represent and the Communications Manager involved in regards to updates, community consultations, development and delivery of strategies (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 8).

*The Communications Manager and *[Research Officers]* will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve **consulting with appropriate community representatives**, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities' survey experience (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9).

2. "Provision is made for appropriate **ongoing advice and review** from the participating community, including mechanisms to **monitor ethics standards** and to minimise the likelihood of any unintended consequences arising from or after the research project " (NMHRC, 2003, p. 17).

Evaluation [of the project will occur in the following ways]:

- **A debriefing session will also be utilised at the end of the completion of the strategy.** The aim of this will be to see how we went with tying in the community, following protocols on Aboriginal research and to provide the opportunity to talk about the positives and the negatives of the strategy. This will provide a benchmark for all future Aboriginal research strategies to allow constructive feedback with the aim of doing better research (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 11).

- A set of formal recommendations will also be presented at the completion of the strategy. **These recommendations will stipulate strategy achievement, strengths, weaknesses and ways to move forward for the future.** The documents will also highlight protocols and policies for data access. It is hoped that these reports will feed into health service organisation delivery and will be utilised to inform policy and planning in the future (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 11).

3. "**Timely feedback** obligations to communities and whether that feedback is **relevant to the expressed concerns, values** and **expectations** of research participants and communities" (NMHRC, 2003, p. 17).

***The WAACHS Steering Committee oversaw development, design, and implementation of the research project and had** the responsibility to control and maintain **appropriate and respectful relations with participants and communities** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1) ... [Furthermore], **support for the project was conditional upon community and**

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

participating family involvement throughout the entirety of the research process (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

*[Again], the use of a **plain language story board and presentations to communities** [ensured that project feedback was relevant to the community's needs] ... The Communications Manager and **[Research Officers] (communication strategy team)** will visit communities within each area prior to develop regional specific information (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9). *Further to this, the feedback forums are organised to allow for open discussion time on: health issues presented in the feedback; relevance of the feedback material to the community; and survey experience of participants.*

4. "Agreed arrangements regarding publication of the research results, including **clear provisions relating to joint sign off for publication** and the **protection of individual and community identity** if appropriate" (NMHRC, 2003, p. 17).

After the release of each volume, the Communications Manager and [Research Officers] will visit each region to disseminate the information from each volume, particularly the information specific to that region. The purpose of these visits is to inform key stakeholder groups and the Aboriginal community about the findings from the survey and about how this information could assist local groups and organisations about program development and areas of need. As the gate keepers of the WAACHS data, the steering committee approves the publication of all data.

*Again, the use of ATSIC boundaries for data collection and for the presentation of results **secured the anonymity of the participating families.***

5. "Clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it" (NMHRC, 2003, p. 17).

The **Aboriginal Steering Committee** are the gatekeepers of the WAACHS and its data, they provide the broader advice and direction and have the **final say and decision on what happens to the information and data from the survey** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

Demonstrating the value of Survival and Protection

The case study interview used the following definition of Survival and Protection.

"Aboriginal and Torres Strait Islander Peoples continue to act to **protect their cultures and identity from erosion by colonisation** and marginalisation. A particular feature of Aboriginal and Torres Strait Islander cultures and these efforts has been the importance of a **collective identity**. This collective bond reflects and draws strength from the values base of Aboriginal and Torres Strait Islander Peoples and cultures" (NHMRC, 2003, p. 18). The

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

value of Survival and Protection was demonstrated throughout the WAACHS through the following examples:

1. "Whether the project contributes to or erodes the **social and cultural bonds** among and between Aboriginal families and communities" (NHMRC, 2003, p. 19).

***The WAACHS Steering Committee oversaw development, design, and implementation of the research project and had** the responsibility to control and maintain **appropriate and respectful relations with participants and communities** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1). It was clearly defined in the beginning that **support for the project was conditional upon community and participating family involvement throughout the entirety of the research process** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

The WAACHS data contributes to the social and cultural bonds of the participating families and communities by providing:

- *evidence of the diversity that exists among the Aboriginal people of Western Australia;*
- *a snap shot of Aboriginal health by identifying what impacts on social and emotional development;*
- *knowledge that could be used to educate non-Aboriginal people about Aboriginal health issues; and*
- *evidence-based research on Aboriginal health that could increase the effectiveness of future health interventions targeting Aboriginal people.*

2. "What **safeguards** are in place against the research project contributing to discrimination or derision of Aboriginal culture" (NHMRC, 2003, p. 19).

*The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant **communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

*The Communications Manager and Regional Representatives will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will **involve consulting with appropriate community representatives and community members** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9).

Additional safe guards include:

- *Pre/post-publication forums;*
- *Aboriginal people being involved in: data collection; data analysis; feed back process; and write up; and*
- *The Steering Committee having final say before data publication.*

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

3. "Whether the proposal **respects the intrinsic values, expectations** and identity of Aboriginal communities including the **balance** between **collective and individual identity**" (NHMRC, 2003, p. 19).

*A set of formal recommendations will also be presented at the completion of the strategy ... These **recommendations will stipulate strategy achievement, strengths, weaknesses and ways to move forward for the future.** The documents will also highlight protocols and policies for data access (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 11).

4. "How the proposal **contributes to** the opportunity for **Aboriginal** peoples' ability to enjoy their **cultural distinctiveness**" (NHMRC, 2003, p. 19).

***The WAACHS Steering Committee oversaw development, design, and implementation of the research project and had** the responsibility to control and maintain **the cultural integrity of survey methods and processes and to maintain appropriate and respectful relations with participants and communities** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

Furthermore the objectives of the WAACHS and the benefits for community involvement were considered to contribute to the ability of Aboriginal people to enjoy their cultural distinctiveness. For example, the WAACHS data would provide a holistic view of Aboriginal health issues in WA; it is intended that these data could then be used to assist Aboriginal people to self advocate at local and national levels.

5. "**Elimination of threats** to Aboriginal ability to enjoy their cultural distinctiveness" (NHMRC, 2003, p. 19).

*The most critical aspect of the WAACHS has been to **develop and implement a culturally consultative and relevant communication and dissemination strategy** to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

Demonstrating the value of Spirit and Integrity

The case study interview used the following definition of Spirit and Integrity. "This is an **overarching value that binds all others** into a coherent whole. It has two components. The first is about the **continuity between past, current and future** generations. The second is about behaviour, which maintains the **coherence of Aboriginal** and Torres Strait Islander **values and cultures**. Any behaviour that diminishes any of the previous five values could not be described as having integrity (NHMRC, 2003, p. 19). The value of Spirit and Integrity was demonstrated throughout the WAACHS through the following examples:

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

1. How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's **cultural, spiritual and social cohesion**, including workable timeframes (NHMRC, 2003, p. 20).

*The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant **communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

*The Communications Manager and [Research Officers] will visit communities within each area prior to, and in conjunction with the release of each volume (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1). These visits will involve **consulting with appropriate community representatives, community members** to understand the **community's survey experience** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9).

2. Whether the proposal recognises in the conduct and reporting of research the **diversity of Australian Aboriginal** culture including the **mechanisms through which communities may make decisions** (NHMRC, 2003, p. 20).

*The Communications Manager and [Research Officers] will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve **consulting with appropriate community representatives, community members and relevant local government** and non-government organisations to develop a regional specific feedback plan and to determine:

- **The methods to be used for feedback of findings**
- **What regional specific information is needed from the survey**
- **Communities survey experience** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 9).

Regional forums (pre/post-publication) these regional **forums will focus on gaining regional support** and assistance from each of the identified key stakeholders as to what sorts of information will be needed by each of the regions and also notify us of how the regions want the information fed back to them and how they might suggest the information is fed back to the families and the communities who were involved with the survey (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 12).

Providing forums for open discussion of participants' research experiences helped to create community trust in the WAACHS and hopefully in future health interventions.

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

3. Whether the proponents of the proposal are able to clearly demonstrate **personal integrity**, specifically in the development of their proposal (NHMRC, 2003, p. 20).

*All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey **Steering Committee** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

***The WAACHS Steering Committee oversaw development, design, and implementation of the research project and had** the responsibility to control and maintain **the cultural integrity of survey methods and processes and to maintain appropriate and respectful relations with participants and communities** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 1).

Building relationships of trust in the early/formative stages was essential to the success of the WAACHS.

4. Does the proposal **demonstrate a commitment** to working within the spirit and integrity of Aboriginal people? (NHMRC, 2003, p. 20)

*It was clearly defined in the beginning that **support for the project was conditional upon community and participating family involvement throughout the entirety of the research process** (Kulunga Research Network & Telethon Institute for Child Health Research, no date, p. 3).

Furthermore, the development of the dissemination strategy demonstrates the WAACHS commitment to working within the spirit and integrity of Aboriginal people.

Conclusion

The WAACHS Communication Strategy provided informative suggestions for demonstrating how the Aboriginal values and principles relevant to health research (NHMRC, 2003) can be applied in order to maintain the cultural security of project participants and their communities. Table 1 presents the strategies collected from both case studies used for the development of the proposed framework.

* This Communication Strategy example has been used to demonstrate a previous principle within this case study.

5.2 Development of proposed framework

Common themes in the case study data were coded and placed into categories according to the Aboriginal values and principles (NHMRC, 2003). These common themes were combined with the literature to form generic framework examples that could facilitate a collaborative ethics process with Aboriginal communities in child health research in Western Australia (WA). These generic framework examples and case study suggestions of descriptions for demonstrating the framework examples in Aboriginal child health research are presented in Table 1. The information in Table 1 was presented in Part A of the expert panel instrument (Appendix 2).

Table 1
Framework examples and suggestions from the case studies for demonstrating the Aboriginal values and principles relevant to health research (NHMRC, 2003)

Framework Examples These examples propose how the principles outlined in the NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* can be applied or demonstrated in a health research project.	**Suggestions from the Case Studies** Descriptions of ways the framework examples can be demonstrated in Aboriginal child health research.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Prior to the project proposal, a community committee or group is formed to guide the project and make sure that community culture is respected and community health matters are represented throughout the whole research project (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.
Reciprocity, Respect and Equality can be demonstrated by: ▪ The community committee agrees that the research project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy (Case study, 1, 2; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; Waples-Crowe & Pyett, 2005).	• Feedback of project data provides the community with knowledge for decisions on the acceptance of future projects.

Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Aboriginal people and Aboriginal health organisations inform the project about the things that are important to them to keep their community strong and healthy (Case study, 1, 2; Donovan & Spark, 1997; Dressendorfer et al., 2005; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• Use of national Aboriginal health priorities and local community based reference groups including non-Aboriginal groups who work with an Aboriginal network. • A community owned project will naturally inform researchers of the health issues important to the community.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The committee informs the project to make sure that the local health goals are represented and to confirm what the community wants to do about local health matters (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; Miller & Rainow, 1997; National Health and Medical Research Council, 2003).	• The committee will help manage the project and keep things going smoothly. • The committee advises researchers on the best direction of the project for the community. • The committee advises researchers what the community wanted to happen to the project information.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Communication between the committee and the project is transparent – phone calls; letters; emails; and consultation meetings are all noted to make sure that the project remains culturally appropriate for the needs of the community (Case study, 1).	• The committee informs the project when and how modifications to the project are required. For example when sensitivity is needed so that community members involved in the project can meet their cultural obligations should the need arise. • A flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. For all visits to the community throughout the project. It also ensures the project remains truthful in fulfilling its commitments to the community.

Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members are given the opportunity to speak to researchers about the project in a group or one-on-one (Case study, 1, 2; Hearn & Wise, 2004; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Miller & Rainow, 1997; Sheehan et al., 2002; Thomsen, 2003).	• A project information night or workshop is presented within the community prior to the commencement of the project and then as often as the committee feels is necessary. • Researchers allow for one-on-one time to make sure carers and children have all their questions answered.
Reciprocity, Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project is given back to the community or region in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).	• Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progress are briefly described in dot points. • Use of story boards to feed project information back to the community.

Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project only tells a story about the community or region involved in the project (Case study, 1, 2; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).	• The use of 'regions', rather than the community's geographic name provides anonymity to project participants. • Diversity means allowing for Aboriginal people to be different to other Aboriginal people from different areas: data collected in urban Aboriginal projects only represents urban Aboriginal people; rural projects represent rural people; and remote projects represent remote people.
Reciprocity, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project can be used to help the community make strong decisions in the future about their health (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Knowledge gained from the project can be used to educate non-Aboriginal people about the community's health issues.
Reciprocity, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project might be useful to help the community get funding in the future for other health projects (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A successful pilot study provides support for future funding grants on the same or related topic in the same community or region.

Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members are personally invited to be involved in the project (Case study, 1).	• Invest time into getting to know the community and their school children before data collection by being involved: attend sports days; jump on the school bus; and meet the parents when they pick up their kids after school.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members who want to be involved in the project are invited to share their thoughts about their own health and the health of their community (Case study, 1; Thomsen, 2003).	• As part of the data collection participants are asked what they think about health: for themselves, their families and their community.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The community committee and community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.

Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A written agreement is made so that the community agrees with: how the project will be conducted, and what will happen to the project information (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• A statement of cultural consent and participation is developed through committee negotiations with the project. • The statement is in-line with the community's protocols.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The way the agreement was made is recorded (Case study, 1).	• If the agreement was made by a show of hands it is recorded that 'the agreement was accepted by the community by show of hands'.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The meeting for the agreement is held in a neutral or safe place for the people involved in the project (Case study, 1, 2).	• Somewhere outdoors is preferable, not in an office or in a school building.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members who are involved in the project can share their feelings about what they liked and did not like about the agreement, their feelings are recorded and actioned by researchers (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Sheehan et al., 2002; Thomsen, 2003).	• A 'time of reflection' is allocated at the conclusion of the committee/community meetings to give community members an opportunity to raise their concerns. • Community concerns are recorded in a 'processes journal' that is actioned by researchers.

Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Permission for access to project information must be applied for in writing to the committee (Case study, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Information access agreement – information from the project can not be accessed unless a written application is made. The data must be interpreted for the new project in consultation with an Aboriginal researcher (or assistant).
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A management plan or communication strategy is used to make sure that the project actions the required ethical processes. Progress of the management plan is reported back to the community committee throughout the research project (Case study, 1, 2; Hearn & Wise, 2004; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A matrix or flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. First visit, second visit through to final feedback after project completion. • Stages are matched up with ethics application to keep the project truthful and transparent.
Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Children of all ages, adults, males and females – the whole community is welcomed to be involved in the research project (Case study, 1).	• All children involved in the project sign their name, with an 'X' if necessary, to feel important and included. • Potential participants (children) are also invited to attend the project information session with their carers. • Researchers will attempt to match the gender of data collectors with participants.

Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information sheet and consent form are in an appropriate language and style for the community, and that people who want to be involved in the research project understand what it is about (Case study, 1, 2; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998).	• Large font is used for both the adults (to cater for poor eyesight from diabetes) and the children's information sheet. • The information and consent forms are presented to both the carers and the children one-on-one. • Both the carers and the children are given the opportunity to indicate their level of project participation eg. Permission to have photographic/video footage.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The community members who want to be involved in the research project understand that they can change their minds about being involved in the project whenever they want (Case study, 1).	• Carers are assured that they can withdraw their children from participating in the project at any time without a fuss from researchers.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ All communication with the community committee is written down or noted to make sure that the project continues to be open and truthful eg. meeting minutes (Case study, 1).	• Emails, phone calls, and meeting minutes are recorded to track project progress and process changes negotiated by the community committee.

Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Regular progress reports about the project to the community from meeting minutes and the management plan. Reports are in an appropriate language and style for the community eg. newsletters and meetings. (Case study, 1, 2; Donovan & Spark, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • A written review is also done at the conclusion of the project as an overall evaluation.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Before and after the information collected from the project is published it is presented and discussed with the community or region (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Pre and post publication information sessions are held in the participating community to provide: a background summary of the project; the results and what they mean; and to gain continuing support for the project.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The committee is happy with the representation of their community in the project information before it is published (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• The committee is the gatekeeper of all the data collected in the project and must approve all project information prior to publication.

Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A complaints process is established so that community members who are involved in the project can share their feelings about what they liked and did not like about being involved. This will be actioned by researchers and reported back to the community in an appropriate language and style (Case study, 1, 2; Hearn & Wise, 2004; Meyer, 2000; Miller & Rainow, 1997; Sheehan et al., 2002; Thomsen, 2003).	• The community is informed at the first information session that a complaints process is available should they require it. Researchers are accountable for actioning the complaints and reporting them back to the community.
Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A plan for giving project information back to the community is developed before the project begins (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A matrix is constructed to inform/manage what needs to get done at different stages of the project, eg. First visit, second visit through to final feedback after project completion. • Stages are matched up with ethics application to keep things truthful and transparent. • Support for the project is conditional upon assurance that participating families and communities receive feedback at every stage of the project.

5.3 Expert panel results

The literature review and the case studies informed the proposed framework examples (Table 1) to demonstrate the Aboriginal values relevant to health research (NHMRC, 2003). The proposed framework was then presented to an expert panel for content validation. The aim of this expert consultation was to determine consensus that the proposed framework would:

1. maintain the cultural security of participants in an Aboriginal child health research project; and
2. demonstrate the values and principles outlined in the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC, 2003).

An expert panel was considered to be a useful platform for drawing on current knowledge that strengthens information obtained from the literature review and the case studies (Delbecq et al., 1986). Obtaining opinions from individuals who were anonymous to each other enabled independent participation from all panel members (Goodman, 1987; Gupta & Clarke, 1996; Stahl & Stahl, 1991; Sumsion, 1998; Williams & Webb, 1994). The expert panel formed for this project consisted of individuals with a high level of knowledge and experience in Aboriginal health promotion and as such qualified as panel members (Delbecq et al., 1986; Stahl & Stahl, 1991).

5.3.1 Response rate

Nineteen people accepted the invitation to act as panel members and provide content validation for the proposed framework of this project based on their experience in Aboriginal health or Aboriginal health research. Participants were associated with organisations such as: an Aboriginal Health Service; the Health Department of Western Australia; various University-based health centres; and Western Australia's Telethon Institute for Child Health Research. Seven (36.8%) completed questionnaires were received.

5.3.2 Characteristics of respondents

The majority of respondents (n=5) were female. Four of the seven respondents were Aboriginal. One respondent was from a University-based Health centre; one respondent was from the Health Department of WA; two respondents were from an Aboriginal Health Service located in a rural town; and the remaining three respondents were from the Telethon Institute for Child Health Research. On average, respondents had been working in Aboriginal Health for 10.5 years.

5.3.3 Written Comment

Throughout the questionnaire participants were invited to make comments on the proposed framework examples used to demonstrate the values/principles (NHMRC, 2003). Exploring all of these comments (Appendix 13) in depth is beyond the scope of this thesis project, however where relevant, corresponding comments have been included within the results of each value. Changes to the framework based on these comments are identified in **bold** text in Appendix 11.

5.3.4 Group Opinion

The range of responses from the panel members is presented in Appendix 12. In this Chapter, Tables 2-7 show the mean, the standard deviation (SD), and the percentage of agreement among the expert panel for the framework examples demonstrating the six Aboriginal values relevant to health research (NHMRC, 2003). Additionally, the tables show the mean and SD for the ability of framework examples to maintain the cultural security of Aboriginal children who participate in health research projects.

As such, these tables identify the extent to which **respondents agreed to each item** (mean) and the extent to which **respondents agreed with each other** (standard deviation and percentage positive) on each item.

Consensus among panel members was assessed in two ways. For the SD or variation in respondents' views, the higher the SD the greater the differences in views. Percentage positive was also used to assess consensus and shows the percentage of participants that agree (>4.0).

Given the low number of respondents, care should be taken when interpreting these results as one extreme value can influence the SD in a sample of seven. However, a single outlier response is noteworthy for exploring polar views among the expert panel. In these results a high SD was useful in drawing attention to examples during the revision process of the framework.

Reciprocity

Table 2 presents the group opinion for the value of Reciprocity. For the 10 items presented for Reciprocity, respondents agreed (all means >4.0) that the proposed framework examples would demonstrate the principles within the value of Reciprocity (Table 2).

Within the value of Reciprocity the SD was greatest (>1.0) in examples 5a (1.10) and 5b (1.07). One respondent commented with the following about 5a, *"I do not believe that 'projects' are funded or organised to capacity build or establish sustainability."* Consequently, this framework example scored low levels of agreement among panel members every time it was presented throughout the questionnaire.

Despite the overall agreement on framework examples demonstrating the principles within the value of Reciprocity, consensus among the expert panel for the majority of examples (n=6) presented within this value was <100%. One respondent intentionally missed rating their level of agreement on 1b (affecting the percentage of agreement) and commented, *"I am not sure that* [this example] *makes sense! Bearing in mind that there is often a diversity of opinions within communities – how is this to be accommodated? How is the community committee or group to be formed?"*

Examples 3a and 5c had a percentage agreement of 71.4. Respondents provided the following comments for 3a:

"All communication processes need to be documented as evidence. Also agreed upon."
"How will cultural appropriateness be checked? I think there needs to be a check of how communication is recorded. Maybe get people to check notes of meetings to see if issues recorded correctly."
"The agreed outcomes of the project (eg capacity building) are implemented to the level identified at the commencement of the project discussions."

The mean for agreement among panel members that the framework examples presented in the value of Reciprocity would maintain cultural security ranged from 3.54 – 4.54 on a scale of 1 – 5. Higher scores indicate that the example would help researchers maintain cultural security.

Table 2
Group opinion of content validity of the demonstration of ***Reciprocity*** *when conducting health research with Aboriginal school children (n=7)*

Principles and examples of Reciprocity[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
1. Researchers explain how project will improve community health:					
a. community committee guides the project	4.21	0.69	85.7	3.87	0.76
b. research will find evidence to help Aboriginal people stay strong and healthy	4.41	0.49	85.7[d]	3.57	1.17
2. The project is connected to community health priorities and needs:					
a. important to keep community strong and healthy	4.35	0.47	100.0	4.54	0.58
b. local health goals are represented	4.35	0.47	100.0	3.98	0.82
3. Clear discussion about benefits to community from the project:					
a. communication is transparent	4.14	0.74	71.4	4.07	0.73
4. Willingness to make changes in to the project:					
a. community committee guides the project	4.21	0.39	100.0	3.87	0.76
b. community members can speak to researchers	4.57	0.44	100.0	4.41	0.56
5. Building the community's capacity:					
a. project provides training and job opportunities for Aboriginal people	4.35	1.10	85.7	3.78	1.21
b. research information collected used to make future decisions	4.21	1.07	85.7	4.31	0.74
c. research information collected used to help the community get future funding	4.22	0.79	71.4	3.54	1.15

Note. [a] Full descriptions of principles and examples found in questionnaire (Appendix 2). [b] Response to scale: 1 – strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 – strongly agree. [c] Response to scale from 1 – would **not** maintain cultural security to 5 – would maintain cultural security. [d] Missing information (n=1)

Respect

Table 3 presents the group opinion for the value of Respect. The mean response for all examples presented for demonstrating the principles within the value of Respect was >4.0 (agree).

The SD for examples 1b, 3b, and 4c were all high (>1.1) due to the respondent who felt that projects are not generally funded according to community sustainability; this participant continued to rate the framework example at 2 (disagree), as previously identified in the comments of Reciprocity 5b.

Unlike the value of Reciprocity, the majority of examples (n=12) indicated a consensus (100% positive) among panel members for demonstrating the value of Respect. Of the nine examples that did not achieve consensus, example 2b rated the lowest (57.1%) despite having a mean of 4.10. There were no comments provided by panel members to explain the variation in responses for example 2b, where one panel member did not respond and another rated this at 3.6.

The means for agreement among panel members that the framework examples would maintain cultural security was >3.5, however four examples had an SD >1.0. Other than the above examples (1b, 3b and 4c) the only other examples to receive a SD of 1.0 or greater were 3b and 6b. Again, no comments were provided to explain lower ratings on cultural security for these examples.

Table 3
*Group opinion of content validity of the demonstration of **Respect** when conducting health research with Aboriginal school children (n=7)*

Principles and examples of Respect[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
1. Differences between Aboriginal communities:					
a. community committee guides the project	4.50	0.50	100.0	3.87	0.76
b. project provides training and job opportunities for Aboriginal people	4.07	1.42	71.4	3.78	1.21
c. research information only tells a story about the community	4.35	0.74	85.7	4.14	0.94
2. Individual and collective contribution of Aboriginal people:					
a. research information given to community in an appropriate language and style	4.58	0.49	85.7[d]	4.31	0.74
b. community members are personally invited to be involved in the project	4.10	0.78	57.1[d]	3.81	1.00
c. community members share their thoughts about their health	4.26	0.58	71.4[d]	3.87	0.96
3. Differences between Aboriginal and non-Aboriginal cultures and different Aboriginal communities:					
a. community committee guides the project	4.43	0.49	85.7[d]	3.87	0.74
b. project provides training and job opportunities for Aboriginal people	4.26	1.17	71.4[d]	3.78	1.21
c. research information given to community in an appropriate language and style	4.64	0.47	100.0	4.31	0.74
4. Uses Aboriginal knowledge and experience:					
a. community committee guides the project	4.50	0.50	100.0	3.87	0.76
b. community committee share their feelings about research procedures	4.50	0.50	100.0	4.24	0.90
c. project provides training and job opportunities for Aboriginal people	4.35	1.10	85.7	3.78	1.21

Table 3 continued...

Principles and examples of Respect[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
5. Agreement:					
a. written agreement about research procedures	4.42	0.60	85.7	4.38	0.84
b. permission for access to project information must be applied for in writing to the committee	4.50	0.50	100.0	4.22	0.97
6. Community's values for making the agreement are used:					
a. community committee guides the project	4.51	0.50	100.0	3.87	0.76
b. record method of agreement by community	4.51	0.50	100.0	3.82	1.24
c. meeting for agreement held in a neutral or safe place	4.50	0.50	100.0	4.47	0.67
7. Community is happy with the agreement:					
a. community members can share what they liked/did not like about agreement	4.35	0.74	85.7	4.24	0.80
8. Agreement ensures community/participant identity is safe and protected:					
a. community committee guides the project	4.35	0.47	100.0	3.87	0.76
b. community committee share their feelings about research procedures	4.35	0.47	100.0	4.24	0.90
c. written agreement about research procedures	4.51	0.50	100.0	4.38	0.84
d. management plan or communication strategy	4.78	0.39	100.0	4.42	0.73

Note. [a] Full descriptions of principles and examples found in questionnaire (Appendix 2). [b] Response to scale: 1 – strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 – strongly agree. [c] Response to scale from 1 – would **not** maintain cultural security to 5 – would maintain cultural security. [d] Missing information (n=1).

Equality

Table 4 presents the group opinion for the value of Equality. All of the examples presented within the value of Equality received a mean score >4.10 except for example 1a. Example 1a rated the weakest level of agreement for the entire questionnaire in both principle demonstration (mean 3.37; SD 1.57; 42.9% positive) and maintenance of cultural security (mean 3.37; SD 1.7). Respondent comments associated with this example include:

"With their consent always."
"This may not always be appropriate and guidance should be sought from the community."
"Involvement of some members of the community at the same time as others may not always be appropriate. Therefore equality [must] be tempered with cultural appropriateness."
"Culturally appropriate."
"Also related to gender of interviewers/researchers."

In contrast to example 1a, the level of consensus among panel members for all other examples (n=9) presented within the value of Equality was 85.7 or 100 percent. Overall, the examples presented in principle 3 received the second highest level of agreement among respondents for demonstrating an Aboriginal value relevant to health research (NHMRC, 2003) in the entire questionnaire.

The mean agreement for framework examples (other than 1a) in maintaining cultural security was >3.5 with a SD <1.0.

Table 4
*Group opinion of content validity of the demonstration of **Equality** when conducting health research with Aboriginal school children (n=7)*

Principles and examples of Equality[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
1. Community involvement in research shows equality:					
a. whole community involved in the research	3.37	1.57	42.9	3.37	1.70
b. research information given to community in an appropriate language and style	4.43	0.61	85.7	4.31	0.74
c. community committee guides the project	4.42	0.60	85.7	3.87	0.74
d. project provides training and job opportunities for Aboriginal people	4.21	1.07	85.7	4.38	0.84
2. In the agreement everyone is treated with equality:					
a. research information given to community in an appropriate language and style	4.21	1.07	85.7	4.31	0.74
b. community committee guides the project	4.14	1.02	85.7	3.87	0.76
c. community committee share their feelings about research procedures	4.20	1.06	85.7	4.24	0.90
3. Information about the research is understood and usable in decision making:					
a. information sheet and consent form in an appropriate language and style	4.50	0.50	100.0	4.28	0.76
b. community members can change their minds about project involvement	4.50	0.50	100.0	4.55	0.57
c. community committee share their feelings about research procedures	4.50	0.50	100.0	4.24	0.90

Note. [a] Full descriptions of principles and examples found in questionnaire (Appendix 2). [b] Response to scale: 1 – strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 – strongly agree. [c] Response to scale from 1 – would **not** maintain cultural security to 5 – would maintain cultural security.

Responsibility

Table 5 presents the group opinion for the value of Responsibility. All the examples within this value had a mean >4.0.

Of the fourteen examples presented within the value of Responsibility, only three (4a; 4b; 5a) had a percentage positive <100. Example 5a had the lowest level of consensus (71.4% positive) and the greatest SD (1.17), however no comments were provided to explain the variation in responses for this example.

Overall, the examples presented within principle 3 received the highest means (>4.51), the lowest SD (0.50 or less) and the strongest level of agreement (100% positive) from panel members for demonstrating an Aboriginal value relevant to health research (NHMRC, 2003).

Accordingly, the mean agreement of framework examples maintaining cultural security across the value of Responsibility was >3.5 with a SD <1.0.

Table 5
*Group opinion of content validity of the demonstration of **Responsibility** when conducting health research with Aboriginal school children (n=7)*

Principles and examples of Responsibility[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
1. Sharing ideas is open and truthful:					
a. communication is transparent	4.35	0.47	100.0	4.07	0.73
b. community committee guides the project	4.50	0.50	100.0	3.87	0.76
c. community committee share their feelings about research procedures	4.48	0.50	100.0	4.24	0.90
2. Continuing communication with the community:					
a. regular progress reports to community	4.64	0.47	100.0	4.28	0.50
b. community committee guides the project	4.50	0.50	100.0	3.87	0.76
c. community committee share their feelings about research procedures	4.51	0.50	100.0	4.24	0.90

Table 5 continued...

Principles and examples of Responsibility[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
3. Researchers must discuss and try to fix the worries of people about the research:					
a. community committee share their feelings about research procedures	4.51	0.50	100.0	4.24	0.90
b. community committee guides the project	4.65	0.47	100.0	3.87	0.76
c. regular progress reports to community	4.64	0.47	100.0	4.28	0.50
4. Agreement about what will happen to the information from the research project:					
a. community committee guides the project	4.35	0.74	85.7	3.87	0.76
b. written agreement about research procedures	4.35	0.74	85.7	4.38	0.84
c. before research information is published it is presented to community	4.64	0.47	100.0	4.57	0.54
d. committee satisfied with representation of community	4.50	0.50	100.0	4.48	0.53
5. Flexible agreements about the time community partners give to the research:					
a. community committee guides the project	4.07	1.17	71.4	3.87	0.76

Note. [a] Full descriptions of principles and examples found in questionnaire (Appendix 2). [b] Response to scale: 1 – strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 – strongly agree. [c] Response to scale from 1 – would **not** maintain cultural security to 5 – would maintain cultural security.

Survival and Protection

Table 6 presents the group opinion for the value of Survival and Protection. A third of the examples (14) presented for demonstrating the value of Survival and Protection scored a mean >4.0.

Within the value of Survival and Protection, 14 examples had a SD of 1.01 or higher. Example 5c had the highest SD of 1.42. There were no comments provided by the expert panel to explain the variation in responses for example 5c.

Of the seven examples that scored a mean <4.0, four (1b; 3c; 4a; 5a) also scored low level of agreements (<71.4% positive) among panel members. Example 1b scored the lowest mean (3.50) and the lowest consensus (42.9% positive) within the value of Survival and Protection due to two respondents indicating that they disagreed with Example 1b demonstrating this principle.

The mean agreement among panel members that examples within this value would maintain cultural security was >3.5, examples with a high SD (>1.0) have already been identified in previous values.

Table 6
Group opinion of content validity of the demonstration of ***Survival and Protection*** *when conducting health research with Aboriginal school children (n=7)*

Principles and examples of Survival and Protection[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
1. Social and cultural bonds within families and the community:					
a. community committee guides the project	3.78	1.28	71.4	3.87	0.76
b. research information collected used to help the community get future health funding	3.50	1.25	42.9	3.54	1.15
2. The culture of the community is protected and safe:					
a. important to keep community strong and healthy	4.07	1.01	85.7	4.54	0.58
b. community committee guides the project	4.07	1.01	85.7	3.87	0.76
c. project provides training and job opportunities for Aboriginal people	4.07	1.17	85.7	3.78	1.21
d. community committee share their feelings about research procedures	4.35	0.47	71.4	4.24	0.90
e. before research information is published it is presented to community	4.50	0.50	100.0	4.57	0.54
f. research information given to community in an appropriate language and style	4.50	0.50	100.0	4.31	0.74
g. research information only tells a story about the community	4.20	1.07	85.7	4.14	0.94
3. Values, expectations and identity of the community are respected:					
a. community committee guides the project	4.35	0.47	100.0	3.87	0.76
b. community members share their thoughts about their health	4.35	0.47	100.0	3.87	0.96
c. project provides training and job opportunities for Aboriginal people	3.78	1.34	57.1	3.78	1.21

Table 6 continued...

Principles and examples of Survival and Protection[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
4. Cultural distinctiveness:					
a. project provides training and job opportunities for Aboriginal people	3.68	1.39	57.1	3.78	1.21
b. research will find evidence to help Aboriginal people stay strong and healthy	3.97	0.85	71.4	3.57	1.17
c. research information collected used to make future decisions	4.35	0.47	100.0	4.31	0.74
d. written agreement about research procedures	3.90	1.09	71.4	4.38	0.84
5. The project helps the community enjoy their cultural distinctiveness:					
a. complaints process established	3.71	1.28	57.1	4.50	0.51
b. research information only tells a story about the community	4.07	1.01	85.7	4.14	0.94
c. research information given to community in an appropriate language and style	4.07	1.42	71.4	4.31	0.74
d. project provides training and job opportunities for Aboriginal people	4.22	1.13	71.4	3.78	1.21
e. community committee guides the project	4.11	1.07	71.4	3.87	0.76

Note. [a] Full descriptions of principles and examples found in questionnaire (Appendix 2). [b] Response to scale: 1 – strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 – strongly agree. [c] Response to scale from 1 – would **not** maintain cultural security to 5 – would maintain cultural security.

Spirit and Integrity

Table 5 presents the group opinion for the value of Spirit and Integrity. All examples bar one (2c) had a mean >4.0 (agree) for demonstrating the principles of Spirit and Integrity.

Despite the high mean scores for examples within the value of Spirit and Integrity, consensus among panel members was only reached for three examples (2b; 4a; 4b).

Example 2c has repeatedly scored low due to the respondent who felt that projects are not generally funded according to community sustainability as identified in Reciprocity 5a. When presented for demonstrating Spirit and Integrity this example scored a mean of 3.92, a SD of 1.42 and the lowest level of consensus within this value of 57.1% positive.

Mean scores for maintaining cultural security across the value of Spirit and Integrity are duplicates of previous values except for example 4a. Example 4a scored the highest mean (4.72) and lowest SD (0.43) for maintaining cultural security of all framework examples presented within the questionnaire.

Table 7
*Group opinion of content validity of the demonstration of **Spirit and Integrity** when conducting health research with Aboriginal school children (n=7)*

Principles and examples of Spirit and Integrity[a]	Demonstration of Principle[b]			Maintenance of Cultural Security[c]	
	Mean	Standard Deviation	% Positive	Mean	Standard Deviation
1. Research will keep cultural, spiritual and social bonds of community strong:					
a. project provides training and job opportunities for Aboriginal people	4.08	1.08	71.4	3.78	1.21
b. community committee guides the project	4.21	0.69	85.7	3.87	0.76
2. The project accepts differences of culture between different Aboriginal communities:					
a. research information only tells a story about the community	4.08	1.02	85.7	4.14	0.94
b. research information given to community in an appropriate language and style	4.50	0.50	100.0	4.31	0.74
c. project provides training and job opportunities for Aboriginal people	3.92	1.42	57.1	3.78	1.21
d. community members can share what they liked/did not like about agreement	4.17	1.09	71.4	4.24	0.80
3. Demonstration of personal integrity in project development:					
a. community committee guides the project	4.28	0.56	85.7	3.87	0.76
b. communication with the community is written down	4.32	0.50	85.7	4.15	0.97
4. Working within the spirit and integrity of the community:					
a. plan for giving project information back to community developed before project starts	4.35	0.47	100.0	4.72	0.43
b. community committee guides the project	4.35	0.47	100.0	3.87	0.76

Note. [a] Full descriptions of principles and examples found in questionnaire (Appendix 2). [b] Response to scale: 1 – strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 – strongly agree. [c] Response to scale from 1 – would **not** maintain cultural security to 5 – would maintain cultural security.

Chapter Six

Discussion

A comprehensive document review of the NHMRC (2003) ethical guidelines for conducting Aboriginal health research was presented within the literature review for this thesis project. Using the NHMRC (2003) guidelines, case studies were collected from the Aboriginal child health research projects of two experienced Aboriginal researchers. The case studies and the literature were then used to inform a proposed framework for demonstrating the Aboriginal values relevant to health research (NHMRC, 2003). The proposed framework was presented to an expert panel made up of experienced Aboriginal health workers and researchers for content validation.

This Chapter discusses the level of agreement or consensus among the expert panel that the framework examples would maintain the cultural security of potential research project participants and demonstrate the Aboriginal values and principles relevant to health research (NHMRC, 2003). The results of the expert consultation for the framework also represent the results of the case studies as they were used to inform examples within the framework. Before discussing the findings of the expert panel data, the limitations that influence the validity of this project will be outlined.

6.1 Limitations of this project

The findings of this project are tempered by limitations related to: sample selection; sample size; instrumentation; and the researcher and supervisors being non-Aboriginal. These limitations are possible threats to the internal and external validity of the study and may have artificially enhanced or deflated the results reported in Chapter 5.

Firstly, as purposive and snowball sampling techniques were used, selection bias was introduced as inclusion for participation in this research project was restricted to individuals with knowledge and experience in Aboriginal health, Aboriginal health promotion or Aboriginal health research. This was difficult to overcome in as much as the sample size for the expert consultation (n=7) is small due to the limited number of people who work in Aboriginal health in Western Australia. Additionally, the small sample size

contributed to a larger SD when one or two respondents expressed views different to other panel members as presented in Appendix 12.

Secondly, it is recognised that participants in this research project are Aboriginal and non-Aboriginal health promotion practitioners and researchers, rather than community members who are potential research participants. As such the outcomes and framework (Appendix 11) developed for this project can only be used under community direction; this is consistent with the literature and the case studies.

Thirdly, the timeframe allocated to this project did not allow for focus group testing of the proposed framework; instead, content validation was conducted on the proposed framework through questionnaire responses. It was anticipated that a modified Delphi technique, using a series of questionnaire administrations, among the expert panel members would have been an efficient method for obtaining consensus and for fine tuning the framework (Delbecq et al., 1986).

Fourth, limitations in the wording of some questions within the case study and expert panel instruments did not become apparent until data collection or data analysis. It is also possible that in summarising the values and principles of the NHMRC (2003) guidelines, the detail of some principles was misrepresented or lost. It was anticipated that the expert panel would detect these shortcomings in the proposed framework. Unfortunately, the length and repetition of framework examples presented in the expert panel instrument (Appendix 2) may have made this difficult for panel members to do. Nevertheless, participant comment and feedback were taken into consideration during the framework revision.

And lastly, it is acknowledged that the student researcher and thesis supervisors are non-Aboriginal. The literature describes the caution with which Aboriginal people regard non-Aboriginal research; this may have contributed to a reduced level of acceptability of the nature of this thesis project by Aboriginal people. Every precaution was taken to minimise the effects of this limitation through extensive consultation and support from participants for this thesis project and Aboriginal researchers involved in the CHPRU Aboriginal bully prevention and reduction project.

6.2 Discussion of the findings

As presented in the *Framework examples and suggestions from the case studies for demonstrating the Aboriginal values and principles relevant to health research (NHMRC, 2003)* on page 74, the case study data were consistent with recommendations in the literature . Of the 29 framework examples only seven examples did not have correlating support from the literature. The additional seven examples were from the case study respondents own experiences in conducting culturally secure research among Aboriginal children and their communities.

Twenty-nine framework examples for maintaining the cultural security of participants in Aboriginal health research were presented to the expert panel for content validation. On a continuous scale of 1 (would not maintain cultural security) to 5 (would maintain cultural security) every framework example received a mean rating >3.5. Twenty three framework examples were rated >4 for maintaining cultural security by the expert panel.

These 29 framework examples were then matched to the Aboriginal values and principles relevant to health research (NHMRC, 2003) and re-presented to panel members (repetition produced a total of 87 items). Panel members rated the examples for their ability to demonstrate the principles within the NHMRC (2003) guidelines. On a categorical scale (1 = strongly disagree; 2 = disagree; 3 = neither; 4 = agree; 5 = strongly agree) 79 out of 87 items received a mean rating >4.0.

Consensus among the panel members for framework examples that demonstrated the Aboriginal values relevant to health research was reached for 60 of the 87 examples. That is to say that 31.03% of the examples presented to the expert panel did not receive a score of 4 or more (agree; strongly agree) by the majority of respondents for demonstrating a principle of the NHMRC (2003) values. This can be explained, in part, by the small sample (n=7) of this project. However, based on comments by respondents, it is believed that if some of the examples (such as Reciprocity 1b) were reworded a greater level of consensus could have been reached among the expert panel. At the same time, polar views expressed by some panel members indicate that rewording of all the examples with a SD >1.0 would not have increased the level of consensus, such as Survival and Protection 3.c

and 4.b. Discussion on these examples (Reciprocity 1b; Survival and Protection 3.c & 4.b) is provided in more detail in 6.2.1 and 6.2.2.

6.2.1 Cultural security

The six framework examples presented to the expert panel for maintenance of cultural security that received a mean rating of 3.5-4.0 are discussed below.

Research will find evidence to help Aboriginal people stay strong and healthy (Reciprocity 1b; Survival and Protection 4b)

Two respondents indicated that this framework example would maintain cultural security (5.0); the remaining five respondents answered at 0.5 intervals (2.0; 2.5; 3.0; 3.5; 4.0). The variation in responses shows an uncertainty about this example. However, both case studies recommended that ethical research projects should provide Aboriginal people with additional knowledge about their health (Case study, 1, 2). The range of responses may be explained by a panel member comment that the wording used for this example did not "... *make sense!*" Although pilot testing was conducted, as described in the limitations, there was insufficient time for focus group testing of the instrument.

Project provides training and job opportunities for Aboriginal people (Reciprocity 5a; Respect 1b, 3b, 4c; Equality 1d; Survival and Protection 2c; Spirit and Integrity 1a, 2c)

The majority of respondents (n=6) were divided as to whether this example would maintain moderate (n=3; 3.0 – 3.5) or higher (n=3; 5.0) levels of cultural security. This was surprising, given the emphasis within the literature and the case studies advocating empowerment through community involvement, consultation and ownership (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Henry et al., 2002; Sheehan et al., 2002; Shibasaki & Stewart, 2005). Both the case studies and the literature suggest that appropriate and relevant acknowledgement of local knowledge, such as payment for cultural consultancy; paid assistance in data collection, analysis and write up can strengthen the cultural security of a project (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Henry et al., 2002; Sheehan et al., 2002; Shibasaki & Stewart, 2005). One respondent's view that they "... *do not believe that*

'projects' are funded or organised to capacity build or establish sustainability" provides an explanation for the lowest score (2) awarded to this example.

Research information collected used to help the community get future health funding (Reciprocity 5c; Survival and Protection 1b)

The majority of respondents (n=4) rated this example relatively low (2.0 – 3.0). This was interesting considering the focus the NHMRC (2003) guidelines and the case studies place on long term reciprocal benefits to Aboriginal people who participate in health research. In the questionnaire, the example uses the phrase 'might be useful' and it is recognised that this may be ambiguous wording. However, as there are no comments available for this example it is difficult to determine the exact cause for the low mean. Further exploration of this example is required in future research.

Community members are personally invited to be involved in the project

Although the mean for this example (3.81) is less than agree (4.0) it did not warrant an in depth analysis given missing respondent information (n=1). This decision is further supported by the case studies. Case Study 1 suggested that part of the process for building relationships of trust with potential communities or participants includes getting to know the people. Further to this, Case Study 1 found that this recruitment strategy was successful in providing access to 70% of the participant's parents. Although Case Study 1 is a pilot study with a small sample size (n=50), participants for the WAACHS (n=5200 from 2000 families) were recruited throughout the state by door knocking over 139 000 homes (Telethon Institute for Child Health Research, 2005).

Record method of agreement by community (Respect 6b)

In isolation, this example received a low mean (3.82) for maintaining cultural security with an SD of 1.24. However, when placed against the NHMRC (2003) guidelines in Part B of the instrument (Appendix 2) the mean increased to 4.51 which is consistent with information collected in Case Study 1. The change in mean scores demonstrates that some of the proposed framework examples may have been difficult for respondents to rate out of context. Furthermore, 'recording' is a process rather than an outcome which is likely to maintain cultural security on its own.

Whole community involved in the research (Equality 1a)

This example received the lowest mean (3.37) for maintaining cultural security (Part A, Appendix 2) due to ratings of 'strongly disagree' (n=1) and 'disagree' (n=2). The mean remained unchanged when this example was presented again in Part B of the instrument (Appendix 2). The suggestions for modifications to clarify the wording used for this example were taken on board for the review of the proposed framework (Appendix 11). Given the wording in the proposed framework, this example would have been better represented in the principle of Survival and Protection, rather than Equality (Case study, 1).

6.2.2 Demonstrating principles for the Aboriginal values relevant to health research (NHMRC, 2003)

Of the 87 framework examples presented to the expert panel to determine if they demonstrate the Aboriginal values relevant to health research (NHMRC, 2003); eight received mean scores <4.0 (agree); 73 received a mean score of 4.0 – 4.6; six of the examples received a mean score >4.6. Seven examples received a percentage positive <71.4; meaning that for those examples three or more respondents rated the example <4.0 (agree).

Reciprocity and Respect

None of the framework examples presented for demonstrating Reciprocity and Respect scored a mean <4.0. However, within these values the example regarding capacity building of Aboriginal people in health research continued to receive varied responses. This is evident in the SD ranging from 1.10 – 1.42 when it was repeatedly presented as an example for demonstrating a number of principles. The SD indicates a lack of consensus.

Within the principle of Respect one example had a percentage positive <71.4 and two examples score a mean >4.60; examples 2b, 3c and 8d are discussed below.

Respect 2b – *community members are personally invited to be involved in the project*: although the mean (4.10) and SD (0.78) indicate agreement among the expert panel for this example demonstrating the value of Respect, the percentage positive (57.1) indicates

otherwise. This anomaly is primarily explained by missing information (n=1). Support for the importance of this example was presented in the discussion of 6.2.1.

Respect 3c – *research information given to the community in an appropriate style and language*: the mean for this example (4.64) is consistent with recommendations for community appropriate feedback (Donovan & Spark, 1997; Hecker, 1997; Miller & Rainow, 1997).

Respect 8d – *management plan or communication strategy*: this example scored the highest mean (4.78) within a principle and confirms the importance of early and continued community consultation (Hearn & Wise, 2004; Henderson et al., 2002). The mean score for this principle also affirms the need for Aboriginal health research projects to establish a management plan or communication strategy for feeding information back to project participants and their community (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).

Equality

Within this value only one example received a mean score <4.0 and a percentage positive <71.4. This example, 1a – *whole community involved in the* research: was discussed earlier in 6.2.1 and was only presented once for demonstrating the Aboriginal values relevant to health research (NHMRC, 2003) within the questionnaire.

Responsibility

Four examples received a mean score >4.60 for demonstrating Responsibility:

Responsibility 2a & 3c – *regular progress reports to community*: this example scored the same mean (4.64) on both presentations in the framework. This is consistent with the literature and the case studies regarding the importance of regular and appropriately styled feedback about project progress to the community (Case study, 1, 2; Donovan & Spark, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997).

Responsibility 3b – *community committee guides the project*: this example was presented 21 times throughout the questionnaire to demonstrate all six values, and hence recognises the collaborative consultation required between the project and the community for successful and sustainable change (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). Within principle 3, example b received its highest mean score of 4.65 showing that community consultation is essential for effective and appropriate resolution to take place, should an issue arise.

Responsibility 4c – *before research information is published it is presented to community*: it was expected that this example would score highly (4.64) as the NHMRC (2003) guidelines, the *Communication Strategy* (Kulunga Research Network & Telethon Institute for Child Health Research, no date) and the case studies all promote community approval of project information before write-up or publication. As such, this strategy is considered essential to ensuring that the community is happy with the project information.

Survival and Protection

The majority (n=7) of examples to receive a mean score <4.0 (agree) are found within this value:

Survival and Protection 1a – *community committee guides the project*: Given the above discussion regarding this example under Responsibility 3b, it was unexpected that this example would score <4.0 under the value of Survival and Protection. In the context of this value, it was believed that this example would successfully assist researchers in making sure that the community culture remained safe and strong (NHMRC, 2003). There was no additional information provided to explain why two respondents rated this example with a 2 (disagree).

Survival and Protection 1b – *research information collected used to help the community get future health funding*: again, there was no additional information from respondents to

support the low mean (3.50) and consensus (42.9%) for this example. The case studies and the Communication Strategy (Kulunga Research Network & Telethon Institute for Child Health Research, no date) both support the inclusion of this example within the framework and the aim of this particular principle was to build the social and cultural bonds within families and the community (NHMRC, 2003).

Survival and Protection 3c & 4a – *project provides training and job opportunities for Aboriginal people*: as briefly discussed in Reciprocity and Respect within this chapter, this example repeatedly scored a high SD. It was interesting that within the value of Survival and Protection the mean (3.78) and consensus (57.1%) on this example because the aim of this value is to keep the Aboriginal culture of project participants strong (NHMRC, 2003). In Aboriginal health research the provision of employment and training opportunities seems an obvious strategy to facilitate the survival and protection of Aboriginal culture (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997). Comments by panel members (Appendix 13) regarding this example highlight and support the complexities identified in the literature regarding Aboriginal health research, funding institutions and Aboriginal communities (Durie, 2004; Pyett, 2002; Shibasaki & Stewart, 2005).

Survival and Protection 4b – *research will find evidence to help Aboriginal people stay strong and healthy*: the mean for this example in demonstrating Survival and Protection was 3.97. When this example was presented within the value of Reciprocity it received a mean of 4.41. Although 3.97 is close to a consensus for agreement, the discrepancy (0.44) between different values for the same example indicates that this example may be better suited to demonstrating principles within other values. However, the literature supports the use of this example for demonstrating this principle of Survival and Protection. A committee that is made up of community representatives who influence the project topic and design (including data collection, analyses, interpretation and write up) represent the cultural distinctiveness of their community, thus demonstrating Survival and Protection (Case study, 1, 2; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; Waples-Crowe & Pyett, 2005).

Survival and Protection 4d – *written agreement about research*: this example was presented for validation four times within the framework. Within this principle, this example received its lowest mean (3.90) indicating that this example better demonstrates Reciprocity and Equality rather than the value of Survival and Protection (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).

Survival and Protection 5a – *complaints process established*: the mean for this example (3.71) and consensus (57.1%) was unexpected because in isolation, this example scored a mean of 4.50 for maintaining cultural security. No additional information was provided by the expert panel to explain the low ratings of this example in demonstrating this particular principle. Despite the low mean, the case studies and the literature support the need for a grievance process within the project (Case study, 1, 2; Hearn & Wise, 2004; Meyer, 2000; Miller & Rainow, 1997; Sheehan et al., 2002; Thomsen, 2003).

Spirit and Integrity

Within this value, example 2c, related to providing *training and job opportunities for Aboriginal people* received a mean <4.0 (3.92) and a consensus <71.4 (57.1%); a discussion around this principle has already been presented in this chapter under Survival and Protection 3.c & 4.a.

Although none of the examples presented within this value scored extremely high mean (>4.6), one example warrants discussion.

Spirit and Integrity 4a – *plan for giving project information back to community developed before project starts*: this example was only presented once within Part B of the questionnaire (Appendix 2) and scored a high mean for demonstrating the principle (4.35; SD 0.47; 100% positive) and for maintaining the cultural security (4.72; SD 0.43). This response from panel members confirms the importance of a strategy that ensures feed back of project information to the participating community (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).

6.3 Implications of this project

As stated in the sub-questions of this thesis project, the aim of the proposed framework was to determine what researchers can do to demonstrate Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity (NHMRC, 2003) when conducting health research among Aboriginal school children in WA. Recognising the limitations within this project, the above discussion suggests that the framework presented to the expert panel for validation (Appendix 2) required revision and modification. It is important to acknowledge that variables outside the scope of this project also influence the maintenance of cultural security, as one panel member commented, *"All principles are good with examples but still have many hidden variables i.e. done in the right way, by the right person etc. Alone its hard to comment."*

Following the analysis and discussion of the expert panel findings, the framework was reviewed and modified (Appendix 11). Very few changes were made to the new framework (Appendix 11) other than wording of some examples, as directed by expert panel results. Within the new framework (Appendix 11) emphasis is given to expert panel suggestions and feedback by bolded text; where an example scored low consensus among respondents, attention is drawn to the reader by asterisk.

Every effort was made to present the framework (Appendix 11) in a concise and clear manner; despite these efforts it remains quite lengthy and repetitious. The framework (Appendix 11) is in no way is it intended to replicate the NHMRC (2003) guidelines.

It would be interesting if future research was conducted to track the extent to which the revised framework (Appendix 11) facilitates a collaborative ethics process and maintains the cultural security of project participants through the demonstration of the Aboriginal values relevant to health research (NHMRC, 2003). Given that few framework modifications were made, the use of a modified Delphi technique (Delbecq et al., 1986) to obtain greater consensus and develop a more valid framework would also be an interesting research project.

Chapter Seven

Conclusion

This thesis project incorporated a comprehensive literature review, the collection of two case studies and a content validation by an expert panel of a proposed framework. These project components were developed to gain an understanding of the ethical procedures required for maintaining cultural security when conducting health research with Aboriginal and Torres Strait Islander children in Western Australia. The Aboriginal values and principles relevant to health research as established by the National Health and Medical Research Council were used to drive the research questions and instruments designed for this project.

The findings of this study indicate that practice informed evidence (case studies) supported the recommendations within the literature for maintaining the cultural security of Aboriginal health research participants. Both informed the development of the proposed framework. Feedback (content validation) from an expert panel of experienced Aboriginal health promotion practitioners and Aboriginal health researchers on the proposed framework confirmed that, with slight modifications, the framework would assist a research project to demonstrate Aboriginal values relevant to health research and thus maintain the cultural security of Aboriginal participants.

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World Health Organisation. (2005). *The Bangkok Charter for Health Promotion in a Globalized World.* Retrieved 26 October, 2005, from http://www.who.int/healthpromotion/conferences/6gchp/bangkok_charter/en/print.html

Appendices

Appendix 1

Case study instrument

Maintaining cultural security through demonstrating the values of: reciprocity, respect, equality, survival and protection, responsibility and spirit and integrity in Aboriginal child health research.

Case study interviews

Thank you for agreeing to be involved in this interview. It should take no more than 25 minutes to complete. Any identifying information you provide will remain strictly confidential.

The aim of this research project is to develop a framework for ethics procedures that demonstrate the values of Western Australia's Aboriginal people when conducting health research among Aboriginal school children. This interview is divided into the six value categories with their respective principles as identified by the National Health and Medical Research Council.

In each category you will be asked to describe **how you demonstrated these values in your previous research with Aboriginal people** to meet the requirements of Aboriginal health research as set by the Western Australian Aboriginal Health Information and Ethics Committee. The values are: **reciprocity; respect; equality; survival and protection; responsibility; and spirit and integrity** (National Health and Medical Research Council, 2003).

Please feel free to provide any additional information or examples where relevant.

Dionne Paki
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08 92798793

Reference:

National Health and Medical Research Council. (2003). *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.* Canberra, ACT: Commonwealth of Australia.

Date of interview_____ Start time of interview _____

About you

1. How many years have you been working in Aboriginal health research?
   _____ year/s
2. What is your major field of Aboriginal health research? (eg. Child, injury, etc)
   _____
3. What project/s have you been involved in that researched Aboriginal children?
   _____
   _____
4. Are you (circle correct response) male female
5. Are you Aboriginal or Torres Strait Islander? (circle correct response) yes - continue; no - go to value1
6. Are you Aboriginal? (circle correct response) yes - continue; no - go to value 1
7. Are your family/people from Western Australia? (circle correct response) yes - go to value 1; no - go to value 1

1. Reciprocity

*In the research context, reciprocity implies inclusion and means **recognising partners' contributions**, and ensuring that **research outcomes include equitable benefits** to **Aboriginal** and Torres Strait Islander **communities or individuals**.*

(National Health and Medical Research Council, 2003, p. 10).

Demonstrating the value of reciprocity – According to the NHMRC guidelines research projects should demonstrate the following principles for this value:

1.1 Intent to contribute to the advancement of the health and wellbeing of participants and communities.

1.2 Clear links to community **health priorities** that **respond to existing or emerging needs** as articulated by Aboriginal people.

1.3 Evidence of clear and truthful discussions about the **nature of benefits for participants** or other Aboriginal communities **prior to approval**.

1.4 Willingness to modify research in accordance with participating **community values and aspirations**.

1.5 Enhances the capacity of communities to draw benefit beyond the project through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level.

Allied National Statement requirements

Any risks of discomfort/harm to participants are balanced by the likely benefits to be gained – NS 1.14.

Respect for the dignity and well being of participants takes precedence over benefits of knowledge gained – NS 1.4.

1a. How did your Aboriginal Child Health Research (ACHR) project/ethics application demonstrate these principles?

1b. What else can you suggest to demonstrate these principles when conducting ACHR projects?

1c. What were the barriers to demonstrating this value/principle in your research project?

2. Respect

*Respectful research relationships acknowledge and **affirm the right of people to have different values, norms and aspirations**. Those involved in research processes should not be blind to difference.*
(National Health and Medical Research Council, 2003, p. 11).

Demonstrating the value of respect – According to the NHMRC guidelines research projects should demonstrate the following principles for this value:

2.1 The project **responds to the diversity of Aboriginal** people and their communities, including the way decisions are made.

2.2 The project engages with **Aboriginal knowledge and experience**.

2.3 The researchers **minimise the effects of difference blindness** on and in the research process.

2.4 The **processes of reaching agreement** demonstrate engagement with the **values** of the participating communities.

2.5 Whether the participating communities have **expressed satisfaction** with the research agreement and decision making processes.

2.6 Acknowledgement of the individual and collective **contribution** of the community to the research project.

2.7 Appropriate agreements have been **negotiated** about **ownership** and **rights of access to** Aboriginal **intellectual and cultural property**.

2.8 Agreement with participating communities all relevant issues including **management of data, publication arrangements** and **the protection of individual and community identity**.

Allied National Statement requirements

Respect for individual and community customs and cultural heritage – NS 1.2.

Respect for the dignity and well being of participants takes precedence over benefits of knowledge gained – NS 1.4.

Each participant must give informed consent to be involved in the research project – NS 1.9

A person has the right not to participate in the project or to withdraw consent from the project at anytime – NS 1.8, 1.12.

Integrity guides research conduct that is honest in dissemination and communication of results – NS 1.1

2a. How did your Aboriginal Child Health Research (ACHR) project/ethics application demonstrate these principles?

2b. What else can you suggest to demonstrate these principles when conducting ACHR projects?

2c. What were the barriers to demonstrating this value/principle in your research project?

3. Equality

Equality as a value may sometimes be taken to mean sameness. However, Aboriginal and Torres Strait Islander Peoples hold strong belief that ***sameness is not equality****. Aboriginal and Torres Strait Islander peoples have sought the* ***elimination of 'difference blindness'*** *so that* ***Aboriginal*** *and Torres Strait Islander* ***cultures can be appreciated and respected****.*

(National Health and Medical Research Council, 2003, p. 14).

Demonstrating the value of equality – According to the NHMRC guidelines research projects should demonstrate the following principles for this value:

3.1 Participating **communities are included** in the research processes with equality.

3.2 The research agreements have the strength necessary to sustain equality.

3.3 Participating communities have **understood and expressed satisfaction** with the proposed research, its potential benefits and their distribution. Researchers therefore have **responsibility** to ensure that the **information** that they provide is **understood and usable** in decision making by participating communities.

Allied National Statement requirements

Respect for individual and community customs and cultural heritage – NS 1.2.

Respect for the dignity and well being of participants takes precedence over benefits of knowledge gained – NS 1.4.

Each participant must give informed consent to be involved in the research project – NS 1.9

A person has the right not to participate in the project or to withdraw consent from the project at anytime – NS 1.8, 1.12.

Integrity guides research conduct that is honest in dissemination and communication of results – NS 1.1

3a. How did your Aboriginal Child Health Research (ACHR) project/ethics application demonstrate these principles?

3b. What else can you suggest to demonstrate these principles when conducting ACHR projects?

3c. What were the barriers to demonstrating this value/principle in your research project?

4. Responsibility

*A key responsibility within this framework is to **do no harm**, including **avoiding having an adverse impact** on others' abilities to comply with their responsibilities. Researchers and participating communities needs to establish processes to ensure **researchers' accountability** to individuals, families and communities particularly **in relation to the cultural and social dimensions** of Aboriginal and Torres Strait Islander life.*

(National Health and Medical Research Council, 2003, p. 16).

Demonstrating the value of responsibility – According to the NHMRC guidelines research projects should demonstrate the following principles for this value:

4.1 Agreed arrangements regarding publication of the research results, including **clear provisions relating to joint sign off for publication** and the **protection of individual and community identity** if appropriate.

4.2 Provision is made for appropriate **ongoing advice and review** from the participating community, including mechanisms to **monitor ethics standards** and to minimise the likelihood of any unintended consequences arising from or after the research project.

4.3 Timely feedback obligations to communities and whether that feedback is **relevant to the expressed concerns, values** and **expectations** of research participants and communities.

4.4 Clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it.

4.5 Measures are identified to demonstrate **transparency in the exchange of ideas** and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research.

Allied National Statement requirements

Respect for individual and community customs and cultural heritage – NS 1.2.

Respect for the dignity and well being of participants takes precedence over benefits of knowledge gained – NS 1.4.

Risk of harm and discomfort to participants has been minimized by researchers – NS 1.3.

Thorough study of current literature, prior observations and studies justify the research project – NS 1.13.

Privacy and confidentiality of participants is respected – NS 1.19.

4a. How did your Aboriginal Child Health Research (ACHR) project/ethics application demonstrate these principles?

4b. What else can you suggest to demonstrate these principles when conducting ACHR projects?

4c. What were the barriers to demonstrating this value/principle in your research project?

5. Survival and Protection

*Aboriginal and Torres Strait Islander Peoples continue to act to **protect their cultures and identity from erosion by colonisation** and marginalisation. A particular feature of Aboriginal and Torres Strait Islander cultures and these efforts has been the importance of a **collective identity**. This collective bond reflects and draws strength from the values base of Aboriginal and Torres Strait Islander Peoples and cultures.*

(National Health and Medical Research Council, 2003, p. 18).

Demonstrating the value of survival and protection – According to the NHMRC guidelines research projects should demonstrate the following principles for this value:

5.1 Whether the project contributes to or erodes the **social and cultural bonds** among and between Aboriginal families and communities.

5.2 What **safeguards** are in place against the research project contributing to discrimination or derision of Aboriginal culture.

5.3 Whether the proposal **respects the intrinsic values, expectations** and identity of Aboriginal communities including the **balance** between **collective and individual identity**.

5.4 How the proposal **contributes to** the opportunity for **Aboriginal** peoples' ability to enjoy their **cultural distinctiveness**.

5.5 Elimination of threats to Aboriginal ability to enjoy their cultural distinctiveness.

Allied National Statement requirements

Respect for individual and community customs and cultural heritage – NS 1.2.

Respect for dignity and well being of participant takes precedence over benefits of knowledge gained – NS 1.4.

Risk of harm and discomfort to participants has been minimized by researchers – NS 1.3.

5a. How did your Aboriginal Child Health Research (ACHR) project/ethics application demonstrate these principles?

5b. What else can you suggest to demonstrate these principles when conducting ACHR projects?

5c. What were the barriers to demonstrating this value/principle in your research project?

6. Spirit and Integrity

*This is an **overarching value that binds all others** into a coherent whole. It has two components. The first is about the **continuity between past, current and future** generations. The second is about behaviour, which maintains the **coherence of Aboriginal** and Torres Strait Islander **values and cultures**. Any behaviour that diminishes any of the previous five values could not be described as having integrity.*

(National Health and Medical Research Council, 2003, p. 19).

Demonstrating the value of spirit and integrity – According to the NHMRC guidelines research projects should demonstrate the following principles for this value:

6.1 How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's **cultural, spiritual and social cohesion**, including workable timeframes.

6.2 Whether the proponents of the proposal are able to clearly demonstrate **personal integrity**, specifically in the development of their proposal.

6.3 Whether the proposal recognises in the conduct and reporting of research the **diversity of Australian Aboriginal** culture including the **mechanisms through which communities may make decisions**.

6.4 Does the proposal **demonstrate a commitment** to working within the spirit and integrity of Aboriginal people?

Allied National Statement requirements

Integrity guides research conduct that is honest and ethical – NS 1.1

Respect for individual and community customs and cultural heritage – NS 1.2.

Respect for dignity and well being of participant takes precedence over benefits of knowledge gained – NS 1.4.

6a. How did your Aboriginal Child Health Research (ACHR) project/ethics application demonstrate these principles?

6b. What else can you suggest to demonstrate these principles when conducting ACHR projects?

6c. What were the barriers to demonstrating this value/principle in your research project?

That concludes our interview. Do you have anything further you wish to add?

_____

_____

_____

_____

Thank you very much for your time.

END OF INTERVIEW

End time of interview _____

Appendix 2

Expert panel instrument

Part A: *Framework examples and cultural security*

Part B: *Framework examples and the NHMRC (2003) values*

Maintaining cultural security through the demonstration of principles for the 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research'.

Expert panel questionnaire

Thank you for agreeing to be involved in this project. It is expected that the questionnaire will take approximately 15 minutes to complete. Any identifying information you provide will remain strictly confidential.

The aim of this questionnaire is to obtain content validation for a proposed framework designed to investigate the application of the NHMRC (2003) guidelines for ethical research with Aboriginal people to facilitate a collaborative ethics process. The proposed framework used in this questionnaire was developed using information from the NHMRC (2003) guidelines, a comprehensive literature review and interviews with Aboriginal health researchers. Case studies were created from the responses of two experienced Aboriginal researchers who were previously interviewed to find out how the child health research projects that they are involved in demonstrated the Aboriginal values relevant to health research.

The questionnaire is presented in two parts. In **Part A** you are asked to REVIEW the **green** framework examples that propose how the values and their principles outlined in the National Health and Medical Research Council (NHMRC, 2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* can be applied in child health research. **Blue** font has been used to identify suggestions from the case studies to contextualise the common framework examples.

Please INDICATE IN THE LEFT COLUMN whether the proposed framework examples that are identified in **green** font **would maintain the cultural security of Aboriginal primary school children** who participate in health research in Western Australia (WA). Cultural security refers to the ethical procedures that maintain the **"legitimate cultural rights, values and expectations of Aboriginal people"** who participate in health research (Western Australian Health Department, no date, p. 2).

Part B is divided into categories according to the six Aboriginal values relevant to health research of: **reciprocity**; **respect**; **equality**; **responsibility**; **survival and protection**; and **spirit and integrity** (NHMRC, 2003). Within each category the values and principles are identified in **black** font and the proposed framework examples are identified in **green** font, these are the same **green** examples from **Part A**. While **Part B** may seem to be a long document, many of the **green** examples have been repeated in more than one principle in recognition of the overlapping nature of the values. Please REVIEW each principle (in **black** font) and then INDICATE IN THE LEFT COLUMN whether the **green** example would demonstrate the NHMRC (2003) principles in **a health research project with Aboriginal primary school children in WA**.

You are welcome to make any comments you wish to on the principles or examples for each value.

Thank you,
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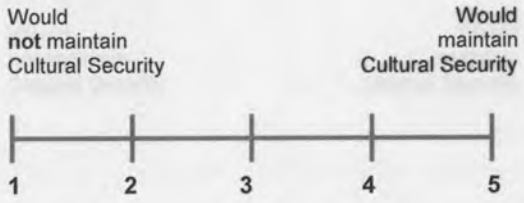
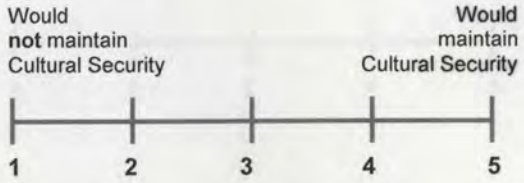
About you:

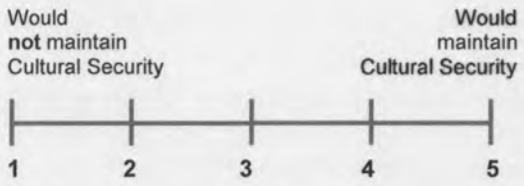
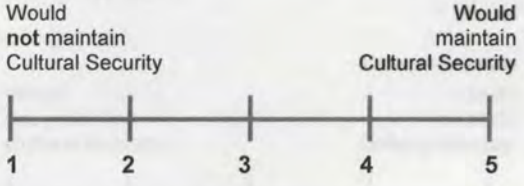
1. For how many years have you been working in Aboriginal health or education? _____ year/s
2. Are you (please circle your response) Male Female
3. Are you (please circle your response) Aboriginal Torres Strait Islander Neither

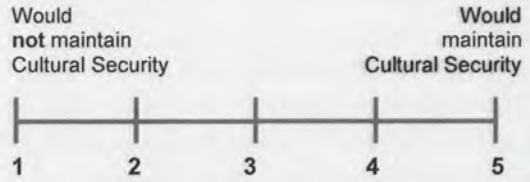
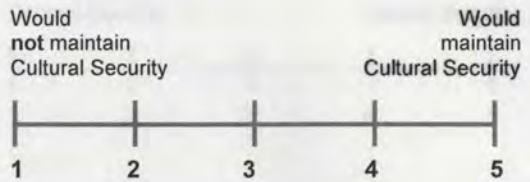
PLEASE TURN TO PAGE 3 TO BEGIN THE SURVEY

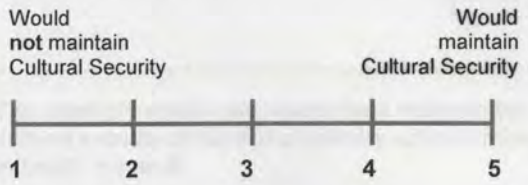
PART A

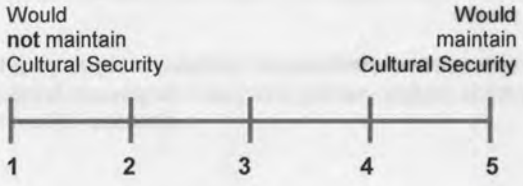
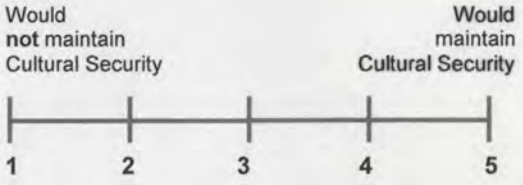
Level of Cultural Security	Framework Examples	Suggestions from the Case Studies
Please place an **X** on the line to indicate whether the **green** example would maintain the cultural security of Aboriginal primary school children who participate in a health research project in WA.	These examples propose how the principles outlined in the NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* can be applied or demonstrated in a health research project.	Descriptions of ways the framework examples can be demonstrated in Aboriginal child health research.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research. Would **not** maintain Cultural Security — **Would** maintain **Cultural Security** 1 2 3 4 5	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Prior to the project proposal, a community committee or group is formed to guide the project and make sure that community culture is respected and community health matters are represented throughout the whole research project (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson, Simmons, Bourke, & Muir, 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.

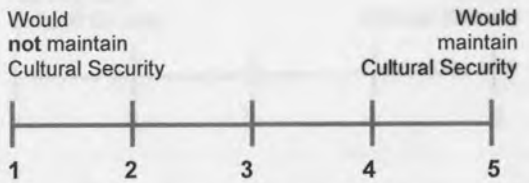
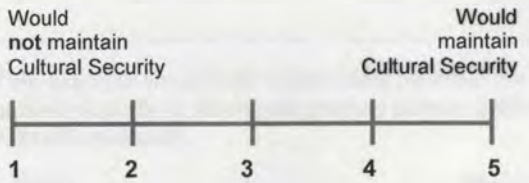
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect and Equality can be demonstrated by: ▪ The community committee agrees that the research project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy (Case study, 1, 2; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson, Kelaher, Williams, & Shannon, 1998; Waples-Crowe & Pyett, 2005).	• Feedback of project data provides the community with knowledge for decisions on the acceptance of future projects.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Aboriginal people and Aboriginal health organisations inform the project about the things that are important to them to keep their community strong and healthy (Case study, 1, 2; Donovan & Spark, 1997; Dressendorfer et al., 2005; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• Use of national Aboriginal health priorities and local community based reference groups including non-Aboriginal groups who work with an Aboriginal network. • A community owned project will naturally inform researchers of the health issues important to the community.

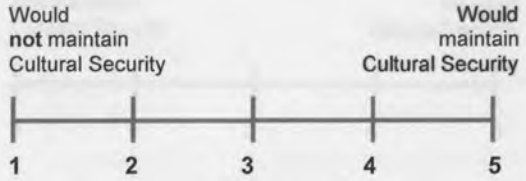
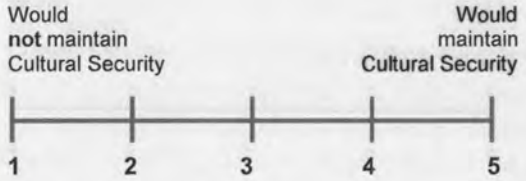
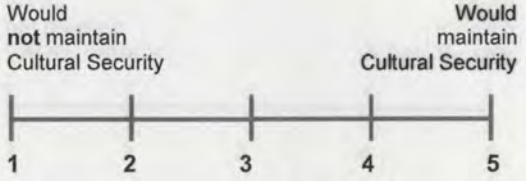
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The committee informs the project to make sure that the local health goals are represented and to confirm what the community wants to do about local health matters (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; Miller & Rainow, 1997; National Health and Medical Research Council, 2003).	• The committee will help manage the project and keep things going smoothly. • The committee advises researchers on the best direction of the project for the community. • The committee advises researchers what the community wanted to happen to the project information.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Communication between the committee and the project is transparent – phone calls; letters; emails; and consultation meetings are all noted to make sure that the project remains culturally appropriate for the needs of the community (Case study, 1).	• The committee informs the project when and how modifications to the project are required. For example when sensitivity is needed so that community members involved in the project can meet their cultural obligations should the need arise. • A flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. For all visits to the community throughout the project. It also ensures the project remains truthful in fulfilling its commitments to the community.

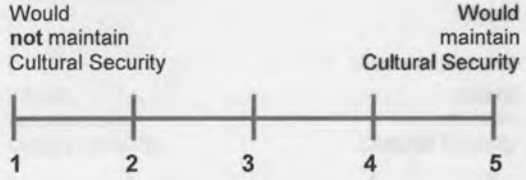
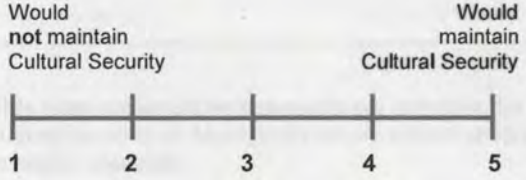
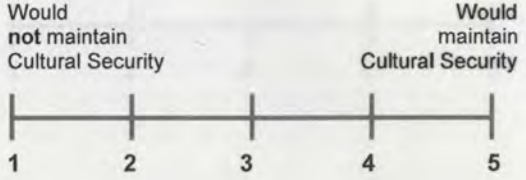
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members are given the opportunity to speak to researchers about the project in a group or one-on-one (Case study, 1, 2; Hearn & Wise, 2004; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Miller & Rainow, 1997; Sheehan, Ridge, & Marshall, 2002; Thomsen, 2003).	• A project information night or workshop is presented within the community prior to the commencement of the project and then as often as the committee feels is necessary. • Researchers allow for one-on-one time to make sure carers and children have all their questions answered.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.

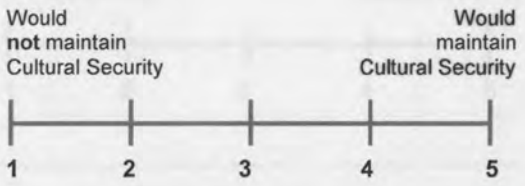
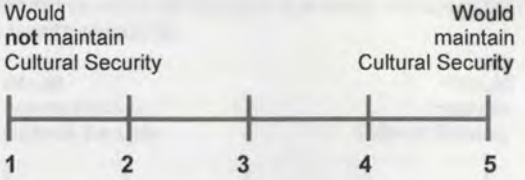
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project is given back to the community or region in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak, McDermott, Plant, & Scrimgeour, 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).	• Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points. • Use of story boards to feed project information back to the community.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project only tells a story about the community or region involved in the project (Case study, 1, 2; Holmes, Stewart, Garrow, Anderson, & Thorpe, 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).	• The use of 'regions', rather than the community's geographic name provides anonymity to project participants. • Diversity means allowing for Aboriginal people to be different to other Aboriginal people from different areas: data collected in urban Aboriginal projects only represents urban Aboriginal people; rural projects represent rural people; and remote projects represent remote people.

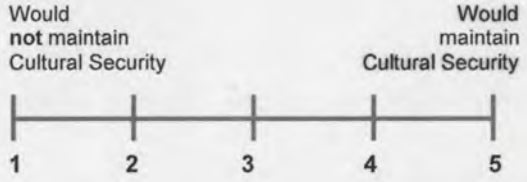
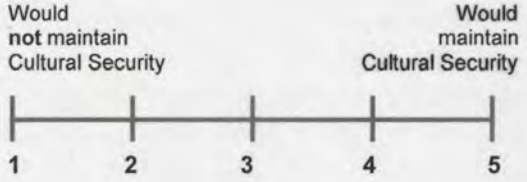
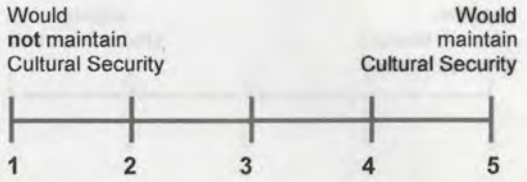
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project can be used to help the community make strong decisions in the future about their health (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Knowledge gained from the project can be used to educate non-Aboriginal people about the community's health issues.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information collected from the project might be useful to help the community get funding in the future for other health projects (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A successful pilot study provides support for future funding grants on the same or related topic in the same community or region.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members are personally invited to be involved in the project (Case study, 1).	• Invest time into getting to know the community and their school children before data collection by being involved: attend sports days; jump on the school bus; and meet the parents when they pick up their kids after school.

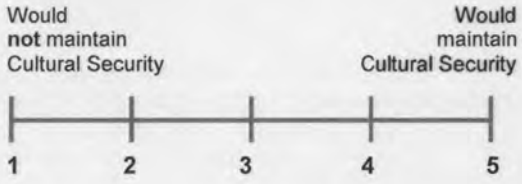
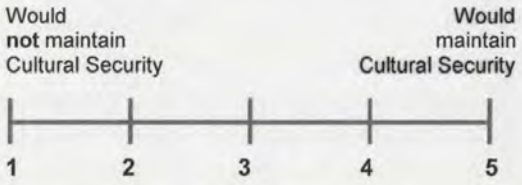
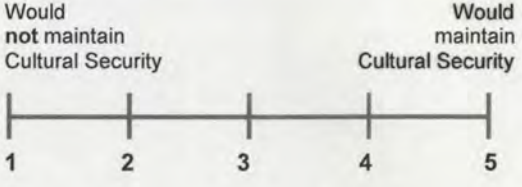
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members who want to be involved in the project are invited to share their thoughts about their own health and the health of their community (Case study, 1; Thomsen, 2003).	• As part of the data collection participants are asked what they think about health: for themselves, their families and their community.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The community committee and community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.

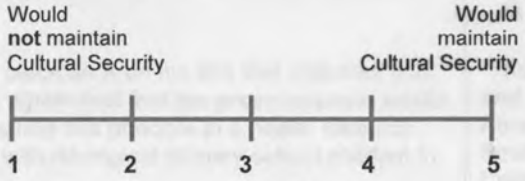
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A written agreement is made so that the community agrees with: how the project will be conducted, and what will happen to the project information (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• A statement of cultural consent and participation is developed through committee negotiations with the project. • The statement is in-line with the community's protocols.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The way the agreement was made is recorded (Case study, 1).	• If the agreement was made by a show of hands it is recorded that 'the agreement was accepted by the community by show of hands'
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The meeting for the agreement is held in a neutral or safe place for the people involved in the project (Case study, 1, 2).	• Somewhere outdoors is preferable, not in an office or in a school building.

This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Community members who are involved in the project can share their feelings about what they liked and did not like about the agreement, their feelings are recorded and actioned by researchers (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Sheehan et al., 2002; Thomsen, 2003).	• A 'time of reflection' is allocated at the conclusion of the committee/community meetings to give community members an opportunity to raise their concerns. • Community concerns are recorded in a 'processes journal' that is actioned by researchers.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Permission for access to project information must be applied for in writing to the committee (Case study, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Information access agreement – information from the project can not be accessed unless a written application is made. The data must be interpreted for the new project in consultation with an Aboriginal researcher (or assistant).
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A management plan or communication strategy is used to make sure that the project actions the required ethical processes. Progress of the management plan is reported back to the community committee throughout the research project (Case study, 1, 2; Hearn & Wise, 2004; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A matrix or flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. First visit, second visit through to final feedback after project completion. • Stages are matched up with ethics application to keep the project truthful and transparent.

This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Children of all ages, adults, males and females – the whole community is welcomed to be involved in the research project (Case study, 1).	• All children involved in the project sign their name, with an 'X' if necessary, to feel important and included. • Potential participants (children) are also invited to attend the project information session with their carers. • Researchers will attempt to match the gender of data collectors with participants.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Respect, Equality, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The information sheet and consent form are in an appropriate language and style for the community, and that people who want to be involved in the research project understand what it is about (Case study, 1, 2; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998).	• Large font is used for both the adults (to cater for poor eyesight from diabetes) and the children's information sheet. • The information and consent forms are presented to both the carers and the children one-on-one. • Both the carers and the children are given the opportunity to indicate their level of project participation eg. Permission to have photographic/video footage.

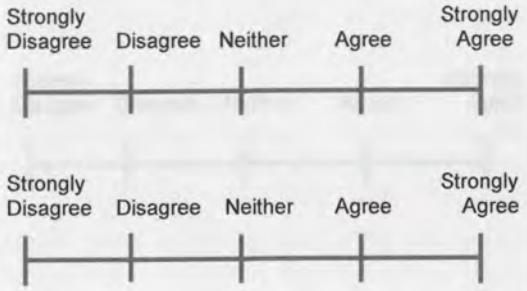
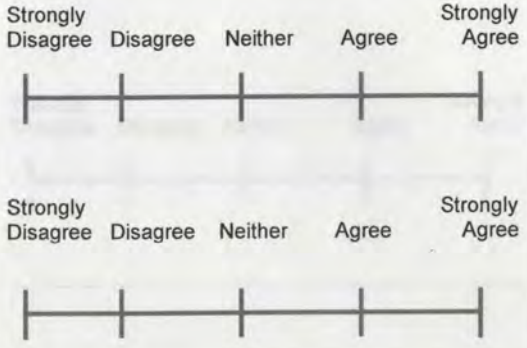
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The community members who want to be involved in the research project understand that they can change their minds about being involved in the project whenever they want (Case study, 1).	• Carers are assured that they can withdraw their children from participating in the project at any time without a fuss from researchers.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ All communication with the community committee is written down or noted to make sure that the project continues to be open and truthful eg. meeting minutes (Case study, 1).	• Emails, phone calls, and meeting minutes are recorded to track project progress and process changes negotiated by the community committee.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Regular progress reports about the project to the community from meeting minutes and the management plan. Reports are in an appropriate language and style for the community eg. newsletters and meetings. (Case study, 1, 2; Donovan & Spark, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • A written review is also done at the conclusion of the project as an overall evaluation.

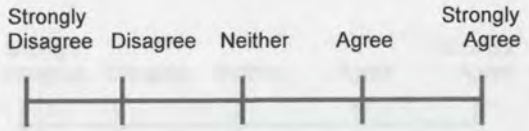
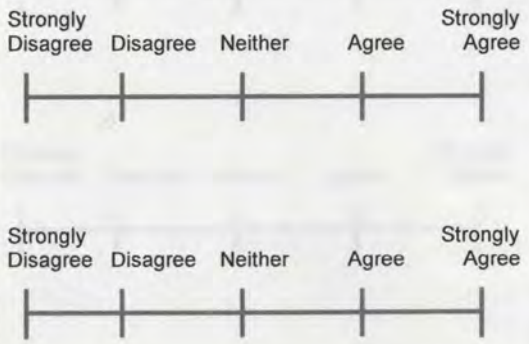
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ Before and after the information collected from the project is published it is presented and discussed with the community or region (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Pre and post publication information sessions are held in the participating community to provide: a background summary of the project; the results and what they mean; and to gain continuing support for the project.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ The committee is happy with the representation of their community in the project information before it is published (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• The committee is the gatekeeper of all the data collected in the project and must approve all project information prior to publication.
This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A complaints process is established so that community members who are involved in the project can share their feelings about what they liked and did not like about being involved. This will be actioned by researchers and reported back to the community in an appropriate language and style (Case study, 1, 2; Hearn & Wise, 2004; Meyer, 2000; Miller & Rainow, 1997; Sheehan et al., 2002; Thomsen, 2003).	• The community is informed at the first information session that a complaints process is available should they require it. Researchers are accountable for actioning the complaints and reporting them back to the community.

This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.  	Reciprocity, Respect, Equality, Responsibility, Survival and Protection and Spirit and Integrity can be demonstrated by: ▪ A plan for giving project information back to the community is developed before the project begins (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A matrix is constructed to inform/manage what needs to get done at different stages of the project, eg. First visit, second visit through to final feedback after project completion. • Stages are matched up with ethics application to keep things truthful and transparent. • Support for the project is conditional upon assurance that participating families and communities receive feedback at every stage of the project.

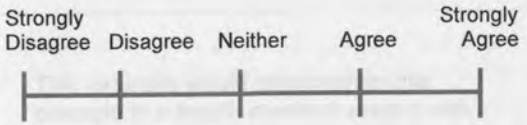
PART B

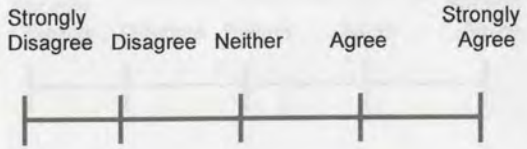
Level of Agreement	Demonstrating the principles for the Aboriginal values relevant to health research	Comment on Principles & Examples
Please place an **X** on the line that indicates your level of agreement that the **green** example would demonstrate this principle in a health research project with Aboriginal primary school children in WA.	"The document contains guidelines for ethical health research on Aboriginal and Torres Strait Islander peoples. In accordance with guidance from Aboriginal people it is written around a framework of Aboriginal and Torres Strait Islander values and principles" (National Health and Medical Research Council, 2003, no page).	
	▪ **Reciprocity** This value aims to make sure that there are **equal benefits for both researchers and participants** for the research project. For an equal exchange to occur, the 'benefits' of the research project must be defined by the priorities and values of the participating community (NHMRC, 2003).	

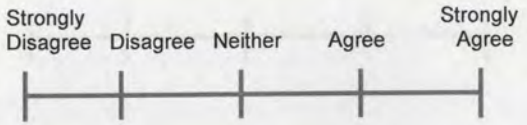
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	1. *Before the research project starts the researchers will explain how the project will try to help improve* ***the health and wellbeing*** *of the community (NHMRC, 2003).* This principle can be demonstrated when: ▪ Prior to the project proposal, a community committee or group is formed to guide the project and make sure that community culture is respected and community health matters are appropriately represented. ▪ The committee agrees that the research project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy.	*Please describe any suggestions of other examples that would demonstrate this principle.*
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	2. *Making sure that the purpose of the project is* ***connected*** *to the* ***community health priorities and health needs*** *that* ***Aboriginal*** *people have talked about (NHMRC, 2003).* This principle can be demonstrated when: ▪ Aboriginal people and Aboriginal health organisations inform the project about the things that are important to them to keep their community strong and healthy. ▪ The committee informs the project to make sure that the local health goals are represented and to confirm what the community wants to do about local health matters.	*Please describe any suggestions of other examples that would demonstrate this principle.*

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	3. *Showing that **clear and truthful discussions** about the **benefits the community will receive for participating** in the research project have happened (NHMRC, 2003).* This principle can be demonstrated when: ▪ Communication between the committee and the project is transparent – phone calls; letters; emails; and consultation meetings are all noted to make sure that the project remains culturally appropriate for the needs of the community.	*Please describe any suggestions of other examples that would demonstrate this principle.*
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	4. *Showing a **willingness to make changes to include** the **community's values and goals** in the research project (NHMRC, 2003).* This principle can be demonstrated through: ▪ Open communication with the community committee so that researchers can be guided to make sure that community culture and health matters are represented throughout the project. ▪ Community members are given the opportunity to speak to researchers about the project in a group or one-on-one.	*Please describe any suggestions of other examples that would demonstrate this principle.*

This example would demonstrate this principle in a health research project with **Aboriginal primary school children in WA:**







5. ***Building the community's capacity to have the benefits from the project continue after the project is finished****, eg through the development of skills (NHMRC, 2003).*

This principle can be demonstrated when:

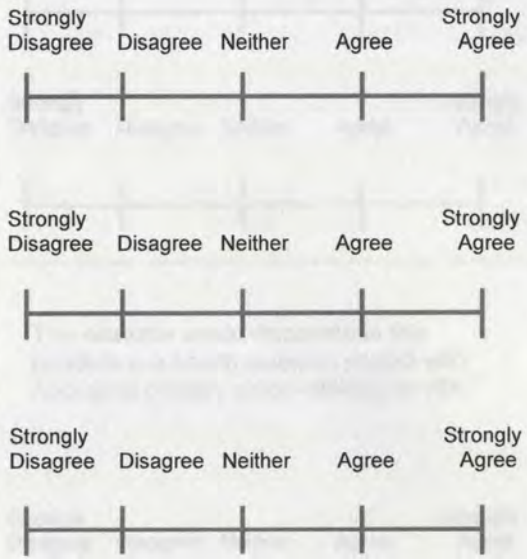
- The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.
- The information collected from the project can be used to help the community make strong decisions in the future about their health.
- The information collected from the project might be useful to help the community get funding in the future for other health projects.

Please describe any suggestions of other examples that would demonstrate this principle.

▪ Respect

This value aims to **acknowledge the contribution of participants** to the research project in a **cooperative and sensitive way**. It also aims to make sure that full **community consultation** happens throughout the entire research process (NHMRC, 2003)

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:

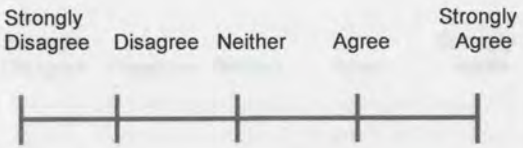
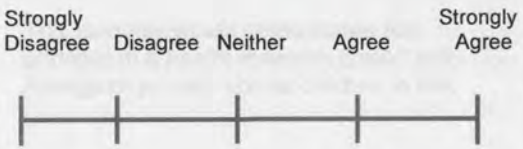
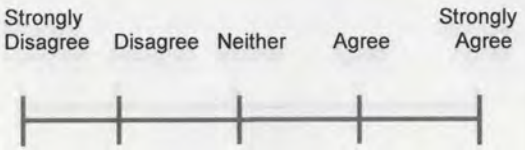
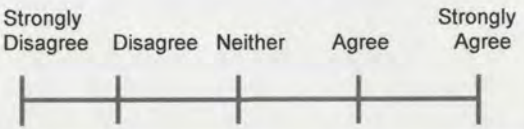


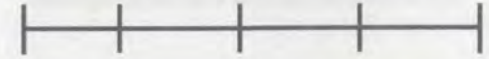
1. *The project **accepts the differences between different Aboriginal communities,** including the way decisions are made (NHMRC, 2003).*

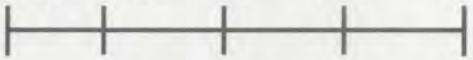
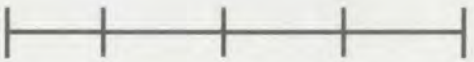
This principle can be demonstrated when:

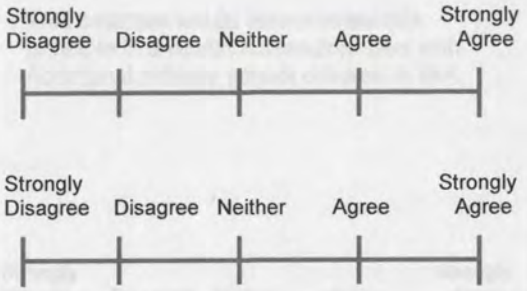
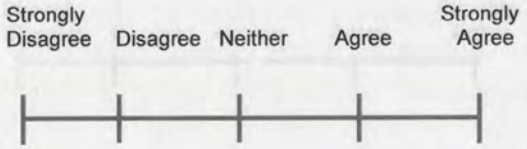
- The committee informs the project about community culture and health matters.
- The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.
- The information collected from the project only tells a story about the community or region involved in the project.

Please describe any suggestions of other examples that would demonstrate this principle.

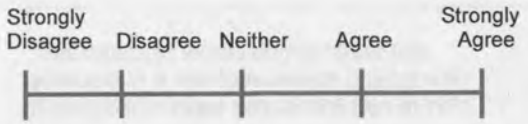
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:    	2. *The project **acknowledges the individual and collective contribution of Aboriginal** people (NHMRC, 2003).* This principle can be demonstrated when: ▪ The information collected from the project is given back to the community or region in an appropriate language and style. ▪ Community members are personally invited to be involved in the research project. ▪ Community members who want to be involved in the project are invited to share their thoughts about their own health and the health of their community.	*Please describe any suggestions of other examples that would demonstrate this principle.*
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	3. *The project **accepts the differences between Aboriginal and non-Aboriginal cultures and between different Aboriginal communities** (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee guides the project to make sure that community culture and health matters are appropriately represented.	*Please describe any suggestions of other examples that would demonstrate this principle.*

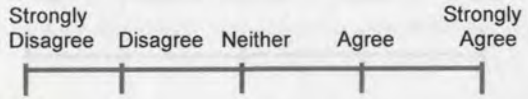
Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree 	▪ The project provides training and job opportunities to (if possible, local) Aboriginal people to help analyse information for the project and develop the results. ▪ The information collected from the project is given back to the community or region in an appropriate language and style.	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree 	4. *The **research project uses Aboriginal knowledge and experience** (NHMRC, 2003).* This principle can be demonstrated by: ▪ Open communication between the committee and the project to make sure that the community culture and health matters are appropriately represented. ▪ Open communication with the community committee so that community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; b) what the results mean for keeping their community strong and healthy; and c) what they liked and did not like about being involved in the research project.	*Please describe any suggestions of other examples that would demonstrate this principle.*

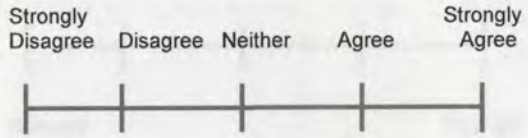
Strongly Disagree Disagree Neither Agree Strongly Agree 	▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree 	5. ***An agreement*** *about the* ***ownership and rights of access*** *to* ***Aboriginal intellectual and cultural property*** *is organised and the community committee is* ***happy*** *with the agreement (NHMRC, 2003).* This principle can be demonstrated by: ▪ A written agreement is made so that the community agrees with: how the project will be conducted, and what will happen to the project information. ▪ Permission for access to the project information must be applied for in writing to the committee.	*Please describe any suggestions of other examples that would demonstrate this principle.*
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree 	6. *The researchers must prove that the* ***community's values*** *for making the* ***agreement*** *are used (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented.	*Please describe any suggestions of other examples that would demonstrate this principle.*

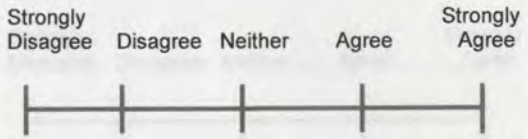
	▪ The way the agreement was made is recorded, eg. if the agreement was made by a show of hands it is recorded that 'the agreement was accepted by the community by show of hands'. ▪ The meeting for the agreement is held in a neutral of safe place for the people involved in the project.	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: 	7. *The community has said that they are **happy with the agreement** for the research project and the way it was made (NHMRC, 2003).* This principle can be demonstrated when: ▪ Community members who are involved in the project are invited to share their feelings about what they liked and did not like about the agreement.	*Please describe any suggestions of other examples that would demonstrate this principle.*

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:









8. *When the **agreement** is made the community committee is happy with the **storage of data and the publication of the information** collected for the research project. The people who are involved in the project are **happy** with the agreement and **feel that their identity is safe and protected** (NHMRC, 2003).*

This principle can be demonstrated when the:

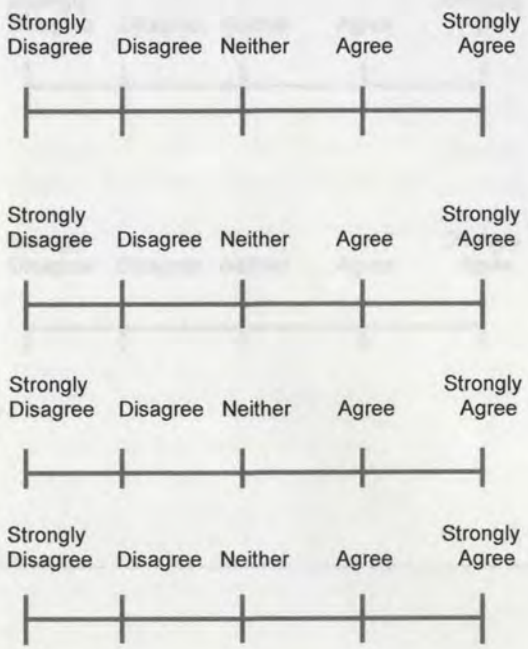
- The committee informs the project to make sure that community culture and health matters are appropriately represented.
- Community members who are involved in the project are invited to share their feelings about:
  a) how the information is collected;
  b) the results;
  c) what the results mean for keeping their community strong and healthy; and
  d) what they liked and did not like about being involved in the research project.
- A written agreement is made so that the community agrees with the storage and publication of the project information.
- A management plan or communication strategy is used to make sure that the project actions the required ethical processes. Progress of the management plan is reported back to the community committee throughout the research project.

Please describe any suggestions of other examples that would demonstrate this principle.

▪ Equality

This value aims to make sure that the **cultural needs** of Aboriginal research participants are catered for within the research project and that the **differences** between **Aboriginal and non-Aboriginal world views are accepted** (NHMRC, 2003).

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:



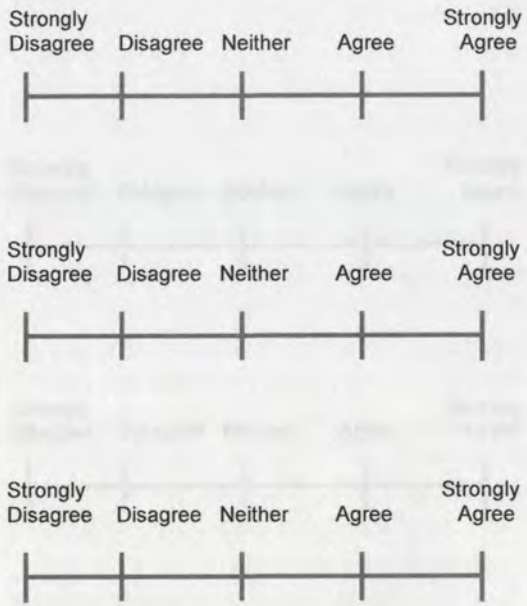
1. *Community **involvement** in the research project **shows equality** (NHMRC, 2003).*

This principle can be demonstrated because:

- Children of all ages, adults, males and females – the whole community is welcomed to be involved in the project.
- The information collected from the project is given back to the community or region in an appropriate language and style.
- The committee informs the project to make sure that community culture and health matters are appropriately represented.
- The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.

Please describe any suggestions of other examples that would demonstrate this principle.

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:



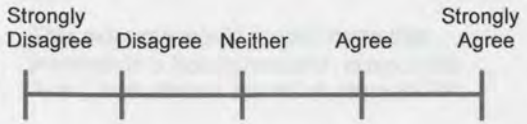
2. *In the **agreement** for the research project everyone is treated with **equality** (NHMRC, 2003).*

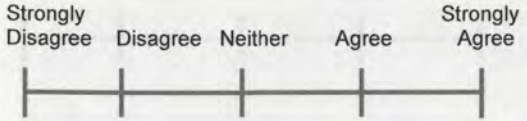
This principle can be demonstrated when:

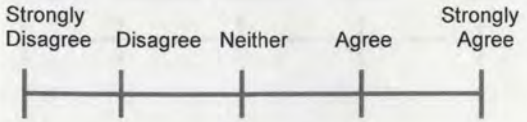
- The information collected from the project is given back to the community or region in an appropriate language and style.
- The committee informs the project to make sure that community culture and health matters are appropriately represented.
- Community members who are involved in the project are invited to share their feelings about:
  a) how the information is collected;
  c) the results;
  d) what the results mean for keeping their community strong and healthy; and
  e) what they liked and did not like about being involved in the research project.

Please describe any suggestions of other examples that would demonstrate this principle.

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:







3. *Researchers make sure that the information that they provide to the community about the research is **understood and usable in decision making**. The **community is happy** with what the researchers say they will do with the **information collected** from the research project (NHMRC, 2003).*

This principle can be demonstrated when researchers make sure that:

- The information sheet and consent form are in an appropriate language and style for the community, and that people who want to be involved in the project understand what it is about.

- The community members who want to be involved in the project understand that they can change their minds about being involved whenever they want.

- Community members who are involved in the project are invited to share their feelings about:
  b) how the information is collected;
  c) the results;
  d) what the results mean for keeping their community strong and healthy; and
  e) what they liked and did not like about being involved in the research project

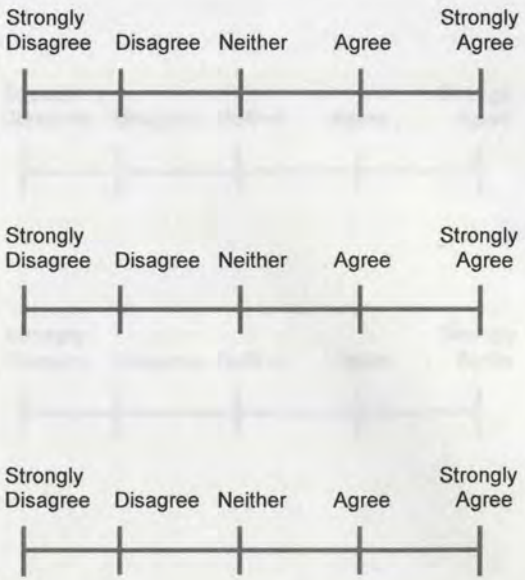
  eg. through community meetings, newsletters, management plan.

Please describe any suggestions of other examples that would demonstrate this principle.

▪ Responsibility

This value aims to make sure that research does **no physical, social, mental or emotional harm** to participants. Researchers have the responsibility to make sure that the research project does not stop participants from doing their **cultural and social responsibilities** (NHMRC, 2003).

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:



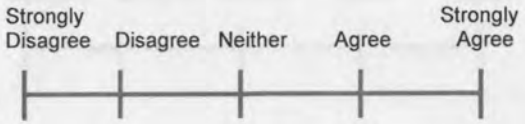
1. *Researchers must make sure that the **sharing of ideas** about the benefits and how the research project will be conducted with the community committee is **open and truthful** (NHMRC, 2003).*

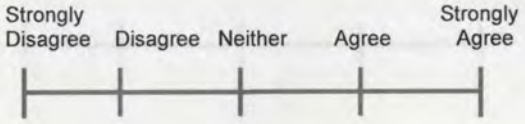
This principle can be demonstrated if:

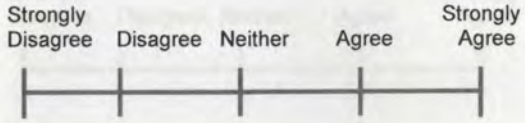
- All communication with the committee is written down or noted to make sure that the project continues to be open and truthful eg. meeting minutes.
- The committee informs the project to make sure that community culture and health matters are appropriately represented.
- The community is happy with:
  a) how the information will be collected;
  b) how the information will be stored;
  c) what the results are; and
  d) what the results mean for keeping their community strong and healthy.

Please describe any suggestions of other examples that would demonstrate this principle.

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:







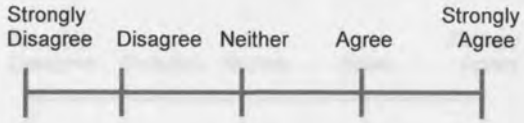
2. *Researchers must show **continuing communication** with the community to make sure **ethical standards are safe** throughout the whole research project (NHMRC, 2003).*

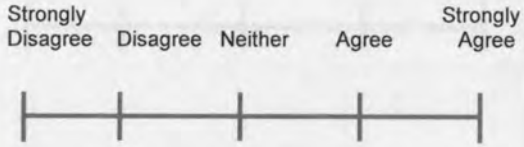
This principle can be demonstrated if:

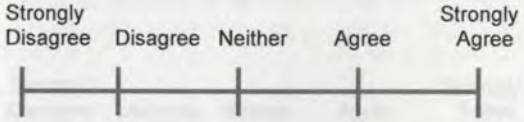
- Regular progress reports about the project to the community from meeting minutes and the management plan. Reports are in an appropriate language and style for the community eg. newsletters and meetings.
- The committee informs the project to make sure that community culture and health matters are appropriately represented.
- Community members who are involved in the project are invited to share their feelings about:
  e) how the information is collected;
  f) the results;
  g) what the results mean for keeping their community strong and healthy; and
  h) what they liked and did not like about being involved in the research project

Please describe any suggestions of other examples that would demonstrate this principle.

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:







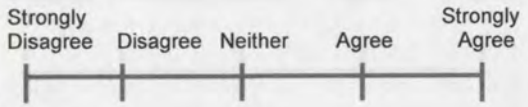
3. *Researchers must **discuss and try to fix the worries** of people who are involved in the project with the community (NHMRC, 2003).*

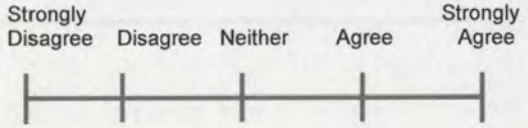
This principle can be demonstrated when:

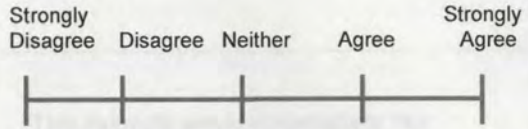
- Community members who are involved in the project are invited to share their feelings about:
  a) how the information is collected;
  b) the results;
  c) what the results mean for keeping their community strong and healthy; and
  d) what they liked and did not like about being involved in the research project
- The committee informs the project to make sure community culture and health matters are appropriately represented, including the best way to resolve problems or worries for people involved in the project.
- Regular progress reports are made about the project to the committee in an appropriate language and style for the community or region.

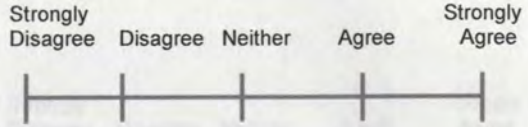
Please describe any suggestions of other examples that would demonstrate this principle.

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:









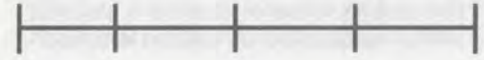
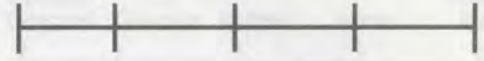
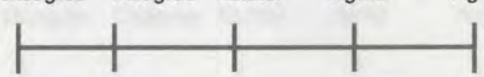
4. *Researchers must make sure the community is happy with the **agreement** about what will happen to the information from the research project, eg. **joint sign off for the publication of results and the protection of identity** for people involved in the project (NHMRC, 2003).*

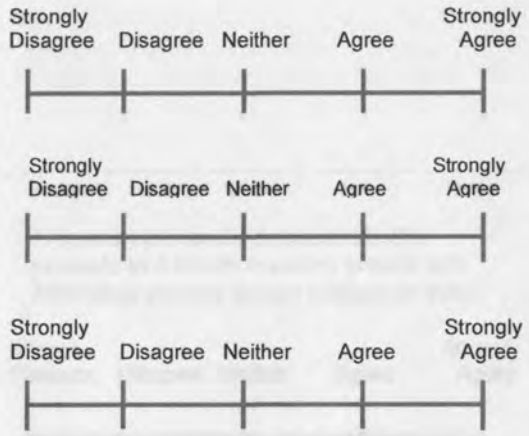
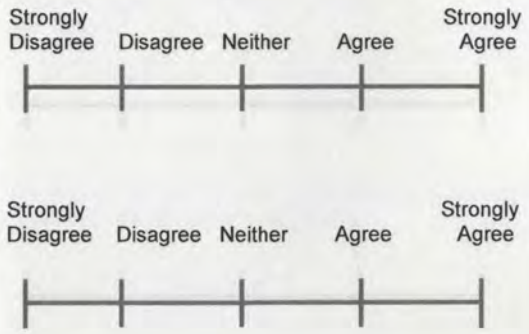
This principle can be demonstrated when:

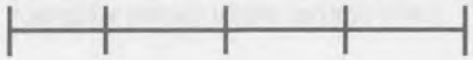
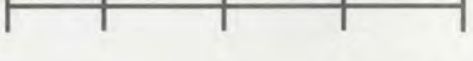
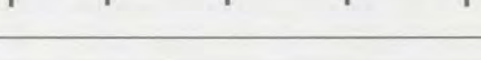
- The committee informs researchers on community culture and health matters are represented throughout the research project.
- A written agreement is made between the researchers and the community about how the project will be conducted and about what will happen to the information collected from the research project.
- Before and after the information collected in the project is published it is discussed and presented to the community or region.
- The community is happy with the representation of the information collected from the project before it can be published.

Please describe any suggestions of other examples that would demonstrate this principle.

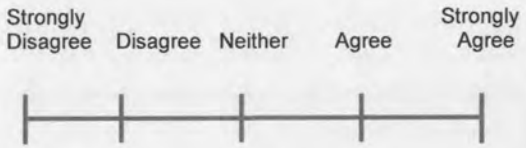
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree	5. ***Flexible agreements*** *have been made for the amount of* ***time research partners from the community*** *give to the research project (NHMRC, 2003).* This principle can be demonstrated if: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented.	*Please describe any suggestions of other examples that would demonstrate this principle.*
	▪ **Survival & Protection** This value aims to make sure that if the research project is accepted by the community, that the Aboriginal culture of the people who are involved in the project stays strong (NHMRC, 2003).	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree	1. *The research project must help build the* ***social and cultural bonds*** *within* ***families*** *and the community (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented.	*Please describe any suggestions of other examples that would demonstrate this principle.*

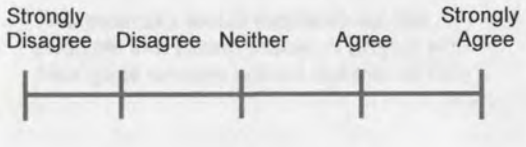
Strongly Disagree Disagree Neither Agree Strongly Agree 	▪ The information collected from the project might be useful to help the community get funding in the future for other health projects.	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree 	2. *Researchers must show how the research project will **protect the culture of the community and keep it safe** (NHMRC, 2003).* This principle can be demonstrated when: ▪ Aboriginal people and Aboriginal health organisations inform the project about the things that are important to them to keep their community strong and healthy ▪ The committee informs the project to make sure community culture and health matters are appropriately represented. ▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information. ▪ Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project.	*Please describe any suggestions of other examples that would demonstrate this principle.*

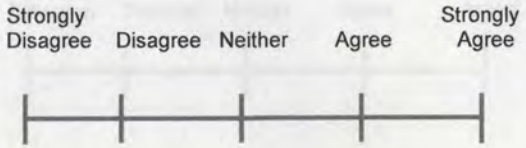
	▪ Before and after the information collected from the project is published it is presented and discussed with the community or region. ▪ The information collected from the project is given back to the community or region in an appropriate language and style. ▪ The information collected from the project only tells a story about the community or region involved in the project.	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: 	3. *Researchers must **respect the values, expectations and identity** of the community or region and help people who want to be involved in the project to find a balance **between collective and individual identity** (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented. ▪ Community members who are involved in the project are invited to share their thoughts about their own health and the health of their community.	*Please describe any suggestions of other examples that would demonstrate this principle.*

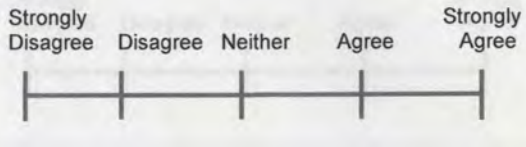
Strongly Disagree Disagree Neither Agree Strongly Agree 	▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree  Strongly Disagree Disagree Neither Agree Strongly Agree 	4. *The project helps **Aboriginal** people have their say about their **cultural distinctiveness** (NHMRC, 2003).* This principle can be demonstrated when: ▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to collect, analyse, interpret and write up the project information. ▪ The committee agrees that the project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy. ▪ The information collected from the project can be used to help the community make strong decisions in the future about their health. ▪ A written agreement is made so that the community agrees with what ill happen to the project information.	*Please describe any suggestions of other examples that would demonstrate this principle.*

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:









5. *Researchers must show how the project will help the community to* ***enjoy their cultural distinctiveness*** *(NHMRC, 2003).*

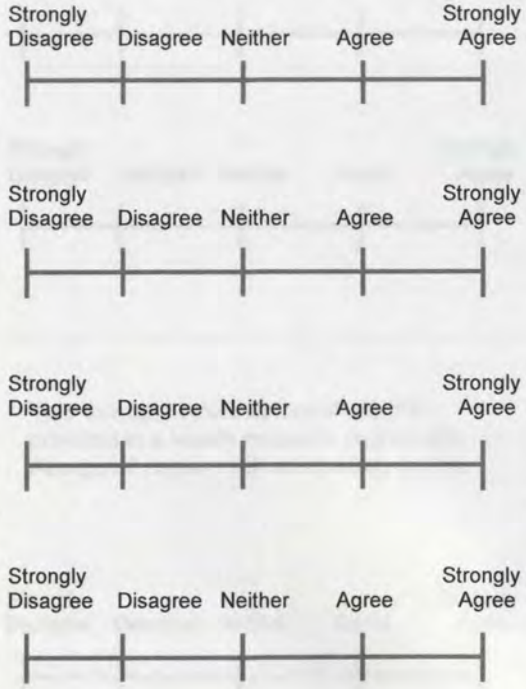
This principle can be demonstrated by:

- A complaints process is established so that community members who are involved in the project can share their feelings about what they liked and did not like about being involved. This will be actioned by researchers and reported back to the community in an appropriate language and style.
- The information collected from the project only tells a story about the community or region involved in the project.
- The information collected from the project is given back to the community or region in an appropriate language and style.
- Using the knowledge and experience of Aboriginal researchers involved in the project. Training and job opportunities will be given to (if possible, local) Aboriginal people to help collect, analyse and develop information for the project.

Please describe any suggestions of other examples that would demonstrate this principle.

Strongly Disagree Disagree Neither Agree Strongly Agree	▪ The committee informs the project to makes sure community culture and health matters are appropriately represented.	
	▪ **Spirit & Integrity** This value is only alive if the research project can show **reciprocity, respect, equality, responsibility, and survival and protection** (NHMRC, 2003).	
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA: Strongly Disagree Disagree Neither Agree Strongly Agree Strongly Disagree Disagree Neither Agree Strongly Agree	1. *Researchers must show how the research project will keep the **cultural, spiritual and social bonds** of the community strong (NHMRC, 2003).* This principle can be demonstrated when: ▪ Using the knowledge and experience of Aboriginal researchers involved in the project. Training and job opportunities will be given to (if possible, local) Aboriginal people to help collect, analyse and develop information for the project. ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented.	*Please describe any suggestions of other examples that would demonstrate this principle.*

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:

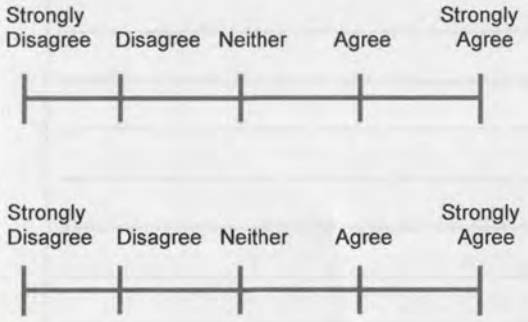
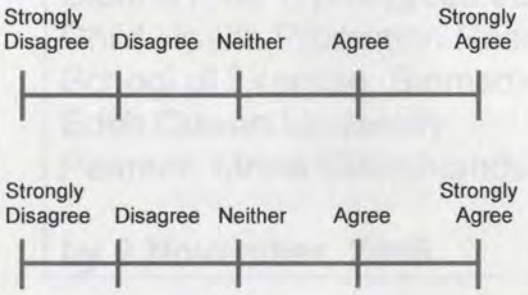


2. *Researchers must show how the research project* ***accepts the differences of culture between different Aboriginal communities and regions****, including the way decisions are made (NHMRC, 2003).*

This principle can be demonstrated when:

- The information collected from the project only tells a story about the community or region involved in the project.
- The information collected from the project is given back to the community or region in an appropriate language and style.
- The project provides training and job opportunities to (if possible, local) Aboriginal people to help collect, analyse, interpret and write project information.
- Community members who are involved in the project are invited to share their feelings about what they liked and did not like about being involved in the research project.

Please describe any suggestions of other examples that would demonstrate this principle.

This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	3. *Researchers must show the community **personal integrity**, in the development of their project* *(NHMRC, 2003).* This principle can be demonstrated by: ▪ The knowledge and experience of the community committee will inform the project to make sure community culture and health matters are appropriately represented. ▪ All project communication with the committee will be written down or noted to make sure that the project continues to be open and truthful.	*Please describe any suggestions of other examples that would demonstrate this principle.*
This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:  	4. *Researchers must show a **commitment to working within the spirit and integrity** of the community* *(NHMRC, 2003).* This principle can be demonstrated if: ▪ A plan for giving project information back to the community is developed before the project begins. ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented before the project begins.	*Please describe any suggestions of other examples that would demonstrate this principle.*

Please use the space below for further comments or suggestions regarding this questionnaire.

End of survey. Thank you very much for your time.

If possible, could you please return your completed questionnaire by email or place in the reply paid envelope provided to:

Dionne Paki d.paki@ecu.edu.au
Child Health Promotion Research Unit
School of Exercise, Biomedical & Health Sciences
Edith Cowan University
Pearson Street Churchlands WA 6018

by 9 November, 2005.

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Appendix 3

Information letter and consent form for case study instrument

INFORMATION LETTER TO CASE STUDY PARTICIPANTS

A descriptive study of ethical procedures that maintain cultural security when conducting health research with Aboriginal and Torres Strait Islander school children in Western Australia.

Dear ,

My name is Dionne Paki and I am a Bachelor of Health Science honours student at Edith Cowan University. As explained by my supervisor, Dr Marg Hall when you spoke recently, my honours thesis is focussing on the development of a framework that informs how to maintain cultural security when conducting health research among Aboriginal school children in Western Australia.

Thank you for agreeing to participate in my thesis project as a case study expert. The information you provide in this interview, by sharing your experiences of demonstrating **reciprocity**; **respect**; **equality**; **responsibility**; **survival and protection**; and **spirit and integrity** in Aboriginal child health research will be used to develop a case study to exemplify the values and principles required for ethical research among Aboriginal school children and their communities. This case study will be shown to an expert panel (of Aboriginal health and education workers in the proposed bullying prevention project) who will be asked to comment on and validate the example. A modified Delphi technique will be used to gather feedback and reach a consensus amongst the expert panel.

In addition, it is possible that my honours thesis and the framework will guide an ethics application for a proposed school-based bullying prevention and reduction study to be conducted by the Child Health Promotion Research Unit in the Midwest, Murchison region of Western Australia.

As discussed, Marg and I will meet with you on Thursday 25th August, 2005 10 am at . It is expected that the interview will take approximately 45 minutes to complete and with your permission I would like to audio record our visit. Dr Hall and I will be the only people with access to the completed questionnaire and will treat all information with the strictest confidence. In the presentation of the results of this project you will not be identified in any way.

If you are still willing to participate in this project please sign and date the consent form on the next page and return it to me at our meeting on the 25th August, 2005. You may withdraw from participation in this research project at any time. If you choose not to complete the interview, I would like to thank you for reading this letter.

Please feel free to contact me during business hours on 08 9273 8793 or by email at d.paki@ecu.edu.au if you wish to discuss this interview. You are also welcome to contact my supervisor Dr Margaret Hall on 08 9273 8237 or by email at m.hall@ecu.edu.au. I would also be grateful for any feedback or suggestions you may have in regards to my thesis topic. Thank you for your time.

Yours sincerely,

Dionne Paki.

This study has been approved by the Edith Cowan University Human Research Ethics Committee. If needed, verification can be obtained either by writing to the Research Ethics Officer, the Edith Cowan University Human Research Ethics Committee, Edith Cowan University, 100 Joondalup Drive, Joondalup WA 6027 or by telephoning 6304 2170.

CONSENT DOCUMENT

A descriptive study of ethical procedures that maintain cultural security when conducting health research with Aboriginal and Torres Strait Islander school children in Western Australia.

I have been provided with a copy of the Information Letter, explaining the above project. I have been given the opportunity to ask questions and any questions have been answered to my satisfaction.

I understand that participation in the research project will involve interview.

I understand that the information provided will be kept confidential, will only be used for the purposes of this project and I will not be identified in any written presentation of the results of this project. I understand that I am free to withdraw from further participation at any time, without explanation or penalty.

I freely agree to participate in this project.

_____

Name

_____

Signature

_____

Date

Appendix 4

Interview A transcript

Case study participant – ***Dr Cheryl Kickett-Tucker***

Case Study A – Interview Transcript

Transcript key:

P case study participant
RA researcher a
RB researcher b
*** information removed in transcribing for confidentiality
Italicised text was used to indicate participant responses
Bold text was used to highlight the most relevant interview dialogue to this thesis topic.
Black font was used for the preamble before using the interview questions.
Green font was used to highlight the interview dialogue relevant to the values and principles from the NHMRC (2003) guidelines.

RA: You have to report to the parents and the school community and so... there's always that extra step because you've got the children and parents, how did you manage that?

P: *Well, with the projects that, well not the one I'm doing now, we actually, do* ***a parent workshop and present the results****, its a huge report and I'm in the process of condensing that down to a ah,* ***for instance a lot of our people have diabetes and they can't read so the font needs to be larger.*** *I'll give you* ***an example – the consent forms.*** *That's the style of the font, that's how big it is because they have to, a lot of them, like I said have diabetes and they can't read.*

RA: But I mean that's also a lot of information to read.

P: *I know, but I mean* ***we go through it though,*** *we don't just hand it out to them.*

RB: At the workshop? So at the workshop you present the information, so its an information evening as well?

P: *Yes.*

RB: Do they also give their consent at the same information evenings? So its a "This is what the project is, this is what we'd like you to do, here's the information, this is what the information says and its in the right font size and we'd like you to sign here." Is that how it works?

P: *Sometimes, no we don't just hand them out and say, we just do a general presentation of everything and* ***we might sit one on one or in pairs together, and go through it****. The thing is a lot of these families have been through this process so many times, they're over researched – they already know what is going on so.*

P: *But the thing is* ***when it comes to*** [consent for] ***photographs and video tapes****, then we have to actually do a box where,* ***we have to allow them to make a choice****, a level of choice, like here, there you go.*

RB: So its a hierarchy?

P: *Yes and* ***we have to go through this individually, with each person****.*

RB: So their carers or, what about the children?

P: *And* ***the kids as well****, this is an adult consent form there is a kids one as well.*

RA: What age are the children?

P: *Ah, the project is up til 18, the other project is ten to 12 and another project is from k-7.*

RA: So, say the k-7 children give their consent as well as the parents?

P: *Ah, yes, but its ...* ***we do it with the parents as well when they're really young, you know? Sometimes those kids can't print their names so they just put a little 'x' or something, just to make them feel important ... We explain to them that they are contributing to something that is going to make the school better*** *or what ever it is, that kind of thing.*

RA: So this is a meeting with the parents and the child, and what sort of time of the day?

P: *This is the hard part, we found that a way of getting parents to school, what I did was, I was quite tricky at one school I went to. This project was about parents perceptions of the school and how effective it was in educating their kids 'cause it was an all Aboriginal school.* ***I went out to their sports day, because that's where I nabbed 70% of the parents of the school, the thing was that the consent dropped, the response rate dropped to 30% when I actually started doing interviews.*** *But you have to nab them anyways.*

RA: At least you get your best chance.

P: *And the way I got to that, I actually went into the school and asked the principal, because I don't work in the school and I said, "Look when is the best time to grab these parents?" Before* ***that I actually jumped on the school bus and I went to every family, because each child was picked up on the school bus, and nabbed parents there and I did the interviews like that as well****. And I didn't do it the second time round because I had too many families*

RA: And you did interviews, how do you think, is there, how do you think they'll go with a survey?

P: *I wouldn't give them something and get them to write, no don't do that. You have to …* ***I've just done that with a school it was a survey and we turned it into a questionnaire – and I had the survey here and I had them there and I had the tape going just in case, and I'd ask them a question and then check it off. But at the end of each section I would have an open response and I would ask them, now what do you want to say about this point, blah, blah, blah and they went on like a pork chop!*** *That's because I am a purely qualitative person I don't really like surveys, I think it limits people's open ended responses, so we had an open ended check just in case, because they always want to say something.*

RA: You get so much out of that.

P: *I do! Its good fun, except when you do millions and trillions, and millions and trillions of them. And I'm going to be going through this process again with kids now for another project we're going to schools and we're looking at 50 kids and doing a survey but it has to be employed by an Aboriginal researcher and there's all bits and pieces that goes with it –* ***how you talk to them, how you dress, where you sit when you actually do the survey, how long its going to take, stuff like that****.*

RA: So all of those sorts of details, are they included in the values?

P: *No, no.*

RA: They are just your research protocol?

P: *But I actually wrote a paper about that, but I don't know where it is… I presented it at a conference, I didn't publish it.* ***'Research implications, for doing research with Aboriginal kids', see but my stuff is always on urban kids, I focus on urban kids, not so much rural and remote.***

RA: It would be interesting to see if it could be transferred.

P: *So what I say is all to do with urban, we'll just go through the thing and I'll just try and remember.*

RA: Well, if you can perhaps sort of talk us through the key things and then if we can get a copy of your application that is approved particularly as it relates to children and their parents. Or which ever one you feel is most helpful and what we don't get down in here we can sort of go back through.

P: *And feed it back to me, because I need to make mine better as well, I did mine really quickly. But they gave me a good response; they said it was good the way I set it all out.*

RA: Well, you're the one that they're recommending we talk to, and we're going to talk to *** *** and *** *** and they also said, "you should speak to *** ***', and I said "We're already talking to you."

P: *'Cause most of the applications that we get in there, when they do that section on this area, you have to submit a 10 page document – and that's really quick … its not very detailed, it just quickly addresses the main points.*

RA: That's what we've said, there is just so much detail, and then to get your head around it and keep it there.

P: *You know the hard part now for me is trying to manage that. I've just done a* ***huge flowchart*** *and I'm* ***"Okay, okay I'm having community consultations and what's got to be done at this community consultation, on the first initial visit and I have to list it all… and what happens on the second one – what did I say in my ethics paper that I've got to actually do with the community?"*** *And that's what I'm doing now, I'm going through a project management plan and I'm thinking "Okay I've written that in there and where do I put that in this meeting/situation – does it come first, does it come last?"*

RA: It's so big; to me it's looking like a checklist.

P: *Yes, it is.*

RA: Because there are so many things in here that you say you're going to do and that you have to say that you're gong to do, and you should do it.

P: You should do it and the thing is you've got to put a 6 monthly report into WAAHIEC anyway, and they will check everything, they are really on the ball.

…

RB: I was just trying to think of somewhere, maybe it was when we were reading that, that we had something on the – did you think that was enough time, for the six month reporting… maybe I'm getting confused now.

RA: That was reporting back for WAAHIEC and how often did you need to report back to the community?

RB: Ah, that was what it was.

P: *Regularly, yes, it might be different for you guys, but* ***for an Aboriginal person if we don't talk to our mob regularly we loose our accountability and they tick us off and we never can go back ever again, we are tarnished for the rest of our lives****. So we can't muck around, we've got to be straight up and it has to be, even though we work in buildings we have to be in the community regularly. And that's one thing I've really pushed, I actually have a research group, its a community based thing and I have to keep that going because when they see us in government buildings they think that we're on the other side of the fence. So for us its really important … when I was collecting study work for my thesis, that was at *** because I went back to my old school there. I actually spent one whole year developing a report*

with that community, all I did was play sport with them, hung around, I went into the staff room so that the teachers didn't think I was analysing them, and we sat and you know, just yarned, so that, that was really important too, I don't know if that comes out in any of this.

RB: Well, its something that we've talked about and I'm not sure if its in this one, so I'm glad you mentioned that six month time. And in lots of the literature that I've been looking at it all says that its so important to keep the community involved and regular feedback is required but nothing is said about the time frame we're looking at, and I know the WAAHIEC – that committee says six months you have to report back to them and so I wasn't ever sure if, does it need to be less?

RA: To the community, once a term, or?

P: *How long is the project?*

RA: It will be a pilot project, so it will just be one year to start with.

P: *You know with the WAACHS, do you know about that, The Aboriginal Child Health Survey? They actually have an Aboriginal Steering Committee that meets monthly, so that gives you an indication. And everybody goes off them because they're so successful in their community consultation, so they have a steering committee and they* ***meet monthly*** *and its made up of community members. I myself would rather go* ***out into the community rather than bring them in here****, be out in the school, wherever and have an open forum rather than the committee.*

RB: So then again, maybe have another information night, like how you said you did the parent workshop, that kind of setting to get right back into the 'This is where we're at, this is what is going on'?

P: *Yes… I've got a one year project that just got funded looking at Education, Success, Well being and Resilience for accomplished West Australians, Aboriginal people. And in that, it's only a 12 month thing and I've written that we're going to do a* ***newsletter and its going to be a one-pager just bam, bam, bam, mostly photographs, visual stuff with a few things so they are always in touch so that if they don't read it, they see it in photographs, so the visual things are important … and its just going to be a one pager.***

RA: And its a newsletter? How will you get it to them?

P: *I'll just mail it out, or I'll send it to the schools, put it in kid's bags but the problem with that is that you'll never get it to the parents. Those sorts, the small logistics I haven't thought about too much but I know that if I do it through the school – put it in their bags, it wouldn't get there. And then to get their, the parents addresses and stuff you have to do a whole heap of rigmarole with the education department with that. The other thing is to* ***go to***

NAIDOC week and community sporting carnivals, stand there – because I know everybody and hand it out – there are a couple of angles.

RA: And these you know other forums, and parent workshops and you talked about how you needed to get on the bus, if you just have the parent workshops, they just don't come.

P: *Well, what's happened, with this parent workshop that's coming up, to disseminate results now, the school is going to send an invitation out but they're going to splat my name on the front of it and say* ***'**** **invites you to blah, blah, blah'**. *So I'm a local girl, see that's the thing –* ***local, well known people to reel people in, and I'm actually presenting these results but we're having a luncheon, a bbq luncheon – the whole school community is involved, not just the parents or the kids, 'cause the report's about everybody, the school community. And we've said a 10am start but, ½ past ten, ¼ to eleven, and probably 45 mins, that's it. Because a lot of them have young kids and they'll be running a-muck, so with that serious stuff you've either got to get someone to watch them but they probably wouldn't like that so, we just have to get through stuff quick, that's the other alternative.***

RB: Then you're forced to keep it concise.

P: *Yes, don't muck around.* ***The really important thing is, that I just don't stand up and lecture, it has to be interactive so every point I have to stop and say, "Right anyone got any questions, do you want to discuss this, do you want to add more to this, to the school?" – whatever, it can't be a one way thing.*** *And I always tell these parents,* ***they own this stuff so, they have to, you know, if they want the school to get better, they have to say something.*** *And we try and head hunt people in the crowd, ones that aren't saying anything, its just sort of communication protocols 'cause they, in the group the main people speak up but because they're doing it means everybody's important. You can sort of suss out the ones that aren't saying anything and head hunt them, and always personally use their name, just little things like that.*

RA: And how do they feel about being asked questions?

P: *Well, if its me saying it, they're not going to have a problem because I've been at that school I've developed the rapport, but if it was someone else it would be a bit tough you know; they haven't done their background, their relationship building.*

RB: And that's why you need to use a local, someone who is well known to them so that there's a greater level of trust.

RA: I think that's a really important point.

RB: For me in reading, the first thing and that needs to be followed through in being, well I think in having integrity in doing what you say you're going to do and then saying what you're going to do.

P: *You got to do it,* ***you can't say that you're going to deliver pineapples and you don't****, I'll get you that article, I think it might be at home, I did it ages ago.*

RA: Sort of like your research protocols?

P: *Yes, well, I did it when I did my thesis and I probably could add more to it too now as well, and that specifically, that was* ***real practical stuff, such as eye level; where do we sit ... how we're sitting here is a no, no. You sit under a tree. The way you dress, the way you talk.*** *Because I sat at that school for a year, I knew the kids backgrounds so if I asked a question about, their brother or sister, I knew their brother or sister's name. You know, because I really did my background and it shows because my transcript records are 60-70 pages long, for kids. And it was harder for a woman to interview a boy, and I think I go through a few things about that –* ***its best to use a male*** *but because I spent that year there I think I overcame that because I still got huge amounts of work from them. But I think probably* ***best to use a guy, if you're dealing with male/boys*** *you know, and there's so many female teachers around its probably good for them to have a, a guy.*

RA: What about ah, survey, you know pen and paper surveys for children, did you ever use them and how did that go?

P: *Yes, ... we employed it verbally, we've just done one for five to eight year olds and we tried a little ... its all test and trial, we tried a little 'roo pallet of kangaroos, big one, little one and bigger and bigger and bigger. And that didn't work; they actually wanted to talk about the kangaroos. And we were talking about, and this project was about how we socialise our kids to get past racism and how much cultural stuff, cultural knowledge and affirmation that we taught our children as parents and we asked the kids 5-8 year olds and the short version, so we made a short version and a longer version and that roo pallet we just threw that out the door, that was so funny, and I timed them and we had to do a toilet break in between and you could see them dropping off.*

RA: And you read the questions, but they still had it in front of them?

P: *Yes, we read the questions but they didn't have them.*

RA: So you filled it in for them, so was that one on one?

P: *One-on-one, you get, I know you're trying to get as much stuff.*

RA: We realise that its going to be different to what we normally do but I'm just confirming that.

P: *Well, this other project, developing a measure of self esteem, this is only a pilot of 50 kids and* ***I'm using 5 researchers and sending them out to 10 kids only, each gets 10. That personal investment that the [research assistant] gives to those kids is really important and I know for a fact that if they just walked in there and think they're going to ah, 50 kids on their own, it ain't gonna happen.*** *And so when we actually do the real thing, then we're in trouble, there's not that many Aboriginal research assistants walking around you know, so that's where the local community.*

RA: Train them up.

P: Oh yes, we'll probably get to that, but there is a, ***you have to train people****, there's a whole protocol to go through with that.*

RA: What do you think about reciprocity? Okay, what are we... is there anything that stood out for you in that, in that value?

P: *Are your questions the same as mine? Oh, oh, here we go ...*

RA: So what have you done there?

P: *Oh, I've done this for the resilience project.*

RA: Those points?

P: *Yes, I've done exactly what you've done.*

RB: So then we're on the right track.

1. Reciprocity –

1.1 How the proposed research demonstrates **intent to contribute to the advancement of the health and wellbeing** of participants and communities.

P: *Most people don't even bother; you've actually gone, way back ... See for this one, I've just written, that first one there, for this resilience project where it says 'contributes to the advancement and wellbeing',* ***the whole point of doing that project is to find out what enables Aboriginal people to become successful in their chosen field*** *so we're looking at 20 people in three different age groups such as young people, adults and mature age. And we're saying 50+ because Aboriginal people don't live that long and 50+ is good for us, and so the whole point of doing that is to find out how they got to where they got to; what helped them - the systems, the people. So we can develop a training and education project for Aboriginal kids with potential that don't have that same support network. So, so in terms of that first one, the whole point in doing it is because of this...* ***so for your project with bullying it would be... you know... it would be for mental wellbeing of kids at school, they can get on with their school work, their coping skills, you know.***

RA: So that's a real outcomes, you know, what will the outcomes of this project be?

P: *Yes, because you know the big thing about WAAHIEC is the like, lots of people do research with our people but what are they going to get out of it? And that's a big deal; they ask that question up front, 'What are you going to get out of it?'*

1.2 Whether the proposal **links clearly to community**, regional, jurisdictional or international Indigenous **health priorities and/or responds to existing or emerging needs articulated by Aboriginal** and Torres Strait Islander Peoples.

P: *The second one, yes the next one is the 1.2.* ***For me I went back to the national strategic framework for ATSI health; I went back to a priority that's been designated by the health department and my work fits in there.*** *So you've got to find where does our bullying project fit in?*

RA: Well, its based on the WAACHS we can link it to the outcomes of the WAACHS.

P: *See that number two, point two is about whether it responds to community, regional or international priorities – you could look on the national scale for bullying or on the international, do you know what I mean? And I reckon you would get a lot of work, you could actually put a few points in there.*

1.3 The **nature of benefits for participants** or other Aboriginal and Torres Strait Islander communities, and whether there is **evidence of clear and truthful discussions** about the potential benefit of the research proposal **prior to approval**.

P: *And for the evidence they want to actually see that you have done something, that's what it's saying – they're going to actually ask you for evidence not 'I'm going to do this and I'm going to do that,' they want to see* ***'We have done this, we have done that, we've spoken to this person.'*** *And in that there, in my project, I've got a* ***matrix of all the groups that I think I'm going to talk to then I've got a contact list, and then I've got a status*** [of] ***where I'm at with those people.*** *And to get them on board, well the first thing they're going to ask is well,* ***'What are we going to get out of it?',*** *so that's where the benefits come into it.*

RA: That's a great idea that one and they can see that.

P: *Yes, you've got to actually list, yes, I'd list them – I did but* ***my project management step was to put a matrix in, I said, "So, did I get that person, who is the next best person?" You don't normally go for the top person,*** *talk to local people, and say* ***"Who's the best person to talk to?"***

*For example I had to do something for the Justice Department just recently and someone said go speak to *** *** and I rang up a friend who runs the Aboriginal Legal Service, like a step cousin –*
*And I said, "*** is she the right person or should I speak to someone else?"*
*And he said, "No, don't speak to her, go speak to *** ***"*
*And I said, "Good 'cause I know *** *** really well"*
And he said "That's the go getter girl, if you want something done, you go see her".
So, you gotta do a bit of, you can't just pick.

1.4 Whether the researcher has **demonstrated willingness to modify research** in accordance with participating **community values and aspirations.**

P: *Okay, ah… oh, that point 'willingness to modify research' and you've got to say that you're going to do that and* ***I said, "That a number of opportunities will exist for that to occur during community meetings, phone calls and emails", for example.*** *'Cause some people just send an email,* ***you've got to keep all those communication levels open.*** *And in that there, basically you've got to,* ***a community owned project****, the research process so something that can know, that they can change something. For instance, if you go there with a pen and paper and do a survey with kids,* ***they might say "Look that's not the right way to do it, are you going to listen to us or are you going to do your own thing?"*** *They gotta know, yes. And I tell you what that WAACHS group they're pretty strict on making sure that the process is right, because the people that are on the grant, that got that, they don't live in our community, you know and things happen that they don't know about so, "so and so passed away, don't go and visit his family." Things like that, stuff like that, have I answered that one?*

RA, RB: Yes, yes.

1.5 Whether the proposed research will **enhance the capacity of communities to draw benefit beyond the project**, eg through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level.

P: So we're up to respect aren't we?

RA: Enhances the capacity of communities to draw benefit beyond the project.

P: *Oh, that one, well in, for instance in this Resilience one, again the project was to develop* ***this training and education project*** *with Aboriginal kids 10-18 years of age. So again beyond the life of my project I'm going to be able to set, its not just the, its the same with you guys with the bullying pilot, you guys are actually* ***developing an intervention program that's, that's, and when it comes to capacity well, you're going to draw communities in to***

facilitate that process, *that sort of thing, see I just wrote a simple paragraph to say that and that was good enough?*

2. Respect –

2.1 Whether the proposal **responds to the diversity of Aboriginal** and Torres Strait Islander Peoples and **communities, including the way decisions are made.**

RA: Respect, its a big one.

RB: And this is the biggest one, I found this one huge when I was doing ... comparing it to the other one, I guess for obvious reasons – that it hadn't been done.

P: *I've done three pages on it, four pages on it. The first one is really important because. And even here –*
The other day we had a workshop and one of the researchers who works with Aboriginal kids said "All Aboriginal kids live in atrocious conditions!"
And I'm like, "No they don't!" and I said to her, "Where have you been doing your work?"
And she said, "Oh, in two remote communities."
And I said, "Yes, they do!"
But you know, on average that's bullshit, ***and you know they focus on the worst statistics all the time but there are pockets of people doing really well. Hence my resilience and wellbeing project – I keep to the positive things, it drives me nuts! But the diversity is not plonking us in one group and saying 'Aboriginal' all the time, all of my papers always have the word urban on it****. And I always say to people that "I'm biased to that group, and that's my mob". And we, we are probably the most isolated lot anyway, not by land, but by other reasons, that has to be really spelt out. And* ***so when it says 'responds to diversity' that basically means that if you are going to go to Yamatji territory up in Geraldton, you use Yamatji people and the results have to be specific for that unique group.*** *See, Geraldton is a really unique community anyway, lots of stuff going on there.*

RA: And I mean that's where the research is run by the community because that community gives direction as to 'who and how and what'.

P: *And so when it says 'the way decisions are made', see here* ***in Perth because we've got so many different groups of people we have, call a community panel together. But in those smaller groups you might have two or three elders****, do you know what I mean? In a remote community its different you probably have one or two there and they're the only people you ever speak to. In Geraldton I'd say they are probably a bit more like us here, a rural centre, but the decisions, yes, 'the way decisions are made', I actually wrote there the diversity, in the actual,* ***the generalisations and limitations are, will be conveniently located in all publications so all readers are aware of the prime recommendations*** *... not covered in that project.*

RB: So recognising again, that its specific to this community because its, and then that reinforces that they own it because it is done for them, about them and will be given back to them?

RA: And I mean anybody reading the research knows and when they read that they are fully aware of that, they're not saying that's for all Aboriginal people.

P: *... and one lady said to me, we where talking about morbidity rates, really depressing stuff and saying, 'we're 19 more times to die and this and that' – And one of the ladies started crying and she said, "I don't know how you can sit there *** and listen to it all."*
*And I said, "Well, I've been living with it for 37 years now ***, so that's the first thing love and the second thing is I always deal with the positive side because it aint all bad!"*
You know far out, crying, in the middle of the meeting.

Actually I did get teary when I heard some of the WAACHS data being, especially when its the stolen children generation, because my father is, and everything they were telling me I lived through it all. That got to me, I had to walk out. ***And see now, that's something wrong that they did, they didn't, the advisors here, they didn't really ... I didn't know it was going to happen, do you know what I mean? They should have prepped us because I was really upset after that, it was hard to stay together.*** *They didn't realise that some of us had family taken away, like one of them was taken away.*

RA: It is highly likely.

2.2 How the proposal **acknowledges the individual and collective contribution of Aboriginal** and Torres Strait Islander Peoples.

P: *I've written here, "This is done by consulting not only with participants but also groups who work with any Aboriginal network* ***that individuals not only speak for themselves but have the capacity and knowledge to represent their respective communities****". The example is, "it is* ***the intention to ensure that individuals are personally invited to engage in open****", that's that personal thing again. Rather than sending a letter out saying 'Oh, we're in the community, you're welcome to come here',* ***you have to target people, then they feel like they're important, like they're valuable. They feel ... its a respect thing you know. So 'the personally invite to engage in open verbal and written communication and opportunities to express themselves as well as their community'. So they've got a right to say what they think about things for themselves and their family but that they can also talk for their community****. 'Cause some people aren't like that, some Aboriginal people won't think they can't talk for their communities, you know because they're not the head of a big organisation, you know you've got to facilitate that, you've got to say "That's happening for you, but what do you think about this?" Do you know what I mean? That sort of stuff,* ***Aboriginal people are quite shy people, and they're very reserved and***

***when a non-Aboriginal person asks a question and we ask a question we're going to get a completely different response and they'll probably tell you what you want to hear**, which happens all the time, you'll get a different story on this side here – they'll probably tell you vague stuff, but you'll get more rich detail over here, you know what I mean?*

RA: Its an important part of this project that local Aboriginal people are,

***P:** That's why **its important that one on-one-stuff** see. You can't do any of this unless, and that's, that's going to be the hard part 'cause when you're trying to get massive data collected, and when your grant funding doesn't last for more than a year its, its really hard. And that's why I agree with a pilot and then going back, 'cause that's what I've done – I've done mini pilots and going back later looking for the bigger lots of money. I s'pose that's the other thing, you know the capacity thing? **You could actually say that, you know the building the capacity on the project? That ... you'll look for larger pockets of money where you can employ Aboriginal people on a longer basis in their community, so you're building their capacity,** that's probably something as well. See, they never work out the way you want hey? ... What are we up to, two?*

RB: Three, minimising difference blindness.

***2.3** How the researchers propose to **minimise the effects of difference blindness** on and in the research process.*

***P:** Okay, I've written here, to make sure that there's, the diversity is recognised that the **"Local community consultants will be consulted to access potential participants, to translate results for the publication of findings and to appropriateness and use of the tool that is developed." Or in your case, your intervention program** and then I've got, **I've actually listed all the people in that network that it thinks is going to be involved, oh, not the people, the groups.** You know what I mean, I actually, listed them so they know that I'm serious and I've thought all about this.*

RA: Just remind me *** what difference blindness is, I know I've read this.

RB: Its not acknowledging that there's a difference between Aboriginal people and non-Aboriginal people and so its...

***P:** So ... to translate the results, **there's a way to do that with our mob, or when you're dealing with the kids.** So that's where that comes in, so that's where the local community has to be consulted too.*

RB: I guess the thing with that principle is that they really do make up the one value and that the values are interrelated but its just to cover every base. Again, its not generalising, 'Okay, well, just do that and you'll be fine', but proving that you've thought about, thought about this aspect and that means that.

P: *A lot of it overlaps, that's right its hard to, and I think "Gee, should I write each point?"*

RA: Yes, and then you feel as if you're repeating yourself, and so many things you think, and its actually okay to repeat yourself – because you should be.

P: *Yes, yes, I did – because then you're being thorough.*

RA: And you're addressing everything.

P: *Ah, the other thing about that, 'the effects of difference blindness', is that* ***all the research findings are translated described based on the criteria.*** *I've got here 'purposeful sampling criteria for the project' such as the specific people that we spoke to. So for instance, for you its going to be kids in certain regions. So,* ***in Geraldton there might be one school there that really lost the plot compared to another school in the same region, you have to translate the findings for that school particular for that community.*** *You know it could be a real racist principal there or something or, or, something, I don't know.*

2.4 How the **research proposal engages** with **Aboriginal** and Torres Strait Islander People's **knowledge and experience**.

P: *Oh, the next point, is point four which is how your research engages Aboriginal and Torres Strait Islander people's knowledge.* ***That's methodology I s'pose*** *... here for me, I'm going to interview people so I'm going to extract their experience and knowledge ... I've written here* ***"Direct verbal communication," that's in terms of the interview with the survey here. And also communication about the methodological processes as well, they get an opportunity to talk about that and that's with the actual participant. But those people who are participants such as community consultants I've put here "Time is allocated for open communication about: methods; results; using findings; dissemination of results", its all done on a regular, open and vital basis. I've said here "An agreement developed during regular communication will be in line with community protocols"*** *which I know, but you guys don't,* ***"to sustain equality in Aboriginal participation."*** *But that's basically, how are you, what are you? You're doing a survey so you're going to extract information via survey, its just, that's pretty straight forward that one.*

2.5 Whether **appropriate agreements** have been **negotiated about ownership and rights of access** to Aboriginal and Torres Strait Islander People's **intellectual and cultural property**.

P: *I've put 5 & 8 together. Five is 'appropriate agreements regarding rights of access of intellectual cultural property'; and the other one ... is very similar its about ... management of data publication arrangement, protection of identity. And this is probably something you might want to do, I've thought about this*

*myself – **I'm actually going to devise a statement of cultural consent and participation and I'm going to devise that in consultation with my community group**. So that particular cultural consensus. 'Cause when you get consultants arrive, they don't have a piece of paper to say they are going to be involved formally. Do you know what I mean? And you need that you need that regular group to talk to. And in that I'm going to have, there's six things ... **we're actually going to discuss and write up an agreement.***

RA: This is your **community management group?**

***P: Yes, about the ownership of the knowledge gained, such as who owns that.** "Access and rights to intellectual property, publication arrangements", such as **authorship** because now they're saying you're supposed to have everyone's name on everything. "The potential use of **commercialisation**", because this is a programme we're coming up with, "management of data and how to protect the community identity".*

RA: So you're going to discuss that with your community management group?

P:** Yes, so my first, my first meeting is a big one. So when I'm looking at my management I go "Okay I've said that, now that can be done straight up, the first one." And that's going to take time, **they have to know that they're, they're valuable and respected for their participation and we're acknowledging it through a written document.

RB: And that makes it all above board too.

P:** Yes, yes, because how, how else? It says here to reach an agreement, **agreement to me is verbal but, but in this kind of research it has to be written, it has to be done properly.

RA: And ...this management group, are representatives of the community, so its not all the community, its just key people that you can talk to?

***P:** That you can readily go to and say, "Oh look, we got trouble at this school, do you know anyone in the community that can go and speak to this person?" Or, "What do you think about the findings shall we disseminate them over here?"*

RA: And how, how many people would you?

***P:** Ah, well, let me think ... this project here this resilience one is only a year. I'll probably get about, 6, 7, and they drop out down to about 5, do you know what I mean?*

RA: Yes, yes and I its 'what's too many and what's too few?'

***P:** You've always got to have that ...'Cause I've, you know I've got 1,2,3,4,5,6,7,8,9,10 but I don't know. 'Cause I've actually got carers, I'm*

going to actually ask a couple of carers to come on board as well. Not just office people, do you know what I mean, community people. But I don't reckon, when you get too many then, the, the project gets weighted down, with too many decisions, too many personalities. And you really, at the end of the day you're really trying to do a benefit to the kids in the community so, I reckon about 5ish, you know.

RA: Because as you say, if you invite, if you try for seven you'll get five.

P: *Yes, I'm going to try for about 10 and hopefully get 7 and then it will go down to about five, that's what I'm thinkin'. We'll see, 'cause its the same people all the time and people get hooked up in so many other projects.*

2.6 *Whether* ***the processes of reaching agreement*** *demonstrate* ***engagement*** *with the values and processes of* ***participating communities.***

P: *... Okay, that one there – number six is about reaching agreement. I'm, I've actually written here that "Group agreements will be made in a group statement and those statements are going to be recorded."* ***They have to be recorded and the process by which we actually came to that, whether or not we all put our hands up, whether or not we went with the majority****, whatever. Whatever the process was at that time, see what happens when you do all this stuff and you find out, so for the next project you know what's going to happen, you see?*

Oh, I just wrote here that ***"These things were facilitated in non-threatening, commonly shared space".*** *So we didn't really, were biased towards one group or another group, or another person...* ***It was a common spot and preferably either outdoorsy or somewhere, where it's, it's home.*** *Not an office. And schools aren't too crash hot either, because people don't like going there at all, but you know.* ***And this is just a plan and if it doesn't work then I report that to the WAAHIEC and find out alternative methods.*** *'Cause when I did my thesis that was ages ago and that was pretty simple because I went back to my own community – I took advantage of things, you know... people and places at the time but these other projects they're going to be a bit different so, I'll make that process. I s'pose you need to say that too, that you'll manipulate the situation, with Aboriginal people you have to be really flexible – like tentative times and things and arrangements can change...*

RA: Yep, I think that's a good point.

P: *Its like this community, this parent workshop.*
I don't know, I said to the principal "How many people do you think will turn up?"
"Ten or 15."
And I'm thinking "Eight or seven."
So, but if you only get eight or seven you can't see it as a failure, because they're the ones that are probably move. That'll be the movers and shakers

anyway so don't ever think numbers because that one person of that seven represents 20 other people because their groups are so big or their families are so big.

2.7 *Whether the participating communities have* ***expressed satisfaction*** *with the research agreement and decision making processes.*

P: *Seven was about "When you express satisfaction with the agreement or decision making process", in my community meetings at the end of each meeting I'm actually going to have a* ***'time of reflection'. I've actually called it that, so that people can assess their satisfaction for the processes of, in that meeting whether it was 'no one had a say' or 'it was too rushed' or 'decisions weren't, they weren't happy' and its all recorded, scribed in a journal.*** *So every meeting has a* ***processes journal*** *and the things that are scribed in there are: who was the head of that meeting, where they came from, all the processes and, but on the other side you actually have the minutes its self, you know? Not minutes, you know, but what's happened during the meeting, but* ***the processes have to be done separately because that goes back into your report, reporting and also manipulating this, it has to reported back to the community****.*

P: *That's okay with respect? Okay, we'll go to equality.*

2.8 *Whether in reaching* ***agreement*** *with participating communities all relevant issues including* ***management of data, publication arrangements and the protection of individual and community identity have been adequately addressed****.*

3. Equality –

3.1 Whether the ways that participating communities are included in the **research processes demonstrate equality**.

P: *Oh, I took this as explaining, whose going to be involved as participants. And in my own, I talked about that* ***genders are going to be equally represented*** *and explained the* ***age ranges****. And I've explained that in this particular project the achievement domains, which are going to represented,* ***really specific, region, schools, government/non-government, Catholic, Aboriginal run schools****. I don't know, you have to really put*

RA: the detail.

P: *Yes, I've got the detail in there, ... okay, yes that's all I did really, basically.*

3.2 Whether the research agreements have the **strength necessary to sustain equality.**

Two, "Whether the research agreements have the strength to sustain equality", that's where I spoke ***about that journal of the research processes. To ensure that equality with the decisions and the***

processes are recorded and who actually made that happen. *So over the time we can say, "Well, everyone had a chance to say something here, so we've demonstrated equality" you know? That we can say that, we can just give them a section of the report or the reporting processes and say, "This is how we've done them up", something like that.*

RA: How much have you got to do for this project?

P: *... Well, I mean this is a lot of work, its an awful lot of work. And I mean keeping the records and keeping track of your records and then, getting them into a*

RA: reportable format.

P: *And that's why I have to get a good team of research assistants so, you can't do it all yourself!*

RA: No, you can't, it sounds huge.

P: *That's only a year project, my ... project is 3 years long.*

RA: Bit of a chance to breathe.

P: *I've got to actually, I've got to find some money ... and employ some people ...*

> ***3.3*** *Whether participating communities have* ***understood and expressed satisfaction*** *with the proposed research, its potential benefits and their distribution. Researchers therefore have a* ***responsibility*** *to ensure that the information that they provide is* ***understood and usable*** *in decision making by participating communities.*

P: *Okay number three ... is about whether they've "Understood and expressed satisfaction of the proposed project."* ***At that first meeting I have to consult by the community as well as the potential participants and their carers****, all that is going to be laid on the line.* ***With the consent form, the information sheet*** *– we go through the information sheet, one by [one]. And it has all that information what they've asked for in that point, its really all the consent, the information and consent session is really important. Its not like in the old days when they just signed anything – I don't allow them to do that, I sit there with them and I, and this is what happens in the first...[meeting].*

RB: The first information night, *** and I had talked about that, that it seems where it would happen.

P: *Well, probably the second, the first one you're letting everyone know what's going on, do you want to be involved, you know 'spread the word' kind of thing. Then, from there, you try and get potential participants, the list up*

and then, ***the second one, once you target people, you know... people don't pay enough attention to that consent section.*** *They don't at all, you know, "We can just do what ever we want", but they can't. And people have a right, and if they choose to pull their kid out anytime, they can do so with no fuss and their told that. They're not reprimanded in anyway, and* ***they're told, they need to know that, 'cause they don't. 'Cause when its in a school based situation, they think that the teachers and the school are always right and they're wrong.*** *You see, when its school based, there's a really bad, I don't know, stigma, yes, that's it and you really have to fight over that and you have to say, you know "We're here for the benefit of the group, of the kids, I'm not really a teacher in the school, I'm helping your child to overcome what ever."*

RA: Okay, so that will go through those meetings.

P: *Yes, when it comes to what the findings are, I think in that question there about the "distribution of the potential benefits". I came up with a* ***results dissemination plan****, which is just as big as always ... Only a talking point, so that* ***when we have our community consultations we can go point by point through it and say whether or not, "Is this the right way to do this?" But I came up with something, so that I don't go in there blank and wait 'til that time.*** *I'll just have a quick look through this and, I think its in here, I'm not sure.* ***It comes up in WAACHS, they had a three stage process where they had a consultation, had a feedback and then it had an evaluation review and then another consultation. You can get this off the WAACHS communication strategy, if you go along that line you'll be fine,*** *so if you get that off them. But I've actually gone through and I've stated who my target audience is, what communication methods, what's my product at the end, what am I going to produce, my strategies. And then I came up with this here and I try to fit 'who, how and what' that we we're going to get,* ***but this hasn't been ratified by the community I just did that to show that I know what I'm talking about ... there's no point doing research if we can't get it out and sell it,*** *and people take notice of it and your project is with the schools so you have to sell it to the education department ... And a selling point and the translation of it, and then the implementation of it, and the results, this results dissemination plan looks at a lot of them. I mean you don't have to do that, I don't know, I mean there's only a small box in that thing.*

RA: I think we can, I think

RB: we can talk about it.

RA: So where can we get that communications strategy from?

P: *Here ...*

RA: is it on their website?

*P: I don't know, *** *** is the manager of that strategy and that's the thing with the WAACHS study, because it was such a big thing, they actually had a manager for their communication strategy and they came out with profiles for each community, based on that data you see. So you might want to speak to her, and I would say speak to her and ask her "How do we get information out? What's the best way of doing it and what have you done?" I'd speak to ..., 'cause I spoke to her and then I took my stuff to the PR lady down stairs "Does this make any sense?"*
And she said, "Yes, its not bad."
And I said, "Okay, that'll do, just to start off."
Because it has to be finalised to work properly and that in itself is just a lot of work, so whilst the project finishes it really doesn't if you know what I mean.

... Where are we up to? Responsibility, is that enough for equality?

4. Responsibility –

4.1 What measures are identified to demonstrate **transparency in the exchange of ideas** and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research.

P: Okay, the first one that "Demonstrates transparency in exchange of ideas and negotiation". Basically I've written here that ***everything is going to be written down, any communication... if I do an email or a phone call, it all has to be communicated, it has to be written down*** *... I have actually taken, not of what people have said, and if its to change a research process then taken it to the community consultation group and talk about it and come up with the decisions, are all recorded. And that's why we need a good [research assistant] to come along.*

The other thing is a, ***a list of representatives will be noted with their respective comments.*** *Decisions in each of those community meetings ... [are] negotiated ... such as getting participants, "How do you get them?" One of my things might be I have to go and sit around NAIDOC week for the whole week and access kids at the NAIDOC day activity, you know what I mean? But you would* ***negotiate how to do that with the community, confidentiality, ownership and rights, they're asking about that there. So, let the community take responsibility for that as well in negotiation ... how data is collected, how its published, who manages it, who stores it.*** *They might say "No, don't leave it in ***'s office, her kids will get to it!" Do you know what I mean? I don't know...*

4.2 How provision is made for appropriate **ongoing advice and review** from the participating community, including mechanisms to **monitor ethics standards** and to minimise the likelihood of any unintended consequences arising from or after the research project.

P: Number two, "Provision is made for appropriate ongoing advice and review". This is going to be tough but I'm actually doing monthly reviews on

this. So ***all that information is going in my monthly reviews****, so its not doubling up its just siphoning into a better, and some of this stuff is going to be reported in the news letter like the monitoring of the ethics, which is the processes … An opportunity for ongoing community advice so that if someone says something* ***we actually report it in the thing, so that we've got that accountability going still.*** *Any,* ***any problems or issues that occur during the research process, any bits of preliminary data, or something exciting, or something not exciting or feedback from that data*** *and just, if there's any progress reports of any research outputs … or whatever, just so that people are informed. So its not gotta be a big deal, but that's where that newsletter comes in.* ***So it sounds like a lot but I'm not doubling up, it just using information*** *… and it has to be done because, because people are so busy, and there's not many of us and the ones that you do get are going to be involved in so many other things that if they are kept up to date in a short, sharp and sweet way. But I said if I can have pictures in it, it will be official and it will have words; and* ***on coloured paper, so it stands out****, you know not this white, you know what I mean? You got to do something different, even if its a cd rom, but that's going to cost money, you know.*

RA: And say in our project that would go to every parent?

P: *I reckon, I mean if they throw it in the bin, they throw it in the bin.*

RB: But then the effort to keep things transparent has been made and we do what we say we're going to do.

P: *Exactly! And you can report that to WAAHIEC, so next time you're going for another grant, you've done your, you've done your*

RA: Your records.

P: *Your records yes. And you've done the right thing, and that's the thing with Aboriginal people if you don't, if they don't come on board, you can't force people. You've done everything that you're supposed to do and that's all that you can do, 'cause we have, we have that problem sometimes too you know. What else? Oh, I've said that a written review is going to be done at the conclusion of the project as well, to do an overall evaluation of the things that I have spoken about, so that everybody's up to date on everything. And … that makes it easier for us to do our projects later on so that if we got the processes wrong we know what to do…*

4.3 What does the proposal say about timely feedback obligations to communities and whether that feedback is relevant to the expressed concerns, values and expectations of research participants and communities?

P: *...see this is all doubling up stuff, but anyway, number three - timely feedback and all that sort of stuff. "****Feedback will always be given during***

community meetings about research processes, expected and realised outcomes, deadlines and concerns,"

RA: When you say community meetings, are you saying ... that, the **community management group or a community**, everybody?

***P: Both**, because the management committee help you steer things and keep things going but its the people that you, general community. It can just be a ½ page flyer, you know, it doesn't have to be anything extravagant. It might have, it might have only a few things on it such as, "We've just passed first stage; we've realised our first outcome which is; we're meeting our deadlines." ...*

RA: So, I guess, that could be a ½ page flyer, it could be, you go to the sports day and you pass the flyer out there.

***P:** You could poster it too. I haven't thought about the practicality of it yet, but you know, you could do a poster up at the school and in one spot you could say, "This is our news!"*

RA: I get a bit worried about pieces of paper just going, I actually think that the newsletter is a good idea but, I think we'll reach that stage, I think we need more than one.

P:** That's when **you're consultations will tell you.

RA: Good point ... I think you've brought me around really nicely because the community consultation will tell us, and we can't necessarily come up with all these ideas.

RB: We can offer suggestions.

***P:** Yes, yes, it might be that a monthly newsletter is too much, but for the point of this, getting this application in, all your intentions are right, and that's what that research process describes, and you can say, "Well, we changed it because the community said this - ".*

4.4 How the proposal demonstrates agreed arrangements regarding publication of the research results, including **clear provisions relating to joint sign off for publication and the protection** of individual and community identity if appropriate.

***P:** Okey-dokey, number four. That there is about the agreed arrangement regarding publication ... that was already considered in the **statement of cultural participation** remember? So, that's already in there and that document would look at publication of results, such as joint-signed authorship, protection of identities and stuff, you know how I spoke about that before? ...*

4.5 Whether there is **clarity about the demand on partners** created by the proposed research and the potential implications for partners arising from it.

P: *Again, five is the same. Because again* ***the partners are consultations, like if you've got a community group*** *... they need to know what their demand is going to be and that's where the* ***cultural consent participation paper*** *comes in. Basically that there is a community thing, not the carers is suppose, they're not involved directly, but I would have one for the community panel if I can. You know you're not going to get everyone, that's the thing; you just do what you can.*

5. Survival and Protection –

5.1 Whether the research project contributes to or erodes the **social and cultural bonds** among and between Aboriginal and Torres Strait Islander families and communities.

P: *And survival and protection, 'erodes the cultural and social bonds'. Okay, in my project I said it actually contributed to the cultural and social bonds because* ***we've got a heap of people involved in my project: children, youth, elderly, men and women and they'll be working together to give up information with the aim of strengthening our community****. Particularly our young people because at the end of our project we're going to extract information from those people to develop this training and education program. But we're going to be taping them and we're, we're taking photos of them so that we can develop a visual package so in that way if an elder's coming up and saying "Okay, I got to be a politician because I did this, this and this is what helped me." And they visually, get a visual project to that youth, well that's were it strengthened those bonds. So, in your case, bullying – let me think about that. I suppose its* ***developing, or contributing to the social, cultural bonds because you're getting people to come together from all walks of life, of all ages for a specific problem across the board, across all communities.*** *But at the time its affecting our young people, so its kind of the same thing:* ***you're getting the old people to say, "Well this is how I dealt with it," or, "I think you should do this", you know, "Our values need to be changed", or whatever because then they're getting information back to the child and the community.*** *So, then there's that* ***exchange of information****, that's what that's about. I think, and* ***its not passive either, its very active, direct feedback****, do you know what I mean?*

5.2 What **safeguards** are in place against the research project contributing to discrimination or derision of Aboriginal and Torres Strait Islander individuals or cultures.

P: *Number five, 'discrimination - '. The way I got around that, and I found that question hard to answer, 'the safeguards that further contribute to the discrimination of our people'. You know how I was saying about that workshop and what that lady said? That researcher said "All Aboriginal children". That sucks! That's, that's exactly what that's trying to stop. For*

her to say things like that. … And the only way that I thought that I could get around that is to ***explicitly detail and define the project objectives and the findings in relationship to the characteristics of the people*** *that we, that we had as participants. So that* ***at all times, in all the publications, during all the presentations it has to be strictly adhered that this information works for this group of people.*** *And* ***try not to use the word 'Aboriginal' too much in those, actually start using group names and stuff because then people will start realising, "Hang on, well this does work for these kids, like Noongar people'.*** *I, I really try to think about that, how else are you going to, you can't completely stop them. …*

RA: Yes, that was a point that was brought up.

5.3 Whether the proposal **respects the intrinsic values based expectations and identity** of Aboriginal and Torres Strait Islander Peoples and communities including the balance between **collective and individual identity**.

P: *... I don't know how you're going to answer that. Well, you'll have to answer the same way – where it looks at identity this next one and 'the balance between collective and individual identity'. I'd say both those constructs,* ***"Collective and individual identity are acknowledged in this proposal" my proposal, "because my methods/tools [aims] to discover [what] both those constructs is."*** *Is there, you know, I'm allowing, you can feed that back to that first value question – that talks about what do people talk about themselves and have the right to talk about their communities, so there's the individual identity and the community identity. So, 'Oh, how did I say that?' So what I did was to ensure that happens, that* ***all my surveys, and my interviews will always ask both of those questions –*** *not just the personal things, but "Collectively what do you think about your Yamatji people in this region here?* ***If this is going to work for you, this bullying project … how is it going to work for all the Yamatji people?"*** *Do you know what I mean? So on all of that stuff you get, in that way the group and the individual are valued and respected.*

5.4 How the proposal **contributes** to the opportunity for **Aboriginal** and Torres Strait Islander Peoples to better advocate for or enjoy their **cultural distinctiveness**.

P: *... Okay, "How" okay, that's a really good one, I like this one and I wrote – Because this is to do with 'how they can advocate and enjoy their cultural distinctiveness'. For me, they, they 'maintain their cultural uniqueness and sameness' which is the question before* ***'in a safe and non-threatening environment' that's the first and foremost thing*** *and the reason that's done, how that is done – is* ***ensuring that the researchers are Aboriginal themselves, the ones that collect data anyway, and they're professionally trained, they might be Aboriginal but they have to be trained to do it.*** *Involved with the Aboriginal community to monitor a friendly research environment, so that people can participate and enjoy their cultural*

distinctiveness without any fear or anything, and that the ***participants themselves; children and carers can tell it like it is in their own words.*** *That's why I said that with the survey,* ***you've got the open-ended response section – so they can, and that's where that one-on-one is important because if you pair people up in focus groups and stuff like that, people don't tell it like it is, they get frightened, that's why the one-on-one is really important.*** *And its tough practically, you know, how to manage it all, I've always kept my sample small but its going to get to a point where I'm not going to be able to do any more.*

RA: I think the WAACHS was one of them.

P: *Yes, and look what they did, they sent teams out, they trained people, see they had to do it like that. So you might have to go down the same track, you should take a really good look in their books and see what they've done.*

RA: They've done a great job, who would be the person to talk to ?

P: *Ah, well ***, *** or *** ... Yes, I reckon, I reckon you should talk to ****

RA: ***?

P: *Yes, 'cause she's been there from the start, she's the one that documents, all the whole thing, she can tell you exactly how its done... I think, and *** *** is the other girl that works with her and she does a lot of the data collection and helps her. If you can get those two in a room together and you'll be able to do exactly what you've done here with me and you'll get all the bits and pieces in, in part of the puzzle.*

RA: Hmm... that sounds good.

P: *And you know what the other thing I should tell you is that whatever we write here, because we're a moving kind of culture it can't stay like that... We're a dynamic group,* ***things change all the time and we're very complex group and this, this actual thing is a guide and it will change as need be and it has to be flexible.*** *I think there's one of the things in there that said that anyway, so I mean, I, I've done the second one and I've changed it already, and I haven't even started.*

5.5 What **strategies have been identified to eliminate any threats** to Aboriginal and Torres Strait Peoples ability to enjoy their cultural distinctiveness.

P: *Oh, number five looks at 'strategies to eliminate threats to people to enjoy their cultural distinctiveness'. That was another thing that I tried to look at here and no one had any policies anywhere and I'm [thinking] "Oh gosh, okay", first of all I said, "Well, what would I do if someone said or did something that made me feel like crap, because of who I am, what would I do?" I would report it. So, I put* ***"Grievances will be reported to the WAAHIEC ... all those complaints will have to be listed in the final***

review of the report itself". *And to* ***ensure that the community, participants – kids, and carers whatever, know that that avenue is available it has to be told up front in the consent form.*** *And it is in my consent form and its got to be a focus of the verbal communication, particularly with the people directly involved. Because there could be grievances from the community, but the participants themselves need a more direct process, and they have to know that there's a process there and that, not to be frightened to say, you know, well say if something happened. And, "For those Aboriginal people who are consultants or community interested peoples, then these reporting avenues will be communicated in the first letter, newsletter and in planned meetings", so its* ***always reinforced.***

RA: Good.

6. Spirit and Integrity –

6.1 How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's **cultural, spiritual and social cohesion**, including workable timeframes.

P: *That's enough for survival is it? ... That first question and I don't know how you'd answer this for you. I wrote, for me, "It looks at demonstrating an understanding and agreement of the relationship between the project and cultural, spiritual and social cohesion, including workable timeframes". And I've done that, I've said that "By* ***utilising previous research and professional experiences with Aboriginal, urban Aboriginal people in local communities."*** *That's enabled me to understand, the cultural, spiritual and social cohesion in the first place. 'Cause I've done all my work with Aboriginal kids, urban kids particularly, so I know. The thing is the north part, south is a bit different see and I know there's a difference. But the north part, particularly in the north-east its, I, I really know that area really well because I come from there. And then as you go south, its a bit different, but then* ***my previous experiences have told me that see.*** *So I don't know how you guys are going to get around, maybe you could say that* ***you've pulled the community in that have that have that experience and knowledge and that their going to rely on them.***

RA: Yes, yes to get it from them.

P: *You know what I'm saying? Yes, see I've actually said here that I've worked 19 years in this area…*

RA: Well, we've sort of had to say that the people on our management committee or the investigators what their experience was.

P: *Yes, 'cause I've said, "Consultation with other Aboriginal people will also guide that process to ensure the partnership", and that sort of stuff, so you kinda have to demonstrate your experience or the community.*

6.2 Whether the proposal recognises in the conduct and reporting of research the **diversity of Australian Aboriginal** and Torres Strait Islander People's cultures, including the **mechanisms through which communities may make decisions**.

P: *... see, that's doubling up again, that number two looks at 'ensuring the diversity of Aboriginal people is reported'.* ***So again, all the results, particularly the results, the translation, so everything, everything, has to be written in such a way that the cultural diversity has to be recognised.*** *If you're doing Yamatji kids in a certain area, then you've got to say that in all the results so that it sticks to that point. And also helps with that other bit about cultural distinctiveness and all the rest of it ... Like I said ... Aboriginal people don't like the word 'Indigenous' so I'd steer away from that. So* ***somehow you have to describe the community and there may not be all just Yamitji kids there****, see that's the thing, see we're urban here and I just say urban Aboriginal kids and I would eventually go down and describe who they are.*

RA: Again, we can take it from the community group.

P: They'll tell you, yes, they will tell you what's going on – what's not going on.

6.3 Whether the proponents of the proposal are able clearly to demonstrate **personal integrity**, specifically in the development of their proposal.

P: *... what did I say here? I said that "My proposal fills a gap, basically, and for the intent of this new knowledge it drives the research", so my personal integrity is to fill a gap that exists. Yours will be something like,* ***there's an issue out in the community and you're trying to alleviate that issue ... by accessing Aboriginal people's cultural knowledge and experience*** *to prevent bullying. Something like that, I don't know but I've just written that, I've just written, "It is intent for new knowledge that drives my research project". Basically, that's what's driving it and to "Capture authentic and valid information, Aboriginal people must be included as participants and community consultants", so the integrity is always there. And in yours, you could say that integrity could come in the community consultants ...*

6.4 Does the proposal demonstrate a commitment to working within the spirit and integrity of Aboriginal and Torres Strait Islander Peoples?

P: *Last one, "Does the project demonstrate a commitment to working within the spirit and integrity?" Yes, of course it does! What I've said here, "To ensure ... that its committed to the spirit and integrity" I've actually said, "That the* ***aims and objectives will be explicitly and continually discussed with the research participants and the community and it will remain flexible to the spirit, needs and aspirations of Aboriginal people."***

RA: That's great.

P: *That's it.*

P: T*he biggest thing from the WAAHIEC point of view would be the benefit to the community, that's the biggest thing. That has to be spelled out in your application; you know "What are they going to get out of this?"*

RA: As you said that's the first one.

P: *Yes, they really, really look … where are you going to use Aboriginal research assistants and stuff like that. Even if you do, go to conferences and stuff, you know how you get the main researchers, you need to have someone go with you, that sort of thing. … But you know what, if you do it right the first time like we've set out, when you go back to that community the second time to actually put that project in that community, you're going to be, once you do, get that respect, when you show that, up front, when you go the second time you won't have anyone slamming any doors on you or anything. They'll be friends for life, especially if you're doing the right thing. And you're accountable, and you're keeping the whole way around, that's why I've never had any trouble with my mob, you know and I can keep going back a hundred times and asking all sorts of questions.*

Appendix 5

Interview B transcript

Case Study B – Interview Transcript

Transcript key:

Italicised text was used to indicate participant responses
Green font was used to highlight the portions of the Communication Strategy relevant to specific principles from the NHMRC (2003) guidelines.
Italicised green font was used to identify respondent comments that were more explicit than what was presented from the on-line interview, as noted by the researcher.
Underlined text and **bolded text** was used to emphasis the importance of a portion of the Communication Strategy or the respondent comments

Reciprocity –

1. How the proposed research demonstrates **intent to contribute to the advancement of the health and wellbeing** of participants and communities.

The purpose of the WAACHS has been to gather an overview of the health and well being, level of adverse health behaviours, psychosocial problems and the educational attainment of a representative community sample of Aboriginal children and you people aged 0-17 years through out Western Australia. This information will be critical to the planning and delivery of health and other human services for Aboriginal people and to inform more effective strategies of prevention, health promotion and community development (p. 1).

Knowledge gained from survey data can be used to educate non-Aboriginal people about Aboriginal health issues.

Snap shot to provide a holistic view of Aboriginal health by identifying what impacts on social and emotional development.

More evidence-based research on Aboriginal health increases the effectiveness of future health interventions targeting Aboriginal people.

2. Whether the proposal **links clearly to community**, regional, jurisdictional or international Indigenous **health priorities and/or responds to existing or emerging needs articulated by Aboriginal** and Torres Strait Islander Peoples.

Although Aboriginal families were not marginally represented in [a state wide child health survey in 1993], the TICHR sought the advice and direction of several key Aboriginal organisations and individuals about conducting a similar survey for the Aboriginal and Torres Strait Islander population of Western Australia (p. 1).

The purpose of the WAACHS has been to gather an overview of the health and well being, level of adverse health behaviours, psychosocial problems

and the educational attainment of a representative community sample of Aboriginal children and you people aged 0-17 years through out Western Australia (p. 1).

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

3. The **nature of benefits for participants** or other Aboriginal and Torres Strait Islander communities, and whether there is **evidence of clear and truthful discussions** about the potential benefit of the research proposal **prior to approval**.

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

One of the most significant aspects for the initial development of the WAACHS was not only the support received from the TICHR and WAACHO, but also the WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders. It was clearly defined in the beginning though that this support would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way (p. 3) – *hence, the development and implementation of the research communication strategy was necessary.*

The research project must be identified by the community as relevant to community health issues through community consultations.

4. Whether the researcher has **demonstrated willingness to modify research** in accordance with participating **community values and aspirations**.

The Aboriginal Steering Committee are the gatekeepers of the WAACHS and its data, they provide the broader advice and direction and have the final say and decision on what happens to the information and data from the survey (p. 3).

The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (p. 3).

5. Whether the proposed research will **enhance the capacity of communities to draw benefit beyond the project**, eg through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level.

Established in 1997, the [WAACHS] Steering Committee has the responsibility to control and maintain:

1. the cultural integrity of survey methods and processes
2. **employment opportunities for Aboriginal people**
3. data access issues and communication of the findings to:
    - the Aboriginal community
    - the general community
4. maintaining appropriate and respectful relations:
    - within the study team
    - with participants and communities
    - with stakeholders and funding bodies
    - with the governments of the day (p. 1)

It is important to note that involvement of key research based and Aboriginal community based reference groups will be the fundamental component to all future work (p. 3).

Increased accountability on ensuring that project data contributes in same way to make a change within the community.

At a community level feedback of project data gives knowledge for decisions on the acceptance of future projects.

At a national level data provides evidence for the steering committee (hence, community) to advocate for future funding and future research projects.

Respect –

1. Whether the proposal **responds to the diversity of Aboriginal** and Torres Strait Islander Peoples and **communities, including the way decisions are made**.

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

Established in 1997, the [WAACHS] Steering Committee has the responsibility to control and maintain:

1. the cultural integrity of survey methods and processes
2. employment opportunities for Aboriginal people
3. data access issues and communication of the findings to:
    - the Aboriginal community
    - the general community
4. **maintaining appropriate and respectful relations:**
    - within the study team
    - **with participants and communities**
    - with stakeholders and funding bodies
    - with the governments of the day (p. 1)

The information collected through the survey provides a snapshot of families telling their stories that represents the diversity of Aboriginal people in WA.

2. How the proposal **acknowledges the individual and collective contribution of Aboriginal** and Torres Strait Islander Peoples.

Regional forums (pre-publication) – will cover the background information on how the survey came about and why, it is also going to cover basic information on the number of participants both household and school surveyed and will also talk about and feature the developments of locations and remote isolation measures for the state and how that compares with the current ARIA index (p. 12).

*** ***check with communication strategy manager on this one***

Instruments and feedback adapted for language groups within ATSIC boundaries.

3. How the researchers propose to **minimise the effects of difference blindness** on and in the research process.

The Communications Manager and research officers (Kulunga research team) will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience

Community consultation on appropriate methods for feedback to communities/regions.

Aboriginal people were employed to analyse the data – mix of education and health workers.

Peer review conducted of the data analysis (including non-Aboriginal professionals with extensive experience in AHR).

4. How the **research proposal engages** with **Aboriginal** and Torres Strait Islander People's **knowledge and experience**.

It was clearly defined in the beginning ... that ... support [from TICHR, WAACHO, WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders] would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way (p. 3).

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

The communication dissemination strategy.

5. Whether **appropriate agreements** have been **negotiated about ownership and rights of access** to Aboriginal and Torres Strait Islander People's **intellectual and cultural property**.

Evaluation - A debriefing session will also be utilised at the end of the completion of the strategy. A debriefing session will also be utilised at the end of the completion of the strategy. This session will be open to all key stakeholders. The aim of this will be to see how we went with tying in the community, following protocols on Aboriginal research and to provide the opportunity to talk about the positives and the negatives of the strategy. This will provide a benchmark for all future Aboriginal research strategies to allow constructive feedback with the aim of doing better research (p. 11).

Regional forums (pre/post-publication) – will cover the background information on how the survey came about and why, it is also going to cover basic information on the number of participants both household and school surveyed and will also talk about and feature the developments of locations and remote isolation measures for the state and how that compares with the current ARIA index (p. 12).

Protocols/policy for data access to survey results – permission to use any of the WAACHS data must be applied for in writing and interpretation of data must be made in consultation with Aboriginal researchers prior to use.

6. Whether **the processes of reaching agreement** demonstrate **engagement** with the values and processes of **participating communities**.

The Communications Manager and research officers will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience (p. 9).

7. Whether the participating communities have **expressed satisfaction** with the research agreement and decision making processes.

It was clearly defined in the beginning ... that ... support [from TICHR, WAACHO, WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders] would be given on the condition that the communities and

families particularly who were part of the survey, would be given back information at every step of the way (p. 3).

The strongest focus of these regional forums is to gain regional support and assistance from each of the identified key stakeholders as to what sorts of information will be needed by each of the regions and also notify us of how the regions want the information fed back to them and how they might suggest the information is fed back to the families and the communities who were involved with the survey (p. 12).

8. Whether in reaching **agreement** with participating communities all relevant issues including **management of data, publication arrangements and the protection of individual and community identity have been adequately addressed**.

Evaluation - A debriefing session will also be utilised at the end of the completion of the strategy. A debriefing session will also be utilised at the end of the completion of the strategy. This session will be open to all key stakeholders. The aim of this will be to see how we went with tying in the community, following protocols on Aboriginal research and to provide the opportunity to talk about the positives and the negatives of the strategy. This will provide a benchmark for all future Aboriginal research strategies to allow constructive feedback with the aim of doing better research (p. 11).

Protocols/policy for data access to survey results – permission to use any of the WAACHS data must be applied for in writing and interpretation of data must be made in consultation with Aboriginal researchers prior to use.

Confidentiality was very important, the use of ATSIC regions secured the anonymity of participating families. Eg. To use one town, say Narrogin, would have made it easy for families in other towns to identify that "so and so doesn't do such and such with their kids, or does do such and such".

Equality –

1. Whether the ways that participating communities are included in the **research processes demonstrate equality**.

The Communications Manager and research officers will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience

Feedback needed to specific to ATSIC regional profiles – eg. Storyboards.

2. Whether the research agreements have the **strength necessary to sustain equality**.

The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (p. 3).

It was clearly defined in the beginning ... that ... support [from TICHR, WAACHO, WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders] would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way (p. 3).

3. Whether participating communities have **understood and expressed satisfaction** with the proposed research, its potential benefits and their distribution. Researchers therefore have a **responsibility** to ensure that the information that they provide is **understood and usable** in decision making by participating communities.

An Aboriginal Communications Strategy Manager ... will coordinate the communications, reporting and dissemination aspects of the WAACHS for, and on behalf of the TICHR and the Kulunga Research Network (p. 8).

The [Regional] representatives will assist in the development, implementation and evaluation of specific strategies and delivery of the WAACHS findings within their area and will liaise continuously with the communities they represent and the Communications Manager involved in regards to updates, community consultations, development and delivery of strategies (p. 8).

The Communications Manager and Regional Representatives will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience (p. 9).

The use of a plain language story board and presentations to communities and numerous associated health, shire, sporting, policing, family and children service, cultural, disability and educational organisations (p. 9).

Information materials and suitable processes will be developed for community feedback from the information and advice gathered in [the consultation] step (p. 9).

Responsibility –

1. What measures are identified to demonstrate **transparency in the exchange of ideas** and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research.

An Aboriginal Communications Strategy Manager ... will coordinate the communications, reporting and dissemination aspects of the WAACHS for, and on behalf of the TICHR and the Kulunga Research Network (p. 8).

The [Regional] representatives will assist in the development, implementation and evaluation of specific strategies and delivery of the WAACHS findings within their area and will liaise continuously with the communities they represent and the Communications Manager involved in regards to updates, community consultations, development and delivery of strategies (p. 8).

The Communications Manager and Regional Representatives will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience (p. 9).

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

Established in 1997, the [WAACHS] Steering Committee has the responsibility to control and maintain:

1. the cultural integrity of survey methods and processes
2. employment opportunities for Aboriginal people
3. data access issues and communication of the findings to:
    - the Aboriginal community
    - the general community
4. **maintaining appropriate and respectful relations:**
    - within the study team
    - **with participants and communities**
    - with stakeholders and funding bodies
    - with the governments of the day (p. 1)

2. How provision is made for appropriate **ongoing advice and review** from the participating community, including mechanisms to **monitor ethics standards** and to minimise the likelihood of any unintended consequences arising from or after the research project.

Evaluation - A debriefing session will also be utilised at the end of the completion of the strategy. A debriefing session will also be utilised at the

end of the completion of the strategy. This session will be open to all key stakeholders. The aim of this will be to see how we went with tying in the community, following protocols on Aboriginal research and to provide the opportunity to talk about the positives and the negatives of the strategy. This will provide a benchmark for all future Aboriginal research strategies to allow constructive feedback with the aim of doing better research (p. 11).

A set of formal recommendations will also be presented at the completion of the strategy. Documented feedback gathered in the consultation phases and with feedback from each of the regional visits will be written. It is anticipated that 1 set of community-based recommendations and 1 set of researcher-based recommendations be produced. These recommendations will stipulate strategy achievement, strengths, weaknesses and ways to move forward for the future. The documents will also highlight protocols and policies for data access. It is hoped that these reports will feed into health service organisation delivery and will be utilised to inform policy and planning in the future (p. 11).

3. What does the proposal say about **timely feedback** obligations to communities and whether that feedback is **relevant to the expressed concerns, values and expectations** of research participants and communities.

The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (p. 3).

It was clearly defined in the beginning though that this support [from TICHR, WAACHO, WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders] would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way (p. 3).

The use of a plain language story board and presentations to communities and numerous associated health, shire, sporting, policing, family and children service, cultural, disability and educational organisations (p. 9).

Information materials and suitable processes will be developed for community feedback from the information and advice gathered in [the consultation] step (p. 9).

The Communications Manager and research officers (communication strategy team) will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey

- Communities survey experience (p. 9).

Feedback forums must allow open discussion time for: health issues presented in the feedback; relevance of the feedback material to the community; and survey experience of participants.

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

Established in 1997, the [WAACHS] Steering Committee has the responsibility to control and maintain:

1. the cultural integrity of survey methods and processes
2. employment opportunities for Aboriginal people
3. data access issues and communication of the findings to:
    - the Aboriginal community
    - the general community
4. **maintaining appropriate and respectful relations:**
    - within the study team
    - **with participants and communities**
    - with stakeholders and funding bodies
    - with the governments of the day (p. 1)

4. How the proposal demonstrates agreed arrangements regarding publication of the research results, including **clear provisions relating to joint sign off for publication and the protection** of individual and community identity if appropriate.

Regional forums (pre/post-publication) – will cover the background information on how the survey came about and why, it is also going to cover basic information on the number of participants both household and school surveyed and will also talk about and feature the developments of locations and remote isolation measures for the state and how that compares with the current ARIA index (p. 12).

The strongest focus of these regional forums is to gain regional support and assistance from each of the identified key stakeholders as to what sorts of information will be needed by each of the regions and also notify us of how the regions want the information fed back to them and how they might suggest the information is fed back to the families and the communities who were involved with the survey (p. 12).

After the release of each volume, the Communications Manager and research officers will visit each region to disseminate the information from each volume, particularly the information specific to that region. The purpose of these visits is to inform key stakeholder groups and the Aboriginal community about the findings from the survey and about how this information could assist local groups and organisations about program development and areas of need.

ATSIC boundaries protect family identities.

The steering committee approves the publication of all data.

5. Whether there is **clarity about the demand on partners** created by the proposed research and the potential implications for partners arising from it.

The Aboriginal Steering Committee are the gatekeepers of the WAACHS and its data, they provide the broader advice and direction and have the final say and decision on what happens to the information and data from the survey (p. 3).

Kulunga Research Network / WAACHS Team
The Network, under guidance from the steering committee, will assist the Communications Manager and Regional consultants on aspects of the strategy (p. 3).

Survival and Protection –

1. Whether the research project contributes to or erodes the **social and cultural bonds** among and between Aboriginal and Torres Strait Islander families and communities.

It was clearly defined in the beginning ... that ... support [from TICHR, WAACHO, WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders] would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way (p. 3).

Showing that diversity exists within the community.

This information will be critical to the planning and delivery of health and other human services for Aboriginal people and to inform more effective strategies of prevention, health promotion and community development (p. 1).

Knowledge gained from survey data can be used to educate non-Aboriginal people about Aboriginal health issues.

Snap shot to provide a holistic view of Aboriginal health by identifying what impacts on social and emotional development.

More evidence-based research on Aboriginal health increases the effectiveness of future health interventions targeting Aboriginal people.

2. What **safeguards** are in place against the research project contributing to discrimination or derision of Aboriginal and Torres Strait Islander individuals or cultures.

The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (p. 3).

The Communications Manager and Regional Representatives will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience (p. 9).

Pre/post-publication forums.

Aboriginal people involved in: data collection; data analysis; feed back process; and write up.

The steering committee have final say of data publication.

3. Whether the proposal **respects the intrinsic values based expectations and identity** of Aboriginal and Torres Strait Islander Peoples and communities including the balance **between collective and individual identity**.

A set of formal recommendations will also be presented at the completion of the strategy. Documented feedback gathered in the consultation phases and with feedback from each of the regional visits will be written. It is anticipated that 1 set of community-based recommendations and 1 set of researcher-based recommendations be produced. These recommendations will stipulate strategy achievement, strengths, weaknesses and ways to move forward for the future. The documents will also highlight protocols and policies for data access. It is hoped that these reports will feed into health service organisation delivery and will be utilised to inform policy and planning in the future (p. 11).

4. How the proposal **contributes** to the opportunity for **Aboriginal** and Torres Strait Islander Peoples to better advocate for or enjoy their **cultural distinctiveness**.

The purpose of the WAACHS has been to gather an overview of the health and well being, level of adverse health behaviours, psychosocial problems and the educational attainment of a representative community sample of Aboriginal children and you people aged 0-17 years through out Western Australia. This information will be critical to the planning and delivery of health and other human services for Aboriginal people and to inform more effective strategies of prevention, health promotion and community development (p. 1).

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

Established in 1997, the [WAACHS] Steering Committee has the responsibility to control and maintain:

1. **the cultural integrity of survey methods and processes**
2. employment opportunities for Aboriginal people
3. data access issues and communication of the findings to:
    - the Aboriginal community
    - the general community
4. **maintaining appropriate and respectful relations:**
    - within the study team
    - **with participants and communities**
    - with stakeholders and funding bodies
    - with the governments of the day (p. 1)

Provides a holistic view to Aboriginal health issues in WA.

Data collected through the survey is Intended to assist Aboriginal people to self advocate at local and national levels.

5. What **strategies have been identified to eliminate any threats** to Aboriginal and Torres Strait Peoples ability to enjoy their cultural distinctiveness.

The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (p. 3).

Spirit and Integrity –

1. How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's **cultural, spiritual and social cohesion**, including workable timeframes.

The most critical aspect of the WAACHS has been to develop and implement a culturally consultative and relevant communication and dissemination strategy to report the findings of the survey back to the Aboriginal families and communities both at a local and regional level (p. 3).

The Communications Manager and Regional Representatives will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings

- What regional specific information is needed from the survey
- Communities survey experience (p. 9).

2. Whether the proposal recognises in the conduct and reporting of research the **diversity of Australian Aboriginal** and Torres Strait Islander People's cultures, including the **mechanisms through which communities may make decisions**.

The Communications Manager and Regional Representatives will visit communities within each area prior to, and in conjunction with the release of each volume. These visits will involve consulting with appropriate community representatives, community members and relevant local government and non-government organisations to develop a regional specific feedback plan and to determine:

- The methods to be used for feedback of findings
- What regional specific information is needed from the survey
- Communities survey experience (p. 9).

Providing forums for open discussion of participants' research experiences.

Regional forums (pre/post-publication) – will cover the background information on how the survey came about and why, it is also going to cover basic information on the number of participants both household and school surveyed and will also talk about and feature the developments of locations and remote isolation measures for the state and how that compares with the current ARIA index (p. 12).

The strongest focus of these regional forums is to gain regional support and assistance from each of the identified key stakeholders as to what sorts of information will be needed by each of the regions and also notify us of how the regions wan the information fed back t them and how they might suggest the information is fed back to the families and the communities who were involved with the survey (p. 12).

Trust + Feedback = increase in intervention uptake

3. Whether the proponents of the proposal are able clearly to demonstrate **personal integrity**, specifically in the development of their proposal.

All phases of the survey and its development, design, and implementation were under the direction of the Western Australian Aboriginal Child Health Survey Steering Committee (p. 1).

Established in 1997, the [WAACHS] Steering Committee has the responsibility to control and maintain:

1. **the cultural integrity of survey methods and processes**
2. employment opportunities for Aboriginal people
3. data access issues and communication of the findings to:
    - the Aboriginal community
    - the general community

4. **maintaining appropriate and respectful relations:**
    - within the study team
    - **with participants and communities**
    - with stakeholders and funding bodies
    - with the governments of the day (p. 1)

Building relationships of trust is essential in the early/formative stages of research project.

4. Does the proposal **demonstrate a commitment to working within the spirit and integrity** of Aboriginal and Torres Strait Islander Peoples?

It was clearly defined in the beginning ... that ... support [from TICHR, WAACHO, WA Council of ATSIC Commissioners and the WA Council of Aboriginal Elders] would be given on the condition that the communities and families particularly who were part of the survey, would be given back information at every step of the way (p. 3).

Development of the dissemination strategy demonstrates commitment to principle.

Appendix 6

Telephone Script for expert panel recruitment

Telephone script for expert panel recruitment

Phone call:

I work at the child health promotion research unit at Edith Cowan University.

I have an Honours student whose research is investigating a **process to facilitate a collaborative ethics process with an Aboriginal community** for a bullying prevention project with school children. Our research unit has been working with a community in the Mid-West Murchison on the project. The project been funded by Healthway.

The honours student has used the

1. NHMRC guidelines for ethical health research with Aboriginal peoples.
2. and Proposes a framework of examples for how the values in the NHMRC guidelines can be demonstrated. She has used a comprehensive literature review, the NHMRC guidelines and interviews with Aboriginal health researchers to develop the framework.
3. She has described case studies of how two Aboriginal researchers have demonstrated the values in their research project for their community.

I'd like to ask if you would consider reviewing the examples in the framework of how to demonstrate the values and tell us if you think they will help maintain cultural security and if you believe they demonstrate the values described in the NHMRC guidelines.

If yes ...

the student will email the document to you, and send it to you in hard copy. Can I please check your email and delivery address details?

Because the student's project is drawing to a close, if you could return your response by 9 November it would be most appreciated.

Thank you

Appendix 7

Email script for expert panel recruitment

Email scripts for Expert panel recruitment

Email after successful phone call:

A framework to facilitate a collaborative ethics process with an Aboriginal community

Thank you for agreeing to review and answer questions on the attached document. The document is easier to read if it is printed in colour. A hard copy of the document will be sent to your office. Please feel free to return your response by either hard copy or email.

Please read the attached information letter and complete the consent form. The consent form will need to be returned by mail.

At present we are inviting 10 people from the following agencies to review the document.

- Kulunga Research Network
- Telethon Institute for Child Health Research
- Combined Universities Centre for Rural Health
- Australian Indigenous HealthInfonet
- Western Australian Department of Health, Aboriginal Health

If there is any other person whom you would like to recommend reviewing this document, would you please send me their details and I will contact them.

If possible, could you please return the attached survey by post or email to:
Dionne Paki d.paki@ecu.edu.au
Child Health Promotion Research Unit
School of Exercise, Biomedical & Health Sciences
Edith Cowan University
Pearson Street Churchlands WA 6018

by 9 November, 2005.

Please feel free to contact Dionne on 9273 8793 or myself if you have any questions.

Email when can't get through on phone:

A framework to facilitate a collaborative ethics process with an Aboriginal community

I work at the Child Health Promotion Research Unit at Edith Cowan University.

Our unit has a research project investigating a **process to facilitate a collaborative ethics process with an Aboriginal community** for a bullying prevention project with school children. Our research unit has been working with a community in the Mid-West Murchison on the project. The project been funded by Healthway.

The NHMRC (2003) guidelines for ethical health research with Aboriginal peoples has been used to propose a framework of examples for how the values in the NHMRC guidelines can be demonstrated. Sources informing the framework are:
a comprehensive literature review; the NHMRC guidelines; and interviews with Aboriginal health researchers. Case studies from two experienced Aboriginal researchers have been used as suggestions for how the values can be applied in Aboriginal child health research.

I'd like to ask if you would consider reviewing the examples in the proposed framework. If you could return your response by 9 November (or as soon after as possible) it would be most appreciated. The document is easier to read if it is printed in colour. A hard copy of the document will be sent to your office. Please feel free to return your response by either hard copy or email.

I have attached the document we would like you to review. Thank you for your consideration of this request.

Yours sincerely

Appendix 8

Information letter and consent form for the expert panel instrument

INFORMATION LETTER TO EXPERT PANEL PARTICIPANTS:

A descriptive study of ethical procedures that maintain cultural security when conducting health research with Aboriginal school children in Western Australia.

My name is Dionne Paki and I am working with the Child Health Promotion Unit (CHPRU) at Edith Cowan University. My research is investigating the application of the National Health Medical and Research Council (NHMRC, 2003) guidelines for ethical health research with Aboriginal and Torres Strait Islander peoples to facilitate a collaborative ethics process with Aboriginal communities that participate in child health research in Western Australia (WA).

I have developed a proposed framework to facilitate this process using information from the NHMRC (2003) guidelines, a comprehensive literature review and interviews with two experienced Aboriginal heath researchers. I have also described examples from two case studies of how these researchers have/will demonstrate the values and principles relevant to Aboriginal health research (NHMRC, 2003). The values and principles are taken from the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* and are: **reciprocity**, **respect**, **equality**, **responsibility**, **survival and protection**, and **spirit and integrity** (NHMRC, 2003).

Would you please share your experience by REVIEWING the proposed framework and case study examples as a member of a panel of Aboriginal health workers or researchers? We need to know if this proposed framework:
1. Maintains the cultural security of participants in an Aboriginal child health research project.
2. Demonstrates the values and principles outlined in the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC, 2003).

After I have received the completed questionnaires you will be presented with the combined **anonymous** responses from the panel. These responses will make up a revised proposed framework for a collaborative ethics process with Aboriginal communities participating in child health research projects.

This research and the revised proposed framework will be used to guide the ethics application for a school-based bullying prevention and reduction study to be conducted by a community committee and the CHPRU in the Midwest, Murchison region of WA.

I would greatly appreciate your help by filling out the attached questionnaire and returning it in the provided self-addressed envelope, if required. Dr Margaret Hall and I will be the only people with access to the completed questionnaire and will treat all information with the strictest confidence. In the presentation of the results of this project you will not be identified in any way.

If you are willing to participate in this project please sign and date the consent form on the next page. You may withdraw from participation in this research project at any time. If you choose not to complete the questionnaire, I thank you for reading this letter.

Please feel free to contact me on 08 9273 8793 or by email at d.paki@ecu.edu.au if you wish to discuss this questionnaire. You are also welcome to contact Dr Margaret Hall by email at m.hall@ecu.edu.au. I would also be grateful for any feedback or suggestions you may have in regards to this research. Thank you for your time.

Dionne Paki.

Reference:
National Health and Medical Research Council. (2003). *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.* Canberra, ACT: Commonwealth of Australia, available at http://www.nhmrc.gov.au/publications/synopses/e52syn.htm.

This study has been approved by the Edith Cowan University Human Research Ethics Committee. If needed, verification can be obtained either by writing to the Research Ethics Officer, the Edith Cowan University Human Research Ethics Committee, Edith Cowan University, 100 Joondalup Drive, Joondalup WA 6027 or by telephoning 08 6304 2170.

CONSENT DOCUMENT

A descriptive study of ethical procedures that maintain cultural security when conducting health research with Aboriginal school children in Western Australia.

I have been provided with a copy of the Information Letter, explaining the above project. I have been given the opportunity to ask questions and any questions have been answered to my satisfaction.

I understand that participation in the research project will involve completion of the enclosed questionnaire.

I understand that the information provided will be kept strictly confidential, will only be used for the purposes of this project and I will not be identified in any written presentation of the results of this project. I understand that I am free to withdraw from further participation at any time, without explanation or penalty.

I freely agree to participate in this project.

_____

Name

_____

Signature

_____

Date

Please place this competed consent form in the reply paid envelope provided.

Appendix 9

Follow up email for expert panel participation

Follow up email for expert panel participation

Email when no response received:

RE: A framework to facilitate a collaborative ethics process with an Aboriginal community

Hello again,

This is a follow-up email regarding feedback on a proposed framework for collaborative ethics processes when researching Aboriginal children's health in Western Australia. I appreciate that this is a busy time of year for everyone and would still value any contribution you are able to make towards the revision of the proposed framework. If you require another electronic copy of the questionnaire and information letter please let me know.

Kind regards,

Dionne Paki

Appendix 10

Thank you letter to case study participants and expert panel respondents

<date>

NAME
POSTAL ADDRESS

Dear ,

A descriptive study of ethical procedures that maintain cultural security when conducting health research with Aboriginal and Torres Strait Islander school children in Western Australia.

Thank you so much for taking the time to respond to my recent invitation for feedback on a proposed framework to facilitate a collaborative ethics process when researching Aboriginal school children in WA. Your comments were helpful in revising the framework.

Please find enclosed a copy of:

- group opinion from the expert panel on the proposed framework
- comments received on the proposed framework
- the revised framework with changes in **bold**

As mentioned in the information letter accompanying the questionnaire, the revised framework will be used to guide the ethics process of an Aboriginal bullying prevention and reduction project. Your contribution to the success of this process is greatly appreciated.

With best wishes, sincerely

Dionne Paki

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Appendix 11

Revised framework

Maintaining cultural security – A framework to inform the demonstration of values outlined in *'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research'* *(NHMRC, 2003).*

The examples within this framework describe how the principles outlined in the NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* can be applied or demonstrated in a health research project.

This framework was developed (Paki, 2005) to facilitate a collaborative ethics process for maintaining the cultural security of participants in Aboriginal child health research projects and to demonstrate the six Aboriginal values relevant to health research identified in the NHMRC guidelines (2003). It was not the author's intention to replicate the NHMRC (2003) guidelines; rather, the aim of the framework was to provide examples of how the NHMRC (2003) values could be demonstrated in Aboriginal child health research in Western Australia.

The proposed framework was created using: a document review of the National Health and Medical Research Council's (NHMRC, 2003) guidelines for Aboriginal and Torres Strait Islander health research; a comprehensive literature review; and data collected through case studies on demonstrating the Aboriginal values relevant to health research (NHMRC, 2003).

The proposed framework was presented to an expert panel made up of experienced Aboriginal and non-Aboriginal health promotion researchers and practitioners in a semi-structured questionnaire. The aim of this expert consultation was to determine consensus that the proposed framework would:

1. maintain the cultural security of participants in an Aboriginal child health research project; and
2. demonstrate the values and principles outlined in the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC, 2003).

Of the 87 items presented to the expert panel for demonstrating the values and principles (NHMRC, 2003), consensus was reached for all items except eight due to polar views among panel members. Comments from panel members were used to revise the framework and are identified in **bold** text.

Queries regarding this framework should be directed to:

Dionne Paki
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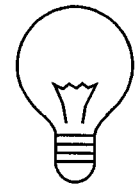
Email: d.paki@ecu.edu.au

Demonstrating the principles for the Aboriginal values relevant to health research	Suggestions from expert consultation
The examples within this framework describe how the principles outlined in the NHMRC (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* can be applied in a health research project.	Suggestions for ways the framework examples can be demonstrated in Aboriginal child health research.
▪ **Reciprocity** This value aims to make sure that there are equal benefits for both researchers and participants for the research project. For an equal exchange to occur, the 'benefits' of the research project must be defined by the priorities and values of the participating community (NHMRC, 2003).	
1. *Before the research project starts the researchers will explain how the project will try to help improve the health and wellbeing of the community (NHMRC, 2003).* This principle can be demonstrated when: ▪ Prior to the project proposal, a community committee or group is formed to guide the project and make sure that community culture is respected and community health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson, Simmons, Bourke, & Muir, 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ **Overall the committee/community are satisfied that** the project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy (Case study, 1, 2; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson, Kelaher, Williams, & Shannon, 1998; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • Feedback of project data provides the community with knowledge for decisions on the acceptance of future projects.

2. *Making sure that the purpose of the project is connected to the community health priorities and health needs that Aboriginal people have talked about (NHMRC, 2003).* This principle can be demonstrated when: ▪ Aboriginal health organisations **contribute to determining that** the project **will focus on issues** that are important to Aboriginal people to keep themselves strong and healthy (Case study, 1, 2; Donovan & Spark, 1997; Dressendorfer et al., 2005; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ The committee/**community confirms the health needs/priorities of the project and contributes to the design of the study** (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; Miller & Rainow, 1997; National Health and Medical Research Council, 2003).	• Use of national Aboriginal health priorities and local community based reference groups including non-Aboriginal groups who work with an Aboriginal network. • A community owned project will naturally inform researchers of the health issues important to the community. • The committee will help manage the project and keep things going smoothly. • The committee advises researchers on the best direction of the project for the community. • The committee advises researchers what the community wanted to happen to the project information.
3. *Showing that clear and truthful discussions about the benefits the community will receive for participating in the research project have happened (NHMRC, 2003).* This principle can be demonstrated when: ▪ Communication between the committee and the project is transparent – phone calls; letters; emails; and consultation meetings are all noted **and documented as evidence** to make sure that the project remains culturally appropriate for the needs of the community (Case study, 1).	• The committee informs the project when and how modifications to the project are required. For example when sensitivity is needed so that community members involved in the project can meet their cultural obligations should the need arise. • A flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. For all visits to the community throughout the project. It also ensures the project remains truthful in fulfilling its commitments to the community. • **Meeting notes are double checked by the committee to ensure community issues are recorded correctly.** • **Agreed outcomes (eg. capacity building) are identified at the commencement of the project.**

4. *Showing a willingness to make changes to include the community's values and goals in the research project (NHMRC, 2003).* This principle can be demonstrated through: ▪ Open communication with the community committee so that researchers can be guided to make sure that community culture and health matters are represented throughout the project (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ Community members are given the opportunity to speak to researchers about the project in a group or one-on-one **in a culturally appropriate environment and at all stages of the project** (Case study, 1, 2; Heam & Wise, 2004; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Miller & Rainow, 1997; Sheehan, Ridge, & Marshall, 2002; Thomsen, 2003).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • **All stages of the project** were carried out under the direction of the committee. • **Contributions/suggestions to project management and process are acted on and in cases where suggestions may not be able to be accommodated, reasons or compromises are sought.** • A project information night or workshop is presented within the community prior to the commencement of the project and then as often as the committee feels is necessary. • Researchers allow for one-on-one time to make sure carers and children have all their questions answered.
5. *Building the community's capacity to have the benefits from the project continue after the project is finished, eg through the development of skills (NHMRC, 2003).* This principle can be demonstrated when: ▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis. • **Skills developed as a result of the project are maintained and supported by continuing education and employment opportunities.**

▪ The information collected from the project can be used to help the community make strong decisions in the future about their health (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Holmes, Stewart, Garrow, Anderson, & Thorpe, 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date). ▪ The information collected from the project might be useful to help the community get funding in the future for other health projects (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Knowledge gained from the project can be used to educate non-Aboriginal people about the community's health issues. • A successful pilot study provides support for future funding grants on the same or related topic in the same community or region.

▪ Respect

This value aims to acknowledge the contribution of participants to the research project in a cooperative and sensitive way. It also aims to make sure that full community consultation happens throughout the entire research process (NHMRC, 2003).

1. *The project accepts the differences between different Aboriginal communities, including the way decisions are made (NHMRC, 2003).*

This principle can be demonstrated when:

- The committee informs the project about community culture and health matters (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).

- The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).

- The information collected from the project only tells a story about the community or region involved in the project(Case study, 1, 2; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).

- In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders.
- Meeting frequency is determined by the committee – it could be once a month or once a term.
- All stages of the project were carried out under the direction of the committee.
- Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data.
- Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
- The use of 'regions', rather than the community's geographic name provides anonymity to project participants.
- Diversity means allowing for Aboriginal people to be different to other Aboriginal people from different areas: data collected in urban Aboriginal projects only represents urban Aboriginal people; rural projects represent rural people; and remote projects represent remote people.

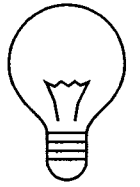
2. *The project acknowledges the individual and collective contribution of Aboriginal people (NHMRC, 2003).* This principle can be demonstrated when: ▪ The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak, McDermott, Plant, & Scrimgeour, 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004). ▪ Community members are personally invited to be involved in the research project (Case study, 1). ▪ Community members who want to be involved in the project are invited to share their thoughts about their own health and the health of their community (Case study, 1; Thomsen, 2003).	• **Recognition of individual/community contribution (e.g. authorship on peer reviewed journals) is discussed with the committee.** • Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points. • Use of story boards to feed project information back to the community. • Invest time into getting to know the community and their school children before data collection by being involved: attend sports days; jump on the school bus; and meet the parents when they pick up their kids after school. • As part of the data collection participants are asked what they think about health: for themselves, their families and their community.
3. *The project accepts the differences between Aboriginal and non-Aboriginal cultures and between different Aboriginal communities (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee guides the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ The project provides training and job opportunities to (if possible, local) Aboriginal people to help analyse information for the project and develop the results (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders; a **reference group with specific representatives established if necessary for larger regions.** • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • Aboriginal research assistants are formally trained **(by experts) in a manner that is culturally appropriate** so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.

▪ The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style **that is approved by the committee** (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).	• Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points. • Use of story boards to feed project information back to the community.
4. *The research project uses Aboriginal knowledge and experience (NHMRC, 2003).* This principle can be demonstrated by: ▪ Open communication between the committee and the project to make sure that the community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ Open communication with the community committee so that community members who are involved in the project are invited to share their feelings about: a) **project design e.g.** how the information is collected; b) the **analysis and interpretation of** results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project. **This information is used to guide future projects** (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003). ▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation. • Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.

5. *An agreement about the ownership and rights of access to Aboriginal intellectual and cultural property is organised and the community committee is happy with the agreement (NHMRC, 2003).* This principle can be demonstrated by: ▪ A written agreement is made so that the community agrees with: how the project will be conducted, and what will happen to the project information (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ **Rights to project information are negotiated between the community and researchers.** Permission for access to the project information must be applied for in writing to the committee (Case study, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A statement of cultural consent and participation is developed through committee negotiations with the project. • The statement is in-line with the community's protocols. • **Adherence to such agreements is observed at all stages of the project.** • Information access agreement – information from the project can not be accessed unless a written application is made. The data must be interpreted for the new project in consultation with an Aboriginal researcher (or assistant).
6. *The researchers must prove that the community's values for making the agreement are used (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ The way the agreement was made is recorded, eg. if the agreement was made by a show of hands it is recorded that 'the agreement was accepted by the community by show of hands' (Case study, 1). ▪ The meeting for the agreement is held in a neutral of safe place for the people involved in the project (Case study, 1, 2).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • If the agreement was made by a show of hands it is recorded that 'the agreement was accepted by the community by a show of hands'. • Somewhere outdoors is preferable, not in an officer or in a school building.

7. *The community has said that they are happy with the agreement for the research project and the way it was made (NHMRC, 2003).* This principle can be demonstrated when: ▪ Community members who are involved in the project are invited to share their feelings about what they liked and did not like about the agreement (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Sheehan et al., 2002; Thomsen, 2003). ▪ **Open communication between committee and project to make sure community culture and health matters are respected** (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• A 'time of reflection' is allocated at the conclusion of the committee/community meetings to give community members an opportunity to raise their concerns. • Community concerns are recorded in a 'processes journal' that is actioned by researchers. • **Community members are given the opportunity to speak to researchers about the project in a group or one-on-one in a culturally appropriate environment and at all stages of the project.** • **Community feedback is: respected, acted upon and relayed into future projects.** • **All stages of the project were carried out under the direction of the committee.**
8. *When the agreement is made the community committee is happy with the storage of data and the **process to be followed for** publication of the information collected in the project. The people who are involved in the project are happy with the agreement and feel that their identity is safe and protected (NHMRC, 2003).* This principle can be demonstrated when the: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • The community has a copy of 'critical' project information.

▪ Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.
▪ A written agreement is made so that the community agrees with the storage, publication **and process to publication** of the project information (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• A statement of cultural consent and participation is developed through committee negotiations with the project. • The statement is in-line with the community's protocols.
▪ A management plan or communication strategy is used to make sure that the project actions the required ethical processes. Progress of the management plan is reported back to the community committee throughout the research project (Case study, 1, 2; Hearn & Wise, 2004; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• A matrix or flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. First visit, second visit through to final feedback after project completion. • Stages are matched up with ethics application to keep the project truthful and transparent.

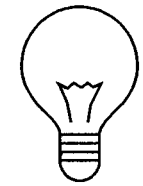
▪ **Equality** This value aims to make sure that the cultural needs of Aboriginal research participants are catered for within the research project and that the differences between Aboriginal and non-Aboriginal world views are accepted (NHMRC, 2003). * a small number of expert panellists did not agree that this example would demonstrate this value/principle	
1. *Community involvement in the research project shows equality (NHMRC, 2003).* This principle can be demonstrated because: ▪ ***With consent and where culturally/project appropriate the whole community is invited to be involved in the project** – children of all ages, adults, males and females (Case study, 1). ▪ The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004). ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• All children involved in the project sign their name, with an 'X' if necessary, to feel important and included. • Potential participants (children) are also invited to attend the project information session with their carers. • The project will attempt to match the gender of **interviewers/researchers** with participants. • Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points. • Use of story boards to feed project information back to the community. • In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.

▪ The project provides training and job opportunities, **supported by appropriate experts and resources,** for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Heam & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
2. *In the agreement for the research project everyone is treated with equality (NHMRC, 2003).* This principle can be demonstrated when: ▪ The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004). ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ Community members who are involved in the project are invited to share their feelings about: a) **Project design e.g.** how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points. • Use of story boards to feed project information back to the community. • In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.

3. *Researchers make sure that the information that they provide to the community about the research is understood and usable in decision making. The community is happy with what the researchers say they will do with the information collected from the research project (NHMRC, 2003).* This principle can be demonstrated when researchers make sure that: ▪ The information sheet and consent form are in an appropriate language and style for the community; people who want to be involved understand what the project is about (Case study, 1, 2; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998). ▪ The community members who want to be involved in the project understand that they can change their minds about being involved whenever they want (Case study, 1). ▪ Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project eg. through community meetings, newsletters, management plan (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Large font is used for both the adults (to cater for poor eyesight from diabetes) and the children's information sheet. • The information and consent forms are presented to both the carers and the children one-on-one. • Both the carers and the children are given the opportunity to indicate their level of project participation eg. Permission to have photographic/video footage. • **Participants have the option to be verbally informed about the project in their own language.** • Carers are assured that they can withdraw their children from participating in the project at any time without a fuss from researchers. • Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.

▪ Responsibility

This value aims to make sure that research does no physical, social, mental or emotional harm to participants. Researchers have the responsibility to make sure that the research project does not stop participants from doing their cultural and social responsibilities (NHMRC, 2003).



1. *Researchers must make sure that the sharing of ideas about the benefits and how the research project will be conducted with the community committee is open and truthful (NHMRC, 2003).*

This principle can be demonstrated if:

- All communication with the committee is written down or noted to make sure that the project continues to be open and truthful eg. meeting minutes (Case study, 1).

- The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).

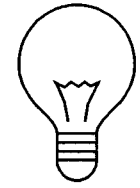
- The committee informs the project when and how modifications to the project are required. For example when sensitivity is needed so that community members involved in the project can meet their cultural obligations should the need arise.
- A flowchart is constructed to inform/manage what needs to get done at different stages of the project, eg. For all visits to the community throughout the project. It also ensures the project remains truthful in fulfilling its commitments to the community.
- **Such communication is recorded in a way that can be understood by the community.**
- In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders.
- Meeting frequency is determined by the committee – it could be once a month or once a term.
- All stages of the project were carried out under the direction of the committee.

▪ The community is happy with: a) how the information will be collected; b) how the information will be stored; c) what the results are; and d) what the results mean for keeping their community strong and healthy (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.
2. *Researchers must show continuing communication with the community to make sure ethical standards are safe throughout the whole research project (NHMRC, 2003).* This principle can be demonstrated if: ▪ Regular progress reports about the project to the community from meeting minutes and the management plan. Reports are in an appropriate language and style for the community eg. newsletters and meetings (Case study, 1, 2; Donovan & Spark, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997). ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • A written review is also done at the conclusion of the project as an overall evaluation. • In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.

▪ Community members who are involved in the project are invited to share their feelings about: a) **project design e.g.** how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary
3. *Researchers must discuss and try to fix the worries of people who are involved in the project with the community (NHMRC, 2003).* This principle can be demonstrated when: ▪ Community members who are involved in the project are invited to share their feelings about: a) **project design e.g.** how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003). ▪ Regular progress reports are made about the project to the committee in an appropriate language and style for the community or region (Case study, 1, 2; Donovan & Spark, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.

▪ The committee informs the project to make sure community culture and health matters are appropriately represented, including the best way to resolve problems or worries for people involved in the project (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.
4. *Researchers must make sure the community is happy with the agreement about what will happen to the information from the research project, eg. joint sign off for the publication of results and the protection of identity for people involved in the project (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee informs researchers on community culture and health matters are represented throughout the research project (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.
▪ A written agreement is made **at the commencement of the project** between the researchers and the community about how the project will be conducted and about what will happen to the information collected from the research project (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• A statement of cultural consent and participation is developed through committee negotiations with the project. • The statement is in-line with the community's protocols.

▪ Before and after the information collected in the project is published it is discussed and presented **in an appropriate style and language** to the community or region. **The community has the right to refuse publication of project information** (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date). ▪ **At the commencement of the project rights to project information are negotiated between the community and researchers.** The **community/committee** is happy with the representation of the information collected from the project before it can be published (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Pre and post publication information sessions are held in the participating community to provide: a background summary of the project; the results and what they mean; and to gain continuing support for the project. • The committee is the gatekeeper of all the data collected in the project and must approve all project information prior to publication. • **If the community/committee is not happy with project information responsive action is taken.**
5. *Flexible agreements have been made for the amount of time research partners from the community give to the research project (NHMRC, 2003).* This principle can be demonstrated if: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.

▪ **Survival & Protection** This value aims to make sure that if the research project is accepted by the community, that the Aboriginal culture of the people who are involved in the project stays strong (NHMRC, 2003). * a small number of expert panellists did not agree that this example would demonstrate this value/principle	
1. *The research project must help build the social and cultural bonds within families and the community (NHMRC, 2003).* This principle can be demonstrated when: ▪ *The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ *The information collected from the project might be useful to help the community get funding in the future for other health projects (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee; **who represent the community's views.** • A successful pilot study provides support for future funding grants on the same or related topic in the same community or region. • **The information collected from the project can be used to help the community make strong decisions in the future about their health.**
2. *Researchers must show how the research project will protect the culture of the community and keep it safe (NHMRC, 2003).* This principle can be demonstrated when: ▪ Aboriginal health organisations **contribute to determining that** the project **will focus on issues** that are important to Aboriginal people to keep themselves strong and healthy (Case study, 1, 2; Donovan & Spark, 1997; Dressendorfer et al., 2005; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• Use of national Aboriginal health priorities and local community based reference groups including non-Aboriginal groups who work with an Aboriginal network. • A community owned project will naturally inform researchers of the health issues important to the community. • The cultural matters of the project are examined by the Aboriginal community to ensure that 'no harm' is done throughout the process of the project

▪ The committee informs the project to make sure community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.
▪ The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
▪ Community members who are involved in the project are invited to share their feelings about: a) **project design e.g.** how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project (Case study, 1, 2; Donovan & Spark, 1997; Durie, 2004; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; Thomsen, 2003).	• Monthly reviews are made by siphoning project information into newsletters, posters, and community consultation sessions. • Newsletters are: brightly coloured; use lots of pictures/photographs; and project information is briefly described in dot points. • Regular information workshops are held as often as the committee feels is necessary • A written review is also done at the conclusion of the project as an overall evaluation.
▪ Before and after the information collected from the project is published it is presented and discussed with the community or region. **The community has the right to refuse publication of project information** (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date).	• Pre and post publication information sessions are held in the participating community to provide: a background summary of the project; the results and what they mean; and to gain continuing support for the project.

▪ The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004). ▪ **The community/committee determines if** the project information will only tell a story about the community/region involved in the project (Case study, 1, 2; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).	• Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points. • Use of story boards to feed project information back to the community. • The use of 'regions', rather than the community's geographic name provides anonymity to project participants. • Diversity means allowing for Aboriginal people to be different to other Aboriginal people from different areas: data collected in urban Aboriginal projects only represents urban Aboriginal people; rural projects represent rural people; and remote projects represent remote people.
3. *Researchers must respect the values, expectations and identity of the community or region and help people who want to be involved in the project to find a balance between collective and individual identity (NHMRC, 2003).* This principle can be demonstrated when: ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ Community members who are involved in the project are invited to share their thoughts about their own health and the health of their community (Case study, 1; Thomsen, 2003).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee. • As part of the data collection participants are asked what they think about health: for themselves, their families and their community.

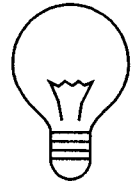
▪ *The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
4. *The project helps Aboriginal people have their say about their cultural distinctiveness (NHMRC, 2003).* This principle can be demonstrated when: ▪ *The project provides training and job opportunities for (if possible, local) Aboriginal people to collect, analyse, interpret and write up the project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997). ▪ *The committee agrees that the project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy (Case study, 1, 2; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Manderson et al., 1998; Waples-Crowe & Pyett, 2005). ▪ The information collected from the project can be used to help the community make strong decisions in the future about their health (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date). ▪ *A written agreement is made so that the community agrees with what ill happen to the project information (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis. • **Provide funding for Aboriginal people from that community to do a house-to-house needs assessment using male and female researchers.** • Feedback of project data provides the community with knowledge for decisions on the acceptance of future projects. • Knowledge gained from the project can be used to educate non-Aboriginal people about the community's health issues. • A statement of cultural consent and participation is developed through committee negotiations with the project. • The statement is in-line with the community's protocols.

5. *Researchers must show how the project will help the community to enjoy their cultural distinctiveness (NHMRC, 2003).*

This principle can be demonstrated by:

- *A complaints process is established so that community members who are involved in the project can share their feelings about what they liked and did not like about being involved. This will be actioned by researchers and reported back to the community in an appropriate language and style (Case study, 1, 2; Hearn & Wise, 2004; Meyer, 2000; Miller & Rainow, 1997; Sheehan et al., 2002; Thomsen, 2003).
- **The community/committee determines if** the information collected from the project only tells a story about the community or region involved in the project (Case study, 1, 2; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).
- The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).
- Using the knowledge and experience of Aboriginal researchers involved in the project. Training and job opportunities will be given to (if possible, local) Aboriginal people to help collect, analyse and develop information for the project (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).
- The committee informs the project to makes sure community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).

- The community is informed at the first information session that a complaints process is available should they require it. Researchers are accountable for actioning the complaints and reporting them back to the community.
- The use of 'regions', rather than the community's geographic name provides anonymity to project participants.
- Diversity means allowing for Aboriginal people to be different to other Aboriginal people from different areas: data collected in urban Aboriginal projects only represents urban Aboriginal people; rural projects represent rural people; and remote projects represent remote people.
- Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points.
- Use of story boards to feed project information back to the community.
- Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data.
- Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
- In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders.
- Meeting frequency is determined by the committee – it could be once a month or once a term.
- All stages of the project were carried out under the direction of the committee.

▪ **Spirit & Integrity** This value is only alive if the research project can show reciprocity, respect, equality, responsibility, and survival and protection (NHMRC, 2003).	
1. *Researchers must show how the research project will keep the cultural, spiritual and social bonds of the community strong (NHMRC, 2003).* This principle can be demonstrated when: ▪ Using the knowledge and experience of Aboriginal researchers involved in the project. Training and job opportunities will be given to (if possible, local) Aboriginal people to help collect, analyse and develop information for the project (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997). ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data. • Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis. • In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.

2. *Researchers must show how the research project accepts the differences of culture between different Aboriginal communities and regions, including the way decisions are made (NHMRC, 2003).*

This principle can be demonstrated when:

- **The community/committee determines if** the information collected from the project only tells a story about the community or region involved in the project (Case study, 1, 2; Holmes et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).

- The information collected from the project is given back to the community or region, **where possible by local people,** in an appropriate language and style (Case study, 1, 2; Donovan & Spark, 1997; Hecker, 1997; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Mak et al., 1998; Miller & Rainow, 1997; Telethon Institute for Child Health Research & Kulunga Research Network, 2004).

- The project provides training and **full time** job opportunities to (if possible, local) Aboriginal people to help collect, analyse, interpret and write project information (Case study, 1, 2; Durie, 2004; Hearn & Wise, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Pyett & VicHealth Koori Health Research and Community Development Unit, 2002; Waples-Crowe & Pyett, 2005; World Health Organisation, 1997).

- Community members who are involved in the project are invited to share their feelings about what they liked and did not like about being involved in the research project (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Meyer, 2000; Sheehan et al., 2002; Thomsen, 2003).

- The use of 'regions', rather than the community's geographic name provides anonymity to project participants.
- Diversity means allowing for Aboriginal people to be different to other Aboriginal people from different areas: data collected in urban Aboriginal projects only represents urban Aboriginal people; rural projects represent rural people; and remote projects represent remote people.
- Reports and project information are: brightly coloured; use lots of visuals/pictures/photographs; and data/results/progresses are briefly described in dot points.
- Use of story boards to feed project information back to the community.
- Aboriginal research assistants are formally trained so they can be employed to: collect, analyse, interpret and write up project data.
- Local community consultants are employed to inform researchers on local protocols and assist in data collection and analysis.
- A 'time of reflection' is allocated at the conclusion of the committee/community meetings to give community members an opportunity to raise their concerns.
- Community concerns are recorded in a 'processes journal' that is actioned by researchers.
- **Community members are given the opportunity to speak to researchers about the project in a group or one-on-one in a culturally appropriate environment and at all stages of the project.**

3. *Researchers must be show the community personal integrity, in the development of their project (NHMRC, 2003).* This principle can be demonstrated by: ▪ The knowledge and experience of the community committee will inform the project to make sure community culture and health matters are appropriately represented (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005). ▪ All project communication with the committee will be written down or noted to make sure that the project continues to be open and truthful (Case study, 1).	• In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee, **including shaping the research question and design.** • Emails, phone calls, and meeting minutes are recorded to track project progress and process changes negotiated by the community committee.
4. *Researchers must show a commitment to working within the spirit and integrity of the community (NHMRC, 2003).* This principle can be demonstrated if: ▪ A plan for giving project information back to the community is developed before the project begins **and implemented as agreed** (Case study, 1, 2; Kulunga Research Network & Telethon Institute for Child Health Research, no date). ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented before the project begins (Australian Health Ministers' Advisory Council, 2004; Case study, 1, 2; Dressendorfer et al., 2005; Durie, 2004; Hecker, 1997; Henderson et al., 2002; Kulunga Research Network & Telethon Institute for Child Health Research, no date; Miller & Rainow, 1997; National Health and Medical Research Council, 2003; Waples-Crowe & Pyett, 2005).	• A matrix is constructed to inform/manage what needs to get done at different stages of the project, eg. First visit, second visit through to final feedback after project completion. • Stages are matched up with ethics application to keep things truthful and transparent. • Support for the project is conditional upon assurance that participating families and communities receive feedback at every stage of the project. • In Perth, the committee may be a panel but in smaller areas it may be a group of 2 or 3 elders. • Meeting frequency is determined by the committee – it could be once a month or once a term. • All stages of the project were carried out under the direction of the committee.

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Appendix 12

Expert panel data

Table 1
Content validation for the demonstration of ***Reciprocity*** *when conducting health research with Aboriginal school children*

Table 2
Content validation for the demonstration of ***Respect*** *when conducting health research with Aboriginal school children*

Table 3
Content validation for the demonstration of ***Equality*** *when conducting health research with Aboriginal school children*

Table 4
Content validation for the demonstration of ***Responsibility*** *when conducting health research with Aboriginal school children*

Table 5
Content validation for the demonstration of ***Survival and Protection*** *when conducting health research with Aboriginal school children*

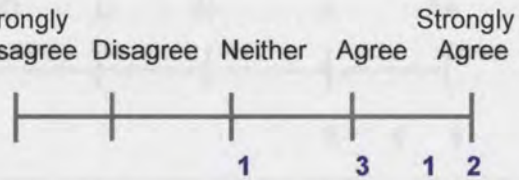
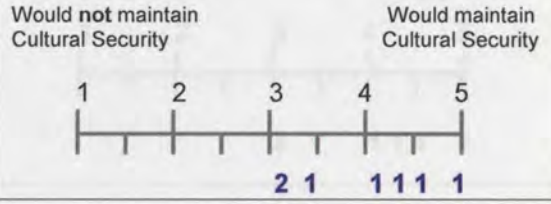
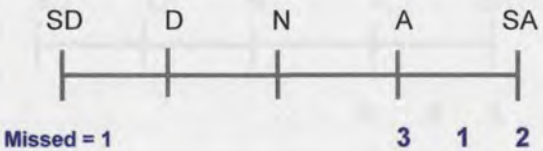
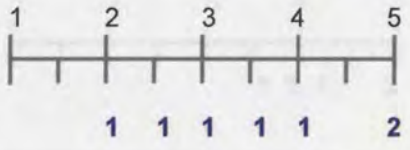
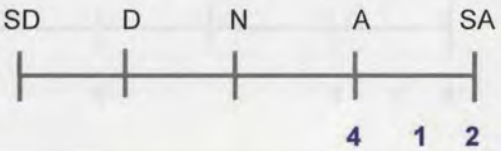
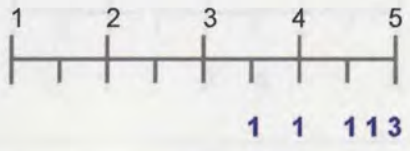
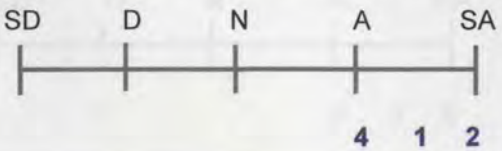
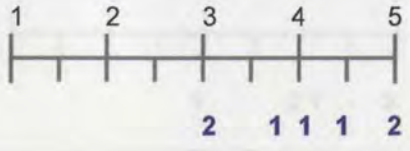
Table 6
Content validation for the demonstration of ***Spirit and Integrity*** *when conducting health research with Aboriginal school children*

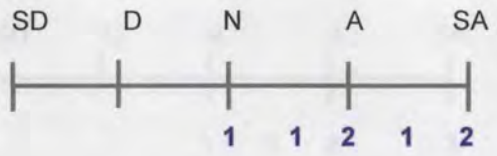
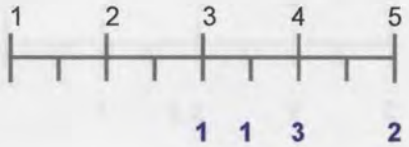
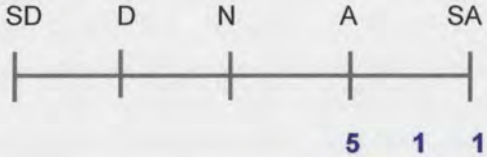
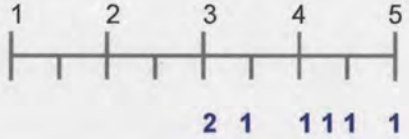
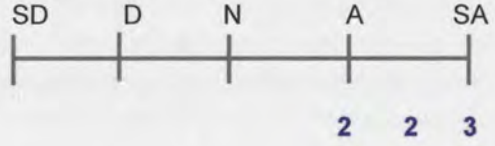
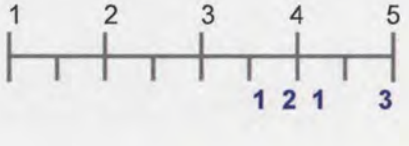
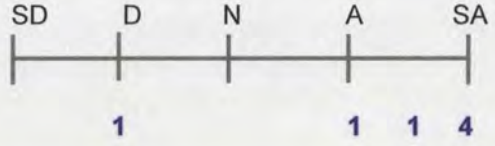
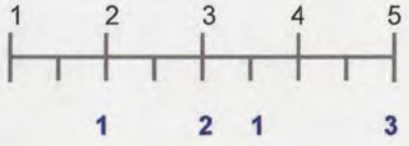
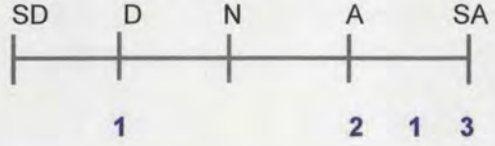
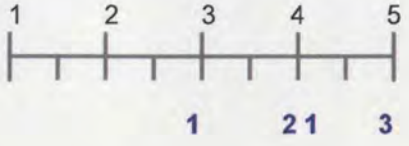
Expert panel respondents –

Mr Daniel McAullay
Professor Steve Zubrick
Ms Deanna Eades
Ms Sue Gough
Ms Juli Coffin
Dr Jane Freemantle

Table 1

*Content validation for the demonstration of **Reciprocity** when conducting health research with Aboriginal school children*

	This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:	This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.
Reciprocity: Principle 1, example a. Prior to the project proposal, a community committee or group is formed to guide the project and make sure that community culture is respected and community health matters are appropriately represented.		
Reciprocity: Principle 1, example b. The committee agrees that the research project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy.		
Reciprocity: Principle 2, example a. Aboriginal people and Aboriginal health organisations inform the project about the things that are important to them to keep their community strong and healthy.		
Reciprocity: Principle 2, example b. The committee informs the project to make sure that the local health goals are represented and to confirm what the community wants to do about local health matters.		

Reciprocity: Principle 3, example a. Communication between the committee and the project is transparent – phone calls; letters; emails; and consultation meetings are all noted to make sure that the project remains culturally appropriate for the needs of the community.		
Reciprocity: Principle 4, example a. Open communication with the community committee so that researchers can be guided to make sure that community culture and health matters are represented throughout the project.		
Reciprocity: Principle 4, framework example b. Community members are given the opportunity to speak to researchers about the project in a group or one-on-one.		
Reciprocity: Principle 5, framework example a. The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.		
Reciprocity: Principle 5, framework example b. The information collected from the project can be used to help the community make strong decisions in the future about their health.		

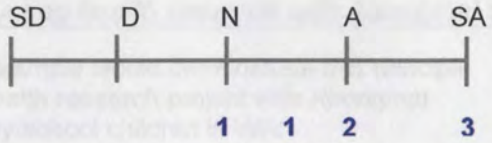
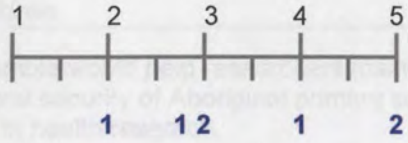
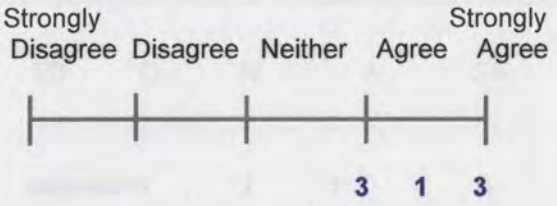
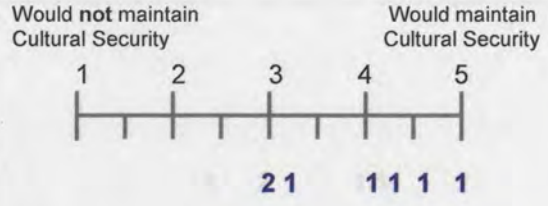
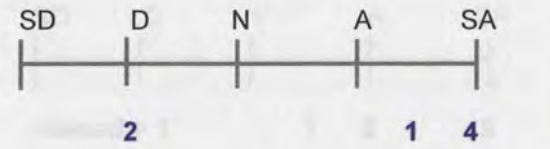
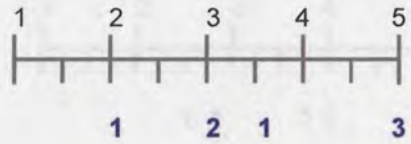
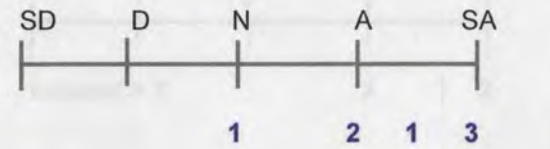
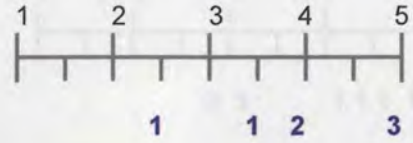
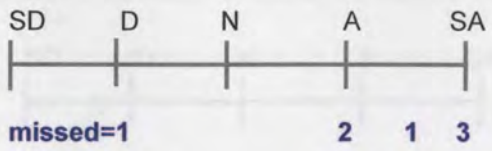
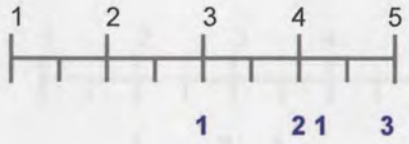
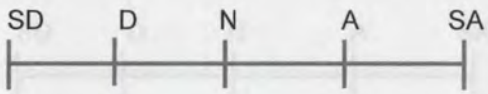
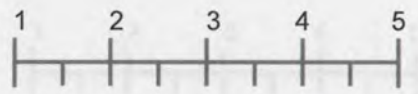
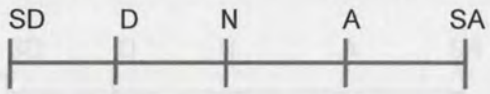
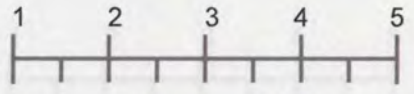
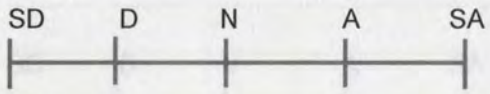
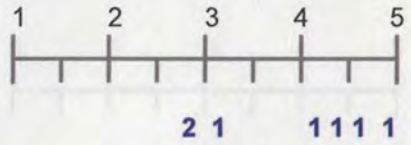
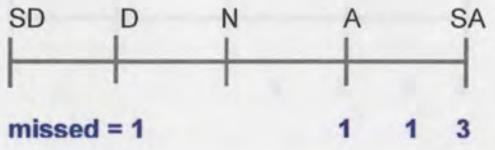
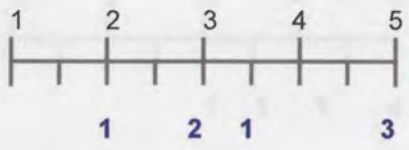
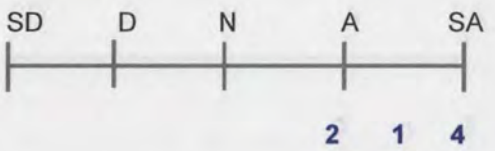
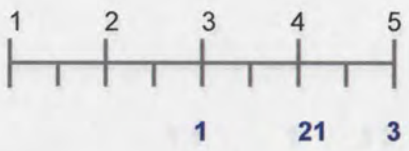
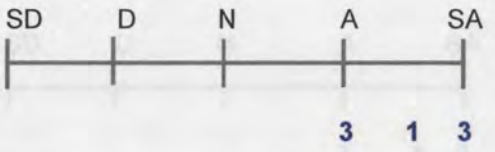
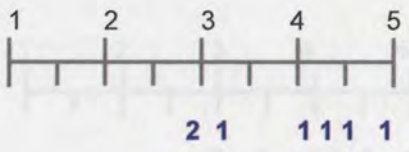
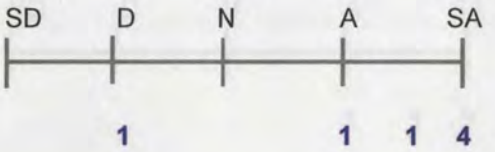
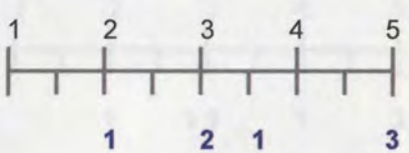
Reciprocity: Principle 5, framework example c. The information collected from the project might be useful to help the community get funding in the future for other health projects.		

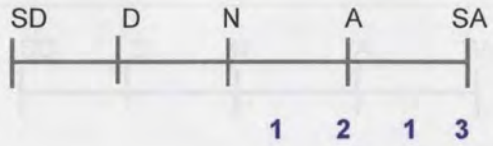
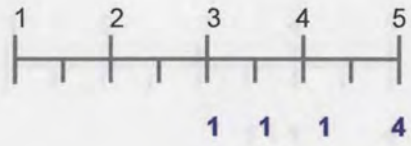
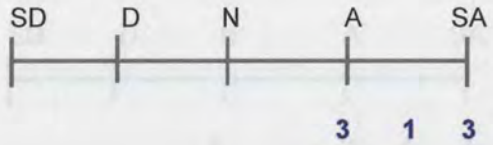
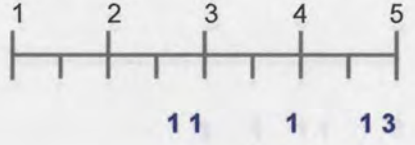
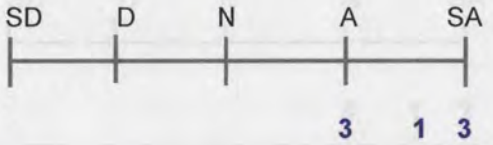
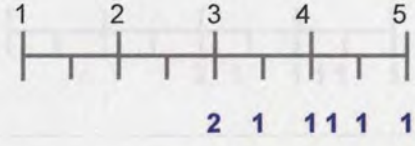
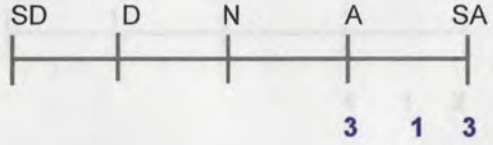
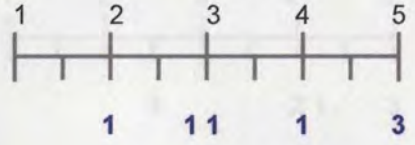
Table 2

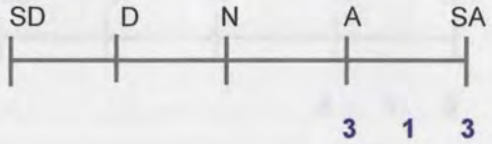
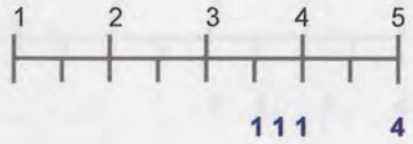
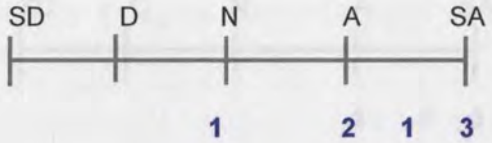
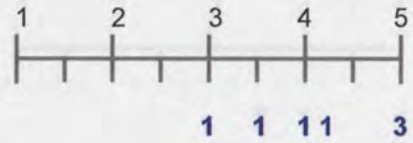
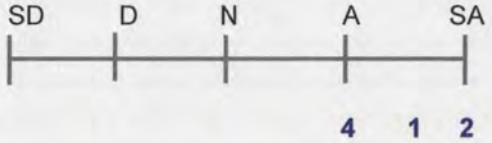
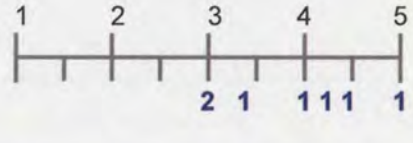
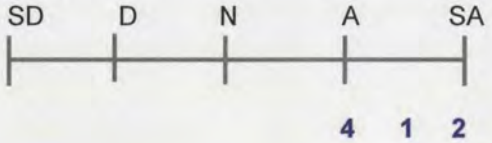
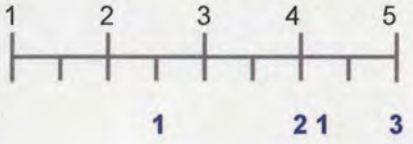
*Content validation for the demonstration of **Respect** when conducting health research with Aboriginal school children*

	This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:	This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.
Respect: Principle 1, example a. The committee informs the project about community culture and health matters.		
Respect: Principle 1, example b. The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.		
Respect: Principle 1, example c. The information collected from the project only tells a story about the community or region involved in the project.		

Respect: Principle 2, example a. The information collected from the project is given back to the community or region in an appropriate language and style.		
Respect: Principle 2, example b. Community members are personally invited to be involved in the research project.		
Respect: Principle 2, example c. Community members who want to be involved in the project are invited to share their thoughts about their own health and the health of their community.		
Respect: Principle 3, example a. The committee guides the project to make sure that community culture and health matters are appropriately represented.		

Respect: Principle 3, example b. The project provides training and job opportunities to (if possible, local) Aboriginal people to help analyse information for the project and develop the results.		
Respect: Principle 3, example c. The information collected from the project is given back to the community or region in an appropriate language and style.		
Respect: Principle 4, example a. Open communication between the committee and the project to make sure that the community culture and health matters are appropriately represented.		
Respect: Principle 4, example c. The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.		

Respect: Principle 5, example a. A written agreement is made so that the community agrees with: how the project will be conducted, and what will happen to the project information.		
Respect: Principle 5, example b. Permission for access to the project information must be applied for in writing to the committee.		
Respect: Principle 6, example a. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Respect: Principle 6, example b. The way the agreement was made is recorded, eg. if the agreement was made by a show of hands it is recorded that 'the agreement was accepted by the community by show of hands'.		

Respect: Principle 6, example c. The meeting for the agreement is held in a neutral of safe place for the people involved in the project.		
Respect: Principle 7, example a. Community members who are involved in the project are invited to share their feelings about what they liked and did not like about the agreement.		
Respect: Principle 8, example a. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Respect: Principle 8, example b. Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project.		

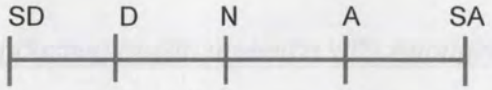
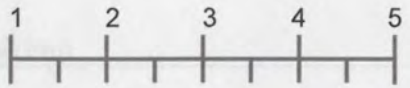
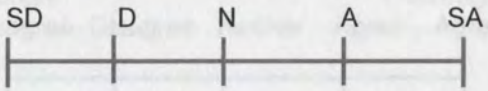
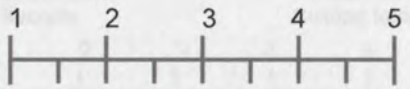
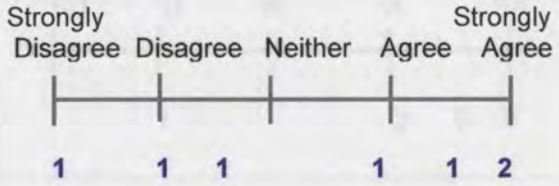
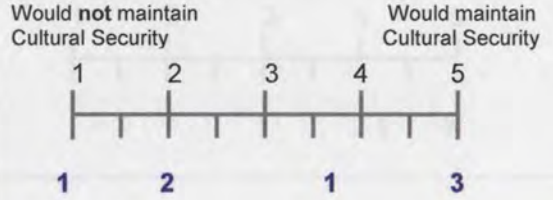
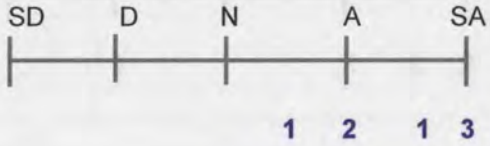
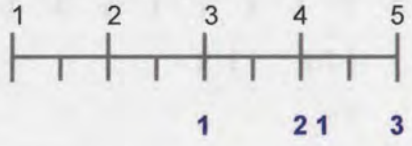
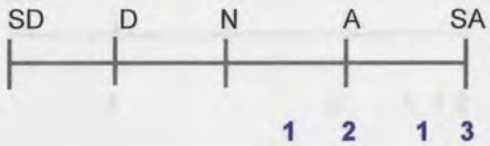
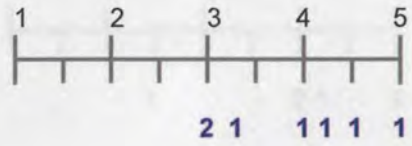
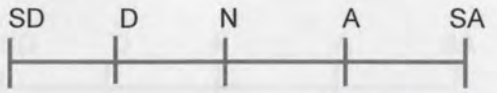
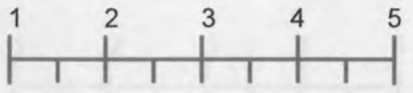
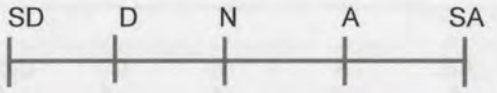
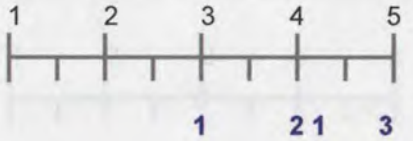
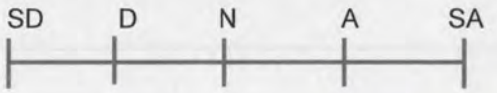
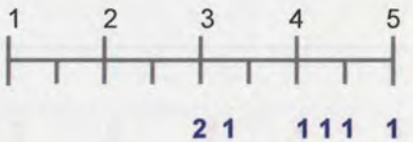
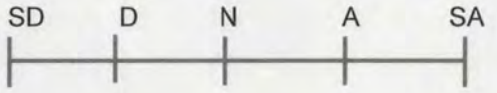
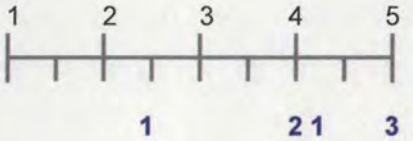
Respect: Principle 8, example c. A written agreement is made so that the community agrees with the storage and publication of the project information.		
Respect: Principle 8, example d. A management plan or communication strategy is used to make sure that the project actions the required ethical processes. Progress of the management plan is reported back to the community committee throughout the research project.		

Table 3

*Content validation for the demonstration of **Equality** when conducting health research with Aboriginal school children*

	This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA:	This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.
Equality: Principle 1, example a. Children of all ages, adults, males and females – the whole community is welcomed to be involved in the project.		
Equality: Principle 1, example b. The information collected from the project is given back to the community or region in an appropriate language and style.		
Equality: Principle 1, example c. The committee informs the project to make sure that community culture and health matters are appropriately represented.		

Equality: Principle 1, example d. The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.		
Equality: Principle 2, example a. The information collected from the project is given back to the community or region in an appropriate language and style.		
Equality: Principle 2, example b. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Equality: Principle 2, example c. Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project.		

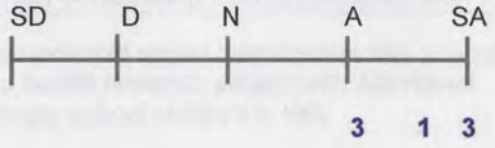
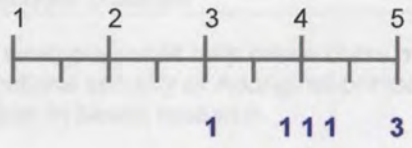
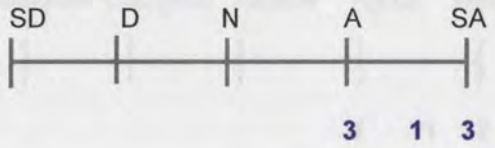
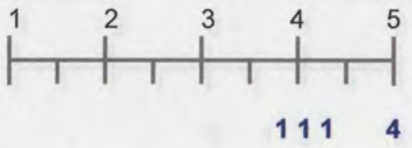
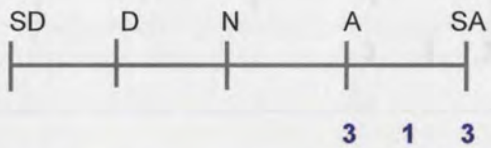
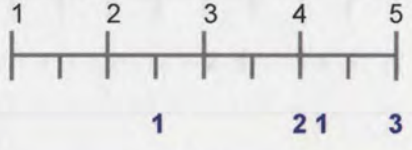
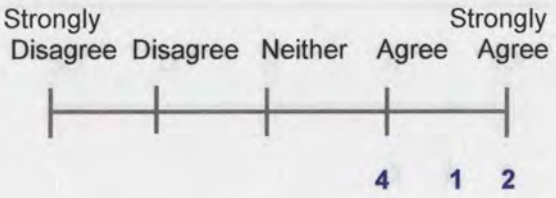
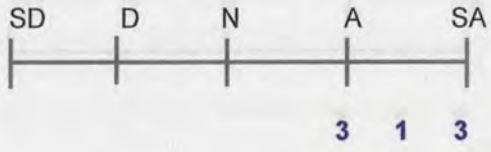
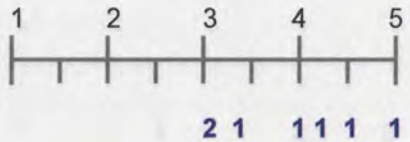
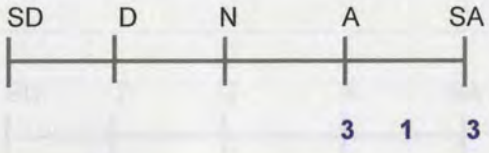
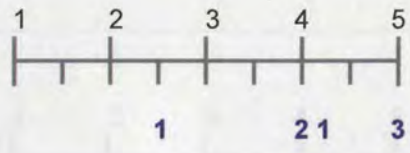
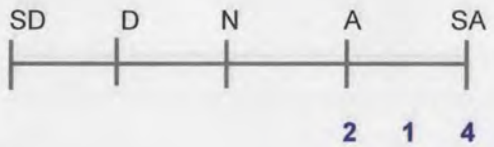
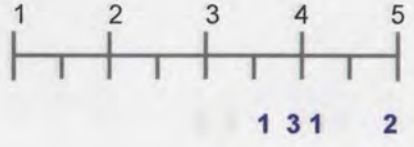
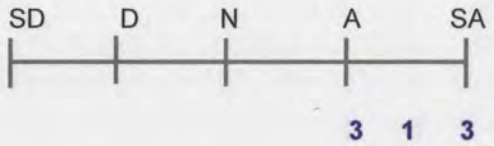
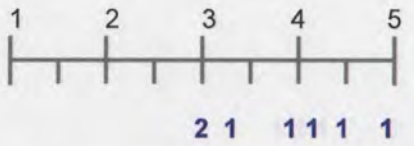
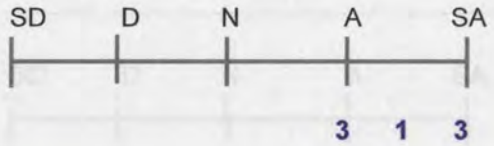
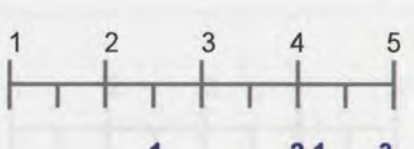
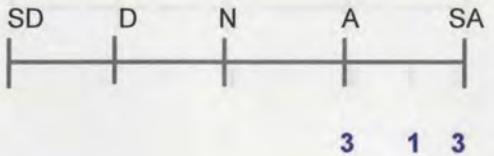
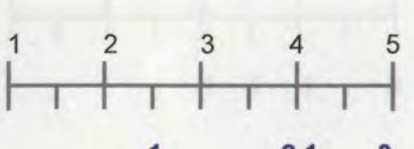
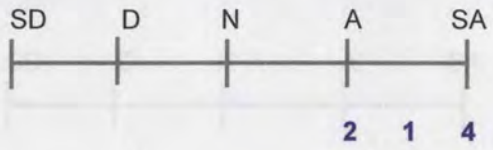
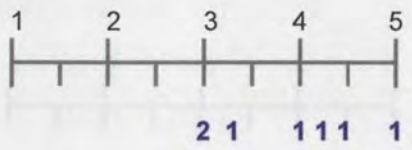
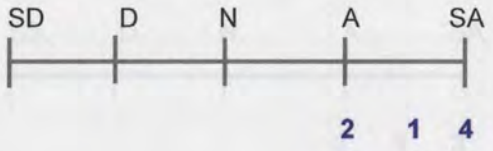
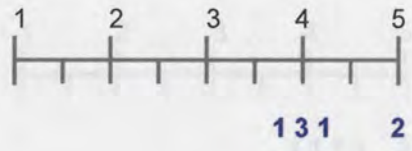
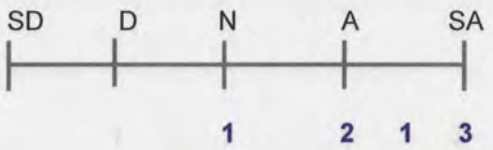
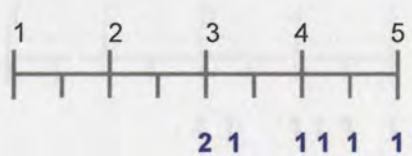
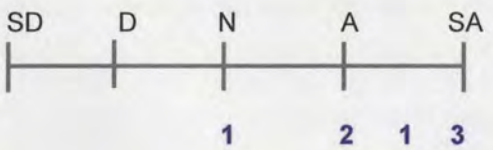
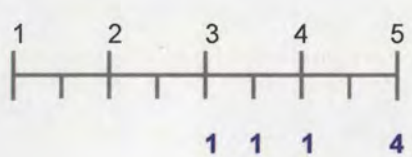
Equality: Principle 3, example a. The information sheet and consent form are in an appropriate language and style for the community, and that people who want to be involved in the project understand what it is about.		
Equality: Principle 3, example b. The community members who want to be involved in the project understand that they can change their minds about being involved whenever they want.		
Equality: Principle 3, example c. Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project eg. through community meetings, newsletters, management plan.		

Table 4

*Content validation for the demonstration of **Responsibility** when conducting health research with Aboriginal school children*

	This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA.	This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.
Responsibility: Principle 1, example a. All communication with the committee is written down or noted to make sure that the project continues to be open and truthful eg. meeting minutes.		
Responsibility: Principle 1, example b. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Responsibility: Principle 1, example c. The community is happy with: a) how the information will be collected; b) how the information will be stored; c) what the results are; and d) what the results mean for keeping their community strong and healthy.		

Responsibility: Principle 2, example a. Regular progress reports about the project to the community from meeting minutes and the management plan. Reports are in an appropriate language and style for the community eg. newsletters and meetings.		
Responsibility: Principle 2, example b. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Responsibility: Principle 2, example c. Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project		
Responsibility: Principle 3, example a. Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project		

Responsibility: Principle 3, example b. The committee informs the project to make sure community culture and health matters are appropriately represented, including the best way to resolve problems or worries for people involved in the project.		
Responsibility: Principle 3, example c. Regular progress reports are made about the project to the committee in an appropriate language and style for the community or region.		
Responsibility: Principle 4, example a. The committee informs researchers on community culture and health matters are represented throughout the research project.		
Responsibility: Principle 4, example b. A written agreement is made between the researchers and the community about how the project will be conducted and about what will happen to the information collected from the research project.		

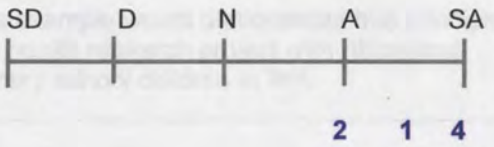
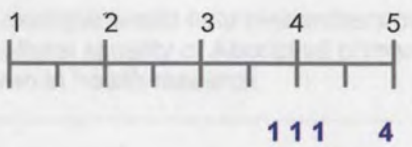
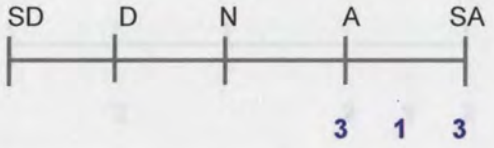
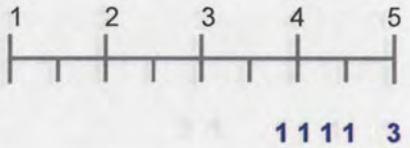
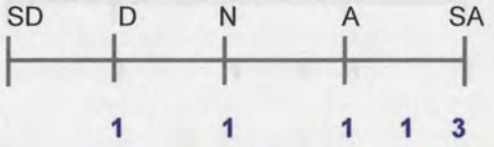
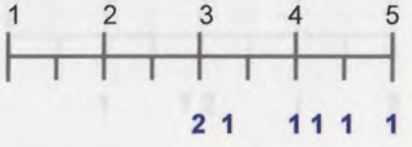
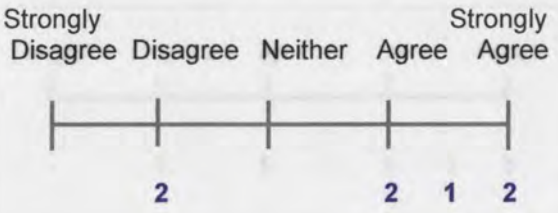
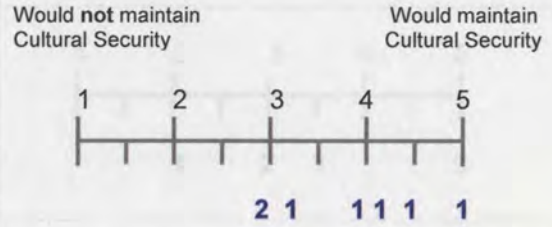
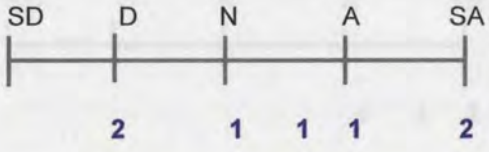
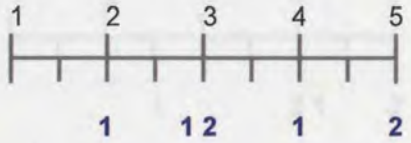
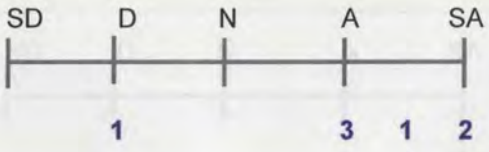
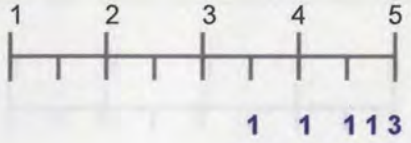
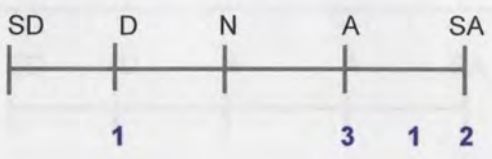
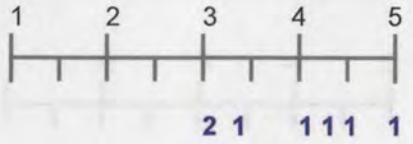
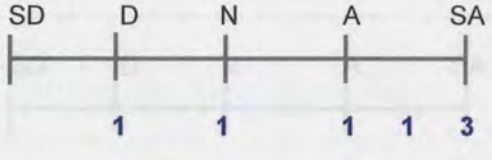
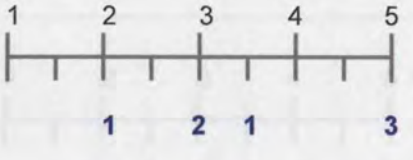
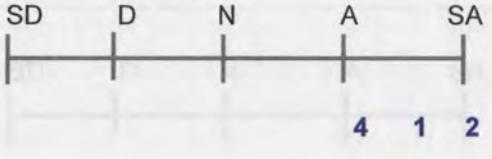
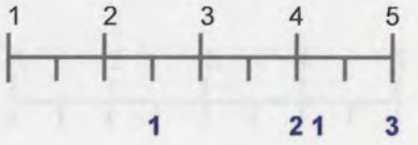
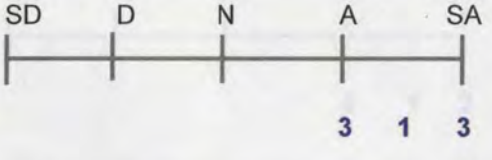
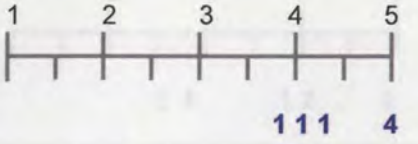
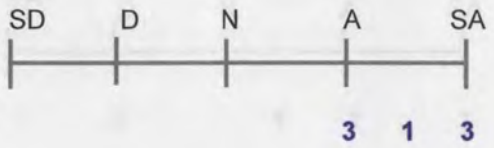
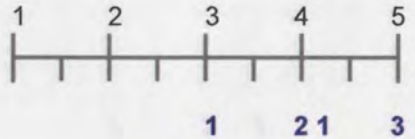
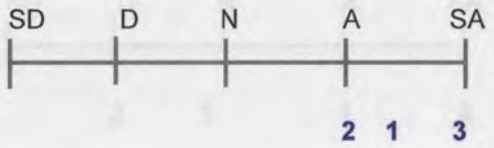
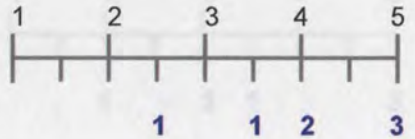
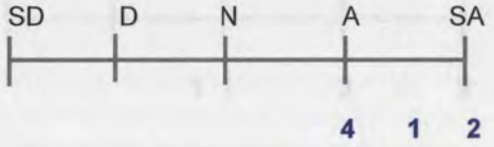
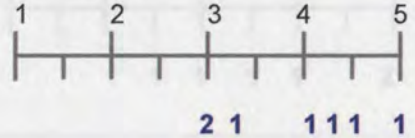
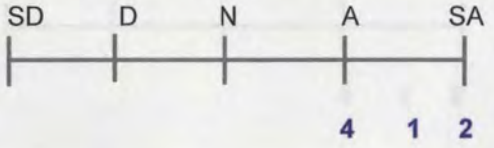
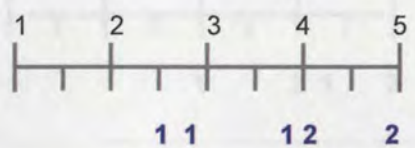
Responsibility: Principle 4, example c. Before and after the information collected in the project is published it is discussed and presented to the community or region.		
Responsibility: Principle 4, example d. The community is happy with the representation of the information collected from the project before it can be published.		
Responsibility: Principle 5, example a. ▪ The committee informs the project to make sure that community culture and health matters are appropriately represented.		

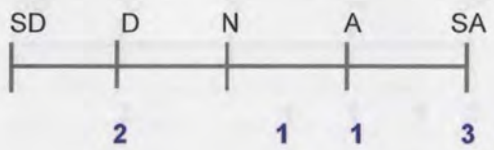
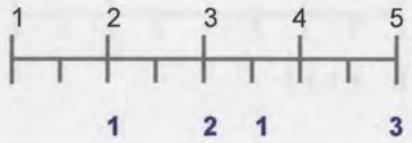
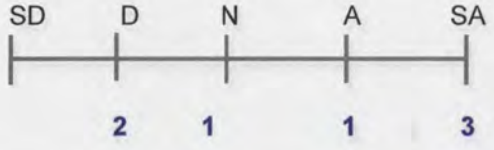
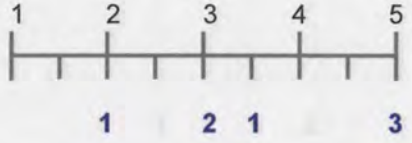
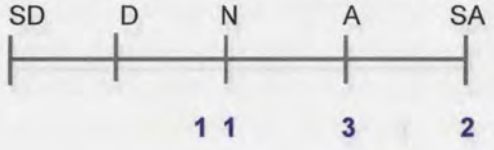
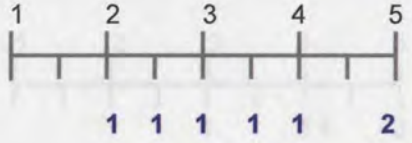
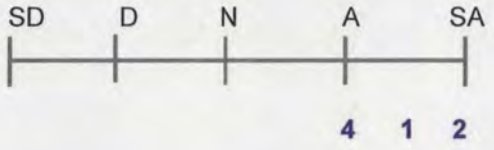
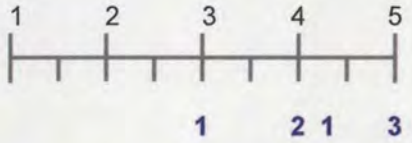
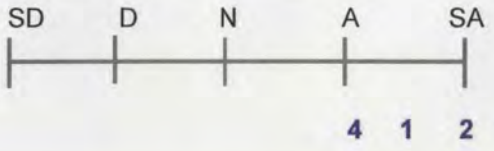
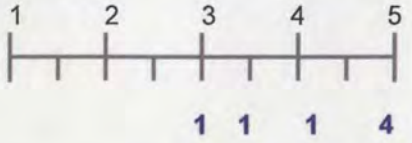
Table 5

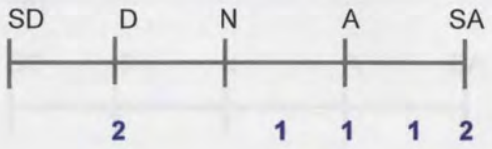
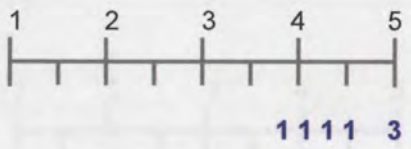
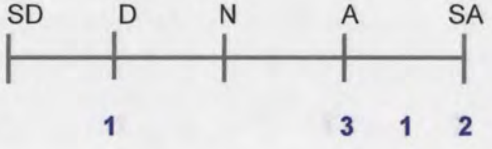
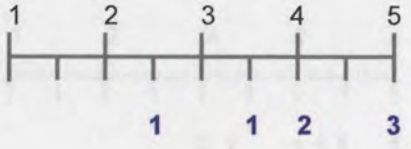
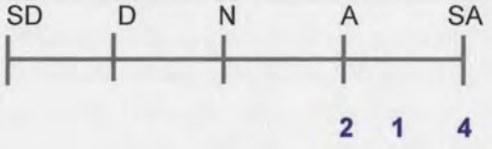
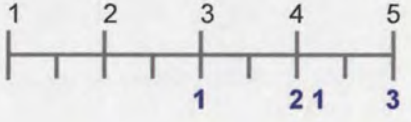
*Content validation for the demonstration of **Survival and Protection** when conducting health research with Aboriginal school children*

	This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA.	This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.
Survival and Protection: Principle 1, example a. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Survival and Protection: Principle 1, example b. The information collected from the project might be useful to help the community get funding in the future for other health projects.		
Survival and Protection: Principle 2, example a. Aboriginal people and Aboriginal health organisations inform the project about the things that are important to them to keep their community strong and healthy		

Survival and Protection: Principle 2, example b. The committee informs the project to make sure community culture and health matters are appropriately represented.		
Survival and Protection: Principle 2, example c. The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.		
Survival and Protection: Principle 2, example d. Community members who are involved in the project are invited to share their feelings about: a) how the information is collected; b) the results; c) what the results mean for keeping their community strong and healthy; and d) what they liked and did not like about being involved in the research project.		
Survival and Protection: Principle 2, example e. Before and after the information collected from the project is published it is presented and discussed with the community or region.		

Survival and Protection: Principle 2, example f. The information collected from the project is given back to the community or region in an appropriate language and style.		
Survival and Protection: Principle 2, example g. The information collected from the project only tells a story about the community or region involved in the project.		
Survival and Protection: Principle 3, example a. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
Survival and Protection: Principle 3, example b. Community members who are involved in the project are invited to share their thoughts about their own health and the health of their community.		

Survival and Protection: Principle 3, example c. The project provides training and job opportunities for (if possible, local) Aboriginal people to help collect, analyse, interpret and write up project information.		
Survival and Protection: Principle 4, example a. The project provides training and job opportunities for (if possible, local) Aboriginal people to collect, analyse, interpret and write up the project information.		
Survival and Protection: Principle 4, example b. The committee agrees that the project will find more evidence about what things can help Aboriginal people to keep themselves strong and healthy.		
Survival and Protection: Principle 4, example c. The information collected from the project can be used to help the community make strong decisions in the future about their health.		
Survival and Protection: Principle 4, example d. A written agreement is made so that the community agrees with what ill happen to the project information.		

Survival and Protection: Principle 5, example a. A complaints process is established so that community members who are involved in the project can share their feelings about what they liked and did not like about being involved. This will be actioned by researchers and reported back to the community in an appropriate language and style.		
Survival and Protection: Principle 5, example b. The information collected from the project only tells a story about the community or region involved in the project.		
Survival and Protection: Principle 5, example c. The information collected from the project is given back to the community or region in an appropriate language and style.		

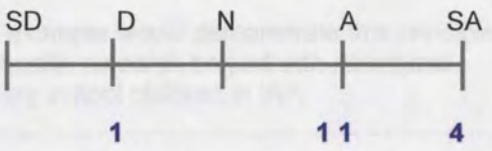
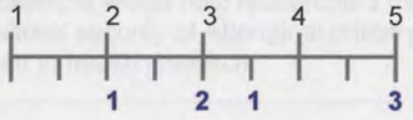
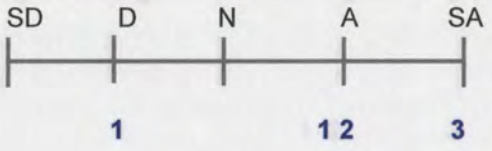
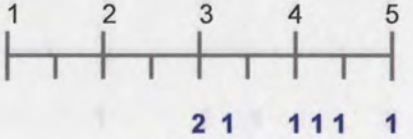
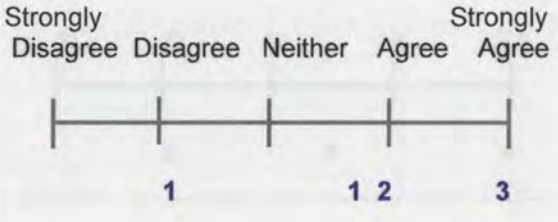
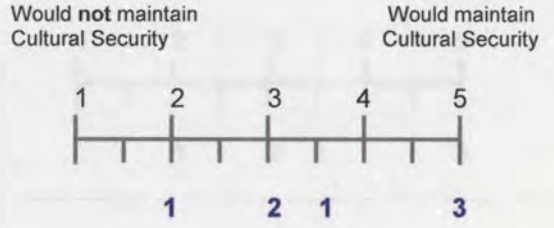
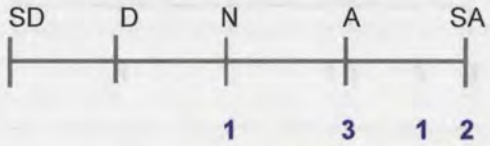
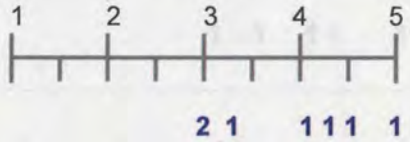
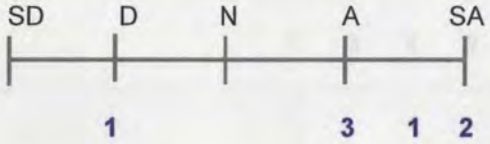
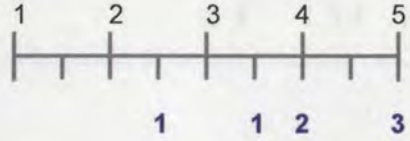
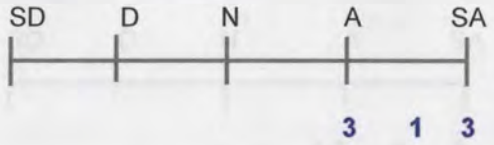
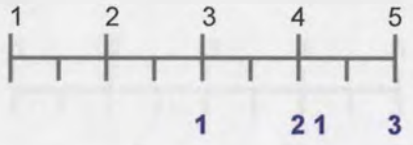
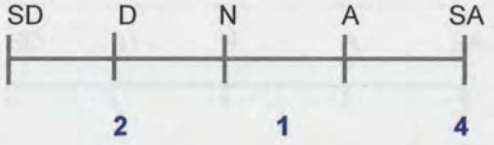
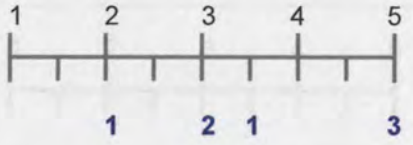
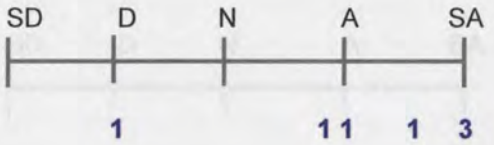
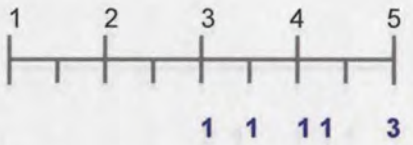
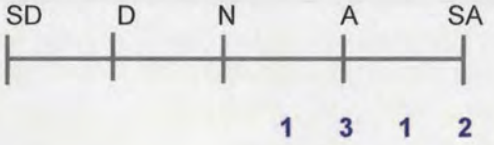
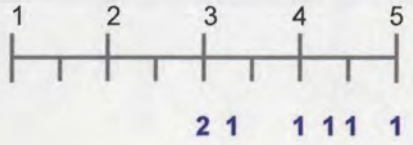
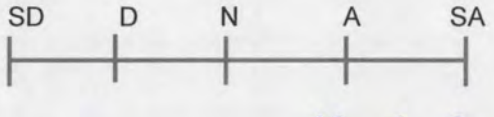
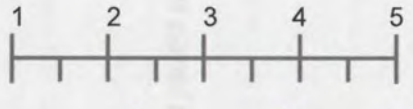
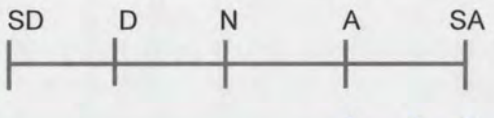
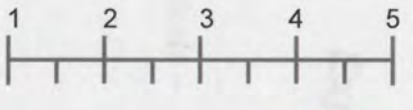
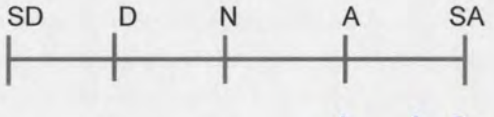
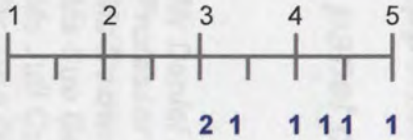
Survival and Protection: Principle 5, example d. Using the knowledge and experience of Aboriginal researchers involved in the project. Training and job opportunities will be given to (if possible, local) Aboriginal people to help collect, analyse and develop information for the project.		
Survival and Protection: Principle 5, example e. The committee informs the project to makes sure community culture and health matters are appropriately represented.		

Table 6

*Content validation for the demonstration of **Spirit and Integrity** when conducting health research with Aboriginal school children*

	This example would demonstrate this principle in a health research project with Aboriginal primary school children in WA.	This example would help researchers maintain the cultural security of Aboriginal primary school children in health research.
Spirit and Integrity: Principle 1, example a. Using the knowledge and experience of Aboriginal researchers involved in the project. Training and job opportunities will be given to (if possible, local) Aboriginal people to help collect, analyse and develop information for the project.		
Spirit and Integrity: Principle 1, example b. The committee informs the project to make sure that community culture and health matters are appropriately represented.		
This principle can be demonstrated when: *Spirit and Integrity: Principle 2, example a.* The information collected from the project only tells a story about the community or region involved in the project.		

Spirit and Integrity: Principle 2, example b. The information collected from the project is given back to the community or region in an appropriate language and style.		
Spirit and Integrity: Principle 2, example c. The project provides training and job opportunities to (if possible, local) Aboriginal people to help collect, analyse, interpret and write project information.		
Spirit and Integrity: Principle 2, example d. Community members who are involved in the project are invited to share their feelings about what they liked and did not like about being involved in the research project.		
Spirit and Integrity: Principle 3, example a. The knowledge and experience of the community committee will inform the project to make sure community culture and health matters are appropriately represented.		

Spirit and Integrity: Principle 3, example b. All project communication with the committee will be written down or noted to make sure that the project continues to be open and truthful.		
Spirit and Integrity: Principle 4, example a. A plan for giving project information back to the community is developed before the project begins.		
Spirit and Integrity: Principle 4, example b. The committee informs the project to make sure that community culture and health matters are appropriately represented before the project begins.		

Appendix 13

Expert panel comments

Expert panel respondents –

Mr Daniel McAullay
Professor Steve Zubrick
Ms Deanna Eades
Ms Sue Gough
Ms Juli Coffin
Dr Jane Freemantle

*Written comments from respondents on the examples for maintaining the ***Cultural Security** of Aboriginal school children in health research (Part A of expert panel instrument).*

Framework example 1
- If committee was "truly" representative.

Framework example 4
- Also should be actively involved in process activities.

Framework example 7
- If there is appropriate acknowledgements.

Framework example 11
- If its an identified (by community) priority.

Framework example 15
- Depends who "agrees" ie: proper representation of community.

Framework example 16
- If show of hands is ok but all present should be inclusive.

Framework example 18
- When? How often?

Framework example 19
- By whom? Outsiders?

Framework example 21
- This may not be appropriate and thus could act against cultural security.
- In most communities gender needs to be separated.

Framework example 22
- Or use of interpreters?

Framework example 26
- Assuming that this reflects the communities' right to prevent publication and presentation and the researchers respecting this right.
- Again if "steering" group or whatever is inclusive.

Framework example 27
- Should be accompanied by responsive action if not happy.
- Must have consent from members.

Framework example 29
- And this plan is implemented as agreed.

* Full descriptions of principles and examples found in questionnaire (Appendix B).

*Written comments from respondents on the examples for the demonstration of *__Reciprocity__ when conducting health research with Aboriginal school children.*

Principle 1
Example a:
- I suspect that the power gradient between researchers and participants is such that 'reciprocity' can only be worked towards rather than truly achieved.
- Congratulations you have done your background homework. I always use these principles before I go ahead with any community project.
- Committee is representative.

Example b:
- Community identified priority.
- I am not sure that [this example] makes sense! Bearing in mind that there is often a diversity of opinions within communities – how is this to be accommodated? How is the community committee or group to be formed?

Principle 2
Example a:
- This assumes that participants necessarily know answers to problems that no-one has answers to.
- The priority for the project needs to be agreed upon prior to commencement ie before study design completed.

Example b:
- Needs to be identified by community to be a need or priority.

Principle 3, example a:
- All communication processes need to be documented as evidence. Also agreed upon.
- How will cultural appropriateness be checked?
- I think there needs to be a check of how communication is recorded. Maybe get people to check notes of meetings to see if issues recorded correctly.
- The agreed outcomes of the project (eg capacity building) are implemented to the level identified at the commencement of the project discussions.

Principle 4
Example a:
- Contributions/suggestions to project management and process are acted on and in case where suggestions may not be able to be accommodated, reasons or compromises sought.
- At all stages of the research process.

Example b:
- Important that it is in a culturally appropriate environment or setting.
- At all stages of the research process.
- Open communication with all of community.

Principle 5
Example a:
- I do not believe that 'projects' are funded or organised to capacity build or establish sustainability
- This is very important in maintaining sustainability.
- Need to ensure that the skills developed as a result of the project are maintained and supported by continuing education and employment opportunities.

Example b & c:
- Dependent on the skills existing skills for grant/funding applications within the community.

* Full descriptions of principles and examples found in questionnaire (Appendix B).

*Written comments from respondents on the examples for the demonstration of *Respect when conducting health research with Aboriginal school children.*

Principle 2, example a:

- Discussion with committee about research track record and importance of this to Aboriginal Researchers. For example authorship on peer reviewed journals.

Principle 3

Example a:

- If different committees, consider community specific reference groups or 1 large one with specific membership and ask how committees want to be represented.
- Also need to understand and respect differences.

Example b:

- These activities must be supported by experts in these areas.
- Important that the training is culturally appropriate.

Example c:

- This principle must be fundamental to any project and steps taken to ensure that it is carried out.
- This process needs to be approved by the committee.

Principle 4, example b:

- Include analysis and interpretation of results and also design – very important.
- Such information should be acted on and used to guide future/other projects.
- Very important process.

Principle 5:

- Happy?

Example a:

- Adherence to such agreements must occur at all stages of the project.

Example b:

- Depends on community may/should include as a presentation?
- This principle must be fully negotiated so that both community and researchers are in accord and ownership of information.
- This is probably not sustainable.

Principle 7:

- So much of this assumes that the 'project' is discrete to a specific community.

Example a:

- Such information should be acted upon; relayed in future projects; respect be given to the comments/feedback given.
- Maybe add – 'Open communication between committee and project to make sure community culture and health matters respected'.

Principle 8:

- Happy with process leading to publication. Can't happen at beginning in the agreement as info for publication not available.

Example a:

- Community has copy of "critical" information.

Example c:

- Process to publication.

* Full descriptions of principles and examples found in questionnaire (Appendix B).

*Written comments from respondents on the examples for the demonstration of *__Equality__ when conducting health research with Aboriginal school children.*

Principle 1
Example a:
- With their consent always.
- This may not always be appropriate and guidance should be sought from the community.
- Involvement of some members of the community at the same time as others may not always be appropriate. Therefore equality [must] be tempered with cultural appropriateness.
- Culturally appropriate.
- Also related to gender of interviewers/researchers.

Example d:
- Supported by appropriate experts and resources.

Principle 3
Example a:
- Information sheet and consent form are presented in a manner/form/language that is understood by participant of those who are unable to read are informed verbally and in language understood by them.

Example c:
- Design of the study.

*Written comments from respondents on the examples for the demonstration of *__Responsibility__ when conducting health research with Aboriginal school children.*

Principle 1
Example a:
- Such communications are recorded in a way that is understood by the community.

Example c:
- Design

Principle 3, example a:
- Design

Principle 4
Example b:
- At the outset of the project.

Example c:
- In a manner that is understood by the community.

Example d:
- This must be negotiated at the outset of the project and the agreement ...

* Full descriptions of principles and examples found in questionnaire (Appendix B).

*Written comments from respondents on the examples for the demonstration of ****Survival and Protection*** *when conducting health research with Aboriginal school children.*

Principle 1
Example a:
- Add (maybe) – 'The information collected from the project can be used to help the community make strong decisions in the future about their health'.

Example b:
- Ensure all community views are included in committee decisions.

Principle 2
Example a:
- The research project will be examined by the Aboriginal community in cultural matters and in ensuring that "no harm" is done through the process of the project.

Example c:
- Design.

Example g:
- Unless otherwise agreed.
- If it is transferable then info becomes non-identifying.

Principle 3, example a:
- Leadership

Principle 4
Example a:
- Provide funding for Aboriginal people from that community to do a house needs assessment. It may involve a male and female.

Example c:
- Community have input into study question and design.

Principle 5
Example b:
- Unless otherwise agreed.

Example c:
- Most communities have strong outspoken community members (work with them).

*Written comments from respondents on the examples for the demonstration of ****Spirit and Integrity*** *when conducting health research with Aboriginal school children.*

Principle 2
Example a:
- Unless otherwise agreed.

Example c:
- Full time employment.

Principle 3, example a:
- How have community been involved in shaping research question and design.

Principle 4, example a:
- Process of correction information ad veto.

* Full descriptions of principles and examples found in questionnaire (Appendix B).

*Written comments from respondents on the ***case study examples** used to describe how the principles in the proposed framework could be demonstrated (Part A of expert panel instrument in blue font).*

Framework example 8
Case studies:

- Delivered by local people.

Framework example 14
Case studies:

- Debriefing session with all involved at completion [of project].

Case study example 2:

- Derogatory.

Final comments from respondents regarding the expert panel questionnaire.

- Some of the questions were difficult to answer as it is so **dependent on the community with whom one is working**, the sensitivity of the topic and the ability of community members. For example, **training community members to collect data on people who are mainly family can be stressful and often they prefer an outside Aboriginal person**. Outside Aboriginal people can feel even more threatened if the results are adverse than non-Aboriginal people. I do strongly believe however in encouraging as much **local participation as the community wants and within the community's capacity and culture**. Again, participation of all community members is **dependent on the topic being researched and whether it is culturally appropriate or not.** Overall I would be happy working within these guidelines for the main part.

- Thank you Dionne for giving me the opportunity to take part in this survey. You have got top marks with all questions because **this is exactly how I work in the community, ownership is very important for Aboriginal people** and with the questions you surely have taken that into account. I wish you all the best and I am only a phone call away if you need me. Thank you and cheers for now.

- Long and time consuming – just not sure how many you will get back. Be good if you get lots! **All principles are good with examples but still have many hidden variables i.e. done in the right way by the right person etc. Alone it's hard to comment.** Enjoyed looking at this – thank you.

- Whew! Good luck

* Full descriptions of principles and examples found in questionnaire (Appendix B).

Appendix 14

Participant email for identification permission

Responses in the affirmative received from one (of two) case study participant and six (of seven) expert panel respondents:

Case study participants –	***Dr Cheryl Kickett-Tucker***
Expert panel respondents –	***Mr Daniel McAullay***
	Professor Steve Zubrick
	Ms Deanna Eades
	Ms Sue Gough
	Ms Juli Coffin
	Dr Jane Freemantle

Participant email for identification permission

Email sent to all participants according to recommendations in the examiner's feedback (April 2006):

RE: honours thesis

Hello again,

I wanted to thank you once again for your participation in the case study/framework developed for my honours thesis last year titled *A descriptive study of ethical procedures that maintain cultural security when conducting health research with Aboriginal and Torres Strait Islander School Children in Western Australia.* I recently received my mark of 78% and attribute that to the generosity of people like you who were willing to share their experiences and expertise to assist me in the development of my thesis. I have been grateful for the opportunity to learn about another culture and I am humbled by the spirit and integrity of the Aboriginal people. Thank you.

Some of the feedback from the examiners suggested that I obtain permission to identify the respondents that contributed to the case study/expert panel data for acknowledgement in the appendices of my thesis. If you feel comfortable, I would love the opportunity to attribute due credit to you for your contribution to my thesis. As I have a due date for amendments and binding of April 24th, I would appreciate a response to this request at your earliest convenience.

Thank you again. Sincerely,

Dionne Paki

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