

2015

Ethical research in indigenous contexts and the practical implementation of it

Graeme Gower
Edith Cowan University

Follow this and additional works at: <https://ro.ecu.edu.au/theses>



Part of the [Community-Based Research Commons](#), and the [Scholarship of Teaching and Learning Commons](#)

Recommended Citation

Gower, G. (2015). *Ethical research in indigenous contexts and the practical implementation of it*. Edith Cowan University. Retrieved from <https://ro.ecu.edu.au/theses/1594>

This Thesis is posted at Research Online.
<https://ro.ecu.edu.au/theses/1594>

2015

Ethical research in indigenous contexts and the practical Implementation of it

Graeme Gower
Edith Cowan University

Recommended Citation

Gower, G. (2015). *Ethical research in indigenous contexts and the practical Implementation of it*. Retrieved from <http://ro.ecu.edu.au/theses/1594>

This Thesis is posted at Research Online.
<http://ro.ecu.edu.au/theses/1594>

Edith Cowan University

Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study.

The University does not authorize you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following:

- Copyright owners are entitled to take legal action against persons who infringe their copyright.
- A reproduction of material that is protected by copyright may be a copyright infringement. Where the reproduction of such material is done without attribution of authorship, with false attribution of authorship or the authorship is treated in a derogatory manner, this may be a breach of the author's moral rights contained in Part IX of the Copyright Act 1968 (Cth).
- Courts have the power to impose a wide range of civil and criminal sanctions for infringement of copyright, infringement of moral rights and other offences under the Copyright Act 1968 (Cth). Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

USE OF THESIS

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

**Ethical Research in Indigenous Contexts and the practical
implementation of it**

Graeme Gower

M.Ed, Post Grad. Dip Ed Stds, B.Ed, Dip T.

**This thesis is presented in fulfilment of the requirements for the degree of Doctor
of Philosophy**

Faculty of Education and Arts

Edith Cowan University

October 2014

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

(i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;

(ii) contain any material previously published or written by another person except where due reference is made in the text; or

(iii) contain any defamatory material.

Signed:

(

Date:

23/03/15 .

Abstract

Research in Indigenous Australia has historically been controlled and dominated by non-Indigenous researchers. However, recent national research guidelines which have been developed by the National Health and Medical Research Council (NHMRC) and together with a number of other research guidelines that have been developed by other institutions, including the Australian Institute for Aboriginal & Torres Strait Islander Studies (AIATSIS), have signalled a shift towards Indigenous ownership and control over research. However, despite these revised guidelines, researching in Indigenous contexts can still result in cultural insensitivities, neglect or disregard by researchers and mistrust by Indigenous participants. Similar issues have also been expressed by Indigenous academics such as Moreton-Robinson, Rigney and Nakata who advocate for further reforms in Indigenous research.

This thesis presents a documentary study on the application of the NHMRC's ethical research guidelines of research involving Aboriginal and Torres Strait Islander people. A unique case study has been chosen to examine the adequacy of the 1991 and 2003 guidelines in conducting ethical research and best practice in Indigenous contexts. The case study evaluation reveals that good ethics practice can be compromised by third parties who are involved in the research process but are not subject to ethical conduct and secondly, by the absence of cultural competence training in research. To minimise risks and to develop effective relationships between researchers and participants, cultural competence training is advocated in this thesis.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

(i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;

(ii) contain any material previously published or written by another person except where due reference is made in the text; or

(iii) contain any defamatory material.

Signed:

Date:

Acknowledgment

I would like to sincerely thank my supervisors: Professor Gary Partington for his patience, encouragement and never-ending support from the commencement to completion of the thesis; Professor Quentin Beresford for his guidance and judgment; Dr Ann Galloway who sadly passed away during the writing of the thesis.

I would also like to thank the many staff from the Faculty of Education and Arts whose unceasing encouragement motivated me during the process.

Finally, thanks to my family, Linda, Stephen and Emily who supported me throughout my studies.

Abbreviations

AEW	Aboriginal Education Worker
AIEO	Aboriginal and Islander Education Officer
AHS	Aboriginal Health Services
AIATSIS	Aboriginal Institute of Aboriginal and Torres Strait Islander Studies
AICS	Aboriginal Independent Community Schools
AMS	Aboriginal Medical Service
ARC	Aboriginal Research Council
ASSPA	Aboriginal Student Support and Awareness (Program)
ATA	Aboriginal Teacher Assistant
CC	Cultural Competency
CHL	Conductive Hearing Loss
DOE	Department of Education
DOTT	Duties Other Than Teaching
ECU	Edith Cowan University
HREC	Health Research Ethics Committee
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NEAF	National Ethics Application Form
NHMRC	National Health and Medical Research Council
NIELNS	National Indigenous English Literacy & Numeracy Strategy
OM	Otitis Media
PD	Professional Development
SAE	Standard Australian English

SSA	Site Specific Assessment
WACCHO	West Australian Aboriginal Community Controlled Health Organisation
WA HREC	West Australian Health Research Ethics Committee

TABLE OF CONTENTS

Abstract	ii
Declaration	iii
Acknowledgment	iv
Abbreviations	v
Table of Contents	vii
List of Tables	xi
List of Figures	xi
Chapter One Introduction	1
Research Questions	9
The Need For Indigenous Cultural Competence Training For Researchers	9
A Case Study	12
Observing Indigenous Protocols	13
Conclusion	13
Chapter Two Literature Review	15
Introduction	15
History of Research Practices in Indigenous Australian Communities	17
The Development of Ethical Research Guidelines: An Historical Overview	17
Development of National Guidelines	17
Guidelines for Indigenous Research	18
Development of Other Research Guidelines	19
AIATSIS Research Guidelines: Eleven Ethical principles	20
NHMRC Current Guidelines	21
Other Research Related Guidelines	26
Process for Ethic Approvals	28
Aboriginal Health Research Ethics Committees	29
Insider/Outsider Research	30
Power Relationships in Indigenous Research	32
Researching Indigenous Issues	32
Informed Consent and Consultative Processes	33
Case for a Participatory Model	34
The Current Challenges in Indigenous Research	35
Participant Observer in Research	37
Research Methodology using Critical Perspective	39
Case Study Approach	42
Recording and Reporting Research Findings: Ethical versus Moral	
Obligations	44
Cultural Competency	45
Conceptualizing CC	49
Cultural Competency Training	54
Conclusion	55
Chapter Three Methodology	57
Introduction	57
Aim	58
The Research Questions	58

Methodology	60
Research Methodology using Critical Perspective and Case Study Theory	60
Scope	61
Limitations of Case Studies	64
Data Collection	65
Ethical Issues	65
The Research Team	66
The Participants	67
Data	67
Data Analysis	68
Coding Method	69
Conclusion	70
Personal Statement	71
Chapter Four The Case Study: What Was Planned	92
Introduction	73
The Research Application	74
University Ethics Approval Processes	75
The Ethics Application	77
Consent Forms	79
Participants Involved in the Study	79
The Research Team	79
Research Committee	80
Conductive Hearing Loss: Steps in Research	80
Flow Chart of Conductive Hearing Loss Project	83
School Selection Process	84
Starting up Issues	88
Health and safety Issues for the Research Team	87
Assessment Tool	89
National Testing Program: An Australian context	92
Language issues	92
Ethical Considerations in National Testing Programs	92
Selecting a Measurement Instrument for the Conductive Hearing Loss Research Project	94
Reflection on the NHMRCs National Statement on Ethical Conduct in Research Involving Humans	99
Conclusion	100
Chapter Five The Case Study: What happened?	103
Introduction	103
Multiple Ethical Clearance and Subsequent Delays	104
Informed Consent	113
Consent Forms - Miscommunication	117
Use of Passive or Negative Consent	118
Issues in Administration of the PIPS Test	119
Travel to Isolated Communities	120
School Communication Issues	120
Contacting Schools	120
Communicating with Principals	121

New Administration Staff	122
Communication Between the School and CHL Project Teachers	122
Teacher Resistance	123
School and Community Issues	123
The Non-Participation of Schools	123
Issues Raised by Teachers	124
Use of Video Recordings	125
Delay to Video Recording	126
School/Education/Health Authority Issues	126
Multiple Agency Issues: Communication	126
Lack of Hearing Records	127
Professional Development of Teachers	128
PD Issue	129
The Involvement of Community Members in PD Sessions	130
Awareness of OM and CHL	130
Industrial Award Limitations	131
Relief Teachers	131
Clash Between Visits and school Activities	132
Student Numbers	133
Delays in Obtaining Ethical Clearance	133
Use of Australia Post Reply Paid Envelopes	133
On-Going Informed Consent: Designated Role of Aboriginal Research Team Member	134
Delays in Handling Consent Forms	134
Ethical Dilemmas Faced by Research Team Members	135
Requests for Confidential Information	135
Police Clearance	136
Other NIELNS Funded Projects	136
Concerns Regarding an Inter-Agency Approach	138
Involvement in Other Literacy Projects	139
Copyright/Intellectual Property Issues	140
Conclusion	169
Chapter Six Current Research Guidelines	145
Introduction	145
What Constitutes an Appropriate Response to the Desired Reforms in Indigenous Research?	146
Current NHMRC Guidelines	146
University Ethics Approval Process	147
Research Involving Health	147
Submitting an Ethics Application to WAAHEC	150
The WAAHEC Ethics Application Form	151
Researching in WA Schools	152
To What Extent do the Guidelines Address the issues in the Case Study?	153
Similarities and Differences of Current Research Guidelines and Policies	157
Rationalising Ethics Guidelines	157
Application of the Case Study to the Guidelines	162
What's Needed?	167
Conclusion	213

Chapter Seven The Contribution of Cultural Competency to Improving Ethically Based Indigenous Research	171
Introduction	171
Definitions of Cultural Competency	174
Cultural Competency in the Case Study	177
Applying Cultural Competency to Indigenous Guidelines for Research	178
Conclusion	182
 Chapter Eight Discussion and conclusion	 185
Introduction	185
Key Finding One: Ethical Approaches to Indigenous Research: Historical Context	186
Summary	188
Key Finding two: Adequacy of Previous and Current Research Guidelines	188
Summary	191
Key Finding Three: The Proliferation of Ethical Guidelines - Do they Assist in Underpinning Ethical Research or do they Foster Inefficiency?	193
Summary	195
Key Finding Four: The significance of Cultural Competency in Indigenous Research	195
Summary	196
Key Finding Five: Examples of Cultural Competency in the Case Study	197
Summary	198
Key Finding Six: A New Framework	199
Summary	200
Contribution to the Body of Knowledge	200
 List of References	 201
Appendix A: Parents/Caregivers Consent Form (First Draft)	216
Appendix B: Parents/Caregivers Consent Form (Final Draft)	218
Appendix C: Principals Consent Form	220
Appendix D: Teachers/Teaching Assistants Consent Form	222

LIST OF TABLES

Table 4.2 Status of Schools involved in the CHL Project	90
Table 6.1 Similarities between Institutional Guidelines that reflect the Conduct of Research that is similar to the CHL Case Study	159

LIST OF FIGURES

Figure 2.1 Cultural competency: Putting knowledge into practice	53
Figure 3.1 Coding categories for CHL case study	70
Figure 4.1 Conductive Hearing Loss: Steps in Research	84
Figure 4.2 Flow Chart of Conductive Hearing Loss Project	86
Figure 5.1 Ethic Clearance: Explaining the Form to Parents	116

CHAPTER ONE

INTRODUCTION

Research in Indigenous Australian communities has historically been controlled and dominated by non-Indigenous researchers. (Fredericks 2007, 2008; Greenhill & Dix 2008; Humphrey, 2001; Liamputtong 2008; Rigney 1999, 2006; Smith 1999). In many instances, the research methodologies used have been inappropriate and invasive, often ignoring the rights of Indigenous Australians to participate or not to participate in research (Fredericks, 2008; Greenhill & Dix 2008). The Indigenous experience in research has often been one of exploitation with little or no participation and no benefit for the Indigenous community. For example, many non-Indigenous academics have gained PhDs as a result of research being conducted in Indigenous communities or have published articles about research for their benefit without any similar benefits being received by those being researched (Thomas, Bainbridge & Tsey, 2014; Fredericks, 2008; Greenhill & Dix 2008; Rigney 2006). The ownership, interpretation and dissemination of research findings and data are other issues of major concern to Indigenous people as often this knowledge has not been shared with Indigenous communities, but rather is typically stored in universities and is used by academics to pursue their academic careers (Fredericks 2008; Liamputtong, 2008; Rigney, 2006). As a result of these past practices in research, Indigenous Australians have become sceptical and, at times, negative regarding research and researchers.

Publications and statements regarding the conduct of research in Indigenous Australian communities began to appear in the early 1980s and 1990s as a result of Indigenous concerns about what was happening in research, particularly in relation to cultural insensitivities, exploitation and inappropriate research methods used by researchers (Fredericks, 2007; Humphrey, 2001; NHMRC, 1991a).

The National Health and Medical Research Council (NHMRC) in Australia developed a set of national guidelines for the conduct of all research involving humans,

animals and the environment in 1991(a), and these were revised in 1999 and 2007. In addition to the 1991(b) guidelines, the NHMRC published a set of *Interim guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* which focused on consultation, community involvement, ownership and publication of data that were endorsed by the National Aboriginal and Islander Health Organisation, but not formally ratified by the NHMRC (Dudgeon, Kelly & Walker, 2010, p. 82). While these guidelines promoted community ownership of research and sought to transform research practices of the past, Dudgeon and others argued that, “issues related to Indigenous control of Indigenous research funding and outcomes, remained contentious” (Dudgeon et al., 2010, p.82). These guidelines were to be read in conjunction with the national statement (NHMRC 1999). This publication was revised in 2003 and retitled, “*Values and Ethics: Guidelines for the Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*” (2003). It was subsequently revised in 2007. Please note that the terms, ‘Indigenous’ and ‘Aboriginal and Torres Strait Islander’ are used interchangeably throughout this thesis. The term, ‘Indigenous’ is inclusive of both cultural groups. It was difficult to refer to one term specifically in the thesis as the source material used refers to both terms.

The Australian Institute of Aboriginal and Islander Studies (AIATSIS) has also developed a set of comprehensive guidelines for the conduct of ethical research in Australian Indigenous Studies in 2000. A revised edition of these guidelines made in 2012 focused on Indigenous authority and ownership of traditional knowledge and the establishment of reciprocal partnerships through agreements between Indigenous people and researchers (AIATSIS, 2012).

A number of government agencies and universities have also developed guidelines and protocols for use by researchers involved in Indigenous research (ECU, 2010; WA Health, 2012; Western Australian Aboriginal Health Ethics Committee (WAAHEC) n.d.

These recent research guidelines have signalled changes to practices in Indigenous research and a shift towards Indigenous ownership and control over research via reciprocal and partnership agreements with researchers (Fredericks 2008; Humphrey 2001; Rigney 2006). In fact, there is a growing number of Indigenous academics participating in research who have developed particular views and/or positions to drive

reforms and discourses in Indigenous research agendas and directions (Martin, 2008; Moreton-Robinson, 2000; Nakata, 2007a, 2007b; Ober & Fasoli, 2008; Rigney, 2007; Walter, 2010). Other Indigenous peoples from countries such as Canada, New Zealand and the United States who have experienced similar neo-colonial research practices are also advocating ownership, control, access and possession over Indigenous research (Liamputtong, 2008; Schnarch, 2004; Smith, 1999). Rigney (2006), an Indigenous academic, adopted a 'resistance' approach in challenging neo-colonial dominance in research practices in Australia. He termed his approach *'Indigenist' research* as a methodological reform that incorporates an Indigenous worldview, autonomy and self-determination in research (Rigney, 2006). A key understanding of Indigenist research is Indigenous control and ownership over research. Rigney (2006) asserted that this doesn't mean that 'Indigenist research' becomes a separate research methodology nor does it exclude non-Indigenous researchers from taking part in Indigenous research activities. "What is central to Indigenist research is that Indigenous Australian ideals, values and philosophies are the core research agenda even if there is a difference about what constitutes such values and ideals" (Rigney, 2006, p.41). Nakata (2007a), on the other hand, presented a different viewpoint in discussing Indigenous research reforms. Nakata explored the differences between Western and Indigenous knowledge systems and used the term, "cultural interface" to describe the contested space where Western and Indigenous knowledges and discourses come together. "It is a space of many shifting and complex intersections between different people with different histories, experiences, languages, agendas aspirations and responses (Nakata, 2007b, p.199). In working in these contested spaces and when dealing with complex Indigenous issues, Nakata (2013, p.290), pointed out that there will be 'tension' on how these issues are thought through and how they are analysed by Indigenous communities and individuals. "This tension, when it arises, often highlights for us particular relations between (a) the Indigenous community, (b) Indigenous academia and (c) our relation to the wider intellectual world of western knowledge, theory and practice" (Nakata, 2013, p.290). Much of Indigenous analysis and debate on Indigenous research reform has been built around the premise of challenging and resisting colonial practice and ways to promote the concepts of self-determination and 'Indigenism' as advocated by Rigney (2006). However, Nakata (2007, 2013) argued that we need to engage with western practices by going beyond the preconceived concept of 'self-determination' and 'de-colonial

knowledge making’ and engage with western knowledge in a meaningful way where discussions between Indigenous and non-Indigenous begin at the ‘cultural interface’ rather than critiquing Western knowledge on the grounds of ‘common grievance, social justice, political, cultural and Indigenous resistance’ (2013, p.296-297). Furthermore, Nakata (2013) argued that critical analysis should be applied to both Western knowledge practices and Indigenous knowledge practices in order to evaluate the limitations and strengths of Indigenous and Western epistemologies in knowledge production, representation and practices. In support of this stance, Nakata stated that, “the intention may be to overcome western mindset, but it is dangerous delusion to pretend that western epistemology disappears just as soon as the Indigenous re-asserts its own epistemic conditions” (2013, p.297).

As a means of developing a framework that can be used by Indigenous academics to engage in debate and guide interactions with western academics, Nakata (2007a, 2007b) presented an “Indigenous standpoint as a process that provides a method of enquiry that engages with the non-Indigenous domain. Other Indigenous academics have also referred to ‘standpoint’ as a means of differentiating between Indigenous and Western research methodologies (Moreton-Robinson & Walter, 2009). Walter pointed out that, “Standpoint encapsulates our position, who we are and how we see ourselves in relation to others and to society” (2010, p.53).

In continuing the debate for Indigenous research reforms, Ober and Fasoli (2008), cited issues that have been raised at several Indigenous research forums held during the 1990s by Indigenous researchers who are concerned about the dominance of non –Indigenous researchers in Indigenous research and the lack of ethical research practice as a result. In addressing these issues, participants at these forums advocated for new research approaches and more Indigenous researchers through mentoring programs provided by experienced Indigenous researchers. This is of course problematic given the small number of experienced Indigenous researchers (Nakata, 2007a; Walter, 2010). Therefore, it would be a complete oversight if all non-Indigenous researchers were excluded as there are a number of non-Indigenous researchers who have experience in Indigenous research, including those with whom I have worked and who follow good ethical research practice and acknowledge Indigenous cultural protocols (Ishtar, 2008). However, many Indigenous communities and Indigenous

academics and researchers still strongly believe that for many non-Indigenous researchers, this may not be the case (Ober & Fasoli, 2008; Walter 2010).

The move to a ‘redistribution of power’ and ‘methodological reforms in Indigenous research may result in some non-Indigenous researchers viewing these changes as a threat to their academic freedom and, as a consequence, may be unwilling to compromise or may no longer wish to be involved in Indigenous research (Rigney 2006; Schnarch, 2004).

While the rhetoric points to changes in Indigenous research practice, authors such as Humphrey (2001,p.201) questions whether these reforms are at times ‘exaggerated’ and/or ‘masked’ by the broader research community, as some research processes are still controlled and maintained by non-Indigenous researchers. Walter (2010, p.49) argues that, “In 2010, the prioritising of research questions, decisions about how data collection is carried out, what data is collected, how data are analysed, interpreted and disseminated are still primarily designed and controlled by non-Indigenous researchers and agencies.” Humphrey's position and those advocated by Nakata (2007a); Ober & Fasoli (2008); Rigney (2006); Schnarch (2004); Smith (1999) & Walter (2010) point to much needed reforms in Indigenous research. Henry et al, (2004) maintain that the proponents of Indigenous research reforms are not necessarily concerned with identifying new research methodologies, however they are more to do with the, “repositioning of Indigenous peoples within the construction of research ” (2004, p.12). The current research guidelines for the conduct of research involving Aboriginal and Torres Strait Islander peoples that have been introduced by the AIATSIS (2012) and NHMRC (2003), and a number of government and non-government agencies such as health departments and Indigenous Land Councils provide a set of ethical expectations and responsibilities that incorporate Indigenous principles and values. Thomas et al., (2014, p.3), however, claim that, “despite these changes, the relationship between researchers and Indigenous organisations and community leaders remained volatile. Trust was often non-existent, and there were very few meaningful conversations between parties.”

The interpretation of the new guidelines and how these are acted upon in the research process by Indigenous and non-Indigenous researchers is also a factor that needs to be addressed. For example, some non-Indigenous researchers maybe reticent to

accept the new approaches and protocols as they may not know what these changes mean or how to go about putting them into practice. This situation is also exacerbated by a lack of knowledge of Indigenous cultural understandings and protocols by researchers and this may inhibit the establishment of sound relationships between them and Indigenous participants which may result in difficulties in continuing the research activity. The NHMRC states that, “within the research process, failing to understand difference in values and culture may be a reckless act that jeopardises both the ethics and quality of research” (2003, p.3).

The issue of non-Indigenous researchers being involved in Indigenous research needs to be unpacked further in order to discuss the different perspectives that may prevail about research methodology and the views that are being expressed by Indigenous academics who advocate for further research reforms.

It is therefore necessary for Indigenous communities and for all researchers to reach agreed understandings of these new approaches in Indigenous research before any research takes place and throughout the research process itself. Rigney (2006, p.42) claimed that, “maintaining Indigenous political integrity throughout the whole research process is vital to self-determination” and that “mutual respect and power sharing in methodological negotiation and collaboration is essential.” Hence, Rigney believes that non-Indigenous researchers can play a role in ‘Indigenist’ research, but it must be based on a relationship that supports ‘Indigenist’ principles, trust and cooperation.

This scenario opens up the debate on the level of involvement of non-Indigenous researchers in Indigenous research, however, it would be remiss to think that only a certain group of researchers or indeed, for one ethical group to research themselves and exclude others. Indigenous academics agree that there is a place for non-Indigenous researchers to be involved in Indigenous research (Nakata 2004; Rigney 2006; Walter 2010). Nakata for example wrote, “we cannot cut ourselves off from the general academic community” and emphasises that research is a ‘public activity’ that is ‘competitive’ and is ‘open to scrutiny’ (2004, p.4).

While some of the issues and concerns regarding past practices in Indigenous research have been addressed through the revision of ethical research guidelines (see AIATSIS, 2012, NHMRC, 2003), the viewpoints which have been expressed by

academics like Moreton-Robinson (2000); Nakata (2004, 2007a, 2007b, 2013); Rigney (1999, 2006) and Walter (2010) signal the need for further discourse and reforms in Indigenous research. While each of these writers may have different views in addressing further reforms in Indigenous research, their positions represent a diversity of needs, challenges and discourse for further debate in establishing an accepted process which is systemic and delivers on best practice in research that involves Indigenous subjects.

The means to achieve a greater understanding of the recent changes to the research guidelines that relate to Aboriginal & Torres Strait Islander peoples (AIATSIS, 2012; NHMRC 2003) is through cultural competency. “Cultural Competency” (CC) has become known as the vehicle for providing the means for developing effective communication practices between people of different cultural backgrounds, in a culturally appropriate manner. CC is a relatively new concept in Australia and was first introduced in the health sector in the 1990s and more recently, in educational contexts since 2004 (Gower & Byrne 2012; Grote; 2008; Thomson 2005). Two key principles of cultural competency are the building of strong relationships and effective communication between two or more ethnic groups and/or individuals (Greenhill & Dix 2008; Liamputtong 2008; Universities Australia, 2011a). In this thesis, the view that CC is essential to achieve reforms in Indigenous research will be explored. While the literature on CC for researchers is limited, there is some evidence to support the inclusion of CC in research for the purposes of improving cultural understandings; developing trust, effective communication and strong relationships between researchers and the Indigenous community (Dudgeon et al., 2010; Harvard Catalyst 2010; Universities Australia, 2011a). To further support the inclusion of CC in research, the NHMRC has alluded to instances when research involving humans may involve significant risks and one example outlined refers to, “ethical insensitivities, neglect or disregard” (2007, p.3). CC is explored further in this chapter and in chapter two and seven.

In drawing upon some of these recent changes in Indigenous research practices; this thesis will make reference to a three year longitudinal case study involving a number of Indigenous Australian communities in metropolitan, rural and remote settings. This case study, which involves Aboriginal children who are affected by a major health condition - Otitis Media (or Conductive Hearing Loss (CHL), is an ideal

vehicle to illustrate elements of Indigenous research practices because it flags a range of factors and issues that can impact on the research process. For example, this case study encompassed a number of Aboriginal communities from three different geographic locations, required multiple ethical clearances, provides examples of both ethical and unethical behaviour and issues, included remote locations and associated health issues which many researchers may be unfamiliar with, required the support from participants from an educational setting and involved the writer of this thesis as a participant observer. The ethical guidelines that were available to researchers during the period 2001-2003 when this study took place will be examined to assess if they were adequately framed and implemented sufficiently by the research team.

Issues arising from the study that impacted on ethics and the research study itself will be examined. Issues such as gaining consent from multiple sites, obtaining consent from afar, the wording of consent forms, the use of passive consent and the need for ongoing consent will be addressed. Despite following ethical research guidelines, researchers in this study encountered factors which both supported and inhibited the research process. At times, the researchers felt that some of the changes which supported Indigenous control over the research process had gone too far and was now jeopardising the research project. Since 2003, there have been revisions of the NHMRC and AIATSIS research guidelines and a proliferation of research guidelines from a number of agencies that provide services to Indigenous Australian clients. The study will examine whether these new guidelines have improved and/or if they are adequate in addressing matters that have been raised by Indigenous academics, advocates and Indigenous communities who had earlier expressed concern about culturally inappropriate research practices and ownership issues in Indigenous related research. In doing so, it will analyse and discuss how each of the various ethical research guidelines match up against one another and how they are implemented when university staff undertake research in Indigenous contexts.

Since 2003, significant reforms have occurred in the development of research guidelines and practices for the conduct of research involving Indigenous participants. While these changes have been necessary to address inappropriate research practices of the past, the literature suggests that a level of tension still remains between Western and Indigenous epistemology and perspectives on research and that there is a need for

further research reforms (Nakata 2004, 2007a, 20130; Rigney 1999; 2006; Walter 2010). This suggests that the research community needs to work towards developing a process that includes both Western and Indigenous perspectives across all research activities and understandings to address issues and concerns from all parties concerned.

While much of the literature promotes Indigenous ownership and control over research, my views on the matter do not endorse this stream in the literature as both Indigenous and non-Indigenous researchers have a role to play in Indigenous research but, it must be accepted that Indigenous empowerment must be sustained.

In closing, this thesis will discuss strategies to support this new approach to Indigenous research and will advocate the requirement for Indigenous cultural competency training for all researchers who research in Indigenous contexts.

The research questions for this thesis are as follows:

1. What constitutes an ethical approach to Indigenous research (from a historical perspective) utilising the case study?
2. To what extent are the ethical guidelines provided by the NHMRC adequate?
3. To what extent does the proliferation of ethics guidelines/processes assist in underpinning ethical research or foster inefficiency?
4. To what extent is cultural competency a significant component of Indigenous research?
5. To what extent were ethical and operational issues evident in the case study?
6. To what extent is a new framework needed to address the issues that arose in the research study?

The need for Indigenous cultural competency training for researchers

The importance of building relationships, showing respect and demonstrating cultural sensitivity and competence are very important aspects when engaging in cross cultural research (Dudgeon et al (2010); Greenhill and Dix, 2008; Harvard Catalyst (2010); Liamputtong, 2008). Demonstrating cultural sensitivity is about understanding another person's culture, beliefs and values and applying these understandings in

practical situations (Liamputtong, 2008). In the light of previous research practices that have been experienced by Indigenous Australians and with the recent changes to the research guidelines and practices involving Indigenous participants, including the views expressed by academics such as Nakata (2004, 2007a, 2007b, 2013) and Rigney (1999, 2006), this thesis will demonstrate that the building of relationships, trust and cultural sensitivity are also important elements to be considered in the research process. As many non-Indigenous researchers are still actively involved in and will continue to be involved in Indigenous research, the need for cultural competence training should become a necessary requirement for all researchers.

Cultural competence is defined as:

The awareness, knowledge, understanding and sensitivity to other cultures combined with a proficiency to interact appropriately with people from those cultures in a way that is congruent with the behaviour and expectations that members of a distinctive culture recognise as appropriate among themselves. Cultural competence includes having an awareness of one's own culture in order to understand its cultural limitations as well as being open to cultural differences, cultural integrity and the ability to use cultural resources (Universities Australia, 2011a, p.48).

Cultural competence embraces a number of key concepts including: cultural awareness, cultural safety; cultural security and cultural respect. Cultural competency builds on the attributes of awareness, knowledge, understanding, sensitivity, interaction, proficiency and skill to interact and communicate effectively with Indigenous Australians (Thomson, 2005, p.3-6). These qualities in turn will greatly assist individuals contribute to and serve Indigenous communities effectively so that differences and diversity are respected and valued.

Cultural competence training is a mechanism which researchers can apply in supporting the new methodologies and principles for conducting research in Indigenous contexts outlined by Fredericks, (2008); Nakata (2004, 2007a); NHMRC (2003) and Rigney (2006). In meeting this goal, universities and/or other NHMRC recognised research agencies are in the best position to provide cultural competence training for

researchers who engage in Indigenous research via workshops or on-line modules. The training should include: Indigenous culture, provide a brief history of Indigenous research in Australia, present some indigenous views on research, outline strategies to develop effective partnerships/relationships with Indigenous communities and, provide an interpretation of the NHMRC guidelines for the conduct of research involving Aboriginal and Torres Strait Islander people.

While this thesis advocates for cultural competency training for all researchers who engage in Indigenous research, the research team did not receive any training prior to undertaking or during the CHL project. At the time of the study, the term ‘cultural competence’ was relatively new in Australia and was commonly associated with the health sector before moving later into the field of education and more recently, in research (Gower & Byrne, 2012; Harvard Catalyst 2009; Thompson 2005). Furthermore, the composition of the CHL research team reflected expertise in specific areas that were required to meet the aims and objectives of the study and as a result, each team member had varying degrees of experience in Aboriginal culture, including working with Aboriginal people and the conduct of research involving Aboriginal and Torres Strait people. For example, two members of the team had individual expertise in statistics and linguistics and had little or no experience researching in Indigenous contexts and/or working with Aboriginal people. The project leader however, had extensive teaching and research experience in Aboriginal education and the other team member was Aboriginal and provided assistance and advice on matters such as Aboriginal protocols and developing relationships with participants and other community members.

The thesis draws upon the CHL case study to highlight a high level of cultural competence that was displayed by the research team and refers to practical examples to demonstrate the importance and contribution of cultural competence in Indigenous research. Despite not receiving any cultural competence training, these examples confirm that the research team acted ethically throughout the research study and engaged with all Aboriginal participants in culturally appropriate ways based on their personal experience, reflective practice and, with the assistance from the Aboriginal research team member.

A case study

The longitudinal research study that has been chosen as a case study for this thesis examined effective practices in teaching Indigenous children with Conductive Hearing Loss (CHL) and involved a number of schools in metropolitan, regional and remote locations in Western Australia. The schools were selected from the state's three educational providers and each were characterised by high Aboriginal enrolment numbers. The selection of schools was also restricted to three districts in Western Australia which were being targeted by the Commonwealth Government's National Indigenous English, Literacy and Numeracy Strategy (NIELNS). One of the key objectives of this strategy was to address hearing problems among Aboriginal & Torres Strait Islander children (Watson, 2003). The main participants in the research were teachers and Aboriginal students, although some non-Aboriginal students were indirectly involved as classroom members. The research team was comprised of university staff members, including the author of this thesis. The research project used in this case study overlapped the NHMRC's 1991 and 2003 guidelines for the ethical conduct in Aboriginal and Torres Strait Islander Health Research. The 1991 guidelines covered three broad categories: Consultation, Community involvement and Ownership and publication of data. In following the 'consultation' guidelines, the research team were required to consult widely with stakeholders at several levels including state and local health authorities and with Aboriginal & Torres Strait Islander controlled health services (NHMRC, 1991b, p.6).

In discussing best practice in research which is outlined in Chapter Eight, the procedures and processes undertaken by the research team while conducting the CHL research project will be analysed against the research guidelines of the day, 2001 – 2003. A further analysis will then be made against the CHL research practices and the current research guidelines that have been produced by the NHMRC and AIATSIS. The observance of Indigenous protocols while conducting research will also form part of this discussion.

A number of ethical issues that arose during the study will be discussed and these include: the need to obtain multiple ethics clearances, the use of culturally appropriate materials to assess student performance, and informed consent. The section of informed consent will deal with the wording used in consent forms, obtaining

consent from afar, misunderstandings associated in approving consent, on-going consent, and the use of passive consent.

Observing Indigenous protocols

With new models of Indigenous research being established by Aboriginal and Islander Health Councils (AIATSIS, 2012; Fredericks, (2008), the NHMRC (2003), and those being advocated by Indigenous academics such as Fredericks (2008); Moreton-Robinson (2000); Nakata (2007a, 2007b); Rigney (2006) and Walter (2010), it will become extremely important for researchers to observe Indigenous values and ways of doing things. Changes in ethical approval processes which support Indigenous ownership and control over research, appropriate levels of consultation, reciprocal agreements regarding the outcomes of the research, data collection and the discussion and dissemination of research findings need to be understood by researchers and become intrinsic in Indigenous research practice.

Conclusion

The landscape of Indigenous research in Australia is changing in response to poor research practices of the past by non-Indigenous researchers and with the implementation of new research guidelines which are based on principles of self-determination, Indigenous ownership and control over research and the establishment of a systematic research process that combines western & Indigenous epistemologies to guide all future Indigenous research reforms. The understanding and implementation of these changes will require further discussion and clarification between all researchers, participants and the Indigenous community to fully understand what these changes and associated cultural protocols mean in working towards a smooth transition to current and future research guidelines and practices. This necessity has been highlighted by incidents taken from a case study which reveal the need for shorter timeframes in approving ethics applications and for all participants who are involved in research to be clear of their role and responsibilities in research matters, and especially those that relate to informed consent. Establishing clear guidelines and protocols prior and during the research activity will assist both researchers and the Indigenous community work towards achieving successful outcomes and identify best practice in Indigenous research. Indigenous cultural competence training and associated understandings is

considered to be a necessary component for all researchers to undertake, so that they can play their role in facilitating this process and supporting self-determination, control over and participation in research.

CHAPTER TWO

LITERATURE REVIEW

Introduction:

The review of literature for this research study required an overview of the developments in Indigenous research practice beginning from an historical position and leading to current practices, including future directions. Current research practices in Indigenous research have been shaped by poor practices of the past. The literature examines the changes resulting from the introduction of national ethical research guidelines and research governance processes that have been established in universities and other institutions to oversee the conduct of research. It was also necessary to examine the ‘landscape’ or contexts that are present when engaging in Indigenous research. For example, power relations in research, the establishment of Indigenous HRECs, the consequences of being an ‘insider’ or ‘outsider’ when working with Indigenous participants who are involved in research, appropriate levels of consultation, the application of the guidelines that relate specifically to the conduct of Indigenous research and the identification of further research reforms that have been advocated by Indigenous academics. A unique research case study that involved the author of this thesis was chosen to examine these ‘contexts’ in a practical sense and this required a review of literature on case study theory and the role of the participant observer in the research process. Critical theory informs the research analysis in this thesis in examining the shift from neo-colonial research practices from the past to those that now reflect Indigenous control and ownership over research. To assist researchers in understanding and applying the new national Indigenous research guidelines and to work in cross cultural contexts, particularly in being more culturally responsive and sensitive in the conduct of research, the role and contribution of cultural competency was explored. The literature review assisted in forming the research questions of this study, in identifying past and current practices in Indigenous research and proposing future developments in Indigenous research.

History of research practices in Indigenous Australian communities

It is well documented that many previous research methodologies and practices on Indigenous issues which have been carried out by non-Indigenous researchers have been inappropriate, unacceptable, devious, culturally insensitive and in many instances harmful to Indigenous individuals and communities (Cruse, 2001; Fredericks 2008; Greenhill & Dix 2008; Taylor & Ward, 2001; Smith 1999).

Melville and Rankine (2000) affirm that Indigenous research today raises sensitive issues, due to its history and some current practices. The collection of data, data analysis and interpretation of data by non-Indigenous researchers has also raised issues concerning the application of ethnocentric research models which are “neo-colonial and paternalistic” in nature and of little benefit or even detrimental to those being researched (Foley, 2000; Nakata 2004; 2007; Rigney, 2006). As a result, research for Indigenous people is often “inextricably linked to European imperialism and colonialism,” a term taken to mean the “continued construction of Indigenous people as the problem” (Smith, 1999, p.1).

The above researchers have also been scathing of past practices of researchers, who often treated Indigenous communities as ‘field laboratories.’ Manderson, Kelaher, Williams & Shannon (1998) sum up their views when they contend that, “Indigenous perceptions of Australian research practice have emphasised their subject status, in which academics have been seen to descend on a community, gain peremptory permission to conduct their work, collect their data (biological or social) and leave, with little or no feedback to the community and no lasting benefits to it” (Manderson et al, 1998, p.2).

In many instances, research has resulted in the appropriation of Indigenous knowledge using procedures that many people consider to be culturally insensitive and inappropriate. Previous practices have often excluded Indigenous participation and ownership of research which, in many cases, has resulted in Indigenous people being wary of proposed research projects. Taylor and Ward (2001) state that, “it is fair to say in the past that there has been suspicion of and even hostility expressed by Indigenous Australians towards some anthropological and archaeological research ideas and practice. Some suspicion continues today” (p.16).

Some research practices have also been culturally insensitive, resulting in secret-sacred materials being published, while other cultural practices have been

sensationalised. An example of cultural insensitivity was reported in the *Sydney Morning Herald* on 10/05/03 regarding the release of a new book on the Hindmarsh Bridge affair in South Australia. The book's author, Margaret Simons, revealed that items in a sealed envelope marked 'for woman's eyes only' were read by a man (Hindmarsh Island bridge affair, 2003)

As a result of experiences such as those outlined above, many Indigenous people have become reluctant to support or participate in proposed research activities. Research for many Indigenous Australians is another form of dispossession because of the appropriation and custodianship of their knowledge by non-Indigenous researchers and institutions that are not accessible to them. The methods used by researchers who conduct research in Indigenous contexts should take account of the principles and values of Indigenous Australian culture and be informed by Indigenous interpretations of advantages, the potential to cause harm and issues concerning intellectual property rights and confidentiality.

The development of ethical research guidelines: An historical overview.

Ethical guidelines have been established for the conduct of research involving humans, animals and the environment, including guidelines developed specifically for research involving Indigenous participants and communities. These guidelines are intended to protect the rights and safety of individuals during both the research and reporting processes. Such documents have their genesis in the Nuremberg findings of World War Two and secondly, the 1964 Declaration of Helsinki. Various forms of human rights have been in existence over the centuries, among them: the Magna Carta, 13th Century (church free from government interference, free citizens to own and inherit land, to be free from excessive taxes); US Declaration of Independence, 1776 (that all men are created equal with certain unalienable rights such as life, freedom, and happiness); Human Rights Movement (19th and 20th Centuries) addressing human rights issues such as slavery, child labour, working conditions and poor wages; and United Nations Universal Declaration of Human Rights (Human Rights Web, 1997).

Development of National Research Guidelines

Before considering specifically issues relating to research involving Indigenous people, a brief overview of the key documents that have informed previous and current ethics guidelines will be presented.

Research ethics in Australia is guided by the National Health & Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Research Involving Humans* (1991a, 1999, 2007). The *National Statement* evolved from the NHMRCs, 'The Statement on Human Experimentation (1964-1990), and referred to ethical standards that applied to medical and later social research in Australia (NHMRC, 1999, p.2). Among the NHMRC's values and principles of ethical conduct was the protection of the welfare and the rights of participants in research. "The ethical and legal responsibilities which researchers have towards participants in research reflect basic ethical values of integrity, respect for persons, beneficence and justice" (2003, p.11). In the revised guidelines which were published in 2007, the authors of the document, NHMRC, Australian Research Council (ARC) and Universities Australia reinforced these values, but extended them to include, "altruism, contributing to societal or community goals, and respect for cultural diversity" (NHMRC, 2007, p.11). The NHMRC believed that in Australia, research involving human subjects should be carried out in a 'safe and ethically responsible manner,' but admitted that there will always be potential risks in research involving humans despite all good intentions, careful planning and practice (NHMRC, 2007a, p.3). The NHMRC contended that at times, 'technical errors or ethical insensitivity, neglect or disregard,' may arise and hence, the need for all researchers to be made aware of these possible outcomes and strategies to prevent them from happening (NHMRC, 2007a, p.3).

Guidelines for Indigenous research

The first set of major guidelines for the conduct of ethical research involving Aboriginal and Torres Strait Islander people was released in 1991. Entitled, "*Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*" (NHMRC, 1991b), this document identified three major areas that were considered to be important in related research activities: consultation, community involvement and ownership; and publication of data. These three areas were to be included in all research proposals together with the then current version of the NHMRC's *National Statement on Ethical Conduct in Research Involving Humans* (1999). The level of *consultation* extended to Aboriginal and Torres Strait Islander health agencies at state, federal and territory levels as well as at locally controlled Aboriginal and Torres Strait Islander health agencies. In addition, the proposed research had to be deemed beneficial and supported the community under investigation or by an Aboriginal and Torres Strait Islander agency

which needed to be satisfied that the research would be conducted in a culturally sensitive way. The process for obtaining informed consent was also outlined in this section. For example, the wording of consent forms and information about the research process had to be easily understood by community members, face to face explanations about the consent form had to be provided whenever possible, sufficient time had to be allowed to obtain written consent from participants and participants had to have the right to withdraw from the research study at any time (NHMRC, 1991b). In meeting *Community involvement* requirements, proposals had to indicate opportunities for the Aboriginal community members being investigated to participate and assist in the research process and payment for these services and other related costs had to be included in budget costs. Matters relating to Aboriginal and Torres Strait Islander women's health and children were to be referred to and assisted by female members of the community and this requirement was similarly extended to Aboriginal and Torres Strait Islander men. In addition, researchers have to 'recognise the right of community members' to request further information about the research project and that any changes to the approved research process be subject to further negotiations and approval (NHMRC, 1991b, p.7). The section on *Ownership and publication of data*, outlined a number of guidelines regarding the ownership and publication of data and the need to have these discussed and negotiated between both parties prior to the beginning of the research project. This requirement extended to the reporting of findings back to the community in a confidential manner, for researchers to seek further approval from the community should they wish to conduct and use research findings outside the approved parameters of the research project as well as negotiation regarding the storage, return and/or destruction of data collected prior to beginning the research project and the de-identification of subjects or communities in any written reports. Also, the use of pictorial material had to follow the wishes of the community, as was the appropriate acknowledgement of community and individuals and the need to seek permission from the community for any release of information about the research study to the media (NHMRC, 1991).

Development of other research guidelines:

A number of agencies such as AIATSIS, Department of Health and Aboriginal Health Councils have developed their own set of research guidelines for research that is sponsored by them or if the research concerns the clients they serve (AIATSIS, 2000,

2012; Fredericks 2007). These guidelines are used in conjunction with the NHMRC's national guidelines when writing ethics research applications. The first set of guidelines that were developed by AIATSIS comprised of 11 principles of ethical research that were covered under the broad categories of: consultation, participation, collaboration and partnerships, benefits, intellectual property and informed consent.

AIATSIS Research Guidelines: Eleven Ethical Principles

The Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS) was established in 1964 and undertook an early role to influence the way in which research is to be conducted in Indigenous communities. "An underlying aim of AIATSIS, in attempting to exert such influence, is to ensure that research about and involving Indigenous Australians is undertaken in ways that are both culturally appropriate and ethical" (Taylor & Ward, 2001, p.15).

In this document, AIATSIS outlined eleven ethical research principles of its own and built on NHMRC's guidelines of 1991 and 1999 for the conduct of research involving Indigenous communities. The eleven key principles are listed below:

1. Consultation, negotiation and free informed consent are the foundations for research with or about Indigenous peoples,
2. Consultation and negotiation is ongoing,
3. Consultation and negotiation should achieve mutual understanding about the proposed research,
4. Indigenous knowledge systems and processes must be respected,
5. Recognition of the diversity and uniqueness of peoples and individuals,
6. Intellectual and property rights of Indigenous peoples must be protected and preserved,
7. Indigenous researchers, individuals and communities should be involved in research as collaborators,
8. The use of and access to, research results should be agreed,
9. A researched community should benefit from, and not be disadvantaged by, the research project,
10. Negotiation of outcomes should include results specific to the needs of the researched community,

11. Negotiation should result in formal agreement for the conduct of a research project, based on good faith and free and informed consent (Taylor & Ward, 2001, p.20).

NHMRC current guidelines:

The NHMRC's national research guidelines are subject to revision and regular updating in order to maintain the best practice ethical research across a number of contexts. The NHMRC has also developed publications to assist researchers and Indigenous Australians in the research process. There are four major research guidelines that have been published by the NHMRC for the conduct of research involving humans. These are:

- NHMRC National Statement on Ethical Conduct in Human Research (2007a).
- NHMRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003),
- NHMRC Australian Code for the Responsible Conduct of Research (2007b) and,
- NHMRC Keeping Research on Track (2006).

In addition to these documents, the NHMRC has also produced a document entitled, *Procedures and requirements for meeting the 2011 NHMRC standard for clinical practice guidelines* (May 2011, version 1.1). These guidelines apply to developers of clinical guidelines who work closely with, "medical colleges, peak bodies representing medical specialists, public and private health organisations, non-government agencies, federal or state government agencies" (NHMRC, 2011, p.3). As the document does not relate specifically to ethical research guidelines, it will not be referred to in the discussion of this chapter and has been included for noting purposes only.

- *NHMRC's National Statement on Ethical Conduct in Human Research* (2007a).

The 2007 National Statement is presented in five parts:

- I. Values and principles of ethical conduct. This section outlines a set of principles to guide the "design, review and conduct of research" that is based on research merit and integrity, justice, beneficence and respect in

“building trust, mutual responsibility and ethical equality” (NHMRC, 2007a, p.11).

- II. Themes in research ethics: risk, benefits and consent. This section provides guidelines on assessing potential risks and benefits of research and consent to participation: an individual’s right to participate in or withdraw from research.
- III. Ethical considerations specific to research methods or fields. This section discusses ethical considerations for a number of different research methods and research areas such as databanks, clinical trials and human tissue samples.
- IV. Ethical considerations specific to participants. This section identifies ethical considerations for specific categories of participants such as children, Aboriginal & Torres Strait Islander peoples, participants who have a mental disability and participants from other countries.
- V. Processes of research governance and ethical review. This section outlines the responsibilities of institutions to research and the processes for the ethical review of research, including the establishment of Human Research Ethics Committees who are responsible for reviewing research applications. The section also provides guidelines on minimising duplication of ethical review, how to manage conflicts of interest, monitoring approved research, handling complaints and the accountability of researchers, review bodies and institutions.

With regards to minimising the duplication of ethical reviews, the NHMRC states that, “whenever more than one institution has the responsibility to ensure that a human research project is subject to ethical review, each institution has the further responsibility to adopt a review process that eliminates any unnecessary duplication of ethical review” (2007a, p.87). This ruling also applied in the 1999 edition of the National Statement under the section, “Multi-Centre Research” and reference to minimising unnecessary duplication of reviewing research involving more than one institution or organisation, “HREC’s are encouraged to ascertain whether the same protocol has been reviewed by another HREC, including reviews conducted overseas” (NHMRC, 1999, p.23). In developing the 2007 National Guidelines, the NHMRC issued a statement on the new inclusions that were not in the 1999 document and these

include: Risk, qualitative methods, data banks, additional categories regarding specific participants in research (Women who are pregnant and the human foetus, people in other countries, people who may be involved in illegal activities) and institutional responsibilities in research governance and ethical review. In addition, the NHMRC also indicated that revisions were made to all chapters but the most significant changes were made to the following: general requirements for consent, qualifying or waiving conditions for consent, children and young people and, Aboriginal and Torres Strait Islander peoples (2007, p.2).

- *NHMRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003). In developing these guidelines, the NHMRC believed that intercultural differences must be recognised and acknowledged in order to develop strong ethical relationships between researchers and the Aboriginal and Torres Strait Islander community, saying that “the construction of ethical relationships on one hand and the research community on the other must take into account the principles and values of Aboriginal and Torres Strait Islander cultures” (NHMRC, 2003, p.5). While the previous guidelines addressed matters relating to consultation, community involvement and ownership and publication, they did not explicitly acknowledge the role of colonisation and assimilation in past research practices and the significant impact it had on Aboriginal and Torres Strait Islander peoples. In order to address the ‘repeated marginalisation of Aboriginal and Torres Strait Islander values’ and the perception that is held by many Aboriginal and Torres Strait Islander communities that research is an ‘exploitive exercise’, the NHMRC’s new guidelines urged researchers to respect and value Aboriginal and Torres Strait Islander culture and values and “demonstrate through ethical negotiation, conduct and dissemination of research that they are trustworthy and will not repeat the mistakes of the past” (NHMRC, 2003, p.18). These guidelines were developed in conjunction with Aboriginal and Torres Strait Islander people with six values being identified and forming the core for ethical assessment:

- I. Reciprocity: Inclusion and mutual benefits in research are the key elements of this value. Inclusion means a respectful and equitable level of engagement

with Aboriginal people in research. Reciprocity requires the researcher to demonstrate benefits that will advance the interests of the Aboriginal and Torres Strait Islander community that are valued by them.

Implementation strategies included:

- Research proposals to clearly identify the benefits to Aboriginal and Torres Strait Islander Communities,
- Clarifying the relationship of the proposed research activity to national priorities and strategies,
- The inclusion of Indigenous participants as research partners and participants in the monitoring of research.

II. Respect: This value relates to the building of strong relationships, trust and cooperation between researchers and Aboriginal and Torres Strait Islander people. Respect encompasses the acknowledgement of cultural differences and protocols, the engagement with Indigenous institutions in matters of research and when seeking HREC approval, the contributions made by the participants in research and any consequences of research, including the publication of research findings.

Implementation strategies included:

- agreement on the reporting and publication of research findings between researcher and participants,
- elimination of cultural bias in the reporting of findings,
- provision of appropriate ongoing advice about the research project and research processes.

III Equality: The importance of respecting and acknowledging cultural differences and the right of Aboriginal and Torres Strait Islander people to be different was considered to be central to ‘equality’. Equality also included valuing the knowledge and wisdom of Aboriginal and Torres Strait Islander people, being treated fairly and ‘equally’ during the research process and shared mutual benefits resulting from the research. “Researchers’ misinterpretation and failure to recognise the cultural values and worldview of Indigenous people is often caused by the application of ethnocentric research models” (Mack & Gower, 2001, p.3).

Implementation strategies included:

- inclusion of Indigenous knowledge and wisdom in research questions, methodology, and dissemination of research findings,
- protection of the intellectual property rights of Indigenous peoples,
- agreement on the collection, storage and use of research data,
- distribution of benefit of the research to be fair and equal, that is, not predominantly to researchers.

IV. Responsibility. Aboriginal and Torres Strait Islander people have cultural responsibilities including those to country, spiritual contexts, family and kinship obligations. Ethical research occurs when these responsibilities are maintained and are not harmed in anyway during the research process. It was considered important for researchers to be held accountable for the protection of participants, particularly in relation to their social and cultural commitments.

Implementation strategies included:

- ongoing monitoring by communities of a project's compliance with ethical standards,
- consideration of the impact the research may have on the social functioning of communities,
- provision of honest feedback to any expressed concerns and expectations made by participants and communities.

V. Survival and protection: Past research practices by non-Indigenous researchers have disempowered and undermined Indigenous communities with little or no Indigenous participation in the research process and with little or no benefits to participants or communities. Furthermore, Indigenous Australians have a strong desire to maintain and protect their culture and identity and this aspect should be foremost in all areas of the research process. Researchers were required to demonstrate that they are respectful and trustworthy and that their research practice will not repeat practices of the past. This also includes a commitment by researchers to actively engage Indigenous and community members in the research process, whenever possible.

Implementation strategies:

- research proposal should reflect the cultural distinctiveness and identity of Aboriginal and Torres Strait Islander peoples and communities.

VI Spirit and Integrity: This is an overarching value that brings together the five previous values and their underlying importance to Aboriginal identity, including the past, current and the future (NHMRC, 2003, p.9-20).

- NHMRC *Keeping Research on Track* (2006). This document provided practical information relevant to Aboriginal and Torres Strait Islander peoples to ensure that research was conducted with integrity and respect; was valued and reflected research priorities of individuals and communities and that the research process was based on strong ethical relationships with researchers, universities and other institutions. The guide explained the Aboriginal and Torres Strait Islander guidelines that relate to research, their involvement and rights to participate or not to participate in research and provided a useful checklist of what happens during the research process and importantly, what to ask researchers during each stage of the research process. ‘Building Relationships’ with researchers at the beginning and throughout the research process was one of eight key elements that was explained in the document and addressed the key element of cultural competency.

The document was useful for researchers as it further reinforced the NHMRC’s National Statement and the guidelines that have been developed specifically for the conduct of research with Aboriginal and Torres Strait Islander communities. In addition, the practical information and checklists could assist researchers in research design and planning and how to work and research effectively with Aboriginal and Torres Strait Islander communities (NHMRC, 2006).

Other research related guidelines and policies:

- *Research guidelines for Ethical Research in Australian Indigenous Studies* (AIATSIS, 2012). This revised edition followed the first publication in 2000 in which eleven ethical research principles were outlined for the conduct of research involving Indigenous Australian communities. The revised edition of 2012 lists 14 principles of ethical research and like the first publication, many of these principles are embedded in the NHMRC’s research guidelines. The latest guidelines have been grouped under the following broad categories:
“Rights, respect and recognition, negotiation, consultation, agreement and mutual understanding; participation, collaboration and partnerships; benefits,

outcomes and giving back; managing research: use, storage and access; and report and compliance” (AIATSIS, 2012, p.1). The changes between the 2000 and 2012 document relate to “changes to intellectual property laws, and rights in traditional knowledge and traditional cultural expressions, and the establishment of agreements and protocols between Indigenous people and researchers” (AIATSIS, 2012, p.1).

These guidelines have been developed specifically for research that is funded by AIATSIS; however, these guidelines can be a useful resource for all researchers who engage in this area. The guidelines for developing an ethics proposal cover four broad areas: evidence of community support, evidence of individual consent, the ethical risks of the project and, compliance of approval conditions. The application form requires applicants to outline the research proposal, the title and aims of the project, the research methods and techniques to be used including: the participants, confirmation of informed consent and community support for the project, potential risks and privacy issues and the storing of, and accessing research data. The guidelines also indicate that if approval from another HREC for the same research project has been granted, then a copy of this document must be forwarded to AIATSIS within a year of the research proposal being approved. In addition, copies of the following documents are required to be submitted: the agreed research proposal between the researcher and community and the informed consent form to be used for the research which should also confirm the terms regarding the ownership of intellectual property, after the research project has been completed (AIATSIS, n.d., p. 1-3).

- *NHMRC Australian Code for the Responsible Conduct of Research* (2007b). This document was jointly written by the NHMRC, the Australian Research Council and Universities Australia and established a code to guide researchers and institutions in responsible research practices and integrity in research. It was specifically written for universities and other public sector institutions to guide research policies and procedures and outlined the responsibilities and expectations of institutions and the research community. Compliance of the code was required for all NHMRC and ARC funded research (NHMRC, 2007b, p.1).

The Code also referred to ‘Special Responsibilities’ to Aboriginal and Torres Strait Islander Peoples.” It is a requirement that the Code be read in conjunction with the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research (2003)* and the *Guidelines for Ethical Research in Indigenous Studies* (AIATSIS, 2002); (NHMRC, 2007a, section 1.5).

With reference to section 1.3, ‘Train staff’ of the Code, the document outlined the importance for institutions to provide training for all research staff in a number of areas including, ethics, research methods, data storage, matters of confidentiality, responsible research conduct and all content of the Code. However, it does not specifically include training on cultural competency for the conduct of Indigenous research or research involving other cultures. The interpretation of the research guidelines by researchers may vary depending on the level of understanding and experience in working with Aboriginal and Torres Strait Islander people and communities. This thesis presents a strong case for the inclusion of cultural competency training for improving ethically based Indigenous research and for promoting a better understanding of the guidelines amongst researchers (see chapter seven) (NHMRC, 2007b, section 1.3).

The Code also provided guidelines for researchers and institutions on how to deal with allegations regarding misconduct in research and breaches of the Code and how these cases may be resolved (NHMRC, 2007b, p.1).

Process for ethic approvals

Research involving humans and animals require approval from an approved Human Ethics Research Committee (HREC) prior to the commencement of the research activity. Ethics committees have been established in universities and in a number of government and non-government departments. The National Health & Medical Research Council (NHMRC) guidelines are used to assess all proposed research activities involving animals and human beings. Most research projects will require just a single ethics review or clearance from HRECs, however, in cases where the research activity involves more than one institution or for instance, Indigenous health, it is likely that two or more ethical applications will be required (WA Health Department, 2012).

Aboriginal Health Research Ethics Committees

Despite the introduction of the NHMRC's "*Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*" (1991), many Aboriginal and Torres Strait Islander people felt that the 1991 *Guidelines* provided insufficient guidance relating to research in Indigenous communities (Cruse, 2001). As a result, a growing number of Indigenous people and academics who had become increasingly involved in research as researchers set up their own Aboriginal Health Research Ethics Committees (AHREC) to oversee the approval of research applications that involved Indigenous people. Members of these new committees felt that the 1991 *Guidelines* did not strengthen Indigenous control over research and as a result, new measures were introduced under these guidelines to require consultation with and approval of the proposed research activity by appropriate Indigenous leaders (Cruse, 2001). While this was welcomed and strongly supported, some Aboriginal and Torres Strait Islander people and organisations remained, and still remain, apprehensive and mistrust the enterprise of research itself as a result of negative experiences with researchers in the past (NHMRC, 2002). AHRECs, therefore, have proven to be important bodies in the move by Aboriginal communities to exert some control over research. Their aim was not appear authoritarian, but to foster co-operation (Cruse, 2001).

Aboriginal and Torres Strait Islander people have also become increasingly involved in research as researchers and have set up their own Aboriginal Health Research Ethics Committees (AHREC) to oversee the approval of research applications. New measures introduced under these guidelines required consultation with and approval of the proposed research activity by appropriate Indigenous leaders (Fredericks 2007; Social Policy Research Centre (SPRC), 2008)

While there has been a shift in the principles and values that guide Indigenous research and support Indigenous self-determination, ownership and control over research, these new understandings and practices will require the development of strong partnerships, collaboration, consultation and observance of cultural protocols between researchers and the Indigenous community. The implementation process of these principles is still undergoing a transitional phase with the transfer and control of Indigenous related research now ultimately resting with the Indigenous community. Researchers and Indigenous communities alike are sometimes apprehensive and

cautious about one another's intention regarding the research process as a result of these introduced guidelines and negative research experiences of the past. "Unless clear protocols are in place and clearly communicated to Indigenous people, researchers are likely to be regarded as 'just another white-fella mob coming to steal our stories'" (SPRC, 2008, p.2).

The development and maintenance of good relationships and trust between the researcher and the participants are vital elements in the research process. Jennings (2001) referred to 'insider' and outsider' knowledge (p.91) to describe the relationship between the researcher and participants involved in a research project. This relationship has important implications for the credibility of the research findings as participants may manipulate their points of view to agree with the views expressed by the researcher or may exaggerate certain responses as a means of "self congratulatory claptrap" (Jennings, 2001, p.91).

Insider/Outsider research

Feminist theorists such as Weiler (1999) and Smith (1999) provide a variety of examples on how insider and outsider knowledge can influence the level and detail of data that are presented and collected. The 'insider' is usually linked to the person or persons being researched and the 'outsider' being the researcher. This understanding however, can interchange and also assume a variety of meanings, particularly when cultural issues are applied. For example, the 'insider' may only be willing to share information that is considered to be of particular importance or of cultural significance. The researcher therefore, may receive a different 'rendition' as an 'insider' or 'outsider.'" (Smith, 2000, p. 66). Some further examples related to researchers are listed below:

- when the 'outsider' has 'insider' knowledge,
- when Indigeneity extends to both the insider and outsider,
- changed status of being an insider. For example, when an 'insider' returns after an absence from a community. This situation may result in not only how others may view the researcher but how the researcher may view themselves,
- shifting status – insider to outsider (stages of insider knowledge or levels) (Smith, 2000, p.66).

For the purpose of this study, insider and outsider knowledge will include issues of Indigeneity, as the writer is Indigenous and issues of the researcher being a participant observer.

In the cross cultural setting, the non-Indigenous researcher may possess only 'outsider knowledge' and so may not completely understand a cultural frame of reference or may misinterpret the view of 'insider' knowledge on Indigenous cultural matters. A number of Indigenous cultural issues need to be considered during all stages of the research process. These include:

- Awareness of possible community tensions and/or events, e.g., funerals, ceremonies, gender issues;
- Likely changes to community/advisory group membership and the need to advise new members;
- Language issues, e.g., some Indigenous communities use English as their second, third or fourth language. As a result, there could be difficulties in understanding consent forms and other literature associated with the research activity.

The issues outlined above can be addressed through professional development by university researchers to school staff. Grundy (in Jennings, 2001, p.95), argues that the expertise of teachers and their knowledge of the local Aboriginal community need to be considered and utilised by researchers when planning events such as meetings and community protocols. Partington (2003) and Selby (2001) also highlight the importance of establishing advisory groups to assist in the research process.

Partington (2003) outlined a number of risks and difficulties that are likely to confront researchers who conduct research involving Indigenous participants and/or communities. These include observing clear protocols when conducting research in Indigenous communities overcoming the perception of the researcher as a 'flying visitor' (Forrest & Sherwood, 1995, cited in Partington, 2003, p.2); ensuring adequate or regular face-to-face contact with the chairperson of the community; appointing suitable local research assistants to carry out interviews, liaise with community to arrange meetings and discuss the research project; locating research assistants who possess suitable qualities, for example, knowledge of the local community, their status in the community, and research skills such as interviewing technique.

To overcome these difficulties, Partington (2003) suggested a number of strategies including: early and extensive consultation with the community to be researched; the

appointment of local research assistants who are respected and have good knowledge of the community, and the establishment of a community reference group.

Power relationships in Indigenous research

Who holds the power in the research process in Indigenous contexts is important in conducting ethical research. The examples above highlight the following power relationships:

- the exclusion of Indigenous people in decision making regarding research of them and among them,
- access to the outcomes of research,
- issues involved in obtaining consent, and
- the language used in written communications.

Today, ethical guidelines have been established for the conduct of research involving humans, animals and the environment, including guidelines developed specifically for research involving Indigenous participants and communities. Such guidelines are intended to protect the rights and safety of individuals during both the research and reporting processes.

Researching Indigenous issues

As the foregoing outline has evidenced, ethical research guidelines are now available to assist researchers to conduct activities in ways that are culturally sensitive, empowering and participatory for individuals and communities. While most researchers strongly support these guidelines and try to conduct their work in a manner consistent with them, the implementation of such guidelines requires further discussion and clarification between the researcher and the researched. This is particularly important in Indigenous contexts where previous negative experiences have left many Indigenous persons feeling reticent toward and wary of research projects on Indigenous issues. Appropriate levels of consultation and ongoing consultation during the research process may help alleviate any concerns that may be raised by the Indigenous community. Related to this consultative process is the matter of ongoing informed consent to participate in the research.

Informed consent and consultative processes

The value and importance of appropriate levels of consultation with Indigenous communities and organisations throughout the research process is very prominent in the literature (e.g., NHMRC, 1991, 1999, 2003, 2007a; Cruse, 2001; Manderson et al., (1998); and Smith, 1997). Furthermore, the importance of establishing appropriate mechanisms for consultation to occur is also highlighted.

The NHMRC's National Statement on Ethical Conduct in Research Involving Humans (1999) and complementary guidelines for the conduct of health research involving Indigenous Australians (NHMRC, 1991b, 2003) included two ethical and legal aspects of consent: information regarding the proposed research, and the right to voluntary choice. Obtaining consent for someone to participate in research should involve, "provision to participants, at their level of comprehension, of information about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research (including the likelihood and form of publication of research results and, the exercise of a voluntary choice to participate" (NHMRC, 1999, p.12). The current NHMRC guidelines (2007a), continue to reinforce the understanding of voluntary choice to participant in research and detailed information about the research project and process: "The guiding principle for researchers is that a person's decision to participate in research is to be voluntary, and based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it" (NHMRC, 2007a, p. 19).

The NHMRC (2003) also stated that in some circumstances, the level of consent required in Indigenous contexts goes beyond individual participants and may include other interested parties such as Aboriginal Health organisations, collectives or community elders. Cruse (2001) advocated, for example, that Aboriginal Health Research Ethics Committees are "important bodies in the move by Aboriginal communities to exert some control over research. This is not to say that our organisations are or want to appear authoritarian, but rather that we prefer to foster co-operation" (p. 23).

Although researchers may have the best intentions to ensure informed consent and ongoing informed consent among participants regarding each stage of the research process, the interest demonstrated by those involved in the research may not always be

evident. Forster (2003), for example, reports that parents did not take up an offer to meet and discuss the research project in which their children were involved.

Mack and Gower (2001) contended that informed consent must be founded on “mutual [and tangible] benefit through short, medium and long term reciprocity. This involves the commitment of resources to negotiation processes that need to occur over timeframes that take into account Indigenous community modes of decision making” (p. 6).

Another issue related to conducting research involving Indigenous people is the process of obtaining clearance to conduct the research. All proposed research activities require ethics clearance from institutional or organisational Human Research Ethics Committees (HREC) that covers the entire research process. Usually one ethics clearance is sufficient for the purpose of research, although additional clearances may be required when research is conducted across a number of fields or involves more than one organisation. This raises the issue of compatibility between institutional and/or organisational ethics guidelines. The compatibility of ethical guidelines of organisations requires further discussion amongst the organisations involved to clarify processes as the need for multiple clearances can lead to lengthy delays in the approval process, delays in accessing data due to system variations, which may in turn render a research project untenable and/or discourage researchers from continuing in a project.

Taylor and Ward (2001) commented that experiences in Indigenous research may not always be ‘plain sailing’ despite the adoption of Indigenous ethical principles by researchers, noting that “Some researchers have already raised problems regarding Indigenous ‘control’ of the research endeavour, and concerns over the initiative being taken away from researchers, and thus the loss of so called ‘freedom of research’” (p. 21). The writers considered these concerns by researchers were ‘illusory’ and that some re-balancing of power was long overdue. This does give a clue to what should be done: negotiate with the communities for their input and ownership so the researchers are working for the benefit of the community.

Case for a participatory model

In addition, other advocates for mutual benefit and Indigenous control were also pressing for Indigenous involvement and control over research. Mack and Gower (2001) presented a case for a participatory model in Indigenous research as a means of

addressing the fundamental issue concerning Indigenous people: the “power and control over research” (p. 4). The authors drew on arguments presented by Williams and Stewart (1992), who contend that Indigenous ‘self-determination’ should underpin the approaches used in the research process. Secondly, it is possible for research to be an ‘empowering’ process when developed and implemented on the basis of mutual benefit, a position supported by Taylor and Ward (2001):

Indigenous communities must be permitted to prioritise their research requirements and to choose among the research projects put to them. The research community and the Indigenous community must mutually acknowledge the respective skills that are brought together in any collaborative research project. Intellectual property rights and the rights of ownership over cultural heritage, by appropriate Indigenous community members, must be recognised by researchers (p. 21).

McTaggart (in Williams & Stewart, 1992), in discussing the use of participatory action research in education, advocated a partnership arrangement between researchers and those researched to ensure the research methodology was appropriate and acceptable to the communities involved. Mack and Gower (2001) saw this as “the most appropriate and powerful research methodology for achieving a self-sustaining process of critical analysis and enlightening action for Indigenous communities as it operated on the basis of collective and collaborative decision-making, implementation and analysis” (p. 4).

The current challenges in Indigenous research

While the recent guidelines which have been developed by the NHMRC (2003, 2007a) and AIATSIS (2012) outline major principles and values of ethical research in Indigenous Australian contexts, they do not completely capture the changes in research methodologies, Indigenous control and ownership over research that have been strongly advocated by a number of Indigenous academics including Moreton-Robinson (2000); Nakata (2004, 2007a, 2007b, 2013) and Rigney (2006). Moreton - Robinson (2000) discussed the power relations between white feminists and Indigenous women in her book, *Talkin' up to the White Women: Indigenous woman and feminism*. Here, Moreton-Robinson highlighted the power of whiteness between white feminists and Indigenous women and in doing so, developed her own Indigenous woman's standpoint theory as a

means to inform methodological reforms in research. Her standpoint theory highlights the 'realities' and 'experiences' of Indigenous women which she felt needed to be included in current research methodologies that predominantly reflect the values and experiences of middle class white women (Moreton-Robinson, 2006, p.16). Rigney claimed that what Moreton-Robinson was seeking was, 'methodological inter-subjectivity' or the need "for non-Indigenous women to move beyond the conditions of their own privilege and therefore their own hegemony, they must begin to understand their own position, and those of Indigenous women through Indigenous realities and experiences" (2006, p. 38).

As outlined in chapter one, Nakata (2004, 2007a, 2007b, 2013) and Rigney (2006), provided clear but different positions concerning the need for further reforms in Indigenous research and research methodology. Rigney (1999, 2006), like Moreton-Robinson challenged neo-colonial research practices, focussing on Indigenous world views, autonomy and self-determination. He adopted a resistance approach to methodological research reforms in what he termed, "Indigenist" research. A key understanding of Rigney's 'Indigenist' research was Indigenous control and ownership over research and was based on the following three interrelated principles:

- 'Resistance' is the key 'emancipatory imperative' of Indigenist research.
- 'Political integrity in Indigenous research' and,
- 'The privileging of Indigenous voices in Indigenist research' (Rigney, 2006, p.39).

In summarising these three key principles, a 'Resistance' approach is taken in order to challenge traditional neo-colonial dominance in research practices using the concepts of 'self-determination' and 'de-colonisation' in addressing Indigenous research reforms. Rigney asserted that he was not promoting a separate research methodology under his resistance approach, but saw it as a means for challenging the 'power and control of traditional research practices' so that Indigenous priorities and concerns could be addressed and incorporated in research practices (2006, p.40).

'Indigenous integrity' relates to Indigenous autonomy and control over Indigenous research with 'Indigenous ideals, values and philosophies' being core to the research agenda (Rigney, 2006, p. 41). Essentially, this principle focused on the 'redistribution of power' in the research process to enable Indigenous research reforms and is a vital component in achieving 'self-determination' (Rigney, 2006, p. 42).

‘Privileging Indigenous voices in research’ relates to giving Indigenous people and communities a recognised voice in research and retaining this voice throughout the research process. Given the history of Indigenous research, Rigney feels that, “it is particularly appropriate that it is Indigenous Australians who determine their own research agenda to make public the voice and experience of their communities in their own way” (2006, p. 42). It will therefore be necessary for researchers, both Indigenous and non-Indigenous to collaborate and cooperate with Indigenous communities whom they are researching to ensure that the research process is conducted in culturally appropriate ways and in accordance with their wishes and aspirations.

Nakata (2004, 2007a) took a different approach in discussing Indigenous research reforms by arguing the need to develop a framework that could be used by Indigenous academics to guide debate and discourse with Western academics (see chapter one). Nakata (2007a) used the term, ‘cultural interface’ to describe the contested space where Western and Indigenous knowledges and discourses come together. It was from this analysis that he developed an Indigenous standpoint and a process that provided a method of enquiry that engages with the non-Indigenous domain. Nakata discussed ‘inevitable tensions’ that would arise on how particular issues were thought through between Western and Indigenous academics and analysed and accepted by the Indigenous community and individuals alike (2013, p. 290). The author of this thesis proposed that these ‘tensions’ could be alleviated through cultural competency training for all researchers so that both Western and Indigenous knowledge systems could complement one another and, importantly, promote best practice in Indigenous research. Cultural competency is discussed later in this chapter.

Participant Observer in research

The writer of this thesis undertook the role of participant observer in the case study that is referred to in the thesis. Participant observation has its roots in the social sciences and in particular, anthropological studies of social relationships among human beings and culture (Iacono, Brown, Holtham, 2009). This technique in data collection is associated with qualitative research methodology and is commonly used in ethnographic and case studies. Ethnographic studies often require the researcher to spend significant periods of time in the field to become part of the cultural group that is being investigated in order to increase their understanding of cultural practices and

protocols that may occur in a variety of situations. A description of case study research follows in this chapter, but in sum this kind of research is the study of understanding phenomena in a particular setting when that phenomenon is not distinguishable from its context. Such phenomena can relate to a program or project that is being evaluated and whereby the focus is on present day events and the experience of the participants (Yin, 2003).

The case study chosen in this thesis examined effective practices in teaching Indigenous children with conductive hearing loss (CHL) and involved a number of schools in metropolitan, regional and remote locations in Western Australia. In this case study, the thesis writer and research colleagues set about evaluating the effectiveness of a variety of teaching strategies that were used by teachers of Indigenous Australian students who had various levels of CHL. The data collection process spanned three years and involved visits by members of the research team to various school locations throughout Western Australia and included interviews with teachers who were involved in the study, analysing diaries that were kept by participating teachers and reflection and discussion by the research team on the data collected. The participant observer research methodology however, can raise some ethical dilemmas, such as the following which occurred in the case study (see chapter four for details). Participant observation can be conducted in an overt or covert manner with both having their strengths and weaknesses (Iacono et al., 2009). All research should be ‘overt’ and be conducted in an open and caring manner where participants are fully informed of the nature and scope of the research activity. Such was the case in the CHL research study. Under this arrangement, researchers have opportunities to form and build relationships with the participants of the study and develop a cooperative understanding between one another. While this may be a positive feature, overt participant observations may present concerns and/or issues as a result of the researcher being present. Participants in the study may feel uncomfortable by the presence of the researcher and this may bring about certain behaviours that could range from being ‘eager to please’ to showing a ‘reluctance to participate’ (Iacono et al., 2009, p. 42). The personal relationships that are likely to develop between the researcher and participants during the study can also influence interaction and the quality of data collected. Iacono et al (2009, p. 42) indicated that, “the researcher may empathise with his/her informants and vice versa” and noted that researchers should be wary of this. The development of personal relationships can also

lead to other ethical dilemmas such as the request to disclose confidential information. This scenario occurred during a CHL field trip when a supervisor requested information about a teacher's performance from a researcher, who was observing the teacher in the classroom.

The participant observer role therefore, can be a powerful tool in research as it allows the researcher to participate in the research study, view the world from the subject's point of view and record observations at the same time. However, it can also pose a number of challenges to the researcher including: how the researcher's presence may influence the participant, managing and interpreting the data collected and, the ethical dilemmas which may occur as a result of forming relationships with certain participants (Iacono et al., 2009).

Research methodology using critical perspective

Critical theory will inform the research analysis in this thesis. The work of critical theorists Adorno, Fromm, Habermas, Horkheimer and Marcuse is well documented in the literature and is identified with the Institute of Social Research or, the Frankfurt School. (Bronner, 2011; Dahms, 2011; Giroux, 1983; Kincheloe & McLaren, 1994; Tripp, 1992).

Critical theory emerged as a result of the Frankfurt School theorists combining Karl Marx's critique of 'political economy' with "motives Max Weber systematized in his theory of rationalization" (Dahms, 2011, p.8). Although these two theories largely formed the early foundations of critical theory, it is problematic to argue that all critical theorists from the Frankfurt School shared similar perspectives during its development and what critical theory has become known today (Bronner, 2011; Dahms, 2011; Giroux, 1983). Marx was concerned about the inequalities in society with particular reference to ownership, capitalism and personal well-being in terms of 'political, social and cultural life' (Dahms, 2011, p. 8). In contrast, Weber investigated whether capitalism shaped modern western societies or whether it was some other process involved. Weber found that in the modern world of economic organisation, 'rationally organised bureaucratic structures had replaced traditional power relations across society' (Dahms, 2011, p. 10).

Subsequent to Weber, critical theory has been informed by the principles of social justice and social enquiry that distinguishes between, 'what is' and 'what should be'

(Giroux, 1983, p. 8). It is associated with Western Marxist doctrine, with human emancipation becoming its major aim in contesting, 'hegemony' over those who are considered to be 'subservient' to the dominant culture and how the working class can be empowered through a 'counter-hegemonic strategy' (Bronner, 2011, p. 2 & 22).

Tripp (1992) stated that the key understandings of critical theory are 'people having equal access' and 'people being in cultural, economic and political control of their lives' and that these goals are achieved through 'emancipation,' a process of empowering those who have been subject to oppression and exploitation (p. 13). "Critical theory insists that thought must respond to the new problems and the new possibilities for liberation that arise from changing historical circumstances.....it is not merely concerned with how things were, but how they might be and should be" (Bronner, 2011, p.1-2).

"Alienation" and "Reification" are two concepts that are closely associated with Critical Theory (Bronner, 2011, p. 4). Alienation is often linked with 'exploitation' and Reification, the treatment of people as 'things' (Bronner, 2011, p.4). Critical theory challenges the positivist view of empirical and scientific data. Traditional researchers see their task as the description, interpretation, or reanimation of a slice of reality, whereas critical researchers often regard their work as the first steps towards forms of political action that can redress the injustices found in the field site or constructed in the very act of research itself (Kincheloe & McLaren, 1994, p. 140). Partington (1998) outlined four key assumptions that provide a foundation for this perspective:

1. Social acts can have multiple meanings which are not immediately apparent and analysis is required to clarify them;
2. The context in which action occurs must be taken into account because the situation in which events takes place influences the nature of events;
3. The influence of power in social relations cannot be underestimated;
4. Knowledge is not absolute (p.14).

Partington (1998) argued that critical perspective offers the most appropriate way to interpret research in Indigenous education settings, the setting of the case study in the proposed project. Tripp (1992) provided a list of methodological principles incorporating a socially-critical perspective. Some of these are listed below:

1. **Participation:** Socially-critical research is most effective when done by mutually supporting groups.
2. **Direction:** Whether group or individual, socially-critical research is always self-directed because the emancipatory interest of the participants will inform the way they themselves work as well as inform what they aim to achieve.
3. **Meaning:** Rather than regarding knowledge as the accumulation of subjectively neutral, objectively verified facts, socially-critical research sees knowledge as socially constructed and therefore artificial and held differently by different groups. It aims to understand people's values and uses of their meanings rather than finding the truth.
4. **Outcomes:** Socially-critical research tends to seek to develop quite new practices rather than to simply make existing ones more efficient. Outcomes will often be incorporated in political action as well as in the development of academic knowledge.
5. **Audience:** The primary audience for the research 'findings' is the participants themselves (pp. 14-15).

Tripp's (1992) key principles as outlined above provide guidance for this thesis. Research outcomes will be diverse and dependent on local context. Ethical guidelines are significant in the conduct of research; however, the researcher will find variations as a circumstance of persons assisting in the research process. In some instances it is anticipated that 'rules' will have been bent. For example in school based research, a school principal may have requested parents 'sign' project participation consent forms, without providing any explanation of what parents are consenting to. On the other hand, principals may instruct their Aboriginal teacher assistants to explain the research project to parents and what the involvement of their child in the research project will mean, before asking them to sign the consent form.

In some instances, teachers who are involved in the research project as participants may have elected not to be observed by the researcher for a number of reasons and instead, provide tape recordings of lessons and journal notes for interpretation.

However, an outline of research methods incorporating principles of critical perspectives will be given here as they provide a good set of criteria for conducting research on Indigenous issues. Tripp (1992), in acknowledging the above principles, advocates a collaborative research model similar to the participatory model of Mack and

Gower (2001), outlined above. Here the characteristics of collaborative research are identified: shared commitment in the research activity; mutual agreement and consent on the proposed research activity; control over the research activity is shared; benefits to both researcher and those being researched; and lastly, the research activity is conducted in a fair and honest manner.

Case Study approach.

This thesis will refer to a case study in highlighting some operational issues that researchers can experience during the research process, despite every effort to conduct the research in an ethical and culturally appropriate manner.

Case study research can be defined as, “an inquiry that focuses on describing, understanding, predicting and/or controlling the individual (i.e., process, animal, person, household, organisation, group, industry, culture, or nationality)” (Woodside, 2010, p.1). Each foci responds to a combination of any of following four major objectives of case study research: *Description* – to investigate answers to who, what, when, how & why questions. *Explanation* – to find answers to the why questions. This includes examining reports from participants who are involved in the study, third party observers who are familiar with the study and, the researcher(s) themselves. The analysis of conversations and communication between individuals forms an important task in case study research. *Prediction* – the forecasting of short and long term events/situations, and *Control* – possible ways in which attitudes, behaviours and events may be influenced in any given case. However, a defining principle objective of case study research is the researcher’s ability to develop a ‘deep understanding’ of the feelings, actions, behaviours, responses that may occur during the process and any given period of time (Woodside, 2010, p.11-12). Furthermore, Woodside (2010) contends that this definition is not restricted to ‘contemporary phenomena’ or ‘real life context’, as there can be cases when there are no clear boundaries between the phenomenon and context (p. 2). For instance, establishing the cause of death of human remains that may be between 50 and 100 years old is an example of case study research. Woodside asserts that, “the defining feature of case study research lies in the supreme importance placed by the researcher on acquiring data resulting in describing, understanding, predicting and/or controlling the individual case” (2010, p. 2). In doing so, the case study researcher is required to develop a deep understanding of the ‘behaviour, interactions, sentiments’

that are evident and/or which are exhibited in the study in order to make sense of how the 'individual' responds to specific stimuli over time (Woodside, 2010, p.6). Sense making includes, "(1) focussing on what they perceive; (2) framing what they perceive; (3) interpreting what they have done, including how they solve problems and the results of their enactments (including the nuances and contingencies in automatic and controlled thinking processes)" (Woodside, 2010, p.6). Deep understanding in case study research is achieved through experiences in a range of research methodologies across a number of time periods or intervals. This is commonly known as 'triangulation' and in this case, it would refer to, (1) direct observation and note taking by the researcher; (2) cross checking data and interpretations with relevant participants through interviews at particular time intervals and, (3) the analysis of written documentation by participants from one or more sites (Woodside, 2010).

For a 'one off' research case study, Woodside (2010, p.13) indicated that, 'ethnographic decision tree modelling,' and 'deep understanding' become appropriate research tools as the researcher is typically looking for information to form predictions across a number of variables, rather than looking to influence outcomes in the research study.

One of the main criticisms of case study research relates to the data collection process and the analysis of data. Data collection can take up considerable amounts of time while data analysis can pose some subjectivity concerns and/or issues. In addition, each case study presents its own uniqueness in terms of context and findings and therefore, is unlikely to be replicated elsewhere and cannot be used to generalise to a population (Iacono et al., 2009; Woodside, 2010). This understanding is supported by the fact that each participant will have varying degrees of knowledge to contribute to the study; the objective of case study research is not to form generalisations about a population, but rather to test or investigate a theory; that any one study can be labelled 'idiosyncratic' in terms of the selection of participants, data collection and data analysis methods used which in turn would prove hard to replicate. However, conclusions can be drawn from a number of case studies to provide deep understandings in relation to consistent patterns and unforeseen events that relate to theory (Woodside, 2010). The basis of achieving 'deep understandings' however, is dependent on the quality of the data collected and the interpretation of the data by the researcher. This is important as the researcher can influence the behaviours of those involved in the study and also be

influenced by their own biases such as beliefs and practices when interpreting the data (Iacono et al., 2009).

Recording and reporting research findings: Ethical versus moral obligations

Among the NHMRC's principles of ethical conduct and associated guidelines for research involving humans is the protection of the welfare and rights of the participants in research. "The ethical and legal responsibilities which researchers have towards participants in research reflect basic ethical values of integrity, respect for persons, beneficence and justice" (NHMRC, 2002, p. 11).

These principles include minimising the risks of harm and discomfort, and identification in all aspects of the research process including the reporting of research findings. Researchers however, are often faced with a number of dilemmas when reporting research findings or other observations that may pose an ethical versus moral issue. Researchers who engage in qualitative or interpretive research establish an intimate relationship with participants and are therefore more likely to 'discover' particular behaviours that may be considered untoward. Howe and Moses (1999) acknowledged this situation by stating that, "these discoveries may put research participants at risk in ways that they have not consented to and that the researcher had not anticipated" (p.40). They go on to suggest that researchers need to tread carefully on this matter, saying that "the problem cannot be eliminated by casting reports in wholly objective language. As description moves toward being more objective in this sense, it simultaneously moves towards a 'thin' description" (p. 45).

Forster (2003), in a review of the literature discussing ethical dilemmas in the reporting of research, reinforced the ethical responsibility of protecting those involved in the research activity from any harm. Forster advocated a style of critique based on achieving a delicate balance between methodological caution and telling a story of significance. "Methodological caution means carrying out criticism in ways that do not attempt to denigrate, or amount to any denigrating insiders' actions" (Forster, 2003, p. 56). The proposed study will address these issues and provide some guidance for researchers.

Another issue that can often cause dilemmas for researchers is the recording and reporting of certain research findings, particularly when some data have implications

that were not anticipated when the study was originally developed. In such circumstances, the researcher may feel a moral obligation to report this, but because of ethical obligations maybe prevented from doing so.

Cultural competency

The growing need to understand cultural diversity in Australia is ever increasing with over 300 different languages spoken across the nation in 2011, including approximately 60 languages spoken by Aboriginal and Torres Strait Islander Australians (ABS 2011; Ethnic Community Council, 2006). In the same year, census data indicated that 23.2% of the Australian population do not speak English as a first language at home and the number of overseas born Australians amounted to 5.3 million or almost 26% of the population (ABS, 2011). It was also reported that 11% of Aboriginal and Torres Strait Islander Australians spoke an Indigenous language at home as a first language (ABS, 2011).

In reflection of these statistics, an ABC news report in 2010 confirmed Australia to be the second most multicultural country in the world (Griffiths, 2010). This scenario means that contact with people from one or more cultures is very likely to occur in a variety of settings and contexts. The mix of different cultural beliefs, values and practices (including languages and religions) presents both an opportunity and a growing need for all Australians to develop an understanding and appreciation of other cultures (including Indigenous culture) and cultural diversity in an ever increasing global society. In addition, it is becoming increasingly important for practitioners and other professionals to communicate in a culturally appropriate manner when dealing with groups and individuals who are culturally different from them. Whilst this understanding has become increasingly important in recent times, the lack of culturally appropriate services and access to these services, particularly in the health sector and those relating to Indigenous groups, has been evident for some time in Australia (Liaw et al., 2011; Thomson 2005).

For example, the need for providing culturally appropriate health services and care to Indigenous Australians has been recognised for many years and has gained momentum since the establishment of the first Aboriginal community controlled health service in Redfern, Sydney in 1971 (Thomson, 2005). Socioeconomic and geographic

factors have also contributed to issues related to accessing appropriate medical services and treatment.

Thompson (2005, p.1) refers to the term, 'cultural chasm' in relating the lack of training that many health practitioners have had in preparing them to provide appropriate health care to Indigenous Australian patients. In an attempt to address this shortcoming, 'cultural awareness' training programs were provided to staff, but this type of training is designed to provide an awareness of cultural, social and historical factors relating to Aboriginal culture and to encourage self-reflection of their own culture and awareness of personal biases and the practice of stereotyping. This type of cultural training also extended to other government organisations such as education departments and the private sector, including the mining industry as many employees were working in Aboriginal settings for the first time had little or no understanding of Aboriginal culture. In essence, cultural awareness training programs do not provide the capacity or guidance to individuals to transfer this knowledge into behavioural practice (Centre for Cultural Competence, 2010). Thompson (2005, p.4) supported this view and argued that cultural awareness alone is 'inadequate' and believes that it needs to be supplemented with training to provide skills to assist professionals to interact appropriately with Indigenous clients.

At the same time and running parallel to the health issues which have been outlined briefly above, were the growing concerns expressed by Indigenous people about the poor practices in Indigenous research. Publications began to appear in the 1980s & 1990s regarding cultural insensitivities, exploitation and inappropriate research methodologies used by researchers (NHMRC 1991a; Fredericks 2007). As a result of this, Indigenous people and communities started to become reticent and sceptical towards research and researchers (see chapter one). As reported in chapter one, the NHMRC first established a set of national guidelines in 1991 for the conduct of research involving humans, animals and the environment. In addition to these guidelines, the NHMRC established a set of 'Interim guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research' which focused broadly on consultation, community involvement and ownership and, publication of data. These new and revised guidelines and protocols have signalled changes in practices in Indigenous research and a shift towards Indigenous ownership over research via reciprocal and partnership agreements in research (Fredericks 2008; Nakata 2007a;

Rigney 2006). Furthermore, there is a growing number of Indigenous academics and activists who are now participating in research and guiding research practices, methodologies and who are advocating the principles of self-determination, ownership and control over research (Fredericks 2008; Nakata, 2007a; Rigney 2006). Chapter one briefly discusses the work of Rigney and his “Indigenist” research methodology as a means of addressing past research practices and a means forward in shifting research principles and practices that reflect Indigenous autonomy and self-determination in research (Rigney, 2006).

These new research guidelines and methodological reforms however, may result in some non-Indigenous researchers interpreting these changes as a threat to their academic freedom and as a consequence, may be unwilling to compromise, and or, may no longer wish to be involved in Indigenous research (Schnarch 2004; Rigney 2006). While this may be a possible outcome, I strongly support the view advocated by Rigney that non-Indigenous researchers can have a role to play in Indigenous research, but it must be based on partnerships that reflect the new Indigenous research reforms.

Therefore, it is important for Indigenous communities and researchers to arrive at mutual understandings and reach an agreement concerning these new approaches before the research process begins and this must continue throughout the research process itself. Rigney (2006, p.42), outlined that ‘self-determination,’ ‘mutual respect,’ ‘collaboration’ and ‘power sharing’ are essential in establishing good research practice, trust and cooperation amongst those involved in research. So how can these qualities become ingrained and feature as best practice in Indigenous research? One approach which is being utilised in building relationships in a number of settings between individuals and organisations and the clients they serve is ‘cultural competency.’

“Cultural Competency” (CC) has become known as the vehicle for developing effective communication practices between people of different cultural backgrounds, in a culturally appropriate manner. “Cultural competence is much more than awareness of cultural differences, as it focuses on the capacity to improve outcomes by integrating culture into the delivery of services” (Universities Australia, 2011a, p.38).

The concept of CC was first developed in the United States in the late 1980s in response to an increasing diverse population and the growing need to increase access and provide appropriate health care and services to patients of different cultural backgrounds. Similarly, cultural safety, an associated concept of CC was introduced in New Zealand in 1992 to improve health services for the Maori population. CC is a relatively new concept in Australia and was first introduced in the health sector in the 2002 and more recently, in educational contexts in 2006 (Thomson 2005; Grote 2008).

Indigenous cultural competency can play an important role in building relationships, trust and cooperation between Indigenous communities and the researcher in meeting the new Indigenous research reforms. Cultural competency is about building relationships between persons from one or more different cultural backgrounds so that individuals and groups can work positively and effectively with one another, while acknowledging and respecting cultural differences. It is important to note here that ‘difference’ does not equal ‘deficit’ when we work and/or socialise with persons from other cultural backgrounds. It is about working together in such a way that persons or groups will feel culturally safe and secure when communicating with one another. In other words, cultural beliefs, values and traditions can be part of or incorporated in the interaction process with all parties knowing that cultural differences will be accepted and/or respected and, not be ridiculed in any way (Gower & Byrne, 2012).

There is no one definition of cultural competence. Definitions have evolved from the early work of Cross, Brazron, Dennis and Iaacs in 1989 to reflect cultural diversity, protocols, particular needs and interests of different cultures and, organisational settings. The more recent definitions of CC however, embrace the concepts and principles of Cross et al., as they have generic application across multicultural settings. Cross et al., defined CC as, “a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross cultural situations” (Cross et al., 1989, p.1). The reference to ‘culture’ encompasses language, attitude, values, beliefs, customs, protocols, thoughts and actions while ‘competency’ refers to an individual’s or organisation’s ability to transform cultural understandings into behavioural practice that embrace cultural beliefs and differences

that are different to their own and, meeting the needs and aspirations of those who they are dealing or interacting with.

The Centre for Cultural Competence Australia (CCCA, n.d.), defined CC at an operational level as, “the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services, thereby producing better outcomes” (Centre for Cultural Competence Australia, n.d.).

Conceptualising CC

In an attempt to develop a conceptual framework for cultural competence, researchers in the United States examined existing models that measured training and/or the evaluation of cultural competency from the literature. They found reference to 18 models that shared common elements relating to cognitive components of ‘awareness and knowledge acquisition’ and behavioural components of ‘skills development, such as being able to engage culturally diverse clients in a genuine accepting manner’ (Balcazar, Balcazar-Suarez, Taylor-Ritzler, 2009, p. 1154). The researchers found limited accounts of validated measures of cultural competency, however. The most common elements that were found in literature relating to psychology, health and social science were cultural awareness, knowledge and skills. The authors also identified environmental and physical factors as being important in promoting cultural competence amongst practitioners and that these contextual factors related to organisational support for cultural competency (Balcazar et al, 2009, p. 1156). In developing a model that incorporated the findings from the literature, the researchers identified four components:

1. Critical awareness: Requires a personal reflection on biases towards others from another culture and an examination of one’s own personal position of privilege in society. The act of reflecting allows an examination of personal attitudes towards others, willingness to accept cultural differences and to consider the rights of others.
2. Cultural knowledge: Refers to the understanding of another culture in terms of history, associated values, beliefs and practices.

3. Skills development: Relates to effective communication and ability to demonstrate empathy in all types of interaction with those from another culture. This includes the inclusion of cultural beliefs, practices and aspirations of others in the planning of projects and/or services that involve those from different cultural backgrounds. This component requires effort and time as empathy relates to the ability of seeing through the eyes of another and being able to compare them to our own.
4. Practice and application: Refers to transforming the previous components into action in particular contexts. (Balcazar et al., 2009, p.1155).

In providing a conceptual framework for organisations to become culturally competent, the National Centre for Cultural Competence at the Georgetown University in the United States advocated that, “cultural competence requires that organisations have clear defined set of values and principles, and demonstrate behaviours, attitudes, policies and structures that enable them to work effectively cross culturally” (National Centre for Cultural Competence (NCCC) (n.d). Associated with this conceptual framework for organisations are five key elements of cultural competence:

1. Valuing diversity in a way that respects cultural differences and acknowledging that individuals and groups may have different needs,
2. Conducting regular self-assessment of the effectiveness of policies and procedures that support effective intercultural communication and introducing strategies to reduce cultural biases,
3. Managing cultural differences to optimise positive intercultural interaction between cultural groups,
4. Acquiring institutional cultural knowledge so that the cultural background of clients can be incorporated in the delivery and provision of services and,
5. Adapting to cultural diversity and cultural contexts for communities they serve so that cultural knowledge can be embedded to all policy statements and guide appropriate behaviours and service delivery (NCCC, 2006).

A Universities Australia report entitled *Best Practice Framework for Indigenous Cultural Competency in Australian universities* (2012a) revealed that there was no

current definition to describe Indigenous cultural competency or a pedagogical model for it. However, the following definition was provided for use in the Australian higher education context:

Student and staff knowledge and understanding of Indigenous Australian cultures, histories and contemporary realities and awareness of Indigenous protocols, combined with the proficiency to engage and work effectively in Indigenous contexts congruent to the expectations of Indigenous Australian peoples (Universities Australia, 2011, p.48).

So what major attributes will a culturally competent person possess? For the individual, it encompasses a number of elements. To begin with, knowing that one's own culture influences how attitudes, perceptions and behaviours are formed towards others, including those from different cultural backgrounds. A culturally competent person values and respects cultural differences, protocols and customs of particular cultures and demonstrates a willingness to learn more about cultural diversity and/or the cultural backgrounds of the people they are working with. An important attribute in the overall scheme of things is the development of skills and experiences that will enable effective communication between persons of different cultural backgrounds and the transformation of these understandings into culturally appropriate behavioural practice (Gower & Byrne, 2012).).

The following schema has been developed by Gower and Byrne (2012) to inform the process of transitioning awareness, knowledge and understanding of culture into behavioural practice. In this process, cultural competence is positioned to inform and guide practice and decisions to achieve positive outcomes and ultimately, make a difference when dealing with people from other cultures and in particular, Indigenous Australians.

An important understanding of this schema is that having knowledge, understanding and awareness of Indigenous culture alone does not necessarily translate to changes in professional practice. This process is guided by the four key components that make up cultural competency:

- **Cultural awareness**

Cultural Awareness training provides a general understanding of Indigenous culture, society and history. It encourages self-reflection and awareness of personal biases and tendency to stereotype. While there has been strong interest and demand for Aboriginal cultural awareness programs since the 1970s, it later became apparent that this type of training did not result in changes in attitude, behaviour and practice that were necessary for improving the delivery of services to Aboriginal people (Centre for Cultural Competence Australia, 2010; Thomson, 2005; Universities Australia, 2011a). Cultural awareness training alone, therefore does not provide the skills necessary for individuals to communicate in an effective and sensitive manner. As a result, there was limited or no change to behavioural or professional practice by practitioners and no improvement in the levels of interaction between Indigenous and non-Indigenous Australians. The shortcomings in cultural awareness training programs were also recognized in other countries such as the United States and New Zealand that introduced cultural competency and cultural safety training programs respectively to complement cultural awareness training (Grote, 2008; Thomson, 2005).

Cultural competency and cultural safety are discussed below. Cultural awareness is now considered to be the first phase in the journey of becoming culturally competent.

- **Cultural security**

A common definition of cultural security that is referred to in the literature is,

An environment that is spiritually, socially and emotionally safe, as well as physically safe for people; where there is no assault or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning together (Williams, 1999, p.213).

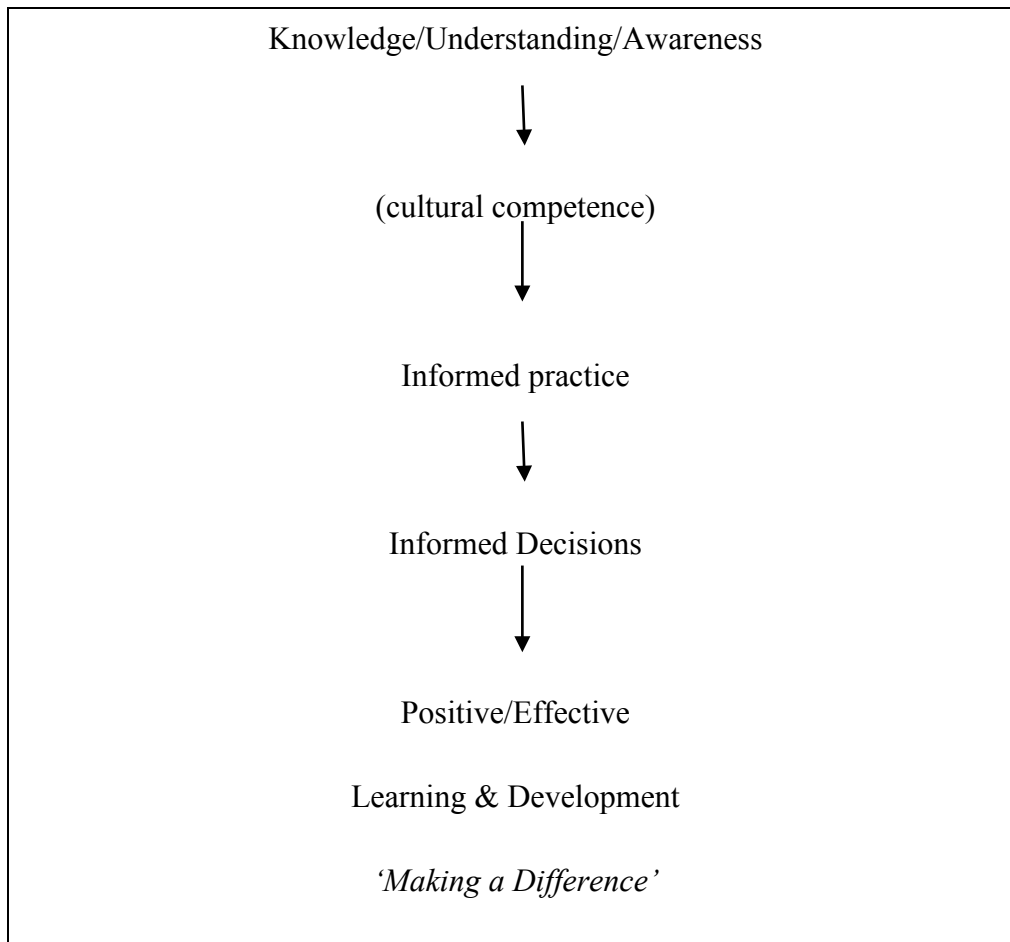


Figure 2.1 Cultural competence: Putting knowledge into practice

A key principle of cultural safety is the understanding one's own culture and how it may influence the way we think and behave towards others from different cultural backgrounds. It also focuses on building trust, engaging in respectful communication and being free of stereotypical views. Thomson (2005, p. 4) asserted that the main emphasis of this principle is the shift from 'attitude' to 'behaviour' among systems and individuals and contends that the concept of cultural security has been incorporated in the much broader concept of cultural safety.

- **Cultural safety**

Cultural safety has been defined as, “ the recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander peoples’ (Australian Health Ministers Advisory Council, 2004, p.7). This concept focuses on cultural sensitivity and equitable power balance, e.g., a practitioner's

reflection and recognition of impact of their own culture when working with people from other cultures,

- **Cultural Respect**

Cultural respect is the recognition and respect of the rights and traditions of Indigenous Australians (Grote, 2008, pp.11-12).

These four elements provide a means for students/practitioners to develop appropriate cultural understandings and skills that will lead to effective communication and interaction with Indigenous Australians and other cultural groups. It is important to note that the development of CC skills to become culturally competent is an on-going process and a life long journey (Weaver, 1999).

An Indigenous cultural competency framework has two main principles:

- (i) To interact & communicate effectively with Indigenous Australians.
- (ii) To respect and value cultural differences and diversity.

Cultural competency training

The benefits and importance of cultural competency is well supported in the literature and this is particularly noted in medical, educational and research contexts (Beach et al., 2005; Boutin-Foster, Foster & Konopasek, 2008; Harvard Catalyst 2010; Kirpalani, Bussey Jones, Katz & Genao, 2006; Pecukonis, Doyle & Bliss, 2008). Of particular note is the proliferation of cultural competency training programs that have been implemented by medical schools throughout the United States (US) in meeting course accreditation requirements. For example, by 2008, more than 90% of medical schools had integrated cultural competency training into the curriculum to meet the growing demands of an ever increasing national diverse population (Boutin-Foster, et al., 2008; Champaneria & Axtell, 2004; Chips, Simpson & Brysiewicz, 2008; Kirpalani, et al., 2006; Pecukonis, et al., 2008). Similarly, cultural competence or 'cultural security' training programs have become mandated in nursing courses in New Zealand as a result of introduced legislation (Thomson, 2005). Cultural competence training and/or education is also offered by health authorities in Australia and Canada to assist staff who work with patients from culturally and linguistically diverse (CALD) backgrounds. In addition, there are a growing number of Australian universities who have included cultural competency content across a number of courses (Grote, 2008; Department of

Health (n.d.[c]; Provincial Health Services Authority in BC (n.d.); Universities Australia, 2011a)

Although cultural competency training programs may vary in content, settings, emphasis and length of time, the aims are generally the same: to improve communication and trust between service providers and their clients/patients, to improve client/patient satisfaction, to increase self awareness of attitudes and biases that may exist towards other cultures (self reflection), to provide an understanding of sociocultural factors and how these may impact and/or influence relationships and the development of culturally sensitive care practices (Bouton-Foster et al., 2008; Kripalani et al., 2006; Thackrah & Thompson, 2013). Despite research studies supporting the benefits of cultural competency training in medical and health courses in the US, it has been problematic in establishing valid measures to assess how well practioners work in cultural diverse contexts. A major factor contributing to this is the inconsistency of current training programs, including the methods used and the duration of the course (Kripalani et al, 2006; Kumas-Tan, Beagan, Loppie, MacLeod & Frank (2007). The literature indicates that further research is required in order to develop standardised and validated measures to assess the impact of training programs on the development of knowledge, skills and attitudes by health practitioners and, patient or client outcomes. In addition, it is also acknowledged that not all cultural competency training will be effective in improving the skills and attitudes of health workers and other professionals who undertake such courses. Factors such as learner resistance and the inconsistency of training courses can inhibit effective outcomes (Boutin-Foster, et al., 2008; Kirpalani et al., 2006; Kumas-Tan et al., 2007). Research studies on the effectiveness of cultural competency training programs in New Zealand, Canada and Australia are also limited and therefore, highlights the need for increased efforts in outcomes based research in order to identify successful strategies and to continue improving intercultural communication and reducing any disparities that may exist or arise.

Conclusion

As foregrounded in both opening chapters, the landscape of Indigenous research practices in Australia is changing in response to poor research practices of the past and, as a result of concerns that have been raised by Indigenous communities and academics.

A number of research guidelines are now available to the research community, including the national guidelines developed by the NHMRC for the conduct of research involving humans, animals and the environment, including those that relate to Aboriginal and Torres Strait Islander people. Whilst these guidelines have addressed earlier concerns about inappropriate research practices, particularly to those involving Aboriginal and Torres Strait Islander people, Indigenous academics such as Moreton-Robinson, Nakata and Rigney have outlined the need for further reforms for Indigenous research. Although the three academics express multiple viewpoints, they all articulate the need to strengthen these guidelines to incorporate Indigenous knowledge in the research process. These discourses are likely to result in tensions between Western and Indigenous academics in debating changes to research methodologies, but an examination of issues arising in the research project that is the central case study of this thesis should provide a path to resolution through the provision of CC training.

CHAPTER THREE

METHODOLOGY

Introduction

As indicated in the literature, historically, researching in Indigenous contexts has not been culturally appropriate nor has it been regarded as being inclusive and/or beneficial to Indigenous participants and communities who have been involved in the research (Fredericks 2008; Greenhill & Dix, 2008; Nakata 2007a; Rigney 2006).

As a result of these experiences, many Indigenous people have become reluctant to support or participate in proposed research activities. Research to many Indigenous Australians is another form of dispossession because of the appropriation and custodianship of their knowledge by non-Indigenous researchers and institutions that are not accessible to them. The methods used by researchers who conduct research in Indigenous contexts should take account of the principles and values of Indigenous Australian culture and be informed by Indigenous interpretations of the advantages, potential to cause harm, and issues concerning intellectual property rights and confidentiality. Smith argued that, “Indigenous participants should essentially own the process, participant in the inquiry and dissemination of results” (1997, p.28).

The proliferation of research guidelines, including those by the NHMRC, have addressed many of the inappropriate research practices of the past, but many Indigenous communities and people are still wary of those practices and are reticent to support and/or participate in proposed research projects (Taylor & Ward 2001; Fredericks 2007, 2008; Greenhill & Dix 2008). Despite researchers supporting these guidelines and conducting their work in a manner that is consistent with the implementation of these guidelines, the literature strongly suggests the need for further discussion between the research community and those Indigenous Australians who are being researched with regards to what these guidelines mean and how they can be implemented to reflect best practice. In addition, Indigenous academics such as Moreton-Robinson (2000); Nakata (2007a, 2007b) and Rigney (2006) present views on how these guidelines should engage with Indigenous knowledge systems, cultural understandings, Indigenist research and Indigenous stand point theory. Although different positions have been presented by these writers, they clearly advocate reforms in research methodology relevant to Indigenous Australians. This chapter will outline the aims, scope and research methodology of the present study and make a personal statement about it.

Aim

The aim of the study is to provide an historical overview of research practice in Indigenous contexts; to highlight the concerns raised by Aboriginal and Torres Strait Islander people regarding culturally insensitive and inappropriate research practices, to examine previous and current national ethical research guidelines that relate to Aboriginal and Torres strait Islander people and assess their effectiveness against a research case study and lastly, explain how cultural competency can address research reforms as outlined by Indigenous academics such as Moreton-Robinson (2000); Nakata (2004, 2007a, 2007b, 2013) and Rigney (2006) and strengthen the NHMRC's national research guidelines.

The research questions

Question One: What constitutes an ethical approach to Indigenous research utilising the case study?

The literature indicates that 'real' concerns have been expressed by Indigenous Australian academics and Indigenous communities that past and some current research practices have been carried out in an unethical and culturally insensitive manner (see Hindmarsh Island incident in chapter 2). Question one of this thesis examines this and states, "What constitutes an ethical approach to Indigenous research (from an historical perspective)." The NHMRC has become the recognised national body that has developed ethical guidelines for the conduct of research involving humans and animals. It has also developed a set of guidelines specifically for research involving Aboriginal and Torres Strait Islander people.

Question 2: To what extent were the ethical guidelines provided by NHMRC adequate at the time of the CHL study and how effective are the current NHMRC guidelines against the same study?

A unique case study has been chosen to examine and assess the adequacy of both sets of guidelines. This particular case study was chosen because a number of ethical and operational issues presented, despite careful planning by the research team and compliance to the research guidelines.

Question 3: "To what extent does the proliferation of ethics guidelines or processes assist in underpinning ethical research or foster inefficiency?"

Research that involves multiple industry partners and sites will be subject to the research governance of those institutions and this may require the submission of more

than two ethical review or clearance applications. The case study chosen for this research study involved multiple industry partners and sites and an assessment will be made against the outcomes that were experienced with this particular study

Question 4: To what extent is cultural competency a significant component of Indigenous research?

With the number of research guidelines that are available to the research community and research ethics committees, inappropriate research practices should now be eliminated and measures put in place to reduce any opportunities to for any breaches of ethics (AIATSIS 2012; NHMRC, 2007). However, as the NHMRC have acknowledged, there will always be potential risks in research involving humans despite all good intentions, careful planning and practice (NHMRC, 2007, p.3). The NHMRC contends that at times, ‘technical errors or ethical insensitivity, neglect or disregard,’ may arise and hence, all researchers need to be made aware of these possible outcomes and strategies to prevent them from happening (NHMRC, 2007, p.3). The literature identifies issues of ‘cultural insensitivity, neglect or disregard’ that may arise in a research study and the thesis will seek to answer the question.

Question 5: To what extent were ethical and operational issues evident in the case study?

The study will refer to the chosen research case study to ascertain whether or not the ethical guidelines of the time were adhered to by researchers who were involved in the study and what research issues did arise at the cultural and technical levels. The fifth research question addresses this and will also examine ethical issues relating to third party participants who were involved in the research case study. Third party participants included participants who were either directly or indirectly involved in the research study, for example, principals and teachers. An examination of whether the guidelines of the day were adequate in addressing these issues will also be made.

By addressing these five research questions the thesis will reveal the need to develop a framework for a pedagogy that links ethics and cultural competency together in strengthening and improving best practice in research involving Indigenous Australians.

Research question six states, “To what extent is a new framework needed to address the issues that arose in the research study?” Based on the outcomes of the

previous five questions, the sixth question addresses the need for a new set of research guidelines.

Methodology

The methodology used in developing this research thesis is a combination of a documentary and qualitative study. The documentary study will provide an overview of the conduct of research in Indigenous Australian contexts by examining past and present practices, it will discuss the proliferation of research guidelines, including those specifically developed for Indigenous contexts, assess the strength of these guidelines in relation to their implementation and relationship with other guidelines, assess whether the guidelines were adequate in meeting Indigenous protocols and needs in research and highlight good and poor ethical research practices based on a case study involving Indigenous subjects.

The documentary study will also examine journals that were kept by the research team who were involved in a three-year longitudinal study. The qualitative component of the methodology will be based on interviews with the researchers who were involved in longitudinal research study and will examine whether the researchers adhered to current research guidelines of the day or if they added value to these guidelines.

Research methodology using critical perspective & case study theory

The framework to examine this research study is critical theory as outlined in the literature review (see chapter two). As the literature reveals, critical theory is informed by the principles of social justice and social enquiry that distinguishes between, 'what is' and 'what should be' (Giroux, 1983, p. 8). It is associated with Western Marxist doctrine, with human emancipation becoming its major aim in contesting 'hegemony' over those who are considered to be 'subservient' to the dominant culture and how the working class can be empowered through a 'counter-hegemonic strategy' (Bronner, 2011, pp. 2 & 22). These key principles provide a means to develop a new framework in Indigenous research methodology that will assist Indigenous communities, the participants and the research community to address any fears that may remain regarding research practices of the past. Secondly, the framework will provide a process whereby all those who are involved in research can confidently participate in the research activity

knowing one another's position regarding ownership, control, mutual benefit, having a shared commitment and respecting these understandings.

Tripp (1992) stated that the key understandings of critical theory are 'people having equal access' and 'people being in cultural, economic and political control of their lives' and that these goals are achieved through 'emancipation', a process of empowering those who have been subjected to oppression and exploitation (p.13). Rigney (2006) referred to 'emancipation' in the development of his 'Indigenist research' methodology which is underpinned by 'self- determination, ownership over research and the liberation from neo-colonial understandings and principles which are applied in research methodologies. Partington (1998) argued that a critical perspective offers the most appropriate way to interpret research in Indigenous education settings, and therefore it is suited to examining the case study used in this thesis. Tripp's (1992) methodological principles of mutual partnerships, ownership and scope of the project, cultural values and protocols, the application of new knowledge and, the dissemination of findings to the participants are key factors in applying critical theory in research and these provide a good basis when discussing and analysing the case study that has been chosen for this thesis.

Scope

This thesis will draw on case study data from a major research project that was conducted by researchers from Edith Cowan University, *Teaching Indigenous students with conductive hearing loss in remote and urban schools in Western Australia* (hereafter, the CHL Project). The study, which ran from 2001-2003, was funded by an Australian Research Council SPIRT Grant and industry partners, the Department of Education, Western Australia; Catholic Education Office, Western Australia, and the Association of Independent Schools, Western Australia.

The project had three main aims:

- to investigate the consequences of conductive hearing loss among Indigenous students;
- to study the effectiveness of teacher strategies to improve learning outcomes of students affected by the disease;
- to determine the effectiveness of professional development of teachers working with Indigenous students.

The study therefore involved both educational and health issues, in particular the educational implications of the medical condition of otitis media. Further, one of the purposes of the study was to bring about pedagogic change in literacy teaching to improve educational outcomes for Indigenous students who suffer from CHL. This condition is very common among Aboriginal children and young adults with higher rates of occurrence of the disease among this group than any other group in Australia (Australian Indigenous Health Infonet, 2012, Australian Bureau of Statistics, 2006). CHL is caused by a bacterial or viral infection which causes fluids to seep from the ear and this condition is commonly referred to as ‘runny ear.’ Blockages can also occur in the middle ear and this is referred to as ‘glue ear’ (Australian Health Infonet, 2012). Left untreated, otitis media can result in varying degrees of hearing loss from acute to moderate as a result of scarring and/or perforation of the ear drum. The end result causes associated difficulties in learning among many school aged children. The disease occurs as a result of living in crowded homes, poor hygiene practices and living in poor conditions. (Australian Indigenous Health InfoNet, 2012). Surveys conducted by the Aboriginal and Torres Strait Islander Health Survey (NATSIHS) reported that one in eight Indigenous Australians had ear or hearing problems in 2004-2005 and one in 10 in 2008 (Australian Indigenous Health InfoNet, 2012). The CHL study therefore, is a very significant one, given the high incidence of the disease among Indigenous Australians and the subsequent impact of hearing loss in learning and communicating.

The selection of schools for the CHL study was restricted to three districts in Western Australia that were being targeted by the Commonwealth Government’s NIELNS. A total of 20 schools were initially chosen from the metropolitan and two regional locations upon the recommendations of the three education providers: Government, Catholic Education and Aboriginal Independent Schools in Western Australia. Four schools later withdrew from the study (see chapter 4). Researching from a distance and research involving Aboriginal communities can present both foreseen and unforeseen challenges and/or circumstances to researchers despite careful planning and engagement in practices which follow ethical guidelines and appropriate research methodologies. For example, many researchers may not be familiar with remote Aboriginal communities and associated factors such as health issues including immunisation against Hepatitis B, issues related to travel on poor roads and the political structures that may exist in some communities such as ‘gate keepers’ who

check external visitors and the purpose of their visit, including research projects. From a research process perspective, obtaining consent from participants who are distant is complicated. Organisations such as schools cannot disclose the names and addresses of students and their parents or care givers to researchers until they have agreed to participate in the research. So the organisations have to obtain consent on behalf of the researchers before they can make contact with the participants. This arrangement may cause delays and unforeseen ethical dilemmas as evident in the CHL case study. The CHL study involved classroom teachers, some of whom were reluctant to participate in the study, and one teacher agreed to participate on the condition that researchers could not observe the lesson. In the case of the latter, arrangements were made for this teacher to keep a diary of classroom interactions. Could these scenarios be anticipated and/or planned for? Whilst it may be problematic to foresee situations that could arise during a research project, it is important for researchers to be trained in how to best deal with such circumstances to ensure success of the study and importantly, to maintain a positive relationship between researchers and those involved in the study. It is equally important for those participating in the research study to be trained in the research process and strategies to assist participants in dealing with issues which may arise. The development of trust and strong relationships between researchers and participants are key principles and practices that will assist maximum participation, cooperation, intercultural understanding and the success of research projects. This particular case study has been chosen as it is rich in data to do with the issues under investigation in a number of areas including:

- ethics and protocols,
- good research practice in Indigenous contexts,
- issues relating to research in Indigenous health and education as this has implications for the research process, for example, multiple ethics clearances.

Yin (2003, p.13), defined a case study as, “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident.” Woodside (2010, p.1) provided a broader definition of case study research, defining it as, “an inquiry that focuses on describing, understanding, predicting and/or controlling the individual (i.e., process, animal, person, household, organisation, group, industry, culture, or nationality.” The fundamental feature of case study research therefore, is focussing the

research issues and/or inquiry on a particular person, group or organisation. The case study researcher places an enormous importance on obtaining data through observations, interpreting and explaining what they perceive and understanding and predicting notions of how and why the participants in the study react or respond to certain prompts that relate to the research study (Woodside, 2010).

Case study research can involve one particular case or may involve a number of case studies that relate to one particular inquiry (Woodside, 2010). The CHL research project has been chosen as a case study for the purpose of analysing the application of existing guidelines, protocols and statements of ethics regarding research into Indigenous issues. This case study represents typical research methodologies and practices for the conduct of research in Indigenous communities given the current available guidelines and protocols available to researchers and as such, fits in with Yin's (2003) single case study design he termed a 'representative' or 'typical' case (p.41). The CHL study also contains elements of Yin's other categories of single case study design, that being 'unique' and 'revelatory' because of the ethical principles outlined by the NHMRC and other organisations such as AIATSIS being in a transitional phase (2003).

Limitations of case studies:

The literature identifies 'subjective bias' and 'generalisation' as two major concerns or issues of case studies (Gerring, 2007; Iacono et al., 2009; Woodside, 2010). Woodside explained that subjective bias and generalisations can be overcome by developing a 'deep understanding' of the case study through experiences in a range of research methodologies across a number of time periods or intervals (2010, p.6). This is commonly known as 'triangulation' and in this case, it refers to: (1) direct observation and note taking by the researcher; (2) cross checking data and interpretations with relevant participants through interviews at particular time intervals and, (3) the analysis of written documentation by participants from one or more sites (Woodside, 2010). The CHL research team acknowledged the importance of triangulation as data were collected from a variety of sources during the course of the longitudinal study and this was achieved by the following: the recording journal entries of each fieldtrip, the cross checking of observation notes by members of the research team following each fieldtrip and, the discussion of data observations from each the three sites at regular reference committee meetings.

For a ‘one off’ research case study, Woodside (2010, p.13) indicates that, ‘ethnographic decision tree modelling,’ and ‘deep understanding’ become appropriate research tools as the researcher is typically looking for information to form predictions across a number of variables, rather than looking to influence outcomes in the research study.

Each case study presents its own uniqueness and therefore, is unlikely to be replicated elsewhere or be used to generalise to a population (Iacono et al., 2009). The CHL project is considered to be unique because of the transitional phase of the NHMRC's existing 1991 document on ethical principles in the conduct of research involving Indigenous people/communities and the revision of these guidelines, *Values and Ethics: Guidelines for the Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003).

Data collection:

The CHL research study that was conducted during 2001 – 2003 has been chosen as a case study for this thesis for several reasons:

1. the writer of this thesis was involved in the research study as a participant observer,
2. a number of ethical issues arose during the course of this particular project,
3. the longitudinal research study took place during the transitioning period of the 1991 and 2003 national guidelines for the ethical conduct in Aboriginal and Torres Strait Islander Health Research and,
4. the study allows this thesis to examine the extent to which these new guidelines address the issues that arose in the case study.

Ethical issues:

A number of ethical issues arose during the course of the CHL research project and these are discussed in greater detail in chapter five. In sum, the ethical issues involved the following:

- multiple ethical approvals were required and this caused delays and also impacted on the study,
- some signatories to consent forms were misinformed by a local third party acting on behalf of the research team,

- some teachers were happy to allow the research team to collect data without consent forms being received,
- missing consent forms, the use of passive consent by the research team and,
- a request to a member of the research team to breach confidentiality.

The Research team

The research team comprised of four academic staff members from the University. Their research profile, background and position on the CHL research project follows:

Project Leader:

This position was held by a non-Indigenous male academic with over 30 years lecturing experience in teacher education, including 20 years in Aboriginal Education. His experience in Aboriginal education and related issues extend to publishing and researching in this field. He completed a PhD in 1984 in Intercultural education and his subsequent research focused on effective schooling for Aboriginal students and examining their experiences in school.

Project Director:

This position was held by a female non-Indigenous academic who had recently completed her doctoral studies in Linguistics. She joined the University soon after the CHL Project had commenced as a research assistant and soon afterwards, was invited by the project leader to take on the role of project director. This appointment was supported by the other research team members as she had assumed these tasks and was very efficient and effective in carrying out such duties. Her previous experiences prior to engaging in the CHL Project included extensive work in language issues and Aboriginal students.

Research Team member:

This position was held by a non-Indigenous male academic with over 25 years lecturing experience in teacher education, including 5 in Aboriginal Education. He completed a PhD in 1988 and was a research team member examining the provision of quality education for Aboriginal students in Western Australian schools prior to the CHL project.

Research team member:

This was the position I held, an Indigenous male academic who at the time of the CHL study had 13 years lecturing experience in Aboriginal Education and Aboriginal studies. The CHL study was my first major research experience having recently completed a Master of Education degree in 1999. Prior to joining the University in 1988, I was employed as a primary school teacher and had taught for eight years in the Pilbara and Kimberley regions of Western Australia.

The participants

The participants included:

- 99 staff and 472 students in junior primary classes in 16 schools across three education districts,
- community members,
- educational administrators,
- health professionals associated with each school,
- CHL case study researchers (4), one Indigenous,
- CHL Project co-ordinators (2),
- research assistants,
- other field participants in the CHL project
- other key CHL stakeholders
- CHL project reference group members.

Data

The data sources for this investigation are:

1. Documents including:

- CHL case-study field notes,
- interview transcripts,
- letters and emails,
- minutes of meetings,
- submissions and applications,
- records of telephone conversations.

2. Interviews: Open ended interviews with:

- CHL researchers,

- project co-ordinators
- research assistants,
- other field participants in the CHL research process, e.g., staff from district education offices.

Data analysis

The data analysis process involved reading the various forms of data, extracting significant content, identifying themes, key trends and features, then categorising and prioritising the material for further analysis. The QSR NUDIST N6 software was used to assist in the process of data analysis. The following categories have been identified:

- the participants,
- data collection
- student status (e.g., at risk, literacy, hearing, speech)
- issues relating to consent:
 - access to participants,
 - issues to do with cross cultural communication,
 - issues to do with confidentiality.
- methodological issues (collection & data analysis),
- the research team
 - reporting findings to participants, to other stakeholders,
 - issues to do with distribution of responsibilities (i.e. whose job is it).
 - contribution to quality research.

Validity of data collected and its subsequent triangulation are important aspects of the research process (Janesick, 2000). The CHL Project primarily employed “respondent validation” (Silverman, 2000, p. 177), where the researcher would confirm observations and interpretations with the classroom teacher. The multiple sources of data available for the proposed study enable comparison across different sources. The model adopted is informed by what Silverman (2000) terms the ‘constant comparative method’ (p. 179).

Coding method:

Nudist 6 coding methodology was used to code responses from the researchers. The coding categories and sub titles were developed as a result of analysing the research journals provided by the researchers and through interviews with the researchers.

N6 Coding (CHL Research Process)**1. Status code:**

1. Education Districts (1.metropolitan; 2 rural; 3 remote)
2. Education system (1.Government; 2 Catholic; 3 Independent)
3. Participants (1 parent 2. child 3. community member 4. teacher 5. principal 6. support staff 7. District Office)
4. Gender (1. female 2. male)
5. Health professionals

2. Data

1. Field journals recorded by ECU research team (1.AG 2.GP 3.JG)
2. Interviews (1.AG 2.GP 3.JG)
3. Correspondence from research team to participants

3. Students (1. at risk 2.literacy 3. hearing 4. speech)**4. Issues surrounding ethics approval**

1. University
2. WAAHIEC (WA Health Information Ethics committee)
3. AMS's
4. Government Health
5. Passive consent

5. Issues relating to consent

1. Parent/community member (1.focus students;2 non focus students)
2. Principal
3. Teachers
4. Support staff
5. Delays

6. Collection
7. Explanation/understanding
8. Existing student records (1. health 2. behaviour 3. attendance)
9. Withdrawal of consent

6. Research team & others

1. Relationships between research members
2. Relationships between researcher & school
3. Gender issues (researcher & participant).
4. School tensions/incidents
5. Access to medical records
6. Inappropriate use of data
7. Feedback & outcomes
8. Other CHL researchers
9. Research team meetings

7. Methodological issues

1. Collection of data
2. Analysis of data
3. Inter-agency CHL programs
4. Copyright

8. Contribution to Quality Research

1. Ethical guidelines

Figure 3.1 Coding categories for CHL case study

Conclusion:

The methodology used for this research study is a combination of a documentary and qualitative study. The review of literature will provide an overview of the history and subsequent developments in Indigenous research practice. A unique case study has been chosen to collect information on how this particular research project proceeded in terms of ethical guidelines and practices that were in place between 2001 and 2003. This case study was also used to assess its performance against the current ethical guidelines that were revised and implemented following the completion of the study. The data collected

from the case study provided the basis for an examination of the implications of the project in relation to ethics.

Personal Statement

I was involved in the CHL research study as a participant observer and was the only Indigenous person on the research team. The CHL study was my first experience in a major research study having recently completed a Masters of Education. My involvement in this study provided me with the opportunity to gain experience in a major research project by actively participating in all aspects of the research process and being mentored by experienced researchers. I was consulted by the research team on all Indigenous matters that related to the project, including ethical practice and community participation. I was also given the role of consulting with parents, caregivers and the Aboriginal community to reconfirm their ongoing consent for the project and understanding of the project and importantly, what they were consenting to and their rights to continue or withdraw from the project at any time.

It is important to note however, the findings made in the literature review, that many of the critics would not endorse a majority membership of non-Indigenous researchers as this position reinforces non Indigenous control over the research process (Smith 1999; Fredericks 2007; Greenhill & Dix 2008; Social Policy Centre 2008). This practice can also be considered to be ‘tokenistic’ or used to give a project Aboriginal legitimacy rather than control over the research process. If research involving Indigenous communities is to reflect Indigenous ownership and control over the research process, then it is important that Indigenous researchers and communities to play a significant role in this process. This outcome is becoming more and more possible as the number of Indigenous students in Australia with doctoral degrees has increased from 55 in 2000 to 400 in 2014 (Bock, 2014). The research team through the project leader and project director sought Indigenous input and participation in the research through membership on the reference group, extending invitations to Aboriginal Education Workers or Aboriginal Teacher Assistants to attend workshops with teachers who were involved in the study and by consulting with Aboriginal leaders or spokespersons, including community members throughout the CHL Project. The research team kept journals of each field trip and daily journal entries would often be

discussed amongst the team after each day and more formally in reference group meetings.

Given the historical experience of research experiences amongst Indigenous people and communities, I strongly believed that the CHL research team conducted the project in a manner contrary to past research practices and one that demonstrated cultural competence and sound ethical principles. As a researcher and Indigenous person, I give my personal commitment to ensure that Indigenous research is carried out in such a manner that the process is founded on the basis of trust, mutual benefit, strong relationships and effective communication, acknowledges all current ethical guidelines, Indigenous protocols and Indigenous participation and incorporates research reforms which have been advocated by Indigenous academics such as Rigney, Moreton-Robinson and Nakata.

CHAPTER FOUR

THE CASE STUDY: WHAT WAS PLANNED?

Introduction:

This thesis will draw on case study data from a complex research project that was conducted by researchers from Edith Cowan University, *Teaching Indigenous students with conductive hearing loss in remote and urban schools in Western Australia*. The study, which ran during the years 2001-2003, was funded by an Australian Research Council SPIRT Grant and three industry partners in Western Australia, the Department of Education; Catholic Education Office, and the Association of Independent Schools.

As this case study is based on another research project, it is necessary to provide a descriptive account of the chosen study itself as case study research focuses on four key elements: description, explanation, prediction and/or controlling a person, group, culture process or industry (see chapter two). In sum, the description explores the who, what, when, how and why questions; the explanation finds answers to the why questions; the prediction is the forecasting of long and short term events/situations and control, the possible ways in which attitudes, behaviors and events may be influenced in any given case.

This case study was unique in many ways as it involved researching from a distance, the involvement of a number of industry partners at both state and regional levels and a number of Aboriginal communities from three geographical locations. It also involved a number of schools from three education providers and a significant number of Aboriginal students who were affected by otitis media or conductive hearing loss. Although the study involved Aboriginal students who had varying degrees of hearing loss, the study was primarily concerned with evaluating the effectiveness of a number of teaching strategies that were designed to improve learning outcomes among students. In addition, the study also involved evaluating the effectiveness of professional development of teachers of students who were affected by the disease. Like all research projects, there are necessary processes that need to be undertaken and finalised before any research activities can take place. This usually follows the outcome of a successful research application to a funding agency to carry out research in an

identified or specified field of study. The initial task of any research project is to gain approval to carry out the research activity and this usually involves submitting a research ethics application to a university's research ethics committee or an ethics committee that is located in an organisation, department or agency.

All research projects will require careful planning by researchers throughout the entire research process to eliminate any possible risks to the participants and the project, to be prepared for anticipated and unanticipated events, to ensure compliance to the approved ethic guidelines and to meet project objectives and deadlines. Most funded research projects are required to meet an established or an agreed completion date and are also subject to reporting intervals to the funding agency to monitor progress and outcomes during the research activity. For example, ARC provided funding to the CHL Project for a two year period and requested the submission of an interim report after the first 12 months of the study and a final report when the project was completed after two years (SPIRT Grant Application, 2001, p.1).

As indicated above, the CHL research study involved multiple agencies and researching from a distance and this required careful planning by the research team. For example, schools within the three identified regions of the state had to be chosen, school principals, teachers and parents or caregivers had to be contacted to confirm their participation in the study, an appropriate standardised test for Pre-primary to Year three Aboriginal students had to be selected and the preparation of field trips and the forming of a research reference group were among some initial tasks that had to be planned for.

This chapter discusses what was planned by the research team regarding the process for gaining ethics approval to conduct the CHL research longitudinal study. The chapter will also reflect on the university's application and approval process for gaining research ethics using the NHMRC's guidelines that applied at the time of the CHL study and will determine how useful they were during the research process.

The Research Application:

A Strategic Partnership with Industry, Research and Training Scheme (SPIRT) research application entitled, "Teaching Indigenous Students with conductive hearing loss in remote and urban schools in Western Australia," was drafted by the research team leader and submitted by the University on 3 May 2000 to Australian Research Council. The application followed discussions between the research team leader and the three educational providers in WA: the Education Department, Catholic Education

Commission and Independent Aboriginal Community Schools who identified the project as a priority as at least 70% of Aboriginal students were affected by CHL, particularly in remote schools and that the disease was a major factor affecting their school experiences and success (Partington, 2000). Furthermore, Partington asserted in the application that, “little research has been conducted into effective classroom strategies to combat the disease” and that this cross-provider and cross-sectoral collaboration would identify ‘effective (literacy teaching) strategies’ and ‘appropriate classroom social contexts’ to assist Pre-primary to Year three students succeed at school (2000, p. 2). The application was endorsed in writing by senior representatives from each of the three educational providers and by the Director from the Office of Research Services at Edith Cowan University.

The research application to the ARC was also timely as in March 2000, the Commonwealth Government launched the National Indigenous English Literacy and Numeracy Strategy (NIELNS), making a strong commitment to improving literacy and numeracy standards among Indigenous students. The NIELN strategy addressed six key elements, one of which was, “effectively addressing the hearing and other health problems that undermine a large proportion of Indigenous students” (Watson, 2003, p.6). Although the research proposal to the ARC was unrelated to the NIELN strategy, the subject of hearing loss and the subsequent impact on learning among Indigenous students was becoming a national focus with important significance.

In November 2000, the university received confirmation from ARC that the CHL application had been successful; however, the requested level of funding had been significantly reduced which resulted in one of the four objectives, which concerned the study of the benefits of involving community members in the work with children being revised to how schools were planning to use parents/caregivers in the program and secondly, their understanding of purpose and processes of the program (Partington, 2004).

University Ethics approval process

Research involving humans and animals requires approval from research ethics committees prior to the commencement of the research activity. Ethics committees operate in universities and also in a number of government and non-government departments and agencies for the purpose of approving research applications and the

research activities and the methodology that is associated with the project. This includes the wording of consent forms, questionnaires or surveys and how they will be administered and/or used in the data collecting process. Ethics Committees are also responsible for monitoring research activities via interim and final research activity reports and for approving any variations that may be requested to the original ethics application.

The National Health & Medical Research Council (NHMRC) guidelines are used to assess all proposed research activities involving animals and human beings. The major purpose of these guidelines is to protect the welfare and rights of all those who are participants in research. For the purpose of the CHL research project, the University's ethics application form reinforces this condition by stating that, "all researchers undertaking projects involving human subjects are required to comply with the NHMRC Statement on Ethical Conduct in Research Involving Humans" (ECU, 2000, P. 1). The university has also established a code of conduct for research practice (ECU, 2002). This document outlines minimal acceptable standards in research practice and ethical conduct expected of staff and students (ECU, 2003, p.3).

The Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS), has also developed a set of research guidelines for the conduct of research concerning Indigenous Australian subjects. These guiding principles are extensive and complement the NHMRC's guidelines and are also useful for researchers when drafting ethics applications and they offer valuable guidance during the research process. Other organisations have also developed their own ethics guidelines and application forms for research that may be conducted under their jurisdiction.

Ethics approval to conduct research is usually granted by one ethics committee, but there may be circumstances when additional ethical approvals will be required and this is particularly so when the research study involves industry partners, health organisations and Aboriginal and Torres Strait Islander communities. When ethics approval was granted for the CHL project to commence, the University's Ethics Committee did not advise that further ethics approvals would be required

The Ethics application:

An ethics application for ethics approval for the research project, “Teaching students with conductive hearing loss in remote and urban schools in Western Australia,” was submitted to Edith Cowan University’s Human Ethics Research Committee on 21 November 2000 and the submission was approved by this Committee on 19 December 2000 (Approval 00-205). The ethics approval included approval to access medical records of participating students’ ear health records; permission to approach parents for their children to participate in ear health screening by health professionals; permission to contact other targeted participants who are involved in the study, for example, principals, teachers and Aboriginal and Torres Strait Islander Education Officers or their equivalent, and consultation with relevant members of the Indigenous community, including health service providers. (EDU, 2000). The ethics application form and approval process also required the applicant to provide details of the proposed research activities including a copy of any questionnaires or interview schedule that were to be used in the collection of data and the confidentiality of records including storage, access and the destruction of materials after the study is completed. The applicant also had to confirm that the NHMRC’s Ethical Conduct in Research guidelines had been read and, following this, respond to a number of questions relating to possible ethical issues that may involve the research activity. For example, whether or not information would be withheld from participants, if participants were to be remunerated, if audio-visual recordings would be made, if any of the research activities would result in participants feeling uncomfortable or stressed in anyway and the listing of any potential risks to participants and how these would be managed if they occurred. (ECU, 2000). The application required the applicant to indicate whether the research study involved children and Aboriginal and Torres Strait Islander people. If the latter, the applicant was required to address the NHMRC’s supplementary guidelines entitled, “*Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*” (1991), that related to Aboriginal and Torres Strait Islander people. This document identified three major areas that were considered to be important in related research activities: consultation, community involvement and ownership; and the publication of data.

In relation to Indigenous participants, the ethics research application identified pre -primary to Year Three Indigenous students, Aboriginal and Islander Education Officers in schools and Indigenous community members as research subjects and that ‘community consultation’ would precede the selection and testing of students (ECU, 2000). The application detailed that, “approaches to parents and community members will be made orally through an Indigenous researcher, a research assistant or a school AIEO or education district officer” (ECU, 2000, Subject Group section). The development of the CHL project involved extensive consultation with members of the Indigenous community and health service providers (A. Galloway, personal communication, May 05, 2003.). The project initially targeted Indigenous students from twenty schools that were located in three diverse regions of the state and therefore, liaison and consultation with parents and community members about the project was planned throughout all stages of the research process. In order to gain access to medical records that would identify students who were suffering from CHL in each of the participating schools, the research team were required to consult with the school nurse or with local Aboriginal Medical Service personnel. It was anticipated that ear health records would be available for the majority of students who were going to be involved in the CHL research study.

The CHL project addressed ‘community involvement’ in both the ARC research funding application and the University ethics application. One of the four aims listed in the ARC application stated, “to study the benefits of involving Indigenous community members in the work with children” (ARC, 2000, p.1) while the ethics application lists a research question as, “What are perceived to be the benefits of community participation in the process of change?” (ECU, 2000, Research Question section). As stated above, however, as a result of lower ARC funding levels, the aim relating to community participation was modified to focus on, “ the extent to which schools were seeking to involve caregivers in the program and how cognisant caregivers were of the purpose and processes of the program” (ECU, 2002, p. 8).

In approving the ethics application, the University’s Ethics Committee, at this time, did not indicate that additional or separate medical ethical clearance(s) would be required.

Consent forms:

As part of obtaining ethical clearance from the University, consent forms to be used in the study by principals, teachers, students, parents and care givers had to be submitted for approval with the application. The information provided in each of the consent forms included a brief outline of the research project, data collection methods to be used, confidentiality assurance of the data collected, how the data would be used during and after the research process, the choice to participate in the research project and the option to withdraw at any time, contact details of researchers involved in the project and the section to be completed by those agreeing to participate in the research. The research team were careful in choosing appropriate wording used in these consent forms, especially in drafting the consent forms for parents and caregivers as it was likely that for some parents English would be second or third language, or they may speak and understand very little English at all (See appendix B).

Participants involved in the study:

The CHL research project involved a number of persons who represented stakeholder groups from education and health as well as research staff from the University. Health sector representation included the WA Health Department and Aboriginal Medical Services from the areas where the project was being conducted. Education sector representation included senior staff from the Aboriginal education branches of the three education providers in Western Australia, district education staff, school principals, school administration staff, classroom teachers and students in the target age group in each of the schools in the study.

The research team

The composition of the research team remained fairly consistent throughout the three year longitudinal research study (See also chapter three for research profile of each member) with the exception of the resignation of two representatives from one of the education providers in the first six months. The CHL research team consisted of five University staff members who held the following positions: project leader, project director (appointed 07/08/02), and three research assistants. The project director had previously held the position of research assistant and research associate in the CHL project. The number of research assistants was reduced to two on 21/05/02 following the resignation of a staff member (CHL Minutes, 05/06/02).

Members of the CHL research team met on a regular basis, particularly the project leader and project director. These two senior members of the research team met frequently to discuss on going items such as the drafting of correspondence to various agencies, meeting with each of the education providers and health agencies on a needs basis, responding to information requested from members of the CHL committee and schools involved in the Project. In addition, the project manager was heavily involved in contacting principals to arrange professional development (PD) and data collecting visits in each of the project schools.

Research committee

The CHL Research Committee comprised of members from the research team and one or two representatives from each of the education providers, Aboriginal Medical Services, Health Department, and a Professor of Health and an education lecturer from the University. The education lecturer was involved in developing a CHL unit in the teacher education course. CHL committee meetings were held monthly and these were usually well attended by members of the research team and the external members representing each of the stakeholders who were linked to the project. Formal minutes were kept throughout the research period. The main purpose of the CHL committee meetings was to monitor the progress of the project and report to stakeholders. A typical CHL meeting agenda covered matters such as reporting on visits made by the research team to different areas, financial statements, the development of resources, and, when relevant, attendance at conferences to present papers about the research findings.

Conductive Hearing Loss: Steps in Research

Planning each step in the CHL project involved members of the research team and consultation with the research committee. Following these discussions and planning sessions, the CHL research manager mapped out the details of each step or stage of the CHL project (see figure 4.1)

A. The Initial steps included:

1. Consultation with agencies: This included the industry partners, local health professionals and schools involved in the project.
2. Development of measures of student attainment: It was proposed that a portfolio of student's work be gathered so that it could be compared with other mitigating

factors such as: attendance, level of achievement, behaviour, literacy teaching and learning experiences, the quality of oral language and written literacy skills being provided by the classroom teacher, teacher awareness of CHL and its impact on learning, the level of interaction between teacher and Indigenous students, the physical environment of the school and provision of sound field systems or amplified sound equipment, the level of school and community links and access to health services.

3. Develop a brochure: The purpose of the brochure was to provide information about the project to the participants, industry partners and other interested parties.
4. Develop a web page: This was to store transcribed data in a secure site on the University's home page.
5. Select and appoint staff: In addition to the research team, additional staff were identified to assist with the project and these included a speech pathologist, an IT expert and the selection of members for the research committee.

B. Liaison

1. Liaison with NIELNS steering committee to cross check between projects and/or programs being offered in Western Australia, especially in the three regional areas that the CHL project was operating in.
2. Liaison with PD person from NIELNS on PD for new teachers. This was an important aspect of the CHL project.
3. Liaison with District Education offices. This was important in obtaining information about each of the schools in each of the regions and the type of resources and support that was being provided to the schools from district office. For example, NIELNS funding was allocated to schools from district education offices and planned meetings provided opportunities to discuss other CHL programs operating in schools and any non-confidential matters that may arise during the research study such as accessing sound field systems for schools (A. Galloway, personal communication, March 26, 2003).
4. Liaison with Health Department. Discussions with the WA Health Department and local Aboriginal Medical Services in each of the three regions were necessary for the CHL study to progress. This became more apparent in the

second year of the study when organisational support for the project was required (see chapter five for further details).

- C. Selection of schools: The process for the selection of schools to be involved in the CHL project is discussed further in this chapter.
- D. Briefings: Regular briefings meetings with stakeholders and teachers who were involved in the project were planned throughout the research study as it was necessary to discuss requirements and expectations of the project and secondly, provide non-confidential information as required.
- E. Initial data collection.
 - 1. Ear testing: The CHL study required the identification of Indigenous students who were suffering from CHL and this was to be obtained by accessing ear health records from local medical authorities or being given a list of names from a health professional. If no student records were available, arrangements would be made for qualified health personnel to conduct ear testing with students.
 - 2. Measurement of achievement: A suitable standardised achievement test that was considered to be culturally appropriate to use with Pre Primary to Year three Indigenous students had to be selected. The selection of this test is discussed later in this chapter. In addition, the research team had to identify other variables that could impact on the educational success for students with CHL. These have been indicated in A.2 above, for example, quality of literacy teaching and teacher awareness of CHL among their students.
 - 3. Attendance and behaviour: One of the key aims of the project was to examine the relationship between CHL and school related variables including behaviour, attendance and literacy achievement. Accessing attendance records and teacher feedback on student achievement and behaviour formed the basis of data collection for this purpose.
 - 4. Language development: This was another key aim of the project as the researchers wanted to assess the effectiveness of a number of literacy and numeracy strategies with students who have CHL. Professional development sessions were planned for teachers in each of the three districts to demonstrate these strategies so that they could be

implemented in classroom learning activities and later observed by the research team.

5. Professional Development: Professional development formed an important aspect of the CHL project as these sessions were designed to provide teachers with methods for identifying students with CHL and to outline a number of effective strategies for teachers to incorporate in their classroom learning activities
6. Classroom observation. A number of classroom visits to each participating school by members of the research team was planned to observe the effectiveness of the teaching strategies that were identified for the project. The classroom visits also provided opportunities for the research team to discuss related matters with the classroom teacher and community members.
7. Further data collection with students. Up to three classroom visits were planned for all schools that were involved in the project over a two year period (A. Galloway, personal communication, 2001).

Flow Chart of Conductive Hearing Loss Project:

In addition to planning the steps in the CHL research process, the Research Manager developed a flow chart of the CHL Project (see figure 4.2). In brief, the flow chart identified the following key descriptors:

1. Obtaining ethics clearance from parents, teachers and students.
2. Checking ear health records of students and consulting with health professionals.
3. Gather data on achievement, attendance and behaviour of students.
4. Provide professional development for teachers on strategies to improve language and literacy performance of students with CHL.

The following points relate to on-going tasks and/or activities during the CHL research process:

Conductive Hearing Loss Steps in Research

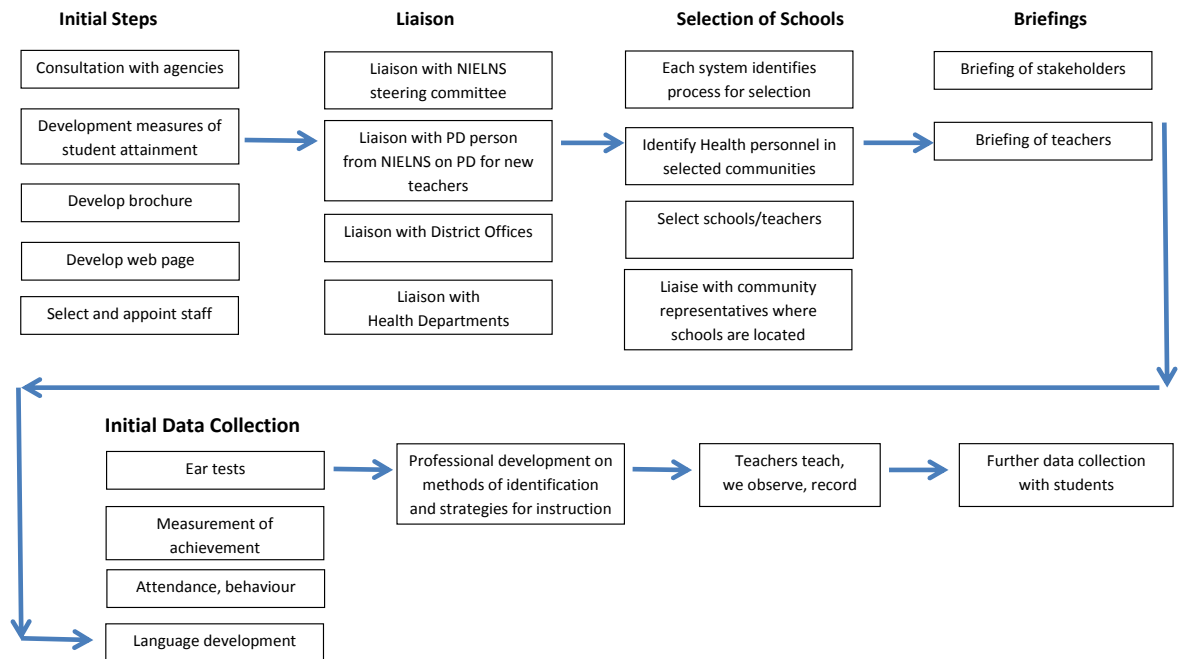


Figure 4.1 Conductive Hearing Loss: Steps in research

5. Monitoring the implementation of strategies through classroom observations, audio and videotaping of lessons and interviews with teachers and students.
6. Gathering further data on achievement, attendance and behaviour of students.
7. Provide feedback to teachers on the effectiveness of the implemented strategies and if required, revise instruction and/or use alternative strategies (A. Galloway, personal communication, May 05, 2001).

School Selection process

The selection process for schools to participate in the CHL research project involved representatives from the three educational providers, school principals and members of the research team. The selection of schools was restricted to three districts in Western Australia which were being targeted by the NIELN strategy and therefore the CHL research project was restricted to choosing schools from these districts. A list of recommended schools characterised by high Aboriginal enrolments from metropolitan, rural & remote locations was supplied by each educational provider to the

research team. Initially, the CHL Project targeted 20 schools, six from the metropolitan region and, seven from each of the two regional areas. The research team leader contacted each of the District Directors in the three districts to inform them of the CHL research project and the level of commitment and expectations of teachers that was required during the research process. The research team leader then contacted principals from each of the recommended schools by letter and followed this with a telephone call, inviting their participation in the CHL project. Information about the research project was provided with the letter and the commitment expected of the school during the research period was explained. The research team then made arrangements to visit each of the schools that expressed interest in being involved in the project to follow up the initial contact and to meet the principals and staff who would be involved in the project.

Flow Chart of Conductive Hearing Loss Project

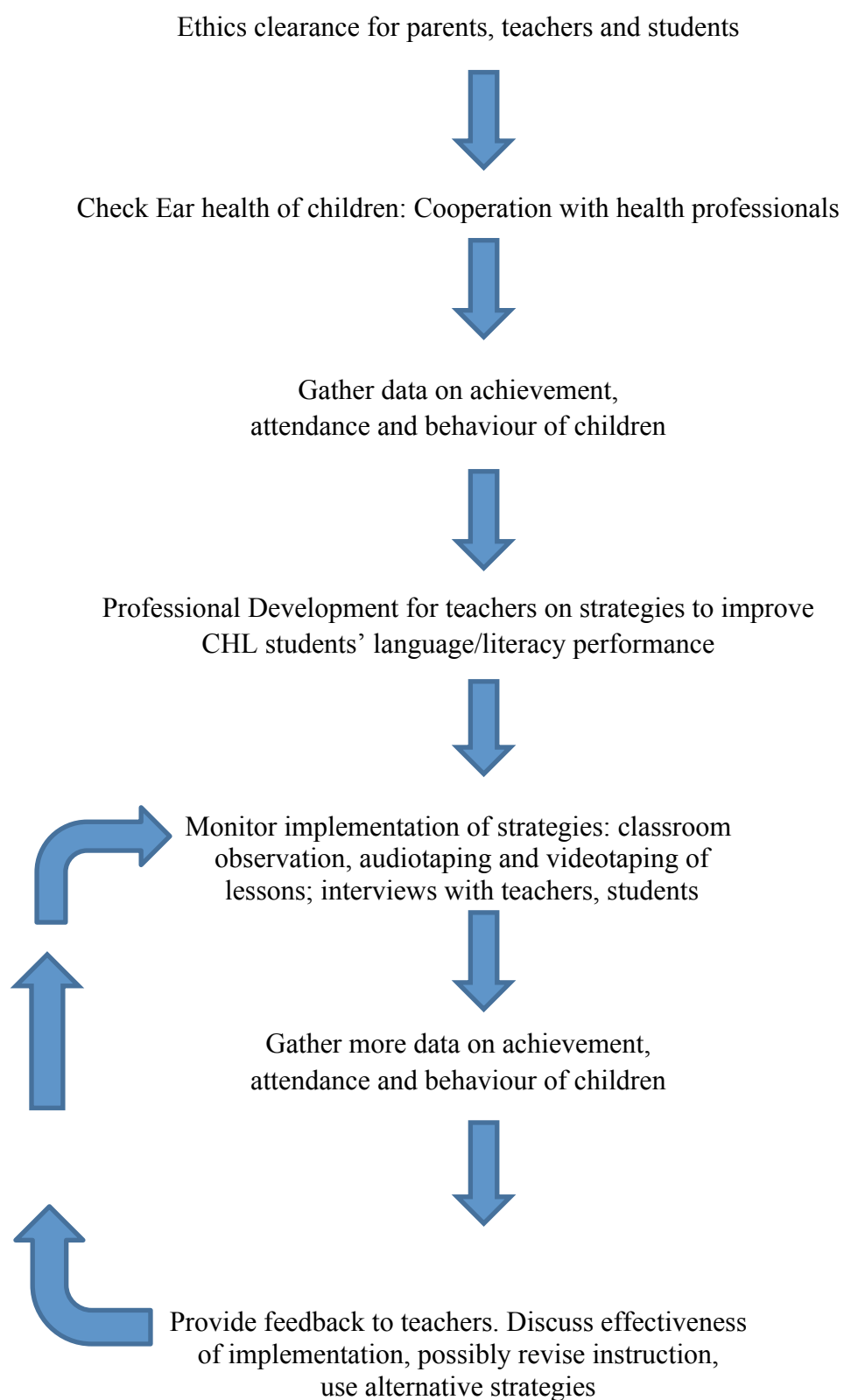


Figure 4.2 Flow chart of conductive hearing loss project

The CHL project leader was keen to include a selection of schools from one particular district as schools in this region had very high Aboriginal enrolment numbers and it was likely that there would be a high incidence of CHL among the children. Although a group of schools in the area agreed to participate, ultimately they could not take part. One of the educational providers allocated funding through the district education office for another CHL project and the same schools were selected. The schools appeared to believe that this second project was a part of the initial approach made to them. The district education office project was designed to carry out acoustic testing and monitoring, and according to the research team leader, this could have influenced the findings of the teaching strategies being examined. Another compelling factor in the decision not to choose schools from this district was the late arrival of the wet season early in 2002 and this would have resulted in delays in accessing some of the targeted remote schools (CHL Minutes, 06/02/02).

Selection of schools commenced in January 2001 and continued through to the end of that year. The research team leader decided to choose schools from one metropolitan district to engage in the CHL project during 2001 while schools in two regional districts would commence in 2002. By November 2001, two government schools were engaged in assessment while ethics clearances were outstanding in three other schools: two independent and one government school. A government school negotiated to commence in the project in 2002, while a catholic school was to be approached to commence in the same year. At the same time, five schools from one of the identified regional districts for the study – two government and three catholic - had confirmed their participation in the project in 2002. Two independent Aboriginal schools were also being approached. Schools in the second regional district had been identified at this time; however, none had been approached to participate in the project (A. Galloway, personal communication, November 11, 2001).

The research team commenced contact with schools in both regional districts in February and initially contacted school principals to request a CHL presentation to their Aboriginal Student Support and Parent Awareness (ASSPA) committees and interested community groups. The research team also planned to speak to teachers to inform them of the project and to confirm their participation in the study (A. Galloway, personal communication, February 13, 2002 & March 04, 2002).

Schools in both regional districts were visited by the research team in late February and in March 2002 (CHL Minutes, 06/03/02). The following table (see figure 4.3) indicates school types, commencement dates and continuing/non-continuing status for each of the three regions

Starting up issues:

Health & Safety Issues for research team

Some of the research sites that were chosen for the CHL study involved travel to a number of very remote and isolated communities in regional areas of the state. Travelling to these destinations consisted of air and road travel, often on unsealed roads and through unfenced cattle station properties.

There were a number of health and safety issues that were identified by the University and the project leader prior to the collection of data for the CHL Project. The Occupation & Health Act (WA) 1984 sets out a number of duty of care principles for employers to acknowledge in providing a safe working place for employees:

- Provide a safe and secure working environment and comply with all relevant and current legislation.
- The Occupational Safety and Health Act (WA) 1984 sets out the General Duty of Care principles and requires that an employer shall, so far as is practicable, “provide and maintain a working environment in which his employees are not exposed to hazards.”
- Provide information, training and protection to employees without cost in cases where potential hazards cannot be avoided (Government of WA, 1999, p.19).

Most of the schools participating in the CHL research project were located in metropolitan suburbs and in country towns readily accessible by vehicle and air transport. However, four schools in the Project required members of the research team to travel considerable distances on unsealed roads. The research team leader recommended that team members without 4WD experience attend a funded course in their use (CHL Minutes, 06/03/02). The University’s Medical Service staff also recommended that staff visiting remote communities to be vaccinated against Hepatitis A & Hepatitis B. It was pointed out that the likelihood of contracting the disease was low; however, the University had a duty of care to all its staff members and would be held responsible if a staff member fell ill. The research team leader confirmed that costs

would be met by the Project and all researchers participating in the data collection were vaccinated.

Assessment tool

The testing and assessment of students participating in the CHL project was an integral aspect of the research activity. The major aim of the CHL Project was to examine the efficacy of the teaching strategies designed to improve student learning outcomes in Standard Australian English (SAE) Literacy.

School	System	Year1 commenced1	Status
Metropolitan district			
School A	G	2001	Withdrew early 2002
School B,	G	2001	Remained in project
School C,	G	2002	Remained in project
School D,	G	2001	Ethics o/s – late starter.
School E	C	2002	Withdrew at the end of 2002.
School F	AISWA	2001	Ethics o/s - late starter.
Regional district 1			
School A-DHS	G	2002	Remained in project
School B - RCS	G	2002	Remained in project
School C	C	2002	Remained in project
School D	C	2002	Remained in project
School E - RCS	C	2002	Remained in project
School F	AISWA	2002	Remained in project
School G	AISWA	N/A	Did not participate. Non-Indigenous gatekeeper.
Regional district 2			
School A	G		Did not participate. Teachers did not want to become involved.
School B	G	2002	Withdrew after 1 yr. Change in principal?
School C	G	2002	Insufficient Indigenous students
School D	G	2002	Remained in project
School E	G	2002	Remained in project
School F	AISWA	2002	Remained in project
School G	AISWA	2002	Withdrew

Table 4.3 Status of schools involved in the CHL project

Key: G=government; C=Catholic; AISWA= Aboriginal Independent School Western Australia; RCS=remote community school; O/S= outstanding

In doing so, it is necessary to point out here that implicit to the CHL project was the acceptance of the premise that Aboriginal children should learn SAE. It was therefore imperative of the CHL research team to find an appropriate test instrument to measure student's progress over time in SAE. A number of issues required further consideration in the process of choosing a test and these included:

- the diverse educational districts and the subsequent different Aboriginal language groups found in each of these districts, and
- the different orientations that was likely to be evident between those Aboriginal students living in urban and remote communities.

The selection of a suitable assessment tool to test the reading ability of Indigenous children who had suffered CHL proved to be a long, sensitive and arduous task for the research team. For example, the research team were mindful that Indigenous community leaders and educators were concerned about the numerous assessment tests that Indigenous children were already subject to. In particular, the use of standardised tests with Indigenous children is considered to be 'unfair,' 'unreliable' and an 'invalid' assessment tool (Godfrey & Galloway, 2004, p.2). These concerns are well supported by the literature as critics have long argued that these tests harbour cultural biases by treating all individuals as culturally homogenous (Cataldi & Partington, 1998; Meadmore, 2001; Domino & Domino, 2006,). When the performance of Standard English is measured across entire populations including those from minority ethnic groups, the literature confirms that issues concerning equity and fairness will always be questioned (Cataldi & Partington 1998; Domino & Domino, 2006; Meadmore, 2001).

Standardised tests are used to assess and compare the performances of student populations and the effectiveness of school educational programs. From test results, decisions are made concerning levels of government funding and the introduction of educational programs to achieve certain standards in educational outcomes among student populations.

Despite improvements in the development of standardised tests for use among a diversity of schools and school populations, the issue of equity and fairness remain a major challenge to test developers and test administrators. Issues relating to validity and reliability of tests are also important for test developers in order to eliminate test bias that is likely to be experienced by minority ethnic groups (Domino & Domino, 2006).

National testing programs – An Australian context

Language Issues.

Language issues present a major concern in the use of standardised tests among minority groups, particularly amongst those who speak English as a second or third language. This raises questions relating to ethical issues regarding the fairness of the test and secondly, the validity of the test itself and subsequent test results

The use of standardised testing and the issue of equity and fairness are well documented in the literature (Caltadi & Partington, 1998; Domino, 2006; McDivitt & Gibson, 2004; Meadmore, 2001). Meadmore (2001, p.22) confirmed that these issues, “extend to students who come from different cultural and ethnic backgrounds, from different geographical areas, and with different kinds of physical and mental abilities.” It also cannot be assumed that all students share similar lifestyles and family experiences and have access to resources and other technologies that support learning. For example, Aboriginal students living in remote communities and who may speak English as a second or subsequent language are likely to be considerably disadvantaged in comparison to those students attending a school in a middle or upper class city suburb when undertaking standardised tests. Domino & Domino (2006, p.273) refer to this as ‘societal bias’ with lower scoring in tests attributed to poverty, prejudice and lack of educational opportunities. For this reason, critical theorists contend that standardised testing and ethical pedagogy are completely opposed to one another. “Critical pedagogy foregrounds the diverse conditions under which authority, knowledge, values and subject positions are produced and interact within unequal relations of power” (Giroux, 2004, p. 41).

Ethical considerations in national testing programs

Despite the efforts of test developers to produce standardised tests that are fair and culturally appropriate for use by all Australian students, normative or performance based assessments when applied across a range of cultural groups and geographic locations will most likely advantage certain groups of students and marginalise others because of differences in cultural and social capital that exists between different socio-economic groups. Australian Aboriginal students in particular have been singled out as

a specific group for whom inherent social and cultural differences are exacerbated in test conditions. Meadmore (2001, p. 22) contended that, “central testing, by its uniform nature, is not tailor-made for groups other than mainstream, and therefore is unable to fairly and justly represent the diversity of Australian students.” Meadmore further argues that national assessment programs are an attempt to ‘standardise diversity’ in a one size fits all testing program. When this test is applied to all Australian children, it is important to consider the effects it will have on those from disadvantaged backgrounds in terms of fairness and justice.

It has been argued in the literature that Aboriginal students are considerably disadvantaged when undertaking standardised tests as the test assumes grounding and knowledge in a mainstream Western education system (Domino & Domino, 2006; Cataldi & Partington, 1998; Kearins, 1988; Malcolm, 2011). The tests reinforce a ‘class based system’ whereby the knowledge and values of Western education are assessed and as a result this benefits children of groups that are most familiar with this education system (Cataldi & Partington, 1998, p.311). The values and concepts found in standardised tests generally fall outside the social and cultural life experiences that Aboriginal children encounter in pre-schooling and schooling years.

A number of other factors contribute to poor performances among Aboriginal students including: resistance to education as a result of experiencing racism at school; resistance towards the teacher and consequent choosing to perform poorly in tests; living in dysfunctional family situations; poor health status such as the impact of alcohol abuse and malnutrition both before and after birth; poor educational experiences and achievement levels of parents; past negative experiences with persons in authority; poor teacher expectations and lack of individual success at school and lack of knowledge necessary for success in early and later years of school. These factors lead to absenteeism, a major factor contributing to poor educational outcomes among Aboriginal students. As a result, students fail to acquire adequate skills education. (Cataldi & Partington, 1998)

Selecting a measurement instrument for the CHL research project

The CHL Research Project involved 16 schools across three regional education districts: Kimberley, Goldfields and the Perth metropolitan area. The schools included government and Catholic schools and Aboriginal Independent schools. A major component of the CHL Project was trialling and evaluating the effectiveness of a number of classroom teaching strategies that were designed to improve the learning experiences and subsequent learning outcomes of Aboriginal students who were identified as having conductive hearing loss.

The research team believes that hearing loss due to Otitis Media may affect the development of auditory discrimination and processing skills and as a consequence, may reduce phonological awareness, short-term auditory memory skills, auditory sequential memory skills and thus numeracy and literacy skills. (Godfrey & Galloway, 2004, p.144)

The selection of a culturally appropriate measurement instrument to assess early literacy and numeracy skills among Aboriginal students in pre-primary to Year three, proved to be a difficult exercise for the research team. They took into consideration the inherent cultural bias of many standardised tests used in Aboriginal school settings and the subsequent response from concerned Aboriginal community leaders and educators who question the fairness, reliability and validity of these assessments.

A number of tests were examined to determine their suitability for the project: The Kimberley Standard English Vocabulary Test (Brandenburg, 1984); the Phonological Profile for the Hearing Impaired Test (Vardi, 1991); the Western Australian Action Picture Test (Kormendy, 1988); and the Hundred Pictures naming Test (Fisher & Glenister, 1992). These tests were assessed as highly unsuitable for a number of reasons including, “unsuitability of language, complexity of administration, length, difficulty in assessing K to Year 3 reading skills, or because they were considered to be outdated “ (Godfrey & Galloway, 2004, p.3).

After close examination the CHL project team selected the Waddington Diagnostic Reading and Spelling Tests 1 & 2 (Second edition). This test was chosen because the research team believed that the instrument used appropriate language for use with K to Year 2 and three option multiple choice was easy to score and also provided a means for statistical analysis to be undertaken.

The items depicted relevant and current items to be recognised such as balls, horses, fish and the sun etc. The tests were easy to score. The use of pictures with option multiple choice items narrowed choices and aided statistical analysis. (Godfrey & Galloway, 2002, p. 145)

To further test the reliability and validity of the Waddington test, a pilot study was conducted by the research team in a rural and remote school in the Kimberley and Goldfields region of Western Australian with promising results. (Godfrey & Galloway, 2004, p. 145).

Although the research team had considered the Waddington test to be the best available at the time for use with Aboriginal children, a number of shortcomings were identified in relation to its application to the CHL Project. The issue of cultural appropriateness was an important consideration in choosing the Waddington test and the following issues became apparent upon further examination during the pilot study:

1. The test was unsuitable for use with children below Year Two as some components of the test relied heavily on prior reading ability and experiences;
2. The test items were not presented in order of difficulty. For example, some 'easy' items were placed towards the end of the test;
3. The test was very long. (A.Galloway, personal communication, January 14, 2008).

Furthermore, the suitability of the Waddington Test for use with Indigenous children attracted criticism among some educators. For example, senior officers from two education systems were strongly opposed to its use by the research team. They felt that the test contained numerous inappropriate items that were considered to be culturally biased (Godfrey & Galloway, 2004). They also thought that the Waddington Test was unsuitable because the test is an achievement test rather than a diagnostic test and therefore, the results could not be used by teachers to identify learning needs (A. Galloway, personal communication, May 7, 2001).

In addition, the research team found that teachers in project schools had varying views and opinions regarding the administration of the Waddington test to Aboriginal children in different regional and metropolitan settings. The research team believed that differences in opinions were influenced by the particular school location. For example,

teachers from remote Aboriginal schools, in particular, voiced strong opposition to the use of the test. The major reason for this reaction was the strong belief that the Waddington test “contained numerous inappropriate, culturally biased items” (Godfrey & Galloway, 2004, p.145). As a result, the project leader decided to abandon the use of the Waddington test and sought advice from Language Education staff from Edith Cowan University in order to find a suitable test to use in the project.

In addition, a senior member from one of the school systems suggested as an alternative to using the Waddington test, the research team should use benchmarks, profiles of students’ work samples and results from other standardised tests (CHL Minutes, 15/05/01). With regard to benchmarking, some teachers expressed their opposition to its use as results tend to be extremely low and they feel that they have failed in meeting standards set in other schools or by national benchmark standards (A. Galloway, personal communication, October 31, 2001).

The strong opposition to the Waddington Test led the research team to further explore alternative instruments to literacy levels among Indigenous children. The test that was finally chosen came by the research team serendipitously. At the time, the university was developing and trialling an Australian version of the Performance Indicators in Primary Schools (PIPS): baseline assessment 2001, which was developed at the University of Durham in the United Kingdom. The PIPS test is a computer based literacy and numeracy instrument designed for pre-primary and Year 1 students. The PIPS developers at the university advised that the test could be used with Year 2 students. The trialling of the test in a sample of Western Australian schools in November 2001 & February in 2002, including those with Indigenous students, indicated that the test was highly reliable and therefore, was chosen on this basis (Godfrey & Galloway, 2004).

Adaptations made for the Australian version included the use of an Australian voice in the test and the use of substituted pictures to represent local depictions of particular items. For example, an illustration of a Dutch windmill was changed to the type of windmill typically found on Australian cattle stations. A further advantage of the PIPS test was the indication from developers that the test was suitable for use with pre-primary to Year two students (V. Pepper, personal communication, January 10, 2008).

After examining and trialling the PIPS test with Aboriginal students from four schools, the research team were happy with the results and reliability of the test and decided to use it in the CHL Research Project. The research team leader noticed a high level of enthusiasm shown by the students and a good level of acceptance by the teachers who found the pre and post intervention results to be very useful. In addition, there was a local PIPS representative at Edith Cowan University at the time and available to provide advice on the test. Further, test developers in the UK were very interested and supportive of the application of the test in an Aboriginal education context, and were willing to work with the research team in applying it in this new context.

The PIPS test is administered on an individual basis at the beginning and end of a school year to measure progress over time. The test usually takes 15-20 minutes to complete and is administered by a suitably qualified person, usually a classroom teacher. The child is only required to give a verbal response and the assessor inputs the answers by moving and clicking the mouse. The PIPS test comprises a number of sections containing questions that become progressively more difficult. The computer program defaults to the next section of the test once three errors are made. The test commences with simple items in each of the sections of the test and progresses to more difficult items. This feature of the PIPS test allows students to progress through the test without encountering too many questions beyond their ability level and therefore eliminating the fear of failure, as they are not aware of remaining questions in a particular section.

With paper-based tests, such as Waddington, however, it is obvious to students how many questions there are to be done, and this can be discouraging for a child who may be struggling. Further, the PIPS test is brightly coloured, with many pictures being Disney-esque, which is also attractive to students more accustomed to watching cartoons on television or video than to engage with print materials. Another advantage of the PIPS test relates to the starting point of subsequent rounds of testing. The next time a child is tested, the computer takes account of what they have been able to do previously, and starts the next test at an appropriate point, meaning that they do not commence at the beginning each time if they have obviously mastered the material covered there.

Godfrey and Galloway (2004, p. 146) summarise the components of the PIPS test as covering:

general vocabulary, knowledge, concepts of print, sounds and phonological awareness, letter knowledge, reading and word attack skills, concepts of maths, digit identification, and number problems.

In addition there are two optional sections, one testing short term memory (which was included in the testing for the Project); the other assessing attitudes (not included in the Project).

The PIPS test is designed as a two point test to be administered at the beginning and end of the school year. However, the CHL Project team negotiated with the PIPS developers to modify the program's software to allow for a three point testing arrangement, with a third round using the same test, which followed six months later. There were several reasons for a third test. One was to test students over a longer period of time to determine whether the strategies were making a difference. Second, the CHL Research Project was a longitudinal study that was conducted over a two year period; and lastly, the PIPS test was changed each year, but to ensure validity of data, the project needed the students to be assessed using the same instrument.

The PIPS test was deemed acceptable for use in Indigenous contexts by a number of professionals including the PIPS agent at Edith Cowan University, University staff, Aboriginal & non-Aboriginal personnel, teachers and educators. The PIPS test was also accepted by Aboriginal community members from a number of CHL project sites in metropolitan, rural and remote locations. This level of support for the test is indicative of the acceptance across all regional settings and across different language groups.

The computer based test allowed students to engage in an interactive way with each test item and for test administrator to incorporate a game-like approach with individual students in answering each question. A member of the research team found that interest among Aboriginal students in doing the test was overwhelming in some locations as students would eagerly queue up to do the test while other students would clamber all over the team member, in waiting their turn to go onto the computer.

Reflection on the NHMRC's National Statement on Ethical Conduct in Research involving Humans (1999).

As stated earlier in this chapter, the CHL research study was subject to the NHMRC's national guidelines for the conduct of all research involving humans, animals and the environment (1999) together with the NHMRC's supplementary guidelines entitled, "*Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*" (1991). The latter document referred to three broad areas that had to be addressed by the project leader in the drafting of the ethics application: consultation, community involvement and ownership; and the publication of data. The University's Research Ethics Committee is the body that approves research applications based on the strict adherence to the guidelines contained in these two documents. This includes the wording of consent forms, the data collection process, the rights of participants, the storage and the publication of data. The involvement of parents/caregivers and the Indigenous community in CHL awareness sessions and the intended dissemination of the associated teaching strategies provided shared levels of 'ownership' over the project. In addressing the NHMRC's guidelines, I believe that the CHL ethics application more than adequately met the requirements that were established at the time. While this may be so, Rigney (2006), provides comments from an Indigenous Researchers Forum that he attended in 2003 which clearly indicates that the Indigenous community felt the need for further research reforms and the strengthening of existing research guidelines and protocols. Concerns were raised about,

- Research meeting the needs of Indigenous communities rather than the researchers' priorities,
- Indigenous ownership and intellectual property,
- Lack of on-going consultation, negotiation and involvement of Indigenous communities in the design, facilitation and publication of research,
- Inappropriate research methodologies and ethical research processes; and
- The need for effective, appropriate and culturally sensitive research in relation to ethics and protocols.

(Rigney, 2006, p.34).

From this list of concerns, it is also clear that the existing NHMRC's supplementary research guidelines pertaining to research involving Aboriginal and Torres Strait Islander people (1999) are perceived to be insufficient in meeting the research needs of Indigenous communities and, in the ways in which research was being conducted with Indigenous communities and/or subjects.

In 2003, the NHMRC replaced the 1999 supplementary guidelines with a more comprehensive set of guidelines and entitled, "Values & Ethics: Guidelines for the ethical conduct in Aboriginal & Torres Strait Islander Health Research."

Conclusion:

The CHL research project provided a complex and interesting study to use to evaluate the adequacy of the existing ethical guidelines of the day and guidelines that are currently in place. The study was unique in so many ways and it contained numerous elements and incidents which took place so that an assessment could be made of the adequacy of existing and current guidelines on a number of criteria. The CHL study also satisfied the four main criteria or elements of case study research: description, explanation, prediction and control. Although this evaluation is based on one particular case study, the data highlights that existing and current research guidelines can be further strengthened with the introduction of cultural competency training (see chapters two & seven).

This chapter has emphasised that successful research projects are grounded on thorough and careful planning. This begins with the process of applying for research funds through until the completion of the project. It is important to appoint a collegial team of researchers who are suitably qualified to assist in carrying out the various research tasks in an ethical and culturally appropriate manner. In addition, the appointment and composition of a research advisory group to the project is also important in order to discuss progress on the project and any on-going issues and events that may arise during the course of the research study. The University's ethical approval processes are based on the NHMRC's national ethical guidelines and applications for ethics clearance must adhere to these guidelines before approval is given. Any changes or amendments to the original ethics application or extensions to the research project must be

submitted for further approval. The NHMRC's 1999 research guidelines that applied at the time to the CHL project also list requirements and details for the composition and responsibilities of an appointed Research Ethics Committees in institutions or organisations who would be assessing research ethics applications. The composition guidelines included, "at least one member who is minister of religion, or a person who performs a similar role in the community such as an Aboriginal elder" (NHMRC, 1999, p. 16). At the time of the CHL research ethics submission, the university had appointed an Aboriginal community member to the Research Ethics Committee (G. Partington, personal communication, October 14, 2008).

The research team's project director mapped out a research plan to illustrate the various steps of the research project to inform the research team and research advisory group (see figure 4.1). However, despite the level of thorough and careful planning, the CHL research team encountered many issues and incidents that almost curtailed the research project. These are discussed in chapter five.

CHAPTER FIVE

THE CASE STUDY: WHAT HAPPENED?

Introduction:

Despite all good intentions and thorough planning, it is still possible for researchers to encounter operational matters or events that were totally unanticipated and/or unexpected during the research process. While some of these matters or events will be possible to resolve, they may take time and a great deal of effort before a suitable conclusion is reached. On the other hand, some matters or issues may not be able to be resolved and therefore, this outcome can either force changes to some aspects of the study or, perhaps jeopardise the research study itself. The CHL case study that was chosen for this thesis unearthed a number of incidents during the research project that were either unethical in nature or had the potential to develop into an unethical outcome had it not been for the intervention or persistence of the CHL research team. These incidents included: delays in obtaining multiple ethics clearances, issues in dealing with consent, the selection of an appropriate standardised test for the study and matters relating to confidentiality. The CHL project leader, in following good research practice, appointed a Research Advisory Committee for the project and the membership comprised of the CHL research team and members from the industry partners who were involved in the study (see chapter four). The involvement of industry partners on the membership provided opportunities to discuss research procedures and developments as the study progressed. The procedures and actions of the research team were also based on the premise of initially establishing good relationships with all those involved in the project and importantly, strengthening and maintaining them throughout the project. A major initiative that was introduced by the project leader was an ethics role that was given to an Indigenous member of the research team. The role was established to assist in discussions in obtaining ethical clearances with AMS officers, to ensure that parents and caregivers were fully informed of the project and understood the consent forms and their rights to consent or to withdraw their consent at any time during the research project. The role also provided an opportunity to develop and maintain relationships with stakeholders and the Indigenous community at a formal and informal level. The move to appoint an Indigenous person in this role and the level of importance that the research team placed on developing good relationships with all those involved in the

research project reflects what has become known today as cultural competency (see chapter two and seven).

As the literature review and introductory chapters have clearly established, research involving Aboriginal and Torres Strait Islander people in the past has been culturally inappropriate and invasive, often ignoring the rights of Indigenous Australians to participate or not to participate in research (Fredericks 2008; Greenhill & Dix 2008). At the time of the CHL research study, the NHMRC's 1999 ethical research guidelines applied together with 1991 NHMRC's Interim guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research which focused on consultation, community involvement and ownership and publication of data. The University's Research Ethics Committee and the CHL project research team observed and carried out these guidelines, however, this did not prevent a number of concerns and issues from arising throughout the project.

This chapter will discuss the issues that arose during the CHL research study, the ensuing consequences to the study and solutions that the research team applied to each matter. The issues discussed will include ethical perspectives and some operational incidents that impacted on the study in some way. In addition, the chapter will present examples of how cultural competency was applied by the research team when dealing with these issues.

Multiple Ethics clearance & subsequent delays

As discussed in chapter four, the application for ethics approval for the CHL research project, *"Teaching Indigenous students with conductive hearing loss in remote and urban schools in Western Australia"* was approved by Edith Cowan University's Human Ethics Research Committee on 19 December 2000 (Approval 00-205). This approval granted permission to make contact with the participants who had been identified for the study, seek their consent to be involved in the study, allow access to ear health medical records of those students who were involved in the study and allow data collection for those who had consented to being involved. As part of the approval process, the research team had to disclose to participants their rights during the research process, how the data were to be stored and used (G. Partington, personal communication, February 02, 2001). At the time of giving ethics approval to commence the CHL study, the university's ethics committee did not indicate that additional or

separate medical ethical clearance(s) would be required. However, following a Research Advisory Committee meeting on 28 August 2001, the CHL project team were advised by an industry representative that further ethics approval would be required from the WA Aboriginal Health & Information Ethics Committee (WAAIHEC). This committee is located in the WA Office of Aboriginal Health and is representative of all regional Aboriginal Medical Services (AMS) throughout the state (G. Partington, personal communication, September 04, 2001).

On 10 October 2001, an application for ethics approval was submitted to WAAIHEC. In addressing the requirements that were stipulated in the application, the CHL project leader had to confirm that the following documents had been read:

- NHMRC National Statement on Ethical Conduct in Research Involving Humans,
- NHMRC Guidelines on Ethical matters in Aboriginal & Torres Strait Islander Research (Interim, 1991),
- Royal Commission into Aboriginal Deaths in Custody.

There were two additional documents listed, but these were either under review or were deemed not yet applicable:

- NHMRC Aspects of Privacy in Medical Research, AGPS, Canberra, 1995,
- WAAHIEC Guidelines (WAAHIEC Ethics Proforma, revised 09/08/00, p.1).

In addition to this information, the application required details about the chief investigator(s), the aims of the project, the participants, justification of the proposal, community participation and consent, consultation, ethical implications, reviewing progress of the project, disseminating information to the community, risks and care measures, how research results or findings will be used and how the information will be stored and disposed of (WAAHIEC Ethics Profoma, 2000).

At the time of lodging the ethics application with WAAIHEC, there was no formal chairperson of this committee. This proved to be very frustrating for the research team as this situation resulted in delays of several months as the interim chairperson was not prepared to make a decision on the application. The interim chairperson also indicated to the project leader that further ethics clearance would be required from each regional and individual member AMS involved in the study. When the WAAHIEC ethics application was lodged, there were no indications given that additional or separate medical ethical clearance(s) would be required from the relevant AMSs in each

individual region. A number of telephone calls and emails were made by the project director between November 2001 and March 2002 to check on the progress of the application to WAAHIEC but information updates were stalled due to several changes of the WAAHIEC chairperson and committee personnel and the cancellation of several scheduled meetings due to the lack of a quorum (G. Partington, personal communication, May 15, 2002).

While WAAIHEC had deferred making a decision on the ethics application for a number of reasons, the project leader sought ethics approval from each of the regional and community AMSs involved in the study as requested. For the purposes of this study, the AMSs in the two regional areas will be referred to as 'regional site one' and 'regional site two.' This process however, resulted in further frustrations for the research team as each regional AMS insisted on ethics clearance being obtained from WAAIHEC in the first instance. For example, members of the CHL research team visited an Aboriginal Health Service in regional site one on 22 February 2002 and spoke to the medical director of the organisation. The purpose of the visit was to discuss the nature of the project and the medical information required with appropriate personnel. During this meeting, the medical director confirmed that an ethics application to the local AMS was required in addition to the WAAHIEC application.

On 14 March 2002, written requests for permission to access medical records relating to the ear health of those Indigenous children participating in the CHL project were sent to Aboriginal Health Services and AMSs in both regional areas. This level of ethical clearance was extraordinary given that the research team were seeking access to school health records of particular students and this procedure involved Government Health Services and did not directly involve the AMSs. The content of ethic clearances is analysed in more detail in chapter six.

The WAAHIE Committee first considered the ethics application at their meeting on 5 April 2002. The outcomes of this meeting were relayed to the project leader via an email sent on 29 April 2002. The committee advised through its Chair that further information was required to be presented by the research team to show evidence of, "a more diverse consultation process than that indicated at present (i.e., mainly Indigenous education providers) including letters of support from the AMSs from each of the two regional areas; the use of written consent and the reasons for the use of video and audio taping with the participants" (G. Partington, personal communication, May 15, 2002).

The project leader felt that the request for this additional information suggested that some of the original information that was included with the ethics application have gone missing as a result of the changeovers of committee personnel.

To follow up on this request, an assistant from the research team endeavoured to speak via telephone on 13 May 2002 to staff from each of the three AMSs in the three regions who had been previously contacted about the CHL project. As a result of these telephone calls, the research assistant found out that there was a staff member change from an AMS in regional site one and that the new replacement knew nothing of the CHL Ethics application. The Aboriginal Health Services contact person from regional site two, who had dealt previously with ethical matters, had also changed. The person who had taken over this responsibility has no details of the ethics application on file. The contact person for Perth region advised that a letter of support was still forthcoming.

A number of telephone calls were made by the project director between 13 and 21 May 2002 to arrange visits by research team members to meet and speak with relevant staff members at all three respective sites. This exercise met with varying degrees of success and as well, further frustration. An AMS contact person from regional site one was away ill for a number of days and when telephone contact was made on 20 May 2002 the project director was informed that the ethics application had been referred to another staff member and an appointment was made accordingly with this staff member (G. Partington, personal communication, May 15, 2002). When this AMS staff member was contacted, they had no knowledge of the ethics application that was sent in March 2002. The AMS staff member recommended that another copy be forwarded to the medical officer in charge who would deal with the application in the first instance, and who would then pass it on to the new administrator. A copy of the ethics application was forwarded as requested on 28 May, 2002, however, the person who was delegated to receive this item was on leave until 6 June, 2002.

In other developments, the project leader contacted a senior industry partner officer to highlight the problems experienced in getting approval from WAAHIEC and subsequent regional AMS offices. Assurance was given by this officer to speak to relevant committee members responsible for approving ethics applications.

The project leader and director visited regional site one on 24 May, 2002 and met with relevant staff to discuss the CHL Project and the ethics application. The ethics

application was recommended for approval and a letter of confirmation would be forwarded from the local AMS committee.

On 27 May, 2002, a research team member visited an AMS in regional site two and spoke with the director. During this meeting the director requested clarification of the project and requested expansion on several points in the ethics application. Following the receipt of the revised application, the matter would be dealt with at the next Executive Committee meeting. These meetings were held every six weeks. On 31 May, 2002, the project leader and director met with the delegated staff member from regional site two who advised subsequently, that the application would be referred to the Medical Officer in charge of the region who would in-turn; make a recommendation, based on his assessment.

On 12 June, 2002, the project director contacted officers from the three respective sites to ascertain progress of the ethics application as no response had been received to date. Telephone contact with all three organisations revealed that the matter was still outstanding. The staff members responsible for progressing the application at the regional site one were unavailable, so the receptionist noted the request for a return telephone call. The contact person at regional site two advised that the medical officer in charge of region had yet to make a recommendation regarding the ethics application. A subsequent telephone call confirmed that the application would go to a committee meeting in the following week as the scheduled meeting for this week had been cancelled (A.Galloway journal, personal communication, November 12, 2002).

The medical officer in charge of Aboriginal Health Services in regional area two indicated that she had passed the original ethics application to a former administrator in March. In the meantime, she had forwarded to the newly appointed administrator the second copy of the application that was sent by the projectdirector. The administrator indicated that the matter would be raised with the region's medical service first before giving a final decision.

Telephone contact was also made on 12 June, 2002 to staff at the Perth and regional area two locations to ascertain progress of the ethics application. The staff members who were responsible for this task were both on leave at the time (A. Galloway, personal communication, November 12, 2002).

In addition to the above, ethics applications were sent to government health services in both regional areas as not all Indigenous students attend AMS/AHS medical

services. Project team members also met with community and school health nurses and school based Aboriginal health workers when in the area. Following this further round of consultation with the relevant AMSs and AHSs, the project leader was in a strong position to address the concerns raised by WAAHIEC in their correspondence dated 29 April, 2002. The additional information requested was sent to WAAHIEC on 13 June, 2002. A WAAHIEC meeting held on the 28 June, 2002 confirmed conditional support for the research project, subject to written endorsement from each of the Aboriginal medical services in the regions in which the project was being carried out.

Correspondence from the project leader to the chairperson of the WAAHIEC dated 26 August, 2002 confirmed that written approval of the project had been received from the Perth and regional one sites. These were received on 23 July and 12 August, 2002 respectively. The project leader also confirmed in this correspondence that verbal support had been received from regional site two; however, written approval was still outstanding as the director of the AMS had referred the ethics application to the medical officer in-charge of the region for endorsement. (G. Partington, personal communication, August 26, 2002).

Records confirm that a research team member spoke to the director from the AMS in regional site two on 27 May, 2002 and made further contact via telephone on 21 June, 25 July and 27 August 2002, seeking a written response in support of the research project. In addition, copies of the application had also been sent to the medical officer in-charge of regional health services by AHSs and a second AMS from the same region. As a consequence to this, the medical officer of the region's regional health services requested a summary of the project, and of details of how children with CHL are identified, how consent is obtained, and how data is handled. This request for information resulted in further frustration for the research team as all these details were included in the ethics application.

As a result of the lack of response from two of the three sites in regional area two, the project leader in the same correspondence asked the chairperson of WAAHIEC to personally intervene to expedite matters so that necessary letters of support could be obtained, thus completing the medical ethics process and allowing the project to proceed (G. Partington, personal communication, August 26, 2002).

A follow up letter was sent by the project leader to the chairperson of WAAHIEC on 13 September 2002, requesting final approval of the ethics application which was

originally submitted on 10 October 2001. At the time of writing this correspondence, the written support requested from the two sites in regional area two remained outstanding.

The project leader reported in a CHL project committee meeting held on 2 October 2002 that the WAAHIEC was due to meet on 27 September 2002 to discuss medical ethics approval for the project, however this meeting had to be postponed to 4 October 2002 as some members were away attending a funeral (CHL Project Committee Minutes, 02/10/02).

In the next CHL committee meeting held on 13 November 2002, the project leader reported that WAAHIEC had formally given ethics approval for the CHL research project, following the 4 October 2002 meeting (CHL Project Committee Minutes, 13/11/02). The initial ethics application was submitted on 10 October 2001, so almost 12 months has elapsed before the WAAHIE committee had given final ethics approval for the research project to finally commence.

The project leader advised the CHL committee at the 13 November, 2002 meeting that the research project was due to finish at the end of the year, however, due to the delays in obtaining ethics approval, he would be applying for an extension of the project to the end of 2003. The request by the WAAHIEC Ethics Research Committee for the CHL research team to obtain further ethics approval for the study from AMSs in each of the three study regions acknowledges the Interim research guidelines that the NHMRC had developed for the conduct of research involving Aboriginal & Torres Strait Islander people. The 1991 guidelines reinforced the requirement of consulting with Aboriginal agencies at federal, state and local levels and this was duly followed by the CHL research team. From what transpired during the period of gaining approval from WAAHIEC and respective AMSs, it became evident to the research team that both parties were unsure about the process of approving ethics applications and who was responsible for doing so. For example, the WAAHIEC had deferred giving ethics approval until the AMSs had confirmed their approval, however, the AMSs indicated that they were reluctant to give their approval until WAAHIEC had done so (CHL Minutes, 02/10/02, A. Galloway, personal communication, May 09 & 24, 2002).

Of special note is the acknowledgement by the health service providers that obtaining medical ethical clearance involves a very complex process (CHL minutes, 05/06/02). This matter however, requires attention to minimise delays and expedite

ethics approval among health service providers. Despite addressing each of these requirements via the submission of ethic research applications for each agency, delays of almost a year resulted in getting these ethics clearances. Many of the delays were due to internal approval processes as there were no controversial ethical health issues that required an in-depth discussion as the research study was principally educational in nature and not particularly health orientated (A. Galloway, personal communication, May 09, 2002).

The delays were caused by internal events such as changes to the membership of WAAHIEC, the postponement of scheduled meetings at the state and local AMS level, the lack of clarity as to who in the AMS had the responsibility or authority to give approval, and the misplacement of consent forms and other supporting documentation as a result of the changeover in committee membership (CHL Minutes, 02/10/02, A. Galloway journal, personal communication, May 09 & 24, 2002). In one case, the application form was passed to a medical doctor by an AMS chairperson for approval and the form was neglected for months. This happened twice in the one AMS office and only on the third approach was approval given.

Such significant delays can jeopardise a research project as funding authorities such as the Australian Research Council (ARC) approve research funds on the basis of established milestone dates and/or a final completion date for the project. The delays in obtaining consent from WAAHIEC and AMSs caused the CHL project leader to seriously consider abandoning the research study. Despite addressing all the requirements that were listed in the ethics application form and personally discussing the project with personnel from WAAHIEC and the various AMSs, further delays continued to result (A. Galloway, personal communication, June 20, 2002). Whilst it was unfortunate that delays did occur, the process of approving ethics within the health system needs to be examined and streamlined to assist managers and those responsible for dealing with ethics applications to make decisions within reasonable timelines. This process, however, should not in any way ignore established ethical guidelines which have been produced by the NHMRC and/or specific requests made by Indigenous communities which relate to the research activity.

The delays in obtaining consent from WAAHIEC also meant that the research team could not receive information from the school nurse that would identify students who had CHL. However, despite this situation, the research team were able to record

educational data and make classroom observations as the Project had been cleared by the University's ethics committee. This arrangement however, caused some concern from one school nurse as she was aware that the medical ethics clearance was still outstanding. This circumstance also resulted in confusion for one teacher who was involved in the CHL study as she did not clearly understand what data collecting was ethically permissible under this arrangement. The project director explained on each occasion that the project team were operating ethically in collecting educational data under the University's ethics clearance form (A. Galloway, personal communication, May 10 & 14, 2002). The lack of medical ethics clearance proved very frustrating for the research team as, under these conditions, an assumption was made that all Indigenous students might have hearing problems. However, the exposure of the CHL strategies to all students was also considered to be educationally beneficial and good practice for all (A. Galloway, personal communication, May 14, 2002). The project director also confirmed with the school and with other schools that were involved in the CHL Project that students with CHL could not be identified until medical ethics clearance had been received, but as the project had been cleared by a university ethics committee, it was permissible for the research team to continue with classroom observations and collection of educational data (A. Galloway, personal communication, May 10 & 25, 2002).

In addition to obtaining multiple ethics clearance, the CHL committee advised the research team to seek support and approval from local Aboriginal Student Support and Parent Awareness (ASSPA) groups and/or governing school councils or school boards and in discrete Aboriginal settlements, support from the governing body of communities. A CHL committee member advised the research team to make personal visits to these communities in seeking their support and participation and, to beware that all communities are different and therefore, it may not be suitable to use a generic approach when consulting particular members of the community (A. Galloway, personal communication, May 15, 2001).

The delays in obtaining consent from WAAHIEC also resulted in the CHL project leader having to make two requests to the ARC to extend the period of the research activity. An initial request of six months was made in May 2001 to extend the study until the end of 2002 (CHL Minutes, 15/05/01). However, this timeline was no longer possible given that ethics approval was finally granted on 4 October 2002. The project

leader advised CHL committee members that he would seek a further extension of twelve months from the ARC, taking the end date of the study to 31 December 2003 (CHL minutes 13/11/02).

The process of securing multiple ethics approvals allows representative agencies to become involved in the approval process and ensure that the research is going to be conducted appropriately and is supported by the Aboriginal community. However, this process also presents some challenges and frustrations to researchers, despite appropriate levels of consultation. In addition, research projects are often subject to deadlines and, therefore, lengthy delays in obtaining ethics approvals may jeopardise research projects as per the case with the CHL project.

The requirement of consulting and applying for ethics approval from various Aboriginal stakeholder groups is not in question here as this condition serves to give Indigenous ownership over the research and also involve and protect Indigenous participants during the research process. This process not only follows the NHMRC's Interim guidelines for research involving Aboriginal and Torres Strait Islander people, but also the dialogue relating to research reforms that have been outlined by Moreton-Robinson (2000); Nakata (2004, 2007a, 2007b) and Rigney (2006) and the principles espoused in critical theory.

Informed consent

One of the major requirements in good ethical practice is gaining informed consent from participants who are involved in the research study. This requirement informs the participant of the research study and research methods to be used, the obligations of the researcher in protecting the identity of the participant, the option to participate or not to participate in the research study, the storage of data that has been collected and the publication of research findings. The importance of informed consent and the appropriate use of language in the development of consent forms were given high priority by the research team (A. Galloway, personal communication, May 02, 2003). Three consent forms were developed for the CHL project for use with principals (see appendix C), teachers (see appendix D) and parents or caregivers. The university's Ethics Committee had established guidelines regarding the format and content of consent forms and these were duly followed by the research team. The following points outline the development and content of the consent forms.

The information on the consent form was to be clear to parents and teachers and that each consent form had to be signed individually by each respective party. The research team however, considered the first draft to be too long and ambiguous and several revisions were made (See appendix A) (A.Galloway, personal communication, May 02, 2003). For example, the language used and the length of the form were adjusted and simplified so that parents and/or caregivers could easily understand the purpose of the study and the involvement of their child(ren). In addition, the CHL research committee also voiced the importance of using appropriate language in the consent forms for parents and caregivers. The CHL research team sought permission from the university's Ethics Committee to revise the parents/caregiver consent form accordingly and this request was supported (A. Galloway, personal communication, May 02, 2003). Other changes made by the research team included: (1) the rearranging of sentences to focus on the issue being investigated and what the research activity hopes to achieve. Previously, the opening sentence introduced the research project. (2) the simplification of medical terms used, i.e. 'glue ear' as opposed to 'Otitis Media.' (3), the alteration of some sentences to describe how the data were to be collected and (4), rather than signing a statement to acknowledge consent, a series of boxes with statements were added so that parents could 'tick' off what they were agreeing to (see appendix B) (A. Galloway, personal communication, May 02, 2003).

Each consent form was required to be signed by the parent or care giver to acknowledge confirmation that the content of the form has been understood and importantly, that they have agreed or have not agreed to the proposed study. A CHL committee member and senior officer from one of the education systems also reinforced the importance of obtaining written consent from parents and care givers prior to commencing the research activity by stressing that under no circumstances could a school or community member give consent on the behalf of the group. It was agreed that schools participating in the CHL project would be required to implement an appropriate process to obtain consent from parents and/or caregivers (CHL Minutes, 12/03/01). Under the Privacy Act (1988), the research team could not carry out this task. It was recommended that AIEOs and ATAs in respective schools be assigned to carry out this task on the behalf of the research team and therefore, it was the school's responsibility to send and receive forms. The research team also provided additional notes for the AIEOs and ATAs that they could follow when speaking to parents and/or

caregivers. For example, what to tell parents; what steps are involved in this particular research process, confidentiality and what it means when you sign the form (See figure 5.1).

Some schools however, opted to send the consent forms home with students for parents to read and sign. This arrangement proved to be unsuccessful at one particular school as only three forms had been returned despite the form being sent home twice. The project director recommended to the school principal that AIEOs or ATAs be used to explain the form to the parents and for the parents sign off appropriately in order to expedite this process (A. Galloway journal, personal communication, May 14, 2002). In one case, a school telephoned parents to discuss and obtain verbal consent if they had low literacy levels. The school then signed on the behalf of parents who had given their verbal consent (A. Galloway journal, personal communication, May 27, 2002). The research team did not favour this approach to obtaining consent but the failure of all other avenues due to parental literacy, and their ready accession to the project when it was explained verbally to them, confirmed this as an acceptable strategy for obtaining informed consent.

Ethics Clearance: explaining the form to parents

Outline the research to parents. Tell them:

- We are doing the research on teachers who work with Aboriginal children.
- The teachers will be using new methods that help children with hearing problems.
- A lot of Aboriginal children get Conductive hearing Loss, and this affects their learning to read. The new methods should help the children read better.

The steps in the research are:

1. Children's hearing is tested by school nurses or Aboriginal medical Services nurses.
2. So we can see if children learn better with the new methods, we need to look at their performance before the teachers learn the new methods. So we will get information on the children's achievement, attendance, behaviour and self-esteem how good they feel about school).
3. Then the teachers will be taught the new methods.

4. Then we will see if the teachers use the new methods properly.
5. After they have been using the new methods for a while, we will get more information on the children's achievement, attendance, behaviour and self-esteem to see if the methods make a difference.
6. Also, we may interview you about your son or daughter's schooling.
7. If you agree, we will also put pictures of some children and schools on the internet to show how the research is going.
8. The children should benefit from the research. Their literacy should improve and they should get extra help with their work.
9. There may be opportunities for parents to learn the methods the teachers use so they can help their preschool children in the same way with their learning.

The research will go on in the school for two years.

The research is really about the methods teachers use. Aboriginal children often don't learn to read well because of hearing loss. We hope to improve that.

The research is being run by staff from Kurongkurk Katitjin, the School of Indigenous Australian Studies at Edith Cowan University. There will be a lot of other people involved as well.

Confidentiality

The School will share information about your child's performance with us.

We will use the information to write reports, articles and so on, but no one will know that your child is reported on. We will change names, combine information from children and so on. In the videos, nothing about your child's performance will be reported.

Signing the Form

If you sign the first part, it means your child can take part in the research and the teachers will use the new methods with him or her.

If you sign the second part, it means your child's picture may go on the World Wide Web (internet) and he or she may appear in videos.

Even if you do sign, you can take your child out of the project at any time.

You can also ask the researchers for more information about the research at any time.

Figure 5.1 Ethics Clearance: Explaining the form to parents

Despite the requirement of written consent forms as set by the University's Ethics Committee and which was closely adhered to by the research team, teachers would sometimes give consent despite not receiving official approval from parents. At times, students would turn up occasionally and so the teacher would give approval for video-taping or audio taping to take place. The CHL research team strictly enforced the practice that no video or audio taping would take place without the official receipt of consent forms. The research team would observe classroom lessons and only use the data if consent was later given. This also included incidents where the research team had travelled long distances, only to find out that consent forms had not been received for all students concerned (A. Galloway, personal communication, May 02, 2003).

In another example, a medical community health nurse commented to the research team manager that obtaining consent from Aboriginal parents is a 'major drawback.' "It's not that they don't care, but other issues take precedence and therefore, it is important to make personal contact to get consent" (A. Galloway, personal communication, March 28, 2002). Personal contact is always considered better as many Aboriginal parents prefer oral rather than written communication. This form of communication also allows the informant to gauge whether or not the conversation about the research project and the various processes, including their rights are clearly understood.

Consent forms- miscommunication

The distribution of information and consent forms to parents via the school also resulted in mixed results and miscommunication. There were delays in the distribution of information to parents and the sending out and explanation of consent forms. Some school principals elected to send communications home to parents via newsletters while others chose to use AIEOs to speak directly with parents and inform them about the research project and to explain the consent form and for them to decide if they wanted their child to participate. However, despite the research team explaining the consent forms to ATAs & AIEOs, some AIEOs gave the wrong information to parents regarding the purpose and aims of the CHL project. Rather than explain that the project was about evaluating the effectiveness of a number of introduced teaching strategies to improve learning among those students who had suffered CHL, some parents were informed that permission was sought for the project team to conduct hearing tests with their children.

This miscommunication was later corrected by a research team member whose role was to confirm ongoing informed consent with parents and care givers and to provide information about the research project. To add to the delays in the return of consent forms, one school principal had misplaced some consent forms that had been returned signed by parents thus necessitating the need to resend these forms out to parents. (A.Galloway, personal communication, June 18, 2002).

In another instance, a mix up with consent forms occurred when one school principal sent out two forms to all parents for signing, not realising that one form was for use for Indigenous students and the other for non-Indigenous students. This situation caused confusion among some non-Indigenous parents as the nature of involvement by Indigenous and non- Indigenous students in the project was very different and the type of response being requested in the consent forms differed as well. For example, the consent forms for Indigenous participants had to be signed, while the format of response for non-Indigenous participants was via giving negative consent or a written response if the parent did not wish their child to be involved in the project. It was necessary to obtain permission from non-Indigenous parents to make the incidental audio and video tape recordings that may include their child. Despite the mix up in consent forms, all non-Indigenous parents had consented for their child's incidental involvement in the project (A. Galloway, personal communication, June 18, 2002).

Use of passive or negative consent

The research team used passive or negative consent on one occasion. The research team successfully applied to the University's Ethics Committee to use 'negative or passive consent' forms for the purposes of sending out to non-participating Aboriginal and non-Aboriginal students who may be included in the process of video-taping and/or audio taping of classroom interactions. Negative or passive consent means that parent or caregivers only need to reply in writing if they do not want their child involved. If they do not reply, it is assumed that permission is given (CHL Minutes, 06/02/02). One school principal informed the research team manager that some parents do not like the use of negative consent as they consider them to be easily misunderstood. However, he also agreed with the research director that positive consent forms could also be easily misunderstood (A. Galloway, personal communication, May 13, 2002).

The University's Ethics Committee approved the use of negative consent on the condition that the forms were to be mailed out to each parent/caregiver, with a reply paid envelope included for the return of the form to the school. Under the provisions of the Privacy Act (1988), schools had to address each letter to respective families and receive the replies. This process could not be carried out by the research team or by the University (CHL Minutes, 03/04/02). The research team leader reported that when data recording was underway in all districts, no non-Indigenous parent had refused permission for incidental recording of their children who were in classes involved in the study (CHL minutes, 05/06/08).

The use of negative consent is a matter that has to be carefully considered by Ethics Committees who are responsible for approving such applications. It provides for a convenient and quick method for researchers to obtain 'consent' and there is no need to follow up on outstanding responses. This method of obtaining consent does not provide confirmation that the parent/caregiver has received the form and/or fully understood the request. Given that the CHL research team experienced misunderstandings from Aboriginal parents/caregivers and also from AIEOs/ATAs who were distributing and explaining these forms, this method should be used sparingly, if at all, in Aboriginal contexts or when dealing with parents who speak English as a second or third language. Furthermore, the practice of negative consent, regardless of 'low risk' assessment to the participant, takes away a level of control and authority from Aboriginal parents and/or caregivers and restricts the opportunity to have a particular research activity explained to them in person. The use of verbal communication/explanation with parents and/or caregivers in obtaining consent is reinforced in the 2003 NHMRC guidelines for research involving Aboriginal and Torres Strait Islander people.

Issues in the administration of the PIPS test:

The administration of the PIPS test during the research project was well received by all principals and teachers generally, although there was one occasion where a principal raised concerns about the validity of the test results after observing that an assistant who was employed by CHL project team had acted inappropriately by coaching children to the correct answers. This action is not an indication of a weakness of the test, but rather an example of personal motivation to improve results. When members of the team discussed this matter with the research

assistant later, they said they felt sorry for the children who were struggling and wanted to help them. It appeared that the research assistant had not understood, or did not agree with, testing procedures, even though they had been part of meetings about tests and testing, received professional development in administering the test, and sat in as an observer on several sessions where an experienced researcher administered the test.

Travel to isolated communities

The inclusion of remote Indigenous communities in a research study will pose logistical issues relating to travel costs and travel time. There were three remote schools involved in the CHL project and one of these schools in particular posed a major travel time issue for the research team as it was not located near other schools that were involved in the project. A visit to this school for example would take up to three days because of the timing of flights into and out of the nearest major town to this community. The project leader employed a teacher from the nearest town to visit this community school to collect data twice during the term (CHL minutes, 05/06/02).

School communication issues

Contacting schools

Initial invitations to schools seeking their participation in the CHL project were sent by letter with a follow up telephone call. The exercise of making telephone contact with school principals was largely a 'hit and miss' affair. Journal records clearly demonstrate the number of times when principals were unavailable and the need to follow up on telephone messages left with school administration staff (A. Galloway, personal communication, March 08, 2002, April 04, 2002, June 11, 2002).

There were also a number of issues that surfaced during the selection process of schools that were being considered for participation in the CHL research project. For example, matters arose during the initial communication phase between members of the research team and the school principal and/or community which either delayed the confirmation of participation by some schools or, in some instances, resulted in the research team ruling out certain schools from participating in the project.

There are several incidents that occurred which highlight examples where school principals contributed to delays in the project commencing in their schools. For

example, one school principal demonstrated a level of apathy towards the CHL project responding with comments like, “I don’t know if we are able to do it.” Other principals were reluctant to participate in the project because they were not confident that early career teachers would be able to handle the intrusion of researchers in their classrooms (A. Galloway, personal communication, June 04, 2008).

In one case, a retiring principal appeared to be ‘shielding’ his school from participating in the project. The research team was welcomed and able to present the professional development session to staff, but each time a researcher visited the school, they would go no further than the principal’s office. The principal was always welcoming and happy to chat about the school, but had not arranged for classroom observations to take place, as had been agreed as part of the research project. The researchers did not get into classrooms until a new principal was appointed to the school (A. Galloway, personal communication, June 04, 2008).

Communication with Principals

The research team experienced various communication issues with principals and other school staff during the research project. It was common practice for the research manager to contact school principals and/or deputy principals to arrange visits to conduct research activities associated with the project. Despite this routine practice, the research team encountered several communication issues that caused some concerns between the research team and the participating teachers. For example, there were a number of times when the school principal did not communicate to the deputy principal and/or relevant teachers the dates of planned visits by the research team (A. Galloway, personal communication, May 20, 2002). This level of non-communication resulted in surprised responses from deputy principals and teachers when the research team leader contacted them by telephone to reconfirm the school visit and/or when the research team arrived at schools to meet these staff members. In other instances, the research team would arrive at some metropolitan and regional schools, only to discover that various school activities such as a school assembly was taking place or that a significant number of students were away attending a funeral upon their arrival (A. Galloway, personal communication, August 21, 2002). Note the lack of thought spared for the researchers in this: it would have been a simple matter to call or inform us that the

scheduled visit should be called off and rescheduled. From our point of view, we planned for this in our bookings: all air fares were fully refundable.

New administration staff

The administration staff in each school were major links in the communication process and were often the first point of contact when the research team planned CHL project school visits and when they arrived at each school. The administration staff usually consisted of the principal, and one or two deputy principals. There was an unusual event at one school during the course of the CHL project when the school principal announced her retirement at the end of term two. It was coincidental that both deputies would also be unavailable in term three as one would be on maternity and the other sick leave. The outgoing principal advised the CHL project director to ‘maintain the momentum’ and assume the CHL project as being part of the school’s program, however incoming principal was not as supportive (A. Galloway, personal communication, June 19, 2002).

Communication between the school and the CHL project teachers

The research team communicated to teachers who were involved in the project via the principal or deputy principal. Some principals were happy for the CHL project team to communicate directly with relevant teachers, but the research team always kept principals or deputy principals informed of planned visits. There is one recorded incident where a CHL teacher was aware that students were being collected from her class, but did not know why and by whom. To complicate the situation further, the teacher had received no feedback concerning the PIPS tests (see later in the chapter), and could only vaguely remember what was covered in the CHL PD sessions and as a consequence, was unsure of her role and responsibilities in the project. The project director responded to a request by this teacher to have a copy of the PD notes sent to her. The teacher was happy to continue in the project and didn’t mind herself being videotaped during a lesson (A. Galloway journal, personal communication, May 15, 2002).

Teacher resistance

Despite participation being totally voluntary, there were cases of teacher resistance to participating in the CHL project. This aspect can be anticipated by researchers in any given research involving participants; however, it cannot always be planned for or be known to researchers until the project is underway. In one case, teachers resisted when the principal, without the research team's knowledge, told staff that "they were going to do it!" In another example of resistance, a teacher displayed a friendly persona toward the research team but did not put any effort in to collecting data or being responsive to questions posed by a research team member. In contrast to these examples of resistance, staff in other school systems readily confirmed their participation in the project without question and this raised the question of whether some schools expected staff to accede to requests, putting in jeopardy the notion of voluntary participation (A. Galloway, personal communication, May 17, 2002).

In another example, a deputy principal advised the research team leader of at least five teachers at her school who refused to commit themselves to learning new strategies relating to the CHL project. However, the deputy principal was looking forward to a PD session for all metropolitan teachers that was being scheduled in the near future and was hoping that this would make a difference (A. Galloway, personal communication, June 05, 2001).

School & community issues

The non-participation of schools

Some schools chose not to participate in the research project as they stated that they did not have sufficient students to warrant the study and/or the students were of sound health and so the study was not appropriate for them. The research team found that there was a high correlation between low socio-economic family environments and higher than normal incidence of conducted hearing loss (A. Galloway, personal communication, February 25, 2002, February 25, 2002, CHL Minutes, 06/03/02).

There was also one example where the principal of a school informed the CHL project director that teachers had declined to participate as they felt uncomfortable about being involved in the study, especially with regard to their inclusion on a website. The requirement of having to complete consent forms and the use of AIEOs to

distribute, explain and collect consent forms from Aboriginal parents and caregivers were other concerns raised (A. Galloway, personal communication, March 11, 2002).

In another case, a principal endorsed support for the involvement in the CHL Project but suggested that a final decision be put on hold as a new principal was about to be appointed and that there was likely to be staff changes in the junior primary section, especially in one classroom where a secondary trained teacher in Home Economics was appointed (A. Galloway, personal communication, May 24, 2002).

In another example, a school principal was experiencing a dispute with the school's Aboriginal community as a result of the community's reaction to the disciplining of a child by a teacher at the school. Despite this incident, the chairperson of the community, when discussing the issue with the research team, agreed to support the participation of the school in the CHL project. The research team leader, however, felt it would be best not to involve this school in the project.

In another incident, a research team member found that the communication link into an Aboriginal community was controlled by a non-Aboriginal 'gate keeper.' Despite the research team member following protocol in requesting to speak to the chairperson or recognised elder of the community, the 'gate keeper' refused to allow any communication with community members and denied permission for the research team to visit the community to discuss and/or invite participation in the CHL project. When this incident was conveyed back to the educational provider concerned, the research team were informed that an educational consultant had created friction with some community members on a recent visit and that the stance taken by the community and the 'gate keeper' was in reaction to this.

Issues raised by teachers

There was a range of issues that teachers raised with the research team when they were considering their involvement in the CHL project. Some of the major points included:

- That participation in the project would mean an increased workload. The research team responded by reassuring teachers that relief staff would be provided and paid for by the project when they attended PD sessions. It was also pointed out to teachers that the teaching ideas covered in the PD sessions would be useful to all students and could be used in different settings. However, there

was an expectation that teachers participating in the project would perform tasks that were beyond their normal workload. For example, they were asked to keep a journal of classroom interaction and comment on the strategies introduced in their lessons. Another requirement of the CHL project was a follow up discussion between the teacher and the project team after each classroom observation visit (CHL Minutes, 06/03/08).

- The video recording of classroom sessions concerned some teachers and these teachers indicated that they would not consent to being videoed. The research team respected this right and were happy with the small number of teachers who did agree to have their lessons videotaped.
- One teacher felt uncomfortable at a researcher being present in her classroom but was happy to compensate this situation by making extensive journal entries of classroom interactions and outcomes of lesson activities. Despite the researcher being unable to make classroom observations, the classroom teacher's detailed notes and follow up interviews proved to be a successful arrangement for data collection (A. Galloway, personal communication, March 27, 2002).

Use of video recordings

The research team planned to make video recordings of classroom lessons where CHL teaching strategies were being used in order to analyse the fine detail of each lesson. If these lessons were suitable, it was intended to include the recordings in a package for teachers wishing to acquire skills needed for teaching students with CHL. Schools were generally reluctant to give permission for lessons to be videorecorded but some did indicate that if teachers and parents supported the videotaping of lessons, the recording could not be used later for public consumption (G. Partington, personal communication, November 29, 2001)

The issue of videorecording in classrooms presents some important considerations for researchers who are researching in Indigenous contexts. For example, the use of the video recording in the public domain may expose the whereabouts of children who are at risk or who are under police protection. Researchers and school administrators need to be mindful that students who are gradually gaining confidence in coming to school may feel uncomfortable when video recording is occurring in the classroom (A.

Galloway, personal communication, May 23, 2002). The screening of deceased subjects is also a major concern among Aboriginal people. Another ethical matter for researchers to be aware of is the rights of other classroom members who are not actively taking part in the research project. Permission from parents of these students must also be sought as their child may be included the videorecording.

The research team wished to send letters to parents to request their approval regarding the incidental videorecording of classroom sessions. In doing so, a legal advisor from one of the education systems was consulted to find out whether or not names and addresses could be supplied to the research team. The advice provided was that they could not access the names and addresses and so we provided reply paid letters to the school and they addressed them. (A. Galloway, personal communication, February 26, 2002).

Delay to video recording

Video recording was delayed for two weeks at one CHL school as some students from another metropolitan school had been relocated to this school site because of asbestos roofing fears. As a result of this movement of students, the research team identified cases where no previous consent had been obtained for some of these students. In addition, there was also the possibility that there were no health records available for some of them. The dilemma faced by the research team was that they already knew the parents as they had interacted with them previously, but could the research team communicate with parents for this purpose? When a research team member had explained the situation to the classroom teacher, the teacher responded by approving the video recording on behalf of the parents/caregivers. The research team wisely decided to wait on receiving signed consent forms prior to video recording. The project team leader rescheduled the visit for a date following the return of the relocated students and teachers to their school (A. Galloway, personal communication, May 17, 2002).

School/education/health authority issues

Multiple agency issues - communication

The conduct of research involving a number of stakeholder groups or agencies will present communication challenges for any researcher or research team. In the case

of the CHL project, the challenge involved communicating all aspects of the research activity with a number of stakeholders in metropolitan, rural and remote regions of Western Australia. The stakeholders included representatives from relevant Aboriginal Medical Services, Western Australian Aboriginal Community Controlled Health Organisation (WACCHO) & the National Aboriginal Community Controlled Health Organisation (NACCHO), school principals and teachers, medical and language experts in the field, and senior staff from each of the school systems. The research team leader and committee organised a symposium for metropolitan stakeholder groups to discuss the CHL research project on 11 May 2001 at the premises of a metropolitan Aboriginal Medical Services Centre. The symposium also provided an information forum aimed at attracting targeted schools from the Swan metropolitan region to participate in the CHL research project. Teachers from six government schools and one Aboriginal independent school attended the symposium. The research team leader confirmed that all government schools attending the symposium were interesting in the CHL project and that dates had been set for team members to visit these schools and speak with relevant teachers (A. Galloway, personal communication, May 11, 2001, CHL Minutes 15/05/01).

The program for the symposium included presentations and discussions on: Otitis Media and CHL; the causes of OM; the screening of particular sections of the CD, “Do you hear what I hear?”; the CHL research project and informed consent and the process of obtaining consent. A mock spelling test was administered to participants, simulating the conditions experienced by children who have CHL. Test takers were issued with ear plugs to reduce participants’ hearing ability and the test was administered in such a way that the test administrator was not always speaking directly to the audience, while deliberate noises caused by such events as dropping a book on the floor were made when some words were announced. (A. Galloway, personal communication, May 11, 2001).

Lack of hearing records

The testing of hearing is usually carried out by qualified health personnel using a tympanometer, however, this did not always occur during the CHL research study as some untrained staff were given this task to perform.. This instrument is used to screen patients to identify those with significant hearing loss. The project required access to

hearing medical records so that Aboriginal students aged between Year one and Year seven could be identified for their participation in the research study. The research team found that some health services in a particular region under study did not own or have access to a tympanometer. The instrument was valued at \$8,000 at the time and project funds could not be used to purchase this item. The CHL committee suggested that the 'Lion's Help to Hear' program be contacted for assistance or that it may be possible to hire one from the Speech and Hearing Centre (CHL Minutes, 03/04/02). However, this would have been of little value because medical staff had to be trained in the use of the device. For example, in one case, an Aboriginal Health Worker who had been assigned the task of testing hearing at two CHL project schools in the metropolitan area did not know how to use a tympanometer and therefore, would not be able to carry out testing and interpret the results properly. The project director suggested that contact should be made with one of the hospitals in Perth or with a trained speech pathologist at one of the universities. An audiologist employed by the DOE was also available to train the Aboriginal Health Worker in using a tympanometer (A. Galloway, personal communication, May 09, 2002). Another possible avenue of assistance was the Aboriginal Medical Service. Following enquiries with local health services and school nurses, the project team were advised that hearing testing was conducted as part of their responsibilities and was available in all schools that were participating in the project (A. Galloway, personal communication, May 23, 2002; May 24, 2002; June 19, 2002).

The issue of extra workload in gathering medical records of students was raised by one Aboriginal Medical Service Centre. It was agreed that schools would have medical records for many students as testing was carried out by the local school nurse. There may be only a few cases where records would not be available at the local school and this would require a search to be done by the local AMS. When this was required, the project funds were used to cover these costs. (A. Galloway, personal communication, May 24, 2002).

Professional Development (PD) sessions for teachers

An important feature during the early to mid-stages of the CHL project was the arrangement of on-going PD sessions in all three regions of the state for teachers who had agreed to participate in the research study. These sessions were organised and presented by members of the project team and the first of these sessions targeted

schools from the metropolitan area of Swan. The PD session took place on 17 August 2001 at a conference centre venue which was hired for the day. Teachers from four schools attended this session while staff members from a fifth school declined to participate in the PD session as it was planning to join the CHL project in the following year. This PD session followed the success of a CHL symposium held on 11 May 2001 and which was attended by interested stakeholder groups, including the four schools that were attending the PD session.

The PD program included topics covered in the symposium outlined above and it also had a strong focus on the relationship between language and literacy and the implications for children with CHL. The PD session also outlined the strategies that were to be introduced in classrooms, the classroom visits by research team members who would observe language lessons and the use of these strategies. The teachers were also asked to keep a journal to record how the strategies were working out in their classrooms (A. Galloway, personal communication, August 14, 2001).

PD Issue:

Several weeks after the PD, the research team visited the metropolitan teachers and discovered that many of them could not recall what was expected of their participation in the project. As a result, the research team leader decided that all future PD for teachers would occur on a school by school by school basis, including schools in both regional areas (CHL Minutes, 4/10/01). This new PD presentation strategy was first introduced on 01/02/02 at a metropolitan school that was joining the project this year for the first time. The team leader records in his journal that, “ having a smaller group than was present at the PD last August made for a more responsive group and better interaction” (CHL Minutes, 06/02/02).

Another issue confronting the research team was the annual turnover of teachers who were involved in the project from one year to the next. For example, for the period 2002-2003, 550 permanent teachers left the teaching service and just under 50% were aged over 55 years (DET, 2003, p.131). Reasons for leaving the service were not disclosed in the report, but there would be a number of reasons which would contribute to this outcome. This unavoidable situation concerned the research project leader as the CHL project was being monitored over an 18 month period and such changes were likely to reduce the efficacy of the introduced teaching strategies because of the loss of

teachers trained in their use and the need to train new teachers when they were appointed (CHL Minutes, 06/03/02). The other concern under such circumstances was the possible outcome that the incoming teacher would not give their consent to participating in the project. Fortunately for the research team, this outcome did not eventuate. The research team leader informed members attending a CHL committee meeting that the most effective way to introduce change is for the “strategies to be taught in teacher education courses and bring about pedagogic change that way. It takes time to bring about this sort of generational change in pedagogic practices, but is the most effective way” (CHL Minutes, 06/03/02).

The involvement of community members in PD sessions.

The issue of involving Indigenous community members in PD sessions was raised by a representative from one of the education providers and fellow CHL committee member. The involvement of Indigenous community members in school based learning programs and other school activities is encouraged at all educational levels and this was also encouraged and supported by the CHL research team. This was achieved by inviting community members to participate in PD sessions and, in a significant move, by adding a community consultation role to an Indigenous CHL research member to keep community members informed of the research project and importantly, to monitor on-going consent of the project. While community members were invited to participate in PD sessions that were being presented by members of the CHL research team during school visits, other community matters and priorities often prevented them from attending (CHL Minutes, 07/08/02). It is important for researchers and other visitors to Indigenous communities to have an understanding of the political, social and family structure found in local and large communities. Such happenings or events will determine whether parents and/or other community members are able to attend activities that they may have been invited to.

Awareness of OM and CHL

The research team spoke to metropolitan and regional health personnel as part of informing them of the CHL project. While some community health workers were active in some regional areas in promoting ear health and encouraging schools to use the resource kit, “Do you hear what I hear,” one community health officer indicated that

many teachers, AIEOs and ATAs had no knowledge of CHL. In some instances, ear health records were stored by schools but there was no follow up when there was a change of teacher or when the student moved to another class in the following year. As a result, there was often a lack of knowledge of what had been done previously with the learning program for the child and importantly, the existence of the problem (A. Galloway, personal communication, March 28, 2002).

Industrial award limitations.

The Manager for Aboriginal Education from one of the school systems advised that industrial agreements existed between the Education Department and the teachers and as a result, principals or district directors could not enforce the participation of teachers in the research project. The research team acknowledged this condition and drew a parallel by making reference to the NHMRC's ethical guidelines which state that a participant has the right to withdraw from the research activity at any time and that written consent is required prior to the research activity commencing. The research team leader advised that he would contact district directors, principals and teachers in order to establish what could be expected from those teachers who agreed to participate in the project (CHL minutes, 13/02/01).

Relief teachers

The research team scheduled on-going PD sessions and other meetings out of school hours whenever possible to minimise classroom disruption but when this arrangement was impractical, relief teachers were used. The provision of relief teachers was funded by the project. These teachers played an integral role during the first 12 months of the CHL project as it allowed participating classroom teachers to attend initial and on-going PD sessions with the research team without the need for schools to provide their own teacher relief. It also provided the opportunity for the regular classroom teacher to carry out the individual testing of students for the project. This provision was welcomed by teachers and principals and was a big incentive to be involved. Many of the schools involved in the project had access to relief teachers, but there were cases where the number of relief teachers was insufficient and for schools in remote locations, there were no relief teachers at all (CHL Minutes, 03/04/08). In cases

where there were no relief teachers available, the research team used other personnel and some examples are outlined below.

In one school, understaffing issues meant that some of the added responsibilities associated with the CHL project such as the individual Performance Indicators in Primary Schools (PIPS) testing, would result in increased workload for teachers. The PIPS test is a computer based literacy and numeracy test that was chosen for the CHL project by the research team and is discussed in detail later in this chapter (see Assessment tool). Whenever possible, the research team would conduct individual PIP testing of students during scheduled school visits (A.Galloway journal, personal communication, February 26, 2002).

It was stressed by the research team leader that teachers should not be expected to give up their DOTT (Duties Other Than Teaching) because of scheduled meetings with the research team or, because of shortages of relief teachers (CHL Minutes, 06/03/02). In one regional location, the CHL research team considered using Aboriginal Tutorial Assistance Scheme (ATAS) tutors who were engaged in tutoring the University's Aboriginal students as relief teachers. The use of new University teacher graduates who were without a school posting at the time was discussed. This arrangement however, would need to be supported by the school principal and require each person to obtain police clearances if they did not have them (A. Galloway, personal communication, February 26, 2002). One school participating in the project had no concerns regarding the appointment of relief teachers as each class had an ATA who could cover for teachers when they attended PD and/or debriefing sessions with the research team (A. Galloway, personal communication, March 19, 2002).

Clash between visits and school activities

There were several occasions when the research team had to make adjustments to their planned visits and proposed activities due to late changes in school activities or when the research team were not informed of school assembly or when educational road shows were visiting the school. For example, the research team were informed by the school principal that there would be no students attending school on the day of our next visit due to a switch in the scheduling of another, unrelated PD session for teachers at the request of the PD presenter. Had the school not agreed to this, they would have missed out on receiving this PD activity altogether. The CHL team could not change

their travel plans so were committed to visiting the school as other schools involved in the CHL project were also being visited in this travel schedule. The pre-primary to Year three teachers however, agreed to miss the school's PD session in the morning to attend a session with the CHL team (A. Galloway, personal communication, May 20, 2002).

Student numbers

The fluctuating nature of Indigenous enrolments in schools that were participating in the project drew concern among members of the research team throughout the period of the study. At one school, so many students were leaving that pre-primary classes were being discontinued and, as a result, this would have implications for the project. The project director suggested that the situation be monitored over the school term (A. Galloway, personal communication, June 25, 2002). Despite student numbers falling to four children at this school, the research team continued to interview the teacher.

Delays in obtaining ethical clearance

Use of Australia Post reply paid envelopes

As noted above, in granting approval for the research team to use 'negative or passive' consent, the University's Ethics Committee, it was made subject to the arrangement for a reply paid envelope to be included in the communication between parents and each school. A difficulty emerged, however, when the team were required by the ethics committee to have the envelopes returned to each individual school. This made the process of arranging a reply paid envelopes a complex and time consuming task. The CHL project director stated that, "Australia Post requires each return address to include a unique barcode, and an individual postage account code, which necessitates a separate application for each return address" (CHL Minutes, 03/04/02). To add a further complexity to using reply paid envelopes, the research team director was informed by the commercial mailing firm used in this mailing activity that street numbers would be required for each return or school address. When enquiries were made to schools concerning this matter, the response given back was that schools did not have or use a street number. This message was forwarded onto the mail distributor and the mail out occurred without street numbers (A. Galloway, personal communication, March 28, 2002).

On-going informed consent – designated role of Aboriginal research team member

The research team encountered long delays in obtaining consent from parents and caregivers as they were reliant on each school to distribute and follow up on any outstanding forms. The research team realised the importance of winning trust among parents in the conduct of research involving their children and for them to be aware of issues relating to giving and withdrawing consent and on-going consent. To this end, the project leader designated this role to an Aboriginal person who was part of the research team. The team member assigned to this role would often meet parents and care givers at school and speak to them about the CHL project and their understanding of it. Although many of the parents were interested and supported the study, they did not have a clear understanding of its major purpose, that is, to introduce CHL teaching strategies via classroom teachers and evaluate their effectiveness. The understanding of many parents was that the research team was there to conduct hearing tests with their children. This understanding was corrected when the responsible research team member met and spoke to parents and/or caregivers during each visit.

Delays in the handling of consent forms

As the research team could not be directly involved in sending and receiving consent forms, they were dependent on school personnel to carry out this task and to follow up on outstanding forms. The research team expected that there would be some delays as a result of this process, but these delays were so long in some cases that schedules for school visits and the recording of classroom lessons had to be delayed. The main causes for these lengthy delays was the forgetfulness of a school registrar to post out the consent forms to parents prior to the school holidays or the misplacement of these forms by the school (A. Galloway, personal communication, May 10, 2002). In one example, a school principal telephoned the project director to say that CHL project teachers at his school did not know anything about student consent forms, although the teachers concerned could recall a form inviting their participation. It transpired that consent forms that were left with the principal two months earlier had not been passed onto these teachers and were now lost. A batch of 50 consent forms were posted out to the deputy principal as the principal would be away for a week (A. Galloway, personal communication, May 17, 2002). Further delays were experienced at this particular school as these consent forms were again lost when the deputy principal left the school

to be acting principal at a remote school in the same district (A. Galloway, personal communication, July 16, 2002).

Ethical dilemmas faced by research team members

Research involving classroom observations can sometimes lead to ethical issues and dilemmas for the researcher. For example, some classroom observations may pose ethical versus moral issues, especially when the action observed is considered to be unprofessional and/or inappropriate. As outlined in the literature review, the NHMRC's principles of ethical conduct and associated guidelines for the conduct of research involving humans are designed to protect the welfare and rights of participants in research (NHMRC, 2003, p.11).

The research team members experienced a number of incidents that were considered to be unprofessional and inappropriate during the classroom data collection process. For example, on several occasions, two research team members witnessed a teacher in gross neglect of her duties. There were no instructions or evidence of any teaching taking place during each of the visits to this teacher's classroom. This scenario proved very difficult for the researchers to deal with, as in discussion, they felt a moral obligation to protect the rights of these children but were bound by the ethics of their research to maintain confidentiality regarding access to classrooms.

Requests for confidential information

On two occasions, the CHL project director was approached by school and district administrators to disclose information relating to teachers' performance, following CHL data collection sessions in their classrooms. One request came from a District Education Office staff member, who had concerns about a teacher's ability to teach her students good English as English was not the teacher's first language. "She virtually asked for a report, which of course we couldn't and wouldn't give; the only thing we ever gave was positive news" (A. Galloway, personal communication, October 14, 2009). The second incident was a request from a deputy principal who wanted a copy of a data collection tool, mapping language skills observed being taught in classrooms and strategies used to teach them. This request was also refused by the project director, who suspected that deputy principal wanted to use the tool as evidence to support a perceived concern about the teacher's classroom performance.

The above incidents illustrate a dilemma facing many researchers who engage in classroom observations as part of the data collection process. However, researchers are duty bound not to disclose such information, unless there is a requirement under law, such as the mandatory reporting of actual physical or sexual abuse. In summing up this dilemma, the project director stated, “if you go and report [a teacher’s] performance, you are breaching your confidentiality undertaking as a researcher and you will lose trust of the teacher and potentially other teachers as well” (A. Galloway, personal communication, October 14, 2008).

On each occasion, members of the research team responded appropriately and ethically, in protecting the individual concerned. In the first instance, the researchers commented in general terms to the principal that as classroom observers one sees a lot of good and not so good things happening from one class room to another, identifying no particular individual or school. In the second example, the researcher concerned refused to disclose any information to the senior district education officer, stating that researchers are bound by ethical guidelines and protocols not to reveal or discuss such matters with anyone who not members of the research team. In the third example given, the researcher again informed the principal of the ethical responsibilities that researchers had to abide by and advised that the information could not be supplied.

Police Clearance

The Education Department has regulations that require frequent visitors to its schools to undergo a Police Clearance check. Members of the research team made application to the Education Department (WA) to obtain clearances prior to undertaking school room visits (A. Galloway, personal communication, January 29, 2002). Police clearances were obtained for each research team member. These police clearances primarily serve the purpose of confirming that an applicant has no previous criminal convictions, but the research team were also aware of the need to protect the clients in the study in a broader ethical context. This involved adhering to ethical obligations and practices that have been outline by the NHMRC and the university’s ethical committee.

Other NIELNS funded projects

As indicated at the beginning of this chapter, the Commonwealth Government had allocated national funds for the development and implementation of literacy and

numeracy strategies aimed at improving achievement levels among Indigenous Australian students. Education providers were funded for projects to use in designated targeted areas, i.e., Swan, Goldfields and Kimberley. While schools were being approached by the CHL research team to participate in the project, two other CHL projects were taking place in two remote Aboriginal Independent school locations. These two projects were funded by one of the educational providers and involved two current members of the CHL research committee. The program at these two school locations involved parents and care givers, students and classroom teachers. Sections of the CD, “Do you hear what I hear” were screened to all participants. This activity was followed by a language session with the students and the individualised testing of students using the Waddington test with lower primary students and the St. Lucia test with senior primary students. These activities continued into a second day with the students. The parents and caregivers were invited to participate in the program on the second day and were given tutor packs and were engaged in language skills activities so that they could tutor their child at home. A session with teachers and the school principal was conducted after school to inform them of the activities that took place.

The issues:

Several issues arose as a result of these two activities:

1. The two day program had been video-taped without the consent of participants and as a result, the material could not be used unless written permission had been confirmed;
2. Not all parents were able to attend the designated tutor sessions and therefore parental participation and feedback was limited;
3. No ear health history was kept on any of the students who attended these two schools as medical specialists did not want to work in isolated locations and the students tend to move frequently between communities,
4. That tympanometer screenings to assess degree of hearing loss had to be conducted by the two program presenters and not by a qualified nurse. These screenings were carried without formal medical ethics being approved and therefore, the students could not be identified. Furthermore, there has to be some doubt on the validity of the results given the screenings were conducted by unqualified personnel and, that there was no follow up with teachers and students. Despite these infringements of ethical

practice, the study resulted in a publication by one of the educational providers (A. Galloway, personal communication, May 17, 2001).

Concerns regarding an inter-agency approach

Issues concerning the funding of OM projects to inter-agencies under the NIELN strategy were raised by staff from a district education office with members of the research team. The major concern was that there was no evidence of a co-ordinated inter-agency approach on OM projects that were currently underway in schools from the three NIELNS specified regions of Swan, Goldfields and Kimberley. There were also concerns expressed about the ‘fragmentation’ of funding for a number of small scale projects (A. Galloway, personal communication, March 18, 2002). Some of the major concerns raised were:

- Schools in the Swan, Goldfields and Kimberley Districts were allocated \$50,000 each to carryout projects under the NIELN strategy which identified three major areas in addressing ear health issues among Aboriginal children. The focus areas were classroom acoustics, health factors and teaching and learning programs. While there is merit in exploring different ideas to improve learning outcomes among students who suffer from CHL, these projects must be co-ordinated so that they target specific areas for improvement in a concerted manner. For example, hearing results of students were sent to schools and parents, but as one hearing specialist pointed out, there was little follow up and parents need to be informed of the consequences of OM in their children and the effects of CHL (A. Galloway, personal communication, March 18, 2002).
- The ‘fragmentation’ of funding by inter-agencies to schools. For example, in one district significant funds were allocated to schools in a remote region of the district to examine classroom acoustics, health factors and teaching and learning programs. A large amount of this money was spent on the purchase of 12 sound field amplifier systems which are designed to increase sound levels around a classroom. Classroom teachers wear microphones and their voice is projected via an amplifier to a number of speakers which are placed around the walls of the room. In addition to this project, another agency (Indigenous Language Speaking Students Program - ILSSP) provided funding of \$3,000 per student in Year One who had not achieved Level 1 on the English as Second Dialect (ESD)

band scales, therefore providing funding based on student outcomes or achievement. The band scales refer to 9 levels of writing development from initial exposure to print based literacy through to written proficiency (A. Galloway, personal communication, March 18, 2002).

Funding was also provided by the Health Department to employ ATAS tutors at the schools, but none were available and the timeframe of one school term to complete the task was inappropriate. Under this arrangement, students were taken out of classes which had a trained teacher and were sent to work with untrained tutors who were employed for only one school term. There is no evidence to suggest that improvements among these children would occur under these circumstances (A. Galloway, personal communication, March 18, 2002). In one region however, a qualified speech pathologist who was employed by one of the education systems, provided training for tutors in literacy and numeracy (A. Galloway, personal communication, April 11, 2002).

- Issues concerning the “Do you hear what I hear” resource kit (Education Department WA, 2001)
 - (i) The health history that was asked for by the authors from parents whose child(ren) were affected by CHL, were far too detailed and the questions asked were considered to be very sensitive. The nature of direct questioning is likely to be offensive and generates shame among Aboriginal people (Eades, 2007).
 - (ii) The scales used to classify the degree of hearing loss used in the “Do you hear what I hear” resource kit are not consistent with what the Health Department uses as the author of the CD made changes to the scale.
 - (iii) The author of the resource kit also requested teachers to carry out audiometry and tympanometer testing among their students. These health assessments are not responsibilities of teachers nor are they qualified to interpret test results.
 - (iv) The CHL profile focuses on medical rather than educational issues and matters (A. Galloway, personal communication, March 18, 2002).

Involvement in other literacy projects

There were a number of literacy projects operating in targeted CHL project schools at the time when schools were being approached to participate in the study. For

example, the Kimberley Literacy Project, Literacy Net, First Steps, THRASS, and a phonics program for teaching English as a first or other language. The demands of participating in two projects and the extra pressure being placed on teachers was raised by one school principal (A. Galloway, personal communication, February 26, 2002, March 28, 2002, April 19, 2002). In order to minimise duplication of literacy activities and extra workload on teachers, the CHL research team integrated materials from First Steps in the development of CHL teaching strategies (A. Galloway, personal communication, January 21, 2002). The school that was concerned with being involved in two literacy projects later agreed to participate in the CHL study as any additional workload was considered to be minimal. The concern of teachers being asked to participate in a number of projects was also highlighted by a principal at another CHL school where it was decided that staff involvement would be restricted to two projects, one them being the CHL (A. Galloway, personal communication, May 23, 2002).

Copyright/Intellectual property issues

Incidents of unprofessional and unethical behaviour experienced during the CHL research project relate to matters of intellectual property and copyright. In discussing these matters, this section will, first of all, foreground the meanings of these two terms and outline the university's position on intellectual property and copyright at the time of the study.

Intellectual property (IP) as defined by the Australian Government is the term given to the laws covering patents, trademarks, copyright, designs, circuit layouts and plant breeders rights. Intellectual property laws protect the property rights in creative and inventive endeavours and give creators and inventors certain exclusive economic rights, generally for a limited time, to deal with their creative works or inventions (Commonwealth of Australia, 2008). It is interesting to note that creating IP does not automatically give you ownership rights to it. From the types of IP listed above, only copyright and circuit layouts are automatic in application, while the others require a formal process to register IP and protection of legal rights of ownership (Commonwealth of Australia, 2008). The issue of intellectual property (IP) and, particularly, the issue of ownership of intellectual property have grown in importance and complexity. Most organisations, enterprises and individuals who are involved in business and other commercial enterprises, will face issues concerning the protection of

intellectual property. IP consists of a number of laws which have ‘evolved separately’ over time and serve ‘different purposes’ (Collins & Forrest, 2008, p. 2).

The term ‘copyright’ is synonymous with IP. Copyright is defined as the protection of, “original expression of ideas, not ideas themselves. It is free and automatically safeguards your original works of art and literature, music, films, sound recording, broadcasts and computer programs from copying and other uses” (Commonwealth of Australia, 2008) Despite the introduction of legal protection or legal rights regarding intellectual property, there have been many cases of disputes and litigation reported in the literature. For example, Monotti & Ricketson (2003) and Collins & Forrest (2008) provide numerous examples of legal disputes involving IP that have been brought before the courts. Many of these disputes have occurred in a number of organisational settings, including universities. Australian universities have addressed the issue of intellectual property and ownership of intellectual property by providing clarification and guidelines to staff and senior administrative staff (ARC, 2001). However, university policy guidelines alone do not provide certainty over IP ownership and this position has been confirmed by a decision that was handed down in 2008 by the Federal Court of Australia , for example the *Gray vs UWA* (No 20) 2008 FCA 498. In brief, a federal court judge agreed with a university employee that medical research developed outside his teaching contract was not owned by the university as it was not clearly outlined in the employee’s contract (Australian Government Solicitor, 2008).

The ownership of intellectual property (IP) in particular, is an interesting one to discuss here in light of two incidents which took place in the early stages of the CHL project. A speech pathologist was employed as an independent contractor to develop language activities for the CHL project. The person had earlier refused to accept a university contract for her services to the CHL project and requested an invoicing arrangement with the CHL project leader. The project leader arranged for the filming of the language activities that were developed by the independent contractor. At the beginning of the presentation by the independent contractor, the film crew were instructed not to film any of the work that was depicted in posters, whiteboard notes and in overhead projector displays. As the presenter was filmed standing in front of these media resources throughout the presentation, virtually none of the filming could be used (A.Galloway, personal communication, October 14, 2008).

This incident was unexpected by the research team leader as he believed that the filming would be seen as a partnership between her and the University. He also believed that she was concerned that the CHL project would ‘steal’ her intellectual knowledge, despite many of these strategies being taken from other sources (G.Partington, personal communication, October 14, 2008). Her argument appeared to be based on the perception that all of these strategies were her knowledge. The team leader stated that similar strategies had been already developed by experts in the field. Despite this finding, the information sources for these strategies she presented were not acknowledged in the presentation.

In addition, this contractor was also concerned about copyright on some picture cards she had adapted for use in the CHL project. The team leader pointed out that she was under contract to the University to develop resources for use in the research project and that under such contractual arrangements, the University held copyright over these materials (G. Partington, personal communication, October 14, 2009). This arrangement however, was not expressed explicitly in writing and therefore, any conditions associated with intellectual property would not usually apply. If it was explicitly stated in her contract that she was to produce language cards as part of her duties, then it would be reasonable to assume that IP would be owned by the university. (P.Monger, personal communication, January 21, 2009). In support of this clarification, the university’s IP policy at the time stated, “the intent and specific reference to the University’s IP policy shall be referenced in contracts of employment, letters of offer, position descriptions, induction materials and other relevant policy documentation” (ECU, 2001, p. 8).

It is therefore paramount that universities carefully draft employee contracts concerning IP to establish clearly whether IP ownership is held by the university or by the employee. In order to quickly resolve the situation, the project leader decided that in the best interests of the project, the resources would not be used in any future project activities (CHL minutes, 12/03/01). This example sends a clear warning to managers of research projects who may choose to use verbal agreements in casual or independent contracts with employees, particularly those who are known to them. The importance of explicit contracts has been detailed above, and a way forward for researcher managers in handling this type of matter is to outline the possible risks and risk management

associated with the services required, prior to making an appointment. This strategy is reinforced by the comments of the CHL project leader who said,

I should have got her to sign a consent form in advance, but being a member of the project team and sort of listed as one of the researchers, I thought this was unnecessary in that we'd discussed in advance at the day's workshops and there'd been no problems (G. Partington, personal communication, October 14, 2008).

There was also another incident regarding 'IP' which involved another contracted person and the CHL project leader. The person, who was also a university staff member, was contracted to develop the electronic version of the CHL teaching resource strategies book for the CHL project. In setting about this task, the person was provided with resource cards that were developed by the contractor and with text that was provided by the CHL research team. The software program, 'Adobe Page Maker' was chosen by the person to develop the teaching resource strategies book. Adobe Page Maker was a desktop publishing program used to create publications such as brochures and newsletters. The program provides the user with examples of templates, graphics and design tools. The program also allows the user to make the document a 'read only' file, similar to a Portable Document Format (PDF) document, which protects the format of the file. When drafts of the CHL teaching strategies were sent to the CHL project leader and project director for their perusal, they discovered that each line in the document had been 'locked,' making the task of editing the document very difficult and time consuming. The project leader and director considered this action to be unprofessional and unethical as it was a deliberate act to sabotage the document in a bid to protect what he regarded was his 'intellectual property' (G. Partington, personal communication, June 13, 2008). In the end, the project leader decided not to use these cards as it was felt that other resources which were being used in CHL learning activities were just as effective and it also provided an opportunity for the research team to produce new materials (G. Partington, personal communication, October 14, 2008). The two incidents that have been described above, highlight the need for researchers to receive training in IP and contract matters in order to minimise disagreements and potential cases that could result in a court dispute.

Conclusion:

The CHL project encountered a number of issues during the research process, some of which were unavoidable, some that were beyond the control of the research team while others could have been difficult to address and/or resolve, if it hadn't been for research team's demonstration of cultural competence. The building of relationships with the participants and stakeholders was a key factor in determining positive outcomes for most of the issues and concerns that confronted the research team and the participants during the CHL project. While there were lengthy delays in obtaining ethics clearances, the approval process clearly acknowledged the shift in the control of Indigenous research to Indigenous agencies and/or communities. Nevertheless, the multiple ethics clearances required for the CHL project to go ahead was extraordinary given that the study was education related but required the identification of Indigenous children who were suffering from CHL. While it is important to acknowledge and maintain Indigenous ownership over research involving Indigenous participants, the demands on the research team to secure appropriate ethics approval and the difficulties involved in ensuring sound ethical practice stretched their resources and skills considerably and limited the potential outcomes of the study. At the time of the CHL project, it was evident that some Indigenous agencies were not familiar with the research process and had passed their authority to non-Indigenous personnel. This outcome reflects the arguments and the dialogue that have been presented by academics like Rigney, Moreton-Robinson and Nakata who advocate strongly for further research reforms so that research methods and processes can be understood and followed by all those who are involved in research.

CHAPTER SIX

CURRENT ETHICAL RESEARCH GUIDELINES

Introduction:

The introduction of national ethical research guidelines by the NHMRC and those which have been developed by other institutions for the purposes of meeting their particular needs and/or contexts, have set benchmarks and compliancy requirements for the conduct of ethical research involving humans. These guidelines identify ethical obligations and responsibilities that are required of the research community and for research practice to be conducted with integrity, respect, justice and beneficence.

The NHMRC have statutory responsibility for the development of ethical research guidelines involving humans in Australia. The *National Statement on Ethical Conduct in Human Research* which has been produced by the NHMRC is the recognised authoritative document that provides guidelines for researchers and institutions for the conduct of ethical research, research design and publication and dissemination of research findings involving humans, as well as guidelines for reviewing bodies such as HRECs.

The research guidelines that have been established by the NHMRC and other institutions are subject to regular revision and updates in a continued effort to improve ethical research practices and processes and to address any shortcomings of the existing guidelines that become evident. The NHMRC has recognised the importance of maintaining a separate, complementary set of guidelines for the conduct of research involving Aboriginal and Torres Strait Islander peoples in response to requests from community groups, researchers and health organisations (NHMRC, 2003). The NHMRC have also approved WAAHEC as a separate body to have the responsibility of reviewing research projects involving Aboriginal and Torres Strait Islander health. This chapter responds to the research question, 'To what extent is a new framework needed to address the issues that arose in the research study?' In addressing this question, the chapter will provide a brief review of what constitutes an appropriate response to the desired reforms in Indigenous research, examine the extent to which the new guidelines address the issues that were evident in the case study, discuss the similarities and differences of these ethics guidelines, present a case for the rationalisation of ethics

guidelines and outline what is needed to further improve research practices and outcomes in Indigenous contexts and minimise the duplication of ethics reviews for multiple sites and/or more than two ethical reviews.

What constitutes an appropriate response to the desired reforms in Indigenous research?

While there are guidelines that promote positive outcomes in Indigenous research, these guidelines alone will not guarantee that positive outcomes will always come to fruition (Laycock et al., 2011). Indigenous values and ethics are pivotal in guiding Indigenous research practice but they are dependent on the application of these understandings by researchers during the entire research process. It is reasonable to expect researchers who engage in Indigenous research do so because they want to make a difference to the health and well-being of Indigenous Australians and honour and respect the existing guidelines and research reforms. They also demonstrate that they are advocates of the Indigenous research reform agenda which reinforces Indigenous control and ownership and the setting of priorities for Indigenous research. In addressing this question, the CHL case study will be analysed in the light of previous and existing NHMRC guidelines. Prior to doing so, the chapter will introduce the major developments that relate to Indigenous research.

Current NHMRC guidelines

The current national ethical research guidelines relate to four main documents (see chapter two):

- *NHMRC National Statement on Ethical Conduct in Human Research* (2007a).
- *NHMRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003),
- *NHMRC Australian Code for the Responsible Conduct of Research* (2007b) and,
- *NHMRC Keeping Research on Track* (2006). (see chapter two).

The first three documents are commonly referred to in the reviewing or approval process of ethics research applications by HRECs. The document, “Keeping Research on Track” provides information to assist Aboriginal and Torres Strait Islander people in

understanding and engaging in the research process. This document may be required reading as part of the ethics approval process (e.g., WAAHEC). Researchers may also find this document useful.

University ethics approval process

As discussed in chapter four, universities and other institutions have developed research policies and guidelines for staff, students and, where applicable, external researchers, to ensure that all research is conducted in an ethical manner and complies with the relevant national guidelines for the conduct of research involving humans and animals. The NHMRC's National Statement outlines institutional responsibilities and research governance processes that must be established in overseeing the ethical conduct of research, including the appointment of HRECs to review research applications (NHMRC, 2007).

ECU's research policy requires compliance to the *NHMRC's National Statement on Ethical Conduct in Human Research* (2007) and where relevant, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003) and, *The Australian Code for Responsible Conduct of Research* (2007). The policy also states some human research could also be subject to 'specific statutory regulation' at State, National and Territory levels (ECU, 2010, Section 4.2). Universities, like ECU, have established research offices and have appointed research support staff to assist in the drafting of ethics applications, and guidelines to assist in the drafting of consent forms and letters to participants to inform them about the research project. The research office also has the responsibility of monitoring all approved research projects (ECU, 2010). Research applications are completed and submitted on-line via the University's ethics website and applicants are required to address all sections of the form before submission can take place. The University's HREC has scheduled meetings each month to review research applications, including changes to the original application and, discussion of other research related matters.

Research involving Health

If the research study relates to health issues and/or accessing data from the Department of Health within the state and/or interstate, a research ethics application is required to be lodged with the Western Australian Department of Health. If the research involves health relating to Aboriginal and Torres Strait Islander peoples, a second

application is required to be submitted to the Western Australian Aboriginal Health Ethics Committee (WAAHEC).

The Western Australian Department of Health has recently developed and released two major documents which outline research governance and policy procedures and a major reform in the ethics approval process for the conduct of certain types of health research that are conducted at national and state levels. The documents, *WA Health Research Governance Policy and Procedures* (2012) and *WA Health Research Governance and Single Ethical Review* (2013) have been developed to support a new initiative of implementing a consistent approach to health research involving multiple centres or when more than one Human Research Ethics Committee (HREC) is involved in approving ethics applications, in order to reduce duplications in the ethical review process. The Department of Health claims that, “this is to ensure the efficient use of resources, improve the quality and effectiveness of the ethical and scientific reviews and reduce delays in the commencement of research projects” (2013, p. 5). Under this new procedure, the NHMRC has established a process of certifying a number of Lead HREC’s that will be authorised to approve a ‘once only review’ for sites participating in the National Approach (Department of Health, 2013, p. 6). In supporting a national approach, state and territory governments have signed an agreement for a single ethical review process, which has become known as the ‘National Mutual Acceptance’ for clinical trials to be conducted at participating sites (Department of Health, 2013, p.7). The National Ethics Application Form (NEAF) is used in the submission for projects involving national sites, however, each state will have different legislation regarding certain types of research and corresponding procedures, and these must be addressed as per web site information. For research sites in WA and Victoria, a state specific modular form is currently required to be submitted with NEAF as this additional form addresses ethical issues specific to WA and Victoria that are not included in the NEAF. This includes single and multiplecentre sites (Department of Health, 2012, p. 43). Universities across Australia, including Edith Cowan University, are beginning to accept the NEAF ethics form under a reciprocal approval process (Department of Health, 2013, p. 6).

For single site research projects within WA Health, applicants will need to apply to the local HREC for ethics approval. For example, if a research project has a clinical

component involving a particular WA hospital, an ethics application is lodged with the hospital's HREC. However, if the research project requires accessing information from WA Health data collection as well, a further application is required to be submitted to the Department of Health WA HREC. If the research project relates to accessing information from WA Health only, then an application to Department of Health WA HREC is required. On the other hand, projects involving multiple centres must use the WA Health Single Ethical Review process and this application form is sent to Department of Health WA HREC. This process came into effect on 1 September, 2013 (Department of Health, 2013b, pp.7-8),

The NHMRC has also developed a certifying process to establish Lead WA Health HRECS; however, these are not made mandatory (Department of Health, 2013, p. 6).

The WA Health Research Governance and Policy Procedures (2012) also requires the submission of a 'Site Specific Assessment (SSA) form' for each site if it involves:

- enrolling participants into research;
- carrying out protocol specific research procedures with or on participants; and
- managing and analysing data, tissue and responses from surveys and questionnaires collected for or from research (Department of Health, 2012, p. 19).

For research that is not conducted at a particular site but requires access to 'participants or tissue data', an 'Access Request Review' form is required (Department of Health, 2012, p. 19). This particular procedure is not related to ethical issues but provides an institutional checklist to confirm items such as: the suitability of the site for the research project, suitability of the researchers who have been listed to undertake the research study, the level of resources that have been identified as 'actual' or 'in-kind' to complete the research project, risk management and insurance (Department of Health, 2012, p. 19).

This proposed new format applies to research conducted by Health Department employees and external researchers such as university academics. However, the proposed new initiative of a 'once-only review' does not extend to WA Health and research involving the WA Health Department's data collection (as noted above), Aboriginal people and coronial matters as the policy requires additional approval by the

specialist HREC committees (Department of Health, 2013, p.5). For example, the WA Health Research Governance Policy indicates that the WA Aboriginal Health Ethics Committee (WAAHEC) is the specialist HREC designated for health and medical research involving Aboriginal people regardless of the application having been previously reviewed or made subject to a review by a Lead WA HREC (Department of Health, 2013, p.10). WAAHEC (formerly known as WA Aboriginal Health Information and Ethics Committee), was established in 1996 and has been responsible for overseeing and approving health and medical research involving Aboriginal and Torres Strait Islander people when the research falls under the following categories:

- Aboriginality is a key determinant;
- data collection is explicitly directed at Aboriginal people;
- Aboriginal people as a group, will be examined in the results;
- the information has an impact on one or more Aboriginal communities; or
- Aboriginal health funds are a source of funding (WA Health Ethics Application form, 2013, p. 3).

WAAHEC is an external to the WA Department of Health and is located within the Aboriginal Health Council of WA. WAAHEC is also registered with the NHMRC's Australian Health Ethics Committee (WAAHEC, n.d.). If the research project involved sites in the Kimberley region of WA, the investigators are asked to inform the "Kimberley Health Planning Forum" which is a sub-committee of the "Kimberley Aboriginal medical Services Council" (Department of Health, 2012, p.54).

Submitting an ethics application to WAAHEC

WAAHEC have outlined dates when ethics application submissions are due and when meeting dates have been scheduled on their website. For 2014, five meetings have been organised, approximately nine weeks apart: 31 March, 2 June, 4 August, 6 October and 8 December. These dates are however, subject to change and urgent applications may be considered outside these timeframes. Information on the website also stipulates how to submit an application and this will involve reading the NHMRC's "Values and Ethics Statement: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research" (2003) and, completing the WAAHEC ethics application form and providing supporting documentation as required (WAAHEC, n.d.).

As a point of clarification, the WA Health research ethics guidelines indicate that the term, “Aboriginal,” includes Torres Strait Islanders (Department of Health, 2013b, p.3)

The WAAHEC ethics application form

The current ethics application form is very similar to the form that was in use at the time of the CHL study. The changes to the new application form include:

- The NHMRC’s “*National Statement on Ethical Conduct in Human Research*” (2007) replacing the older version (1999),
- The NHMRC’s, “*Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research*” (2003), replacing “Guidelines on Ethical matters in Aboriginal and Torres Strait Islander Research (Interim, 1991).”
- The following new documents have been added:
 - I. *NHMRC Australian Code for the Responsible Conduct of Research* (2007),
 - II. *NHMRC Keeping Research on Track* (2006).
- The reading of the Royal Commission into Aboriginal Death’s in Custody document has been deleted.
- a description of the research methodology and the identification of any possible consequences,
- The inclusion of a specific list of research areas. For example, “research involving children, innovative therapy or intervention, clinical trials and research involving deception of participants, concealment or covert observation” (WAAHEC, n.d., p.7). This list reflects the research areas that have been identified in the NHMRC’s National Statement on Ethical Conduct in Research involving Humans (1999).
- A specific list of ethical issues has also been added. For example, “audio and visual recordings, accessing confidential data without the prior consent of participants and the use of stimuli, tasks or procedures, which may be experienced by participants as stressful, noxious, or unpleasant” (WAAHEC, n.d., p.7).
- Copies of consent forms are also to be included in the application and,

- Letters of support from the Aboriginal communities who are involved in the research. The application guidelines indicate that this is usually obtained via the Aboriginal Community Controlled Health Services within the region.

What is not included in the current application form is information concerning how the research outcomes are to be disseminated.

Researching in WA schools

- Department of Education (Western Australia) *Research conducted on Department of Education sites by external parties*. In March 2009, the Department of Education produced a policy statement regarding the procedures that are required for research that is being conducted by external parties. The policy statement outlines an administrative process for seeking approval to conduct research involving Department sites, staff, and/or students. Whilst a formal ethics application is not required, the Department requires the submission of a number of documents, including approval documentation from a Human Research Ethics Committee or appropriate approving body. Other supporting documentation that is required in submitting an application to the Department of Education include:

1. Administrative details about the research project. For example, information regarding the research project, researcher details and institution, aims, benefits and beneficiaries of the project, methodology, data collection tools and methods, risks and safeguards, data confidentiality and storage and the dissemination of results.
2. Supporting documentation. Copies of surveys, questionnaires and/or interview schedules; information letters and consent forms, consent forms that relate to the publication or public use of photos, video, audio recording, a Certificate of Currency that covers insurance of researchers for public liability and a Working with Children Check Card.
3. Also required is confirmation that the Department's policy statement has been read and that all matters relating to this document have been addressed. This includes the publication and the reporting of research findings and the requirement to provide copies to the local site manager and Central Office. (Department of Education, 2009).

Following approval from Central Office, researchers must seek agreement from Site Managers or School Principals to participate in the research project.

Catholic Education Office of Western Australia. The Catholic Education Office requires a similar administrative process to that of the Education Department of WA for the approval of research within Catholic schools in WA. Research guidelines provide information to researchers about the application and approval process that have been established by this school system. Applications are required to be sent to the Executive Director, Catholic Education in WA, and these are later reviewed by a Research Review Panel. Any approval by central office is in principle only and researchers will need to seek further approval from local research sites or school principals, a process which is also similar to the Department of Education, WA. In addition, the researcher is required to sign declaration forms regarding confidentiality if the research involves children and a form regarding an agreement to provide research findings to the Catholic Education Office of WA (Catholic Education Office, WA, n.d.).

- Aboriginal Independent Community Schools (AICS). Researchers who wish to conduct research in AICS are required to approach the school principal for discussion and approval. This process may also involve discussing the research project with the community (R.Gorman, personal communication, August 21, 2014).

To what extent do these new guidelines address the issues in the case study?

Since the CHL project (2001 – 2003), the various national and institutional guidelines for ethical research involving humans, including Aboriginal and Torres Strait islander peoples have been revised as discussed above. In addition, the NHMRC have produced *The Australian Code for the Responsible Conduct of Research* (2007) to guide researchers and institutions in responsible research practices and integrity in research. The NHMRC have also provided information to assist Aboriginal and Torres Strait Islander communities to understand the research process, how to work with researchers and how to establish mutual benefits as a result of research through the publication of, “Keeping research on track” (2006). This next section will address how the new guidelines address the issues in the CHL case study.

1. Multiple ethics clearance.

As outlined in chapter five, the CHL project was subject to eight research ethics applications: the University, WA Health Department, WAHIEC, the AMSs in each of the three study regions and, two submissions to Government Health Services. The number of ethics clearances that were required at various organisation levels was extraordinary high and involved the submission of similar ethics applications and information to each agency (see chapter five). In the ensuing process of gaining ethical approvals from each of the agencies, on-going delays were experienced for almost a year and this outcome resulted in the project leader seriously considering withdrawing the CHL study (G. Partington, personal communication, October 14, 2008). While it is important and necessary for multiple sites to participate in the approval process and be informed of the research study, unnecessary duplication of multiple reviews should be minimised as outlined in the NHMRC's *National Statement* (1999 and 2007). The level of ethics clearances that were imposed on the CHL study is questionable given that many of the ethics applications were almost identical in nature (A. Galloway interview, personal communication, May 02, 2003).

In addition to the above ethical clearances, the CHL project team were required to obtain approval to conduct the research study in each of the participating schools from the Education Department of WA, Catholic Education Office and from principals of Aboriginal Independent Schools. While a formal ethics application was not required, the CHL project leader had to submit copies of the approved HREC application form from the university, provide information about the research project and the processes involved, provide copies of information letters and consent forms for school principals, teachers and parents, outline how the data were to be stored and used, the benefits of the research study and a final report when the research project was completed. Approval at this level is only in principle as further approval was then required at each school site by the school principal. For Aboriginal Independent Schools, approvals were submitted directly to the principal. The research team considered that the level of approval was appropriate given the

submission requirements to the Education Department and the Catholic Education Office and that the Aboriginal Independent School had no formal research policy (G. Partington, personal communication, October 14, 2008).

If the CHL project were to be conducted today, only three ethics applications would be required: the University, WA Health Department and WAAHEC. Under the WA Health Department's new research policy guidelines, research involving multiple sites will now require a single review; however, if the participants are Aboriginal and Torres Strait Islander peoples, a further application to WAAHEC is also required. As stated above, if the research involves Aboriginal health sites in the Kimberley region of Western Australia, the investigators are asked to inform the Kimberley Health Planning Forum which is a sub-committee of the Kimberley Aboriginal Medical Services Council (WA Health Department, 2012).

The national and state streamlining of the Department of Health's single ethical review process has significantly reduced the number of ethics research applications that are now required to conduct health research at multiple sites. In addition, regular WA Health Department and WAAHEC HREC meetings have been scheduled and are advertised on both respective websites so that researchers can plan and submit applications in a timely manner. It is expected that the reduced number of ethics applications will expedite the reviewing process and as a result, eliminate uncertainties regarding when and what data can be collected, as per the experience in the CHL research study.

Whilst the number of ethics applications has been reduced, it is important to point out that the level of consultation and involvement in the research process has not diminished in any way. For example, as discussed earlier in this chapter, all respective research guidelines, including those that have been developed for Aboriginal and Torres Strait Islander peoples require these and other important issues to be addressed in ethics applications and for researchers to demonstrate respect, research integrity, justice and beneficence throughout the research process. (NHMRC, 2007). Researchers would still need to discuss research projects with individual communities before any research could take place. If the researchers comply with the NHMRC research ethics the rights of Indigenous communities should be respected.

2. The wording and content of consent forms.

The University's HREC has produced guidelines and requirements for the drafting of all consent documents and information letters for participants. While these guidelines provide an important and thorough checklist to assist researchers in drafting consent forms and information letters, it is also necessary to ensure that the language which is used and the contents of the document will be understood by the participants who will be involved in the study. The NHMRC's guidelines require HRECs to ensure that all information about research should be provided to participants in a way that it is clearly understood by them and for decision making to be based on these understandings. This includes how research information can be best communicated to the participants who may not speak English as their first language and that the communication is appropriate to their educational background and level (NHMRC, 2007, p. 84). The University's HREC demonstrated flexibility in the wording of consent forms that were designed for the CHL project in allowing changes to initial drafts and this is also considered in current ethic approvals.

The NHMRC also recommends face to face communication between researchers and participants when discussing research and informed consent in order to minimise misunderstandings when written communication is being used (2007, p. 84). While this was not possible for the CHL project due to the Privacy Act, the CHL team sought support through the local Aboriginal and Islander Education Officer (AIEO) or equivalent at each school to inform parents and/or caregivers about the research project and to explain the consent form and their rights to allow or not to allow, the participation of their child in the research project.

3. Communication with schools and participants.

Research involving schools and the school community will invariably require clear lines of communication, especially when they are located in rural and remote areas of the state or when researching from a distance. Under the Commonwealth Privacy Act 1988, researchers are still required to make contact with parents and/or caregivers through the school for the purposes of gaining informed consent and providing information about the research (Department of Education, 2009). The conditions of the Privacy Act also apply to researching in Catholic Education and Aboriginal Independent schools. The school principal has the authority to decide the method of communicating the research

information and consent forms to parents and/or caregivers that have been provided by researchers. These may be sent out via a newsletter or by personal visits by an AIEO or equivalent worker. The principal may also arrange for parents to come to the school to meet with researchers who will have the opportunity to explain the research project and discuss the consent form.

Similarities and differences of current research guidelines and policies:

The following table illustrates the range of similarities and differences of research guidelines and policies from selected institutions that apply to research similar to that of the CHL case study: that is, research that involves health and education issues relating to Aboriginal and Torres Strait Islander peoples. To illustrate the similarities, the table lists research ethics items which are common across each of the ethics review forms. The WA Health Department's ethics application is more extensive in comparison to other institutional review forms that have been identified in the table below. For example, there are extensive checklists and questions relating to clinical research, human tissue sample, genetic research, accessing Commonwealth data and funding sources. While ethics applications are required for the WA Health Department and WAAHEC in applicable cases, the WAAHEC form does require applicants to confirm if an ethics application has been submitted to another HREC and if so, to indicate the outcome of the submission (WAAHEC, n.d, p. 2). This would apply to a project like the CHL research study today.

Rationalising ethics guidelines:

All research guidelines that have been developed by institutions and/or other agencies, including research governance procedures and policies, must conform to the NHMRC's *National Statement* and associated published guidelines as applicable (NHMRC 2007). As a result, many ethics application forms that have been developed by a variety of institutions, share many common elements such as those that are illustrated in the table above. While this is not an issue for research involving single sites, it has the potential to cause many issues and unexpected problems for researchers when it involves the combination of more than one industry partner and multiple sites, as was the situation in the CHL case study (see chapter five). The number of ethical reviews that were required for the CHL project was extraordinary high despite NHMRC guidelines at the time supporting the minimisation, where possible, of the duplication of ethical reviews

(NHMRC, 1999). The minimisation of ethical reviews is also reinforced in the 2007 NHMRC's *National Statement* and current guidelines for research that involves more than one institution. A relevant section states, "Different institutions that regularly have review responsibilities for the same research (for example universities and related teaching hospitals) should agree on a single review body to review the research" (NHMRC, 2007, p.87). However, and as stated above, research involving health and Aboriginal and Torres Strait Islander peoples will involve more than one ethical review. This requirement not only supports the principles of critical theory of empowering minority groups, it also supports Aboriginal and Torres Strait Islander control and ownership over research, engagement with researchers, participation in research, the establishment of accepted and recognised research protocols and, defining mutual benefits as a result of research. However, despite the approval of ethics, some organisations may not be supportive of the research that takes place and may not accept the validity of ethics clearances and request additional information as experienced in the CHL study (G.Partington, personal communication, October 14, 2008).

The state and national health department have taken a major step in minimising the duplication of ethical reviews or ethics clearances within their own organisational structure by recently implementing a single review process. This new initiative, in many instances, has significantly reduced the number of required reviews that once applied to research involving Aboriginal and Torres Strait Islander health related issues at multiple sites, in particular. This initiative is greatly welcomed by members of the CHL research team, as this new process not only reduces the duplication of ethics application forms but importantly, will invariably minimise possible delays that may occur under a multiple approval process (G. Partington, personal communication, August 19, 2014).

	ECU	WA Health	WAAHEC	Education Department	Catholic Education
Ethics application required	✓	✓	✓	X	X
NHMRC <i>National Statement</i>	✓	✓	✓	X	X
NHMRC <i>Values & Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research</i>	✓	✓ Application to WAAHEC	✓	X	X
NHMRC <i>Code for the conduct of responsible research</i>	✓	✓	✓	X	X
NHMRC <i>Keeping Research on Track</i>	X	X	✓	X	X
Ethics approval from a University or other HREC	N/A	N/A	N/A	✓	✓
Research information sheet	✓	✓	✓	✓	✓
Consent forms	✓	✓	✓	✓	✓
Specific consent, e.g., video & audio recording	✓	X (*However, it is implied).	✓	✓	✓
Questionnaires	✓	✓	✓	✓	✓
Letters of support from	✓	X	✓	X	X

Aboriginal communities					
Research protocols	✓	✓	✓	✓	✓
Research team & qualifications	✓	✓	✓	✓	✓
Category of participants	✓	✓	✓	✓	✓
Data collection	✓	✓	✓	✓	✓
Data storage	✓	✓		✓	✓
Privacy & confidentiality	✓	✓	✓	✓	✓
Publication/dissemination of data/results	✓	✓	X	✓	✓
Intellectual property	✓	✓		✓	✓
Remuneration	✓	✓	✓	✓	✓

Table 6.1: Similarities between institutional guidelines that reflect the conduct of research that is similar to the CHL case study

Many universities have also made efforts to minimise ethics reviews in circumstances whereby the same research project involves researchers from more than one university or in some cases, when more than one institution is responsible for undertaking an ethics review and approval process. This practice is also in line with the NHMRC's guidelines for minimising ethics reviews. For example, ECU's HREC requires researchers to submit a copy of an approved ethics review and related documents when the research is associated with another university who is leading the project. The University also accepts an approved National Ethics Application Form (NEAF), when ECU researchers undertake national health research projects. However, it was confirmed by the University's HREC that if the CHL project was taking place today, an ethics application would also be required, in addition to an application to the WA Health Department and WAAHEC (K.Gifkins, personal communication, July 07, 2014).

While the NHMRC continues to support the minimisation of ethics reviews or clearances, it is accepted that certain fields of research will attract additional ethics reviews. It is also accepted that institutions such as the health department will likely require a more comprehensive review application given the wide range of specific health fields that may be involved in research. While this may be the case, there will be common elements that will be similar to other review documents that have been developed by other institutions. These similarities have been highlighted in the table above and this justifies a further examination of the possibility of minimising the duplication of ethics reviews for research involving multiple sites and/or industry partners. The examination could include the development of a state or national ethics review form that is accepted by universities for research involving multiple sites and/or when more than one ethics review is required that are external to the university. For example, if HRECs from universities and WAAHEC agreed to a common review form and a single review process, this would further eliminate duplication. Under this arrangement, only two reviews would be required for research involving health issues among Aboriginal and Torres Strait islander people. In recognising WAAHEC as an approved HREC by the NHMRC, the single review would become their responsibility but the research process would be monitored by a university's HREC. This arrangement is similar to the procedures whereby a university accepts another university's HREC

approval for multi-institutional projects. Alternatively, universities could consider accepting a single review process for applications that are approved by the WA Health Department as per the arrangement for research that are submitted under the NEAF category.

Application of the case study to the new guidelines

This section examines the application of the CHL case study to the new guidelines to demonstrate the level of compliance with the 2007 *National Statement* and in turn, identify examples to indicate instances where the CHL research team exceeded the guidelines that applied at the time. As outlined above, the NHMRC's revised National Statement in 2007 resulted in a range of revisions but the most significant changes were concerned with consent, qualifying and waiving conditions for consent, children and young people and research involving Aboriginal and Torres Strait Islander people. For the purposes of this thesis, consent and the revised statement relating to Aboriginal and Torres Strait Islander peoples will be discussed below.

- A. Consent: The 2007 revised edition of the *National Statement* provides a more comprehensive set of guidelines regarding the conditions or requirements for obtaining consent, processes of communicating information about consent to participants, information about the research project and the research process (for example, how privacy and confidentiality will be protected, contact details of researchers and person to receive complaints, withdrawing consent, how results will be disseminated, including publication), renegotiating consent, the future use of data and reimbursing participants (NHMRC, 2007). While many of these 'requirements for consent' were evident in the 1999 National Statement, the guidelines were not as extensive in comparison to those found in the revised 2007 *National Statement*.

The CHL case study: Three consent forms were developed for use with school principals (see appendix C), teachers (see appendix B) and parents or care givers (see appendix A & B). While both 1999 and 2007 NHMRC guidelines refer to the appropriate use of language in consent forms and conditions for gaining consent, the research team provided additional measures that align well with the current guidelines, in assisting parents/caregivers to make informed decisions about participating in the research project. For example, the following procedures that were introduced by the

CHL research team match the current guidelines that refer to communicating information on matters concerning consent with participants in ways that are appropriate and will be clearly understood, that the transfer of written and verbal information is accurate and reliable and, the need to reconfirm consent for projects that are complex or extend over long periods of time (NHMRC, 2007).

1. The form identified specific areas or statements requiring consent and if agreeable, confirmation is indicated by ticking a corresponding box (see appendix B).
2. Under the conditions of the Privacy Act (1988), the research team were obliged to negotiate with school principals the options for communicating research related information, including the gaining of consent with parents/caregivers. Although they were unable to engage directly themselves, they sought the assistance of the school's AIEO or Aboriginal Education Workers (AEWs), although this option was not always possible or agreed to by principals. Privacy legislation prevented the CHL team from conducting face to face meetings despite NHMRC strategy. (A.Galloway, personal communication, May 02, 2003); interview, 02/05/14). The CHL research team believed that face to face communication would help increase the level of understanding and would provide an opportunity for parents/caregivers to clarify points and/or ask questions about the research and matters relating to the consent form (A.Galloway, personal communication, May 02, 2003).
3. To further assist AIEOs and AEWs in communicating the research project and consent form with parents/caregivers, the project director developed a set of additional notes for the purposes of guiding each informant in this process and for them to deliver an accurate and reliable account of the information that is presented to each recipient (A. Galloway, personal communication, May 02, 2003). Another significant aspect of the CHL case study regarding consent was the project leader's decision to appoint an Aboriginal research team member to the role of ethics officer. The major responsibilities included communicating with parents/caregivers to ensure they understood the research and its relevance to their children. This contributed to the promotion of positive relationships with the families so that they were willing to communicate with the researchers. This

particular initiative is referred to as “renegotiating consent” in the revised guidelines and states, “In some research, consent may need to be renegotiated or confirmed from time to time, especially where projects are complex or long running, or participants are vulnerable” (NHMRC, 2007, p. 20). As the reference to ‘negotiated consent’ was not part of the 1999 guidelines, the CHL research team’s initiative to insist on the confirmation of on-going consent from parent/caregivers throughout the research process is proof of exemplary ethics practice and was groundbreaking at the time. By taking this initiative in the CHL project, the research team placed a high value on consent by keeping participants informed at all times and reconfirming their willingness to continue to participate or the opportunity to withdraw.

The above examples indicate that the CHL research team sought to maximise sound ethical approaches in matters concerning consent and in some cases, these were above the current ethical guidelines that were in place at the time. There were further examples of good ethical practice that were demonstrated by the CHL research team with regards to consent and confidentiality and these have been discussed in chapter five. For example:

1. Insisting on parent/caregiver signatures in giving consent wherever possible,
2. Not accepting a teacher’s approval to video and audio tape without official consent,
3. Denying a request by a senior departmental officer to provide confidential information about a teacher who was participating in the research study (A.Galloway, personam communication, May 02, 2003).

While the CHL research team displayed a high level of ethical conduct throughout the research project, less experienced or less sensitive research teams may have infringed their ethical responsibilities through ignorance or convenience. Ethics guidelines do not always guarantee that researchers will do the right thing and there needs to be a stronger emphasis placed on rigour and honesty to ensure that researchers meet their responsibilities and obligations (Laycock et al., 2011).

B. NHMRC *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Health Research* (2003). These guidelines were launched by the NHMRC mid-2003 and in the closing stages of the CHL project. The following

examples provide further instances where the CHL research team had implemented research practices that exceeded the 1991 guidelines and those that reflected statements found in the revised document. This section will also provide examples that conflicted with the guidelines.

1. Reciprocity:

One of the aims of the CHL research project was to involve parents and community members in the program so that they could experience at first hand the purpose and processes of the research. The research team talked to parents and community members at project information sessions, Aboriginal Student Support and Parent Awareness (ASSPA) events and at morning teas; and met regularly with AIEOs and AEWs and community members during school visits. AIEOs and AEWs also participated in PD sessions that were presented by the CHL project team. These meetings also confirmed that there were no major concerns or issues that were expressed by parents/caregivers (G. Partington, personal communication, October 14, 2008).

The CHL team also established a reference group of Aboriginal and non-Aboriginal members to advise and participate in the monitoring of the research project. For example, there were instances when reference group members insisted that all consent forms had to be signed by parents/caregivers (G. Partington, personal communication, October 14, 2008). However, while the CHL team demonstrated good ethical practice, this was not always reciprocated by other participants. For example, there were a number of occasions when teachers would offer the confirmation of consent to the research team without official approval from parents (A. Galloway, personal communication, May 02, 2003).

2. Respect:

Despite the number of ethics reviews that were required and the subsequent delays, the CHL research team sought to inform and engage with relevant members of various organisations, including Aboriginal and community leaders, the purpose and benefits of the research project and respond to the request for additional information during the review process. The Indigenous ethics officer discussed with parents/caregivers and community members

how the research results would be disseminated to each participating school and how it would be used in publication of articles by the research team.

The appointment of an Aboriginal research member to the position of ethics officer, demonstrated the project teams intention to build strong relationships, trust and cooperation with all Aboriginal and Torres Strait Islander people who were participating in the project (G.Partington, personal communication, October 14, 2008).

3. Equality:

The CHL research study covered three different Aboriginal language groups and in three different settings; metropolitan, rural and remote. The CHL research team made every effort to encourage input by participants and members of the Aboriginal community throughout the research process and were always respectful of contributions and the language used in all communications. The benefits that were to be shared as a result of the research project were also conveyed during these interactions.

4. Responsibility:

Despite careful planning, the CHL research team adopted a flexible approach to arranged school visits with the understanding that unexpected priorities or community events may take precedence over the prearranged research activity. This outcome occurred at one remote community when the entire Aboriginal community moving to a larger community nearby to mourn the passing of an elder (A. Galloway, personal communication, May 02, 2003).

5. Survival and Protection: The research process that was mapped out by the project leader and the research team was built on developing trust, respect and strong relationships with all participants who were involved and/or associated with the study. This included the participation of Aboriginal community members in the research project and outlining the mutual benefits of the research study. However, while the CHL research team displayed many examples of best practice, it did not address the key issue of Indigenous ownership in research.

6. Spirit and Integrity: From a participant/observer perspective, the research process that was planned and carried out by the CHL research team reflected

good research practice which often exceeded the ethical guidelines that applied at the time. In submitting the final report to the funding body, the project leader was able to demonstrate the success of the project in meeting all research objectives, despite a challenging start to the project (G.Partington, personal communication, October 14, 2008).

What is needed?

Despite the revised ethical guidelines and associated guidelines that have been developed by the NHMRC (2003, 2006, 2007a, 2007b) and other institutions (AIATSIS 2012; WA Health, 2012 & 2013; ECU,2010), Indigenous academics such as Nakata (2007a, 2007b); Moreton-Robinson (2000); Rigney (2006); Dudgeon (2010) and Walter (2010) and together with agencies like the Cooperative Research Centre for Aboriginal and Tropical Health, are still advocating for further reforms in Indigenous research. These Indigenous peak bodies and others like AIATSIS and NIELNS play a strategic role in identifying research needs in Indigenous communities, provide funding for research projects and also reinforce best practice in the conduct of research. The key Indigenous research reforms which are being identified call for a re-distribution of power in the research process so that Indigenous concerns and priorities can be addressed and guide research in this area. These include: Indigenous control and ownership over research, the prioritising of research by the Indigenous community, developing mechanisms and/or processes to challenge and transform traditional research practices and institutional approaches to Indigenous research, research methodologies that engage collaborative and participatory practices; also methodologies that are culturally appropriate and have been negotiated with Indigenous participants, including how the data is being collected, analysed, interpreted and disseminated. Indigenous critics and supporters of Indigenous research reforms have also expressed the need for the NHMRC and other funding research bodies to consider additional or alternative criteria when assessing research performance. For example, rather than focus heavily on research publications as a criterion, there should be similar or greater emphasis placed on researchers demonstrating evidence of meaningful research practices that have benefitted Indigenous communities and have addressed Indigenous priorities (Dudgeon et al, 2010).

The issues raised above point to the need for the NHMRC and research funding authorities to consider introducing further Indigenous research reforms in meeting these identified priorities in consultation with the Indigenous research community and Indigenous community. The literature, from both national and international sources have also identified cultural competence as being critical for researchers who engage with participants whose cultural or ethnic background is different from their own (AIATSIS, 2010; Dungeon et al., 2010; Harvard Catalyst, 2010; Universities Australia 2011a; Reich 2006). There is no evidence in the current NHMRC's 2007 *National Statement* or other related guidelines that refer to Indigenous cultural competence and/or cultural competence training of researchers who engage in Indigenous research or in research involving other cultural groups. The inclusion of cultural competence training therefore, should be seriously considered by the NHMRC as part of the Indigenous research reform agenda. Chapter seven discusses the contribution of cultural competence to improving ethically based Indigenous research.

The other matter requiring consideration relates to the NHMRC's guideline to minimise the duplication of ethical reviews, particularly when the research activity involves two or more institutions or multiple sites as discussed earlier in this chapter. The Health Department at national and state levels have addressed this issue significantly by introducing a single review process for most types of research, however, opportunities exist to further refine the ethics application and reviewing process for research that involves Indigenous health. While it is acknowledged that different contexts will have different or particular needs in an ethics review; for example, institutions like the Health Department will have specific or additional requirements that need to be addressed in an ethics application, there are many common elements in the review process undertaken by university HRECs and other NHMRC approved HRECs for research involving Indigenous health as outlined in the table 6.1. Therefore, ethical approval processes involving more than two reviews should be examined by the NHMRC, Universities Australia and, approved HRECs that are external to universities.

Conclusion:

There have been significant developments and changes in the guidelines for the conduct of ethical research involving humans and also in institutional research governance and ethical review processes since the completion of the CHL study in 2003.

Of particular note have been the revised guidelines for research involving Aboriginal and Torres Strait Islander people, and the publication of additional guidelines to assist Aboriginal and Torres Strait Islander people in understanding the research process, including how to engage effectively with researchers; and a code of conduct for responsible research practices. However, despite all these developments, Indigenous academics and the Indigenous community have identified the need for further reforms in Indigenous research that will require further negotiation with the NHMRC and other research authorities so that these issues can be discussed and considered for inclusion in future research guidelines and governance procedures that relate to Aboriginal and Torres Strait Islander research.

The ethics review process involving multiple sites also requires further review on the part of HRECs to minimise the number of required ethic reviews. The Health Department at national and state levels have been exemplary in addressing this issue by introducing a single review process for most types of research.

The issues raised in this chapter support the need for a new research framework to be developed so that research practices and procedures that relate to Aboriginal and Torres Strait Islander peoples and research processes such as ethics reviews can be improved further. The issue of cultural competence training for all researchers who engage in Aboriginal and Torres Strait Islander research is also a significant component for inclusion in the proposed new research framework. The contribution of cultural competency to improving ethically based Indigenous research is discussed in chapter seven.

CHAPTER SEVEN

THE CONTRIBUTION OF CULTURAL COMPETENCY TO IMPROVING ETHICALLY BASED INDIGENOUS RESEARCH

Introduction:

The term, ‘cultural competency’ has received much attention in health, nursing, psychology and education literature (Balcazar et al., 2009; Grote 2008; Ranzijn, McConnochie, Nolan, 2008; Sue 2001; Thomson 2005). Most of the literature has emerged from the health sector as a result of an identified need to provide high quality health services in cross cultural contexts. Many countries have culturally diverse populations and cultural competency has become recognised as a vital component in meeting the needs of a wide range of culturally and linguistically diverse groups in health and across a number of other service professions (Grote, 2008; Thomson, 2005).

The importance of cultural competency in research is also beginning to emerge in the literature with the identified need for researchers to have a greater understanding of their study participants, particularly those from specific populations or diverse backgrounds. More important however, is the application of this understanding across the entire research process, including: research design, conduct, interpretation and participation in the study (AIATSIS, n.d; Dudgeon et al., 2009; Harvard Catalyst 2009; Reich (2006); Universities Australia (2011a). In essence,

Cultural competence is critical for researchers to ensure: (1) effective communication and interaction between researchers and study participants, (2) adequate analysis and interpretation of results as they relate to patient/population impact; and (3) appropriate engagement in study design and implementation for community/population based research (Harvard Catalyst, 2009, p. 7).

The landscape of Indigenous research in Australia has entered ‘an era of post-colonisation’ as evidenced by a gradual paradigm shift through the development of ethical research guidelines and practices that recognises the rights of Indigenous people to ‘equality’ and ‘self-determination’ (Universities Australia, 2011a, p. 96). Indigenous academics, including Martin (2008); Moreton-Robinson (2000); Nakata (2007a, 2007b); Rigney

(2006) and Walter (2010), have also challenged the dominance of Western research paradigms and have called for a redistribution of power and methodological reforms in Indigenous research. Their Indigenous research reforms and agenda extends to the control and ownership over research and the development of a recognised framework that can be used to engage debate and discourse with current Western research epistemologies.

While there have been significant changes made to the conduct of Indigenous research in Australia, there remains a perceived need for researchers and the research community to be better prepared for engagement with Indigenous communities or participants during the conduct of research and research discourses. (Dudgeon et al., (2010, p. 82), for example argue that,

there is a critical need to incorporate cultural competence at a system, organisational and individual level to ensure all researchers are more culturally responsive and sensitive in developing, implementing, and disseminating research in partnership with Aboriginal and Torres Strait Islander people.

Ethics guidelines alone cannot guarantee that research will always be carried out in a manner that is most consistent with them. “Ethics is not about filling out an ethics application, but about fundamental research values and how they are put into practice” (Laycock et al., 2011, p.42). The NHMRC has also acknowledged that despite careful planning, culturally inappropriate practices may still occur as a consequence of intentional or unintentional actions by researchers (NHMRC, 2007). Research is a very relational activity and the importance of developing strong relationships, building trust and mutual partnerships between researchers and participants has been advocated across a number of fronts, including the NHMRC (2007). However, the importance and the role of cultural competency in research are not part of current NHMRC research guidelines although they have published a guide that emphasises the importance of cultural competency in health for the development of ‘policy, partnerships and participation’ (NHMRC, 2005). AIATSIS on the other hand have outlined a

cultural competence framework in an effort to develop cultural proficiency in Indigenous research, although the document, “*Towards Cultural Proficiency*” does not demonstrate the implementation of the framework (AIATSIS, n.d).

From the literature it is clear that Aboriginal and Torres Strait Islander people are still vulnerable in research despite the new guidelines which promote culturally sensitive practices and the emphasis on empowerment and participation of Indigenous people and communities in research (Cruse 2001; Dudgeon et al., 2010; Moreton-Robinson, 2000; Nakata, 2007a; NHMRC, 2003; Rigney, 2006; Taylor & Ward, 2001; Universities Australia 2011a). The call for further emancipatory measures and an equal position in research by Indigenous academics, including the author of this thesis are founded on the principles of critical theory. Critical theory espouses principles of social justice and contests hegemony of a particular cultural group over another and seeks ways of empowering those who wish to exercise cultural, economic and political control over their lives through “counter hegemonic strategies” (Tripp, 1992, p.13). This circumstance reflects the history of Indigenous research when research practices were dominated by non-Indigenous researchers. The Indigenous community has demanded justice and equality on the conduct of research into their lives. Tripp has also identified a number of methodological principles that incorporate a socially critical perspective and these can be applied to Indigenous research contexts: (1) Participation through collaborative partnerships, (2), Direction through the setting of research priorities by Indigenous people, (3) Meaning through the understanding and respecting differences values and knowledge, (4) Outcomes through the development of new practices rather than making existing ones more efficient, and (5) Audience to which the research results will be disseminated (Tripp, 1992, 14-15). This chapter addresses the research question, “To what extent is cultural competency a significant component of Indigenous research?”

Definitions of cultural competence

There is no uniform definition of cultural competence nor is there agreement among scholars regarding the conceptualisations of CC. (AIATSIS n.d; Grote 2008; Reich 2006; Universities Australia ,2011a). The literature reveals numerous terms that have been used to define cultural competence and some of these include, awareness, responsiveness, respect, security, safety and sensitivity (Dudgeon et al., 2010; Grote, 2008; Harvard Catalyst, 2009; Thomson, 2005). However, cultural competence means more than these terms alone, as it is about transforming these terms into action and is a concept that ‘embeds the notion of reciprocity’ (NHMRC, 2005, p.1). Cultural competency is a behaviour that requires self-motivation and a willingness to challenge one’s own cultural values and beliefs in developing empathy towards accepting cultural differences and a connected knowledge with those from other cultural backgrounds (Walker & Sonn, 2010).

A commonly used definition refers to cultural competency as, “A set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency or professional to work effectively in cross-cultural situations” (Cross et al., 1989, p.13). However, this definition has evolved to suit a range of different operating contexts and the diverse needs of different cultural groups, including Indigenous Australians (AIATSIS, n.d; Grote, 2008; Universities Australia, 2011a). There are limited definitions in the literature that define cultural competence in research; however, the following example provides an extensive description:

Cultural competence in research is the ability of researchers and research staff to provide quality research that takes into account the culture and diversity of a population when developing research ideas, conducting research, and exploring applicability of research findings. Cultural competence in research plays a critical role in study design and implementation processes, including the development of research questions and hypotheses, outreach and recruitment strategies, consent activities, data collection protocols, analysing and interpreting research findings, drawing conclusions and presenting results (Harvard Catalyst, 2010, p. 6).

The role and purpose of cultural competency in research is clearly identified in the definition above but there are issues in relation to applying it to Indigenous Australian contexts.

- (i) The diversity among Indigenous Australians and the application of the six values that are identified in the NHMRC's *Values and Ethics: Guidelines for the Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003)*,
- (ii) The incorporation of Indigenous research reforms that have been advocated by Indigenous academics and,
- (iii) The process of integrating the above mentioned qualities in research is reliant on the willingness and/or the 'ability' of researchers to develop a sound understanding of Indigenous culture that will enable them to fulfil their ethical responsibilities in an effective and culturally appropriate manner (Walker & Sonn, 2010). Furthermore, it is also important for researchers to have a good understanding of the research guidelines that relate specifically to Indigenous people and communities and their application across the research process, including how they address specific incidents that may occur during the study. For example, with reference to the signing of consent forms, parents need to be empowered in the research process and therefore, researchers should not accept approval from a third party, such as teachers who sign on the behalf of parents.

Without the requirement for all researchers to complete training in cultural competency prior to engaging in research involving Indigenous people, the implementation of the guidelines and the manner in which the research study is conducted is subject to the researcher's own interpretation and understanding of these guidelines and therefore challenges Indigenous ownership and control over research.

Universities Australia affirms that, "Cultural competency research relies on having mechanisms in place to ensure that research is culturally safe and of benefit to Indigenous peoples and community from which the research is drawn" (Universities Australian, 2011a, p.13). The 'mechanism' that is being proposed

by Universities Australia is the establishment of an ‘Indigenous Research Ethics monitoring subcommittee’ that would be affiliated with a University’s HREC. Universities Australia assert that the establishment of such a committee would hold researchers in Indigenous research accountable, insisting that, “non-Indigenous researchers investigating Indigenous peoples and Indigenous cultures to be subject to Indigenous cultural hearing of proposed research intentions and purposes” (Universities Australia, 2011a, p.97).

This committee would provide a ‘collective Indigenous voice’ in overseeing all Indigenous related research and would ensure that researchers would incorporate Indigenous values and reflect an Indigenous world view. Similar committees have been established in universities in the United States, Canada and New Zealand (Universities Australia, 2011a, pp.97-98). While the proposal for an Indigenous Research Ethics monitoring subcommittee has merit, it does not provide guidance and/or strategies to researchers to be culturally competent in the conduct of research and their interaction with Indigenous participants. For example, there is no stereotypical view of Indigenous people and researchers need to be aware of cultural differences within groups, knowing when to suspend their own cultural paradigms in demonstrating cultural sensitivity and respect in their interactions with Indigenous participants and knowing the cultural protocols that may apply to approaching and communicating with Indigenous communities. “There is not one approach. The research values can be embedded in different ways and depend on local settings” (Laycock, et al., 2011, p. 42).

The development of trust is a very important element in the research process and any subtle indiscretions towards Indigenous values and principles on the part of researchers, whether they be intentional or unintentional, will erode trust and as a consequence could jeopardise the research study. Therefore, cultural competency needs to be strongly considered as a component in the preparation of doing Indigenous research. The CHL case study is a good example to refer to in demonstrating the value of having a team of culturally competent researchers.

Cultural Competency in the case study

The issues and number of incidents that were presented to the CHL research team during the study were numerous and required a level of patience, careful negotiations and building and maintaining trust and relationships. Although the CHL research team did not receive any formal cultural competence training, two members of the team were experienced in Indigenous research and/or Aboriginal culture and community protocols and therefore, were able to provide guidance to the two other members who had less knowledge and experience in this area. Part of this guidance involved reflecting on experiences or incidences that occurred on field trips and this proved to be a useful means of building cultural competence among the research team. The building of relationships with research participants was identified as a key element by the experienced members of the research team. For example, at the school level, the building of relationships included administrative or front office school staff (including principals, deputy principals, receptionist and the school nurse) as well as teachers and students. The research team regarded the school receptionist to be an integral person concerning the status of messages and school events. In dealing with multiple industry partners in each of the three research settings, the CHL research team maintained regular contact via face to face meetings and other forms of communication. This was particularly necessary when discussing and gaining ethics consent at various levels, as it required the CHL team not only to be conversant with each ethics guidelines, but also, to negotiate and carefully address the issues that were raised by various representatives who were responsible for approving ethics applications. The CHL project leader also signalled a strong intention to build relationships between the Indigenous community, parents and caregivers by appointing an Indigenous research team member to the role of communicating information about the study, to ensure a clear understanding of it and importantly, confirming parents/caregivers on-going consent and rights to withdraw their consent. Building relationships with the teachers who were participating in the study was also very important as a certain level of trust and professional friendship had to be obtained and maintained throughout the research project. However, as discussed previously, some teachers did not want to participate in the study.

Applying Cultural Competency to Indigenous guidelines for research

The NHMRC's *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* outlines six values that guide ethical assessment and engagement in the development and design of research proposals and in the conduct of research. Despite the introduction of these guidelines, Indigenous academics still advocate further research reforms as discussed earlier as well as the need for researchers to be 'culturally responsive' and 'sensitive' to Indigenous values and principles in the conduct of research (Dudgeon, et al., 2010, p.82). Universities Australia have also established a guiding principle for Indigenous research and assert that, "University research should be conducted in a culturally competent way that empowers Indigenous participants and encourages collaboration with Indigenous communities" (Universities Australia, 2011b, p. 13). The implication of these identified needs is that cultural competence should be taught to researchers intending to research Indigenous issues, however, there is little evidence in the literature to support that cultural competence training is provided to the research community on a scale as evident in health and educational contexts (Universities Australia, 2011b). This is possibly due to the emerging importance of cultural competency in research as outlined in the literature (Harvard Catalyst, 2009; Reich, 2006; Universities Australia (2011a). Many universities, various government and non-government agencies in Australia provide cultural competency training for their employees. The training is provided by fellow employees or private consultants who have considerable expertise in the subject area. For example, at Edith Cowan University cultural competence is taught to undergraduate students by Indigenous lecturers in courses such as education, speech pathology, public health and law. The teaching of cultural competence has been endorsed by Vice Chancellors and this has resulted in the teaching of cultural competence in various courses throughout Australian universities (Universities Australia, 2011a). The author of this thesis also engages in the presentation of cultural competency workshops to university staff, school principals, teachers and government agencies. The content for the teaching and workshop programs include the following topics: Aboriginal culture, Aboriginal history, contemporary Indigenous Australia and Indigenous cultural competency (elements of cultural competency, building relationships, communication and language, community protocols and racism). The

feedback from students and workshop participants provide the current means of quality assurance of cultural competence training and education that is offered through the university. As reported in the Literature Review (Chapter two), the level of inconsistency in cultural competency training programs in US medical schools have made it difficult to develop a standardised instrument to assess its effectiveness among patients (Kirpalani et al., 2006; Kumas-Tan et al., 2007). Similarly, there is limited literature to support the effectiveness of cultural competency training programs in Australia and particularly, in research. This finding confirms the need for an increased effort in outcomes based research to develop quality assurance mechanisms and to standardise the process of evaluating the effectiveness of cultural competency training and educational programs.

Edith Cowan University does not offer a specific cultural competency training program for researchers; however, the research community can attend the workshops that are currently being offered.

It is important to note that cultural competence training should target both Indigenous and non –Indigenous researchers. ‘Insider’ and ‘Outsider’ researchers as discussed in the literature review (see Chapter two) applies to Indigenous and non-Indigenous researchers. For example, Indigenous researchers who are researching a language group other than their own are considered to be ‘outsider’ researchers and therefore, need to be aware of specific and general protocols including background history that may apply to that particular community. Similarly, an ‘insider’ researcher may encounter reticent behaviour from their own language group who may feel uncomfortable in disclosing family or other personal information. It is noted that some Australian universities have implemented other methods for ensuring that research involving Indigenous people is conducted in a culturally safe and appropriate manner. For example, an ethics sub-committee of the HREC has been established specifically for Indigenous research at the University of New England. In another example, Flinders University requires that all Indigenous research proposals be submitted to the Director of the Yunggoorendi First Nations Centre for Higher Education and Research for confirmation and approval (Universities Australia, 2011b, p. 14). In applying cultural competency against the six values, the following examples are provided:

1. Reciprocity: This value is about mutual obligation, inclusion and benefit in research and requires researchers to engage with Indigenous people and communities in developing collaborative partnerships in research. The intent here is for researchers to contribute to 'making a difference' and 'sharing research information in a meaningful way' (Brimblecombe, 2011, p.34). Researchers need to demonstrate empathy in their 'thoughts, attitudes and behaviour' towards Indigenous people and communities by 'being sincere and genuine in being a catalyst of change' (Gower & Byrne, 2012, p. 387). This understanding extends to being prepared to listen to Indigenous voices and confirming roles, expectations and arrangements during and after the research process.
2. Respect: Researchers need to have an understanding of Indigenous culture and cultural diversity so that they can place themselves in a position of knowing when to 'suspend cultural paradigms' by putting aside their own cultural beliefs, values and customs and accepting those of the Indigenous peoples that they are working with (Gower & Byrne, 2012, p.392). A respectful relationship is founded on trust, cooperation and showing genuine care for one another and this is gained by taking time to build research relationships and leaving positive and lasting impressions among Indigenous people and communities. The following example highlights the importance of taking time to build relationships with Indigenous communities. An Indigenous researcher took a group of non-Indigenous researchers out to a community to discuss a proposed research study that involved them. The community was a little hesitant in becoming involved initially, so the importance of building strong relationships between the research team and the community was recognised by the Indigenous research team member. Four days were allocated for a visit and the first three days were spent fishing with community members and spending time talking to them without mentioning research. The non-Indigenous members were getting a little concerned that, after three days, no research negotiations or discussions had taken place with the community. On the fourth day of the visit, a meeting was held between the researchers and community representatives to discuss the research study. Initially, there was resistance to the research study but a sufficient level of trust had been established in the previous three days to

convince the community representatives to support it (M.Nakata, personal communication, October 25, 2013).

3. Equality: This value is about sharing knowledge and resources, working collaboratively and treating all partners equally throughout the research process, while at the same time, 'recognising and respecting difference.' Researchers who decide to ignore Indigenous knowledge and understanding are likely to 'create mistrust' and may also 'misinterpret data or meaning' (Laycock et al., 2011, p.38).

The following example highlights the likely consequences as a result of an incident involving mistrust. A group of non-Indigenous university research staff who were awarded a research grant to study dugongs did not include an Indigenous person on the research team. When the Indigenous community involved in the study became aware of this, the researchers were informed that they would not support the research unless there was Indigenous representation from the community on the team. This act of ignorance reinforced power relations in research and could have led to an abrupt end of the research study. An Indigenous staff member was appointed to the research team and the study proceeded (J.Sellwood, personal communication, October 25, 2013).

4. Responsibility: Researchers need to conduct open and transparent conversations with participating communities in making clear the demands of research and ensuring that participant involvement will not harm or interfere with cultural obligations and values. These conversations and negotiations need to be ongoing throughout the research process to acknowledge and act on changing circumstances and reconfirm partnership agreements. The appointment of an Indigenous ethics officer to confirm ongoing consent and understanding of the research process and the research study itself, is a good example of demonstrating cultural competence and good ethical research practice.
5. Survival and protection: Researchers need to be aware of the history of Indigenous research and ensure that necessary safeguards are in place to protect Indigenous cultural values and identity. In acknowledging and accepting Indigenous control and ownership over Indigenous research, non-Indigenous researchers should demonstrate advocacy and commitment in uniting Western and Indigenous knowledge systems in research, with a strong focus improving

outcomes for Indigenous Australians, rather than improving outcomes for themselves.

6. Spirit and Integrity: All researchers who engage in research that relates to Indigenous issues do so because they want to work alongside the Indigenous research reform agenda and also, make a difference in the way that research honours and respects Indigenous values and, contribute to improving the lives of Indigenous Australians. The demonstration of cultural empathy is an important element in being part of Indigenous research.

Cultural competence is all about developing relationships, effective communication, respect and understanding cultural differences and values; its application to Indigenous research will enable the fulfilment of the six values and also promote best practice throughout the research process.

Conclusion:

The value, purpose and application of cultural competency in cross cultural settings are well documented in the literature. It signals appropriate behaviour and understandings that are required in developing strong relationships, respect, trust and effective communication among different cultural groups. The inclusion of cultural competency principles and practices in health, psychology and education has encouraged practitioners to be culturally responsive and sensitive when dealing with those from different ethnic backgrounds (Balcazar et al., 2009; McAllister & Irvine, 2000; Ranzijn et al, 2009; Universities Australia 2011a). The benefits and contribution of cultural competency in research are also beginning to emerge in the literature (Balcazar et al., 2009; Dudgeon et al., 2011; Harvard Catalyst, 2009; Universities Australia 2011a). The application of cultural competency in Indigenous Australian research should also be part of the Indigenous research reform agenda given the history of past research practices by non-Indigenous researchers and the shift away from neo-colonialism research practices to Indigenous control and ownership over research. Despite these changes, Indigenous people and communities may still be reticent towards researchers and becoming involved in research as a result past practices. As a consequence, this situation further strengthens the need for researchers to be culturally competent in their efforts to build trust, respect, relationships and integrity with Indigenous communities, in ways that demonstrate an understanding of Indigenous values and collaborative partnerships that

are based on Indigenous control and ownership over research. Furthermore, researchers may regard ethics research guidelines to have significance in the writing of ethics applications and the approval process only and may not feel compelled to encompass the intended outcomes and/or practices throughout the research project. “The difference between the ethics proposal and ethical research is critical; it is possible for researchers to meet rule-based ethics requirements without embracing the values and principles that are relevant to the research” (Laycock et al., 2011, p.30). The NHMRC has acknowledged the importance of cultural competency in developing policy, partnerships and participation in health and has also indicated the importance and necessity of building relationships in research; however, the NHMRC makes no reference to cultural competence in the current research guidelines or associated guidelines such as the Australian Code for the Responsible Conduct of Research. There is sufficient evidence in the literature, the CHL case study and from personal anecdotes to justify the inclusion of cultural competence in research and particular, Indigenous research.

CHAPTER EIGHT

DISCUSSION AND CONCLUSION

Introduction

As stated in the Methodology chapter, this study had five aims including: an historical overview of research practices involving Aboriginal and Torres Strait Islander people; to highlight concerns expressed by Aboriginal and Torres Strait Islander people who often described past practices as being culturally inappropriate and insensitive; to examine previous and current national research guidelines and assess their effectiveness against a research case study; to explain how cultural competency can assist all researchers in becoming more culturally responsive and sensitive throughout the research process, and also in becoming strong advocates of Indigenous research reforms that have been espoused by Indigenous academics like Martin (2008); Moreton-Robinson (2000); Nakata (2007a, 2007b); Rigney (2006) and Walter (2010), and lastly; in implementing the NHMRCs guidelines in a consistent and culturally appropriate manner. The six research questions identified for this research study were derived from a number of sources: the NHMRCs national ethical research guidelines, including previous and current guidelines and those relating to Aboriginal and Torres Strait Islander people; the literature review; and a unique case study research project.

The first research question investigated what constitutes an ethical approach to Indigenous research (from an historical perspective) and involved a review of literature regarding past research practices and the concerns that were raised by Indigenous people. The second research question examined the adequacy of the NHMRCs previous and current research guidelines in reference to a case study that investigated effective practices in teaching Indigenous students with CHL and involved multi sites and industry partners and also contained a number of ethical issues. Research question three examined the proliferation of ethical guidelines and processes and extent to which these assist in underpinning ethical research or if they foster inefficiency. Research question four explored the significance of cultural competency in Indigenous research and required a literature review to ascertain its importance and role in achieving best practice. Research question five required an examination of the case study for examples where cultural competency contributed to effective outcomes during the research

process. Research question six examined the need to develop a new framework to address the issues that arose in the research case study.

This chapter will present key findings from each of the research questions and will present the study's contribution to the body of knowledge in achieving best practice in Indigenous research through cultural competency.

Key Finding 1: Ethical approaches to Indigenous research: historical context

There is overwhelming evidence in the literature to confirm that, historically, the conduct of research on Indigenous issues by non-Indigenous researchers has often been culturally inappropriate, insensitive, devious, exploitive and often harmful to many Indigenous individuals and communities (Cruse, 2001; Fredericks, 2008; Greenhill & Dix, 2008; Humphrey, 2001; Laycock et al., 2011; Liamputtong, 2008; Taylor & Ward, 2001). These past practices have often excluded Indigenous participation and have had no benefit for the Indigenous community. For many non-Indigenous researchers, involvement in Indigenous research has resulted in opportunities for career advancement and the acquisition of Indigenous knowledge and/or new understandings as a consequence of research (Fredericks, 2008; Greenhill & Dix, 2008; Laycock et al., 2011). This practice also raised Indigenous concerns about the ownership, interpretation and dissemination of data as often this knowledge was not shared with Indigenous communities (Fredericks 2008; Laycock et al., 2011; Liamputtong 2008). These past practices in Indigenous research are “tied to the history of colonisation” and “power and privilege” which resulted in research practices that “de-humanised” or regarded Indigenous people as “objects in scientific research” (Laycock et al., 2011, p.5). This dominance and control over research resulted in Indigenous knowledge being interpreted from a non-Indigenous perspective using the knowledge system of Western scientific thought with the consequence, for example, of Indigenous cultural practices being misinterpreted (Laycock et al., 2011; Nakata, 2007a; Rigney 2006). Concerns about the use of inappropriate research methodologies, cultural insensitivities and exploitation in the conduct of research involving Indigenous people began to appear in publications and statements in the early 1980s (Fredericks, 2007; NHMRC, 1991). These unacceptable research practices demanded intervention and change in how Indigenous research should be conducted. The need for such intervention reflects the key understandings of critical theory which are informed by principles of social justice

and equality that distinguishes between, ‘what is and what should be’ (Giroux, 1983, p.8). Critical theory also provides a construct in contesting hegemony and ‘empowering those who have been subject of oppression and exploitation’ (Tripp, 1992, p.13). This change came about when the NHMRC introduced a set of Interim guidelines on *Ethical Matters in Aboriginal and Torres Strait Islander Health Research* in 1991. These guidelines emphasised a major shift away from research practices of the past and promoted Indigenous consultation, community involvement and ownership over research. The NHMRC also introduced a *National Statement for the Conduct of Ethical Research Involving Humans* in 1991. The National Statement evolved from the NHMRCs, ‘*The Statement on Human Experimentation* (1964-1990), an earlier version of ethical standards that applied to medical and later social research in Australia (NHMRC, 1999, p.2). Research required the application of both sets of guidelines in the development of research proposals needing an ethical review or clearance by an HREC and in the conduct of research. In 1992, the NHMRC became a national statutory authority for the development and implementation of ethical research guidelines and ethical matters relating to health (NHMRC, 1999). The 1991 Interim guidelines for Indigenous research were revised in 2003 and outlines six values to guide researchers in the development of research proposals and the research process. The six values are: Reciprocity, Respect, Equality, Responsibility, Survival and protection; and Spirit and Integrity (see Chapter two). These six values reinforce Indigenous ownership and control over research and promote collaborative partnerships between researchers and Indigenous communities. The NHMRC has also revised the *National Statement* in 1999 and 2007 (see Chapter two).

Running parallel to the development of research ethical guidelines have been the voices of a number of Indigenous academics who have challenged the dominance of Western research paradigms and have called for the redistribution in power and methodological reforms in Indigenous research. The incorporation of Indigenous knowledge and values are key elements of their research reform agenda. (Martin, 2008; Moreton-Robinson, 2000; Nakata, 2007a, 2007b; Rigney, 2006; Walter 2010). For example, Rigney (2006) has challenged the neo-colonial dominance in research practices in Australia through the development of an ‘Indigenist’ research approach that promotes methodological research reforms which reflect Indigenous worldviews,

autonomy and self-determination in research. The Indigenous research reform agenda is also being promoted by agencies such as the Lowitja Research Institute and other peak Indigenous bodies such as AIATSIS who play an important role in funding identified research projects in Indigenous communities and who also reinforce Indigenous control over research and the research process. The Institute also recognises the importance of focussing on research priorities that have been identified by Indigenous communities; research that will make a difference to the health and well-being of Indigenous Australians and, the development of collaborative partnerships between researchers and Indigenous communities in research. (Laycock et al., 2011).

Summary:

Research in Indigenous research have seen a major shift from neo-colonial research practices and the dominance of non-Indigenous researchers to Indigenous control and ownership. Recent developments in ethical research guidelines that specifically relate to research involving Indigenous people are based on:

- a set of values and protocols that are shared among Indigenous Australian communities;
- the promotion collaborative partnerships in research;
- the building of strong relationships, trust and respect in research;
- the setting of Indigenous priorities in research; and,
- Indigenous control and ownership over research.

Key finding 2: Adequacy of previous and current research guidelines

The establishment of national ethical research guidelines and approved HRECs to review and approve research are important measures instituted by the NHMRC to ensure that research involving humans is conducted with integrity, respect, justice and beneficence. HRECs have the responsibility to ensure that all research proposals are compliant with all applicable NHMRC's guidelines (NHMRC 1999, 2007). Any subsequent changes to an approved ethics application also require approval from HRECs. These guidelines are subject to regular updates and revisions in a sustained effort to continually improve ethical research practices and to address any shortcomings of the existing guidelines. The above processes provide a sound basis for the conduct of

ethical research; however, the literature asserts that research guidelines alone cannot guarantee that research will always be carried out in a manner that is most consistent with them (Laycock, et al., 2011; NHMRC, 2007).

The CHL case study (2001-2003) was used to evaluate the adequacy of the NHMRC's previous research guidelines that applied at the time as well as those that are now currently in place. In evaluating the adequacy of previous and current research guidelines, incidents of an ethical nature which occurred in the CHL research study were assessed against each publication of the guidelines. For example, the thesis reveals that third parties who are involved in research are not directly subject to ethical scrutiny by research ethics committees. As a result, teachers may offer to give approval of data collection to researchers, without formal written consent. None of the guidelines addresses or prevented this potential breach of ethics from occurring. There were some minor revisions between the 1999 and 2007 versions of the *National Statement*; however, there were major changes to the 1991 and 2003 guidelines that related to research involving Aboriginal and Torres Strait Islander people (see Chapter two). Despite careful planning and compliance to 1991 and 2003 respective guidelines, the CHL research team encountered a number ethical issues that were beyond their control (see Chapter five). These were;

Due to the Privacy Act (1988), the CHL research team were reliant on schools distributing and explaining the consent form to parents/caregivers. In some cases, AIEOs were given the responsibility to speak to parents/caregivers, however, despite the research team explaining the message to convey to parents/caregivers via telephone and also in providing notes on what to say, there were incidences of miscommunication. For example, parents/caregivers were told that permission was being sought by the research team to conduct hearing tests with their child rather than being informed that the research concerned an evaluation of the effectiveness of teaching strategies to improve learning among those students who suffered from CHL. Some principals opted to contact parents via telephone to gain verbal permission and signing on their behalf. This option disempowered parent/caregivers from signing the form and removed the face to face contact which is recommended by the NHMRC (2007).

In another incident, a principal sent the wrong consent forms to Indigenous and non-Indigenous parents/caregivers and this confused parents as the forms differed regarding the type of permission being sought. The requirement of multiple ethics forms from university and health agencies also confused teachers and school nurses who were unsure if the research team could observe classroom lessons without official approval from all recognised sources. The university's ethics clearance permitted classroom observations however, without ethical clearances from the other institutions; the CHL research team could not use any journal entries or audio recordings made during classroom observations (A. Galloway, personal communication, May 02, 2003).

- The use of passive/negative consent. This was used once by the project team to obtain consent from non-participating Indigenous and non-Indigenous students who may be included in video and audio recordings in the classroom. Negative consent means that parents/caregivers need to apply in writing if they do not wish to give permission. If no response is received, permission is assumed. The University's HREC approved this request under strict conditions, insisting that a reply paid envelope is provided in the mail out. This option of gaining consent disempowers parents and its use should be avoided by researchers. It is interesting that the NHMRC national guidelines do not make reference to the use of passive or negative consent in research.
- Teacher's giving consent. In a number of cases, teachers offered to give consent to video and audio recording of lessons when official written consent had not been received. The CHL team wisely refused this offer and explained to the teachers that this act was unethical. This incident highlights the need for all participants of research to receive research training in order to provide a better understanding of the research process and importantly, to minimise practices that breach ethics and confidentiality.
- Request for confidential information. In one case a research team member was approached by school's a senior staff member to provide information about a classroom teacher who was participating in the project. The researcher refused this request and explained that it was unethical.
- On-going consent. An important initiative that was implemented by the team leader was the appointment of an Indigenous team member to the position of ethics officer. The main responsibilities of this role was to meet parents/caregivers to confirm: (1) on-going consent, (2) understanding of the research project, (3) the right to remain or withdraw from the research project, and to discuss any concerns or issues. This

initiative exceeded the guidelines that applied at the time of the CHL study, but did address the requirements of 'on-going' consent included in the 2007 *National Statement*. The appointment of an ethics officer also complements the values expressed in the 2003 guidelines for the conduct of research involving Aboriginal and Torres Strait Islander people through empowering parents/caregivers.

- Researching in WA schools. While the Department of Education (WA) and the Catholic Education Office of WA require the submission of university ethical clearance, copies of consent forms and interview questions; and information on the storage and dissemination of results, the Aboriginal Independent Community Schools (AICS), only requires researchers to seek permission directly with the school principal. This arrangement may result in ethical shortcomings as the principal may not have an in-depth knowledge of the research process and therefore, may not apply similar requirements as those that are set down by established research policies that apply to researching in Department of Education (WA) and Catholic Education (WA) schools. This arrangement also may convenience researchers who chose to take short cuts to complete data collection quickly by using passive consent methods rather than obtaining written consent from parents/caregivers.

The incidents that have been outlined above clearly indicate that the problems and/or issues that were encountered during the CHL research study could not have been prevented by the existing or current research guidelines as they did not apply to the third parties that were involved in the project. In essence, the research guidelines direct what researchers have to do in order to meet their ethical responsibilities and obligations in the conduct of research; however, they do not extend to the participants or third parties who are also involved in the research activity. While this thesis advocates for researchers to receive cultural competence training prior to engaging in Indigenous research, it is also emphasising the importance for researchers to recognise that third parties who are involved in the research project should also receive cultural competency and research training in order to minimise potential breaches of ethics.

Summary:

The number of ethical issues and dilemmas that occurred during the CHL research study were not attributed to the existing ethical guidelines that applied at the time nor would the current guidelines prevented similar incidences from happening. The

previous and current research guidelines set ethical standards and requirements for researchers to follow during the research process, however, they do not formally guide standards for participants to follow. The CHL research team demonstrated a high level of ethical conduct throughout the three year study by ensuring that all ethical procedures were confirmed and were strictly adhered to. The research team also demonstrated a strong willingness to build relationships, trust and respect among all participants who were involved in the study. The CHL research team included experienced researchers who had a good understanding of Indigenous culture and diversity among groups, demonstrated empathy, observed community protocols and, were driven by desire to make a difference to Indigenous health and through the research study.

The lack of knowledge of Indigenous culture and communities, together with the lack of understanding of ethical principles and standards may result in some researchers taking short cuts in ignorance and/or intentionally to meet research deadlines. “Ethics underpin every aspect of what we do as researchers, and how we do it” (Laycock et al., 2011, p. 30). Therefore, an inexperienced or less sensitive research team may not have achieved the same outcomes that were accomplished by the CHL research team, who not only applied ethical understandings in the research proposal, but also enacted these understandings throughout the entire research process. Good ethical practices in research are dependent on researchers remaining committed to their ethical responsibilities and obligations to participants throughout the research process. The 1991 and 2003 guidelines that relate to Indigenous research and those that are associated with to the *National Statement* (1999 and 2007) therefore, would not have prevented the incidents that occurred in the CHL research study from happening. Ethical dilemmas are unpredictable and are likely to continue despite the best intentions and/or planning by researchers. However, ethics is only part of the issue as, currently, the guidelines provide directions for researchers and not the participants. Participants who are involved in research, directly or indirectly, should be provided with information concerning their role and obligations in the research process and also receive cultural competence training. To formalise this process, cultural competency must be built into existing and future research guidelines. The content and teaching of these training programs has been discussed in chapter seven. The literature indicates there is no standardised mechanism to assess and or guarantee the quality of cultural

competency training programs due to the proliferation and variation of such courses, particularly in health and education contexts. Further research is required in order to ascertain the effectiveness of cultural competence training across a number of settings, including research.

With reference to cultural competency training and the CHL research team, it has been previously reported that none of the members had received any formal training prior to commencing the project. However, the project leader had 20 years of experience in teaching and twelve years of researching Aboriginal education and secondly, another team member was Indigenous and therefore, were able to provide guidance and support to the other two research members who were less experienced in working and researching in Indigenous communities. After each field trip the research team would meet to reflect upon their experiences and discuss any incidents that had occurred as a means of developing cultural competence among themselves and practising cultural sensitivity in all interactions. In addition, the CHL reference group also were in a position to monitor and provide advice to the research team following the reporting of field trip experiences at formal meetings.

Key finding 3: The proliferation of ethical guidelines: do they assist in underpinning ethical research or do they foster inefficiency?

The NHMRC's national guidelines refer to minimising the duplication of ethical reviews or approvals in cases where more than one institution or organisation is involved in the approval process (NHMRC, 1991, 2007). However, if the research involves Aboriginal and Torres Strait Islander health, an ethics application is required to be submitted to WAAHEC (formerly WAAIHEC) regardless of an existing approved ethics application (Department of Health, 2003). WAAHEC is a registered HREC with the NHMRC and operates externally to the WA Health Department. The operation and role of WAAHEC is to endorse Indigenous control and ownership over health related research. Consistent with the principles of critical theory, it is a process to empower Indigenous people and communities. While most research projects may require just the one university ethics review process, there will be instances where two or more ethics reviews will be required.

The CHL case study involved multi sites and industry partners from education and health sectors. At the time of submitting an ethics clearance form to the university,

the CHL team leader was unaware of the need to submit subsequent ethics clearance application forms to HRECs that involved a number of Indigenous health agencies, including WAAIHEC. When this requirement became known, ethics applications were submitted to WAAIHEC and to the WA Health Department. Following a submission to the Health Department, the CHL team leader was informed that ethics clearance applications would be required for each of the AMSs that were located in the three regions of the state where the study was to take place. A further two ethics clearances were required to be submitted to government health services in two regional areas as not all Indigenous students attend AMS/AHS medical services. Thus a total of eight ethics applications forms were submitted by the CHL team leader for formal HREC approval (A. Galloway, personal communication, November 12, 2002). The CHL team leader was also required to submit a copy of the university's ethics clearance together with copies of consent forms, interview questions, information regarding research methodology, the participants, data collection techniques, storage and dissemination of data, administrative matters such as insurance and an agreement to provide a report for approval in principle from the Education Department of WA and the Catholic Education Office. Following approval at department level, the CHL team leader then had to seek permission from principals who were targeted to participate in the study. The process of obtaining ethical clearance from health agencies and WAAIHEC, took almost a year and for a variety of reasons including changes to the membership and cancelled HREC meetings (see Chapter five).

The ethics clearance process for research involving Indigenous health has become more streamlined recently and many research projects will require only a single ethics review or approval process. For example, if the CHL project were to be conducted today, only three ethics reviews would be required: university, Health Department and WAAHEC. While the Health Department has significantly reduced the number of ethics reviews, there still remains unnecessary duplication in the approval process. For example, there are many similarities between the university's and WAAHEC's ethics application form (see chapter six). University HREC's have recognised the Health's Department's NEAF and only require a copy of an approved ethics application form. A similar arrangement should also be investigated in accepting an approved WAAHEC ethics application.

As indicated in Key Finding two above, ethical guidelines will not necessarily guarantee the conduct of good ethical practice or, that research will be carried out in a manner that is consistent with them. The multiplicity of ethics research applications that applied to the CHL research study did not prevent the incidences from happening and there is no evidence that streamlining the number of ethical reviews (which may have other benefits), would have prevented them happening as well, for the reasons stated in key finding two.

Summary:

The landscape in Indigenous research is very different today than to what it was when the CHL research study was conducted in 2001. While the number of ethics reviews has been significantly reduced for research involving Aboriginal health, there are opportunities for HREC's to agree to reducing the review process further, especially in circumstances where ethics application forms are similar in content. This course of action is justified in light of the key findings that have been discussed above and also in key finding two.

Key finding four: The significance of cultural competency in Indigenous research.

The role and importance of cultural competency in cross cultural research contexts is beginning to emerge in national and international literature in relation to preparing researchers to develop a greater understanding of study participants who are culturally or ethnically diverse backgrounds. The application of this understanding across the entire research process to develop effective communication and interaction with participants and to demonstrate empathy with cultural values and aspirations of a cultural group is now regarded as essential (AIATSIS, n.d; Dudgeon et al., 2009; Harvard Catalyst, 2009; Reich, 2006; Universities Australia, 2011a; Walker & Sonn, 2010). Cultural competency in Indigenous Australian research has been identified in the literature as a critical component in assisting researchers in becoming more 'culturally responsive' and 'sensitive' in all aspects of research [see Chapter seven] (Universities Australia, 2011a; Dudgeon et al., 2010; Walker & Sonn, 2010). In addition, by developing cultural understanding, cultural competency can assist researchers to fully understand and embrace the ethical guidelines that relate to Indigenous research and Indigenous research reforms that are being advocated by Indigenous academics (Dudgeon et al., 2010; Laycock et al., 2011; Martin, 2008; Nakata, 2007a, 2007b;

Rigney, 2006). However, these recent research guidelines alone may not totally appease Indigenous communities who have experienced culturally insensitive and inappropriate research practices by non-Indigenous researchers in the past and therefore, may still be reticent towards researchers and/or engaging in research. The guidelines alone also do not ensure that they will be implemented appropriately during the research process nor do they guarantee an unbiased view or an accurate interpretation of them, especially those that relate to Indigenous research (Laycock et al., 2011; Universities Australia, 2011a). In developing cultural empathy, researchers will be in a better position to develop relationships that are built on trust and respect and this will enable them to form collaborative partnerships in research that incorporate Indigenous research guidelines, values and aspirations. Furthermore, the provision of cultural competence training must also be extended to all participants or third parties who are involved in a research study so that they too can understand and apply the guidelines in a culturally appropriate manner and become advocates of good ethical research practices in Indigenous research.

Summary:

There is growing support in the literature for the inclusion of cultural competency in research, and in particular, Indigenous research. Given the history of Indigenous research in Australia and the shift towards Indigenous control and ownership over research, the contribution of cultural competency can play a major role in a greater understanding of the research guidelines that relate to Indigenous research and how to effectively apply them throughout the research process. However, cultural competency involves a learning process that requires a commitment to engage respectfully and sensitively with people from other cultures. This commitment extends to having the ability to suspend one's own cultural paradigm in embracing cultural differences and values of others. Researchers who engage in Indigenous research therefore, should be highly motivated to want to make a difference to Indigenous issues through research practices that are culturally responsive and sensitive and, those that address the research guidelines.

Key finding five: Examples of cultural competency in the case study.

The CHL case study provides a good example of the important contribution that cultural competence can make in Indigenous research. The CHL research team demonstrated a good level of cultural competence at the time, despite cultural competency not being referred to in previous and/or current ethical guidelines (see Chapter six). The CHL research study presented a number of incidents and operational matters that would challenge any experienced researcher. Although most of these incidents proved to be very frustrating to the team leader and the research team, as a participant observer, I was able to witness a level of sustained empathy, sensitivity and respect in the manner in which each incident was handled by the CHL research team. An inexperienced or less sensitive research team may have found the challenges too perplexing and beyond resolution and therefore, would have been happy to terminate the research activity. Although the CHL team leader considered abandoning the research project, his resolve and dedication to Indigenous research influenced his decision to continue on (A. Galloway, personal communication, June 20, 2002). Cultural competency requires a willingness on the part of researchers to put aside personal cultural values and beliefs in embracing and accepting cultural differences of others and applying this understanding in research (Harvard Catalyst, 2009; Laycock et al., 2010).

The following examples highlight the cultural competence that was demonstrated by the CHL research team:

- The building of relationships, trust and respect with all research participants, including members of the Indigenous community. For example, allocating time for both formal and informal discussions on research and non-research matters. This also extended to taking time to listen to Indigenous voices and implementing matters that were agreed upon.
- Demonstrating cultural responsiveness and sensitivity in negotiations and discussions concerning ethical clearances with several Indigenous stakeholders. This response acknowledges and supports the empowerment of Indigenous organisations as well as parents and care givers.
- A demonstrated knowledge of Indigenous culture and the application of this understanding in resolving unplanned and/or unexpected incidents. For example,

an acceptance that community priorities will always override the priorities of researchers and how to communicate this understanding in a sensitive and respectful manner.

- The appointment of an Indigenous research team member as an ethics officer to consult with parent/caregivers and community members on ethical matters, providing information about the research project and, to build a relationships with each participant.

The CHL case study also highlighted issues that resulted from third party participants who were directly and indirectly involved. These issues have been outlined in key finding two and four. Such incidents reinforce the need for all participants of research to receive cultural competence training in order to minimise potential breaches of ethics standards.

Summary:

Cultural competency is a process of applying the knowledge and understanding of another culture in practical situations and the ability to suspend one's own cultural paradigm whilst embracing those of another (Gower & Byrne, 2012). Cultural competency also requires willingness on the part a person or persons to accept and embrace cultural differences and demonstrate empathy towards the beliefs, values and aspirations of other cultural groups. These qualities were demonstrated by each member of the CHL research team in a number of situations during the research study as outlined above; however, these qualities might not occur in other research teams and third party participants such as principals, teachers, AIEOs and AEWs. The application of cultural competency as evidenced in the CHL research study, provided opportunities for the research team to resolve issues that arose in culturally responsive and sensitive manner and this interaction contributed significantly to the overall success of the research project. While the CHL research team demonstrated a high level of cultural competence, these qualities may not always occur in other research teams as competence levels are often unknown. This is why it is necessary to provide cultural competence training to all participants as guidelines alone will not prevent similar incidents which occurred in the CHL study from happening again in the future. The CHL research team provides testimony that culturally competent research teams can be built and how Indigenous empowerment can still be sustained.

Key finding six: A new framework

This thesis highlights the major shifts and developments in Indigenous research from earlier periods when research involving Indigenous issues was dominated by non-Indigenous researchers to the present, Indigenous control and ownership over research is promoted. National research guidelines now stress ethical practices and understandings in Indigenous research that identify the Indigenous values that should shape the design and conduct of research. Indigenous academics have also advocated further reforms in Indigenous research to reinforce control over research, offer alternative research methodologies and develop a process that engages with Western epistemologies in the production and implementation of new research practices. These practices reinforce the Indigenous reform agenda and are being advocated by organisations such as the Lowitja National Institute for Aboriginal and Torres Strait Islander Health Research and AIATSIS. While there have been positive developments in Indigenous research practices, the CHL case study supports the place of non-Indigenous researchers in Indigenous research (Nakata, 2007a; Rigney, 2006). Indigenous issues are not a phenomenon isolated from non-Indigenous professionals who play a significant role in education, health and research involving Indigenous people and communities. The new framework for practices in Indigenous research should encourage non-Indigenous participation in such research. The issues identified in the CHL case study include:

1. The inclusion of cultural competency in national research guidelines and the requirement for all researchers who engage in Indigenous research to complete cultural competency training.
2. Confirmation of competency by Indigenous and non-Indigenous researchers who engage in Indigenous research. This can be demonstrated through past Indigenous research experiences, research design, involvement of Indigenous researchers on the research team, Indigenous community participation in the proposed research, the agreed ownership and dissemination of results and confirmation of completing cultural competency training. It is important for Indigenous researchers to be aware of the protocols when they are researching another language group other than their own (outsider researchers) and when they are working within their own language group (insider researchers).

3. The provision of cultural competence training to also include third parties who are involved in a research study. For example, in educational research involving students, principals, district education staff, teachers, AIEOs and AEWs who are involved in the study would be required to complete cultural competency training.
4. Further reducing the duplication of ethical reviews or clearances that involve more than two institutions or in cases where the application forms are very similar or identical.

Summary:

The conduct of research involving Indigenous issues is very different to what it was when the CHL study took place. Although national research guidelines have improved practices in Indigenous research, this research study has identified justifications to introduce further improvement measures in achieving best practice in Indigenous research. There is also strong justification for cultural competence training to be included in national research guidelines.

Contribution to the body of knowledge:

The practical value, contribution and benefits of cultural competency in Indigenous research have yet to be confirmed by evidence of research. While there is emerging literature that outlines how cultural competency can assist researchers in becoming more culturally responsive and sensitive in working with Indigenous communities, this thesis identifies the need for further research to be conducted to confirm the importance of cultural competency in research, and in particular, in Indigenous research.

LIST OF REFERENCES

Australian Bureau of Statistics (ABS) (2006). *National Aboriginal and Torres Strait Islander health survey*. Retrieved from

<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4715.0/>

Australian Bureau of Statistics (ABS) (2011). Characteristics of Aboriginal and Torres Strait Islander Australians. Retrieved from

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/web+pages/statistics?opendocument#from-banner=GT>

Australian Government (n.d). Intellectual property. Retrieved on 20/01/09 from

<http://www.business.gov.au/Business+Entry+Point/Business+Topics/Intellectual/>

Australian Government Solicitor (2008). *UWA vs Gray: Right to inventions made by employee*. Legal briefing 89. Retrived from <http://www.ag.gov.au/publications/legal-briefing/br89.pdf>

Australian Health Ministers Advisory Council (2004). *Cultural respect framework for Aboriginal and Torres Strait Islander health, 2004 – 2009*. Department of Health, SA.

Australian Indigenous Health Infonet.(n.d). *Ear health*. Retrieved from

<http://www.healthinfonet.ecu.edu.au/other-health-conditions/ear/reviews/our-review>

Australian Institute of Aboriginal and Islander Studies (AIATSIS) (2000). *Guidelines for ethical research in Indigenous studies*. AIATSIS, Canberra.

Australian Institute of Aboriginal and Islander Studies (AIATSIS) (2012). *Guidelines for ethical research in Indigenous studies*. AIATSIS, Canberra.

Australian Institute of Aboriginal and Islander Studies. (n.d). *Towards cultural proficiency: A phased approach to building cultural capability* 2013-2015. AIATSIS, Canberra. Retrieved from http://50years.aiatsis.gov.au/_files/docs/corporate/aiatsis-towards_cultural_proficiency-2013-2015-strategy.pdf

Australian Research Council, Australian Tertiary Institutions Commercial Companies Association, The Australian Vice Chancellors' Committee, Department of Education, Training and Youth Affairs, Department of Industry, Science and Resources, IP Australia, National Health and medical Research Council (2001). *National principles of intellectual property management for publicly funded research*. Retrieved from http://www.arc.gov.au/pdf/01_01.pdf

Balcazar, F., Balcazar-Suarez, Y., Taylor-Ritzler, T. (2009). Cultural competence: Development of a conceptual framework. *Disability and Rehabilitation*, 31(14), 1153-1160.

Bock, A. (2014, March 17). Rise of Aboriginal PhDs heralds a change in culture. *The Sydney Morning Herald*. Retrieved from <http://www.smh.com.au/national/education/rise-of-aboriginal-phds-heralds-change-in-culture-20140316vqm.html>

Boutin-Foster, C., Foster, J., & Konopasek, L. (2008). Physician, know thyself: The professional culture of medicine as a framework for teaching cultural competence. *Academic Medicine*, 83(1), 106-111

Brandenburg, P. (1984). Kimberley Standard English Vocabulary Test. Cited in Godfrey, J., & Galloway, A. (2004). Assessing early literacy and numeracy skills among Indigenous children with the performance indicators in primary schools test. *Issues in Educational Research*. 14 (2), 144-155.

Brimblecombe, J., (2011). What does reciprocity look like in a research project? In Laycock, A., Walker, D., Harrison, N., & Brands, J. *Researching Indigenous Health: A practical guide for researchers* (pp.24-42). Melbourne, Australia: The Lowitja Institute.

Bronner, S. (2011). *Critical theory: A very short introduction*. New York, USA. Oxford University Press.

Cataldi, C., & Partington, G. (1998). Beyond even reasonable doubt: Student assessment. In G. Partington (Ed.), *Perspectives on Aboriginal and Torres Strait Islander education* (pp. 309-332). Katoomba: Social Science Press.

Catholic Education Office (WA) (n.d.). *Professional development and research*. Retrieved from <http://det.wa.edu.au/policies/detcms/policy-planning-and-accountability/policies-framework/policies/research-conducted-on-department-of-education-sites-by-external-parties.en?cat-id=3457972>

Centre for Cultural Competence Australia (CCCA) (n.d.). *Defining cultural competence*. Retrieved from <http://cca.com.au/Competence-Vs-Awareness>.

Champaneria, M., & Axtell, S. (2004). Cultural competence training in US medical schools. *The Journal of American Medical Association*, 291(17), 2142. Doi: 10.1001/jama.291.17.2142.

Chipps, J., Simpson, B., & Brysiewicz, P. (2008). The effectiveness of cultural competence for health professionals in community-based rehabilitation: A systematic review of Literature. *Worldviews Views on Evidence-Based Nursing*, 5(2), 85-94

Collins, C., & Forrest, H. (2008) *Intellectual property*. Chatsworth, N.S.W. Lexis Nexis Butterworths

Commonwealth of Australia (2008). IP Australia: What is intellectual property? Retrieved from <http://www.Ipaustralia.gov.au/ip/copyright.shtml>.

Cross, T., Brazron, B., Dennis, & K., Isaacs. (1989). *Towards a culturally competent system of care*. Washington, DC. Georgetown University Child Development Centre,

Cruse, S. (2001). Encouraging research guidelines to be put into practice: An Aboriginal health research ethics committee in action. *Kaurna Higher Education Journal, Issue 7*.

Department of Education (WA) (2002). *Do you here what I hear? Resource kit*. Department of Education. Perth, WA.

Department of Education and Training (DET) (2003). *Annual report, 2002-2003*. Perth, WA. Department of Education and Training.

Department of Education (WA) (2009). *Research conducted on departmental sites by external parties*. Retrieved from <http://det.wa.edu.au/policies/detcms/policy-planning-and-accountability/policies-framework/policies/research-conducted-on-department-of-education-sites-by-external-parties.en?cat-id=3457972>

Department of Health (2012). *WA health research, governance, policy and procedures*. Research Development Unit, Department of Health, Perth.

Department of Health (2013a). *WA health research governance and single ethical review. Standard operating procedures*. Research Development Unit, Department of Health, Perth.

Department of Health (2013b). *WA health ethics application form (for research conducted within WA health)*. Retrieved from <http://www.health.wa.gov.au/researchdevelopment/home/hrec.cfm#ethics>

Department of Health (n.d.[a]). *Research development*. Retrieved from <http://www.health.wa.gov.au/researchdevelopment/home/hrec.cfm#ethics>

Department of Health (n.d.[b]). *Princess Margaret Hospital: Ethics and research governance*. Retrieved from <http://www.health.wa.gov.au/researchdevelopment/home/hrec.cfm#ethics>

[Department of Health \(n.d.\[c\]. Multicultural Health. Retrieved from
http://www.health.wa.gov.au/multiculturalhealth/home/cultural_competency.cfm](http://www.health.wa.gov.au/multiculturalhealth/home/cultural_competency.cfm)

Domino, G., & Domino, M.(2006). *Psychological Testing: An introduction (2nd Ed.)*. New York, USA. Cambridge University Press.

Eades, D.(2007). Aboriginal English and the criminal justice system. In, Leitner, G., Malcolm, I. (Eds.). In *Habitat of Australia's Aboriginal languages: past, present and future*. (pp. 299-326). Berlin, Mouton de Gruyter.

Edith Cowan University (ECU). (2001). *Intellectual policy*. ECU, Mount Lawley.

Edith Cowan University (ECU). (2000). *Application to undertake research involving human subjects*. ECU, Mount Lawley.

Edith Cowan University (ECU) (2002). *Guidelines on the responsible conduct of research and scholarship*. ECU, Mount Lawley.

Edith Cowan University (2010). Conduct of human ethical research. Retrieved from http://www.ecu.edu.au/GPPS/policies_db/tmp/ac023.pdf

Ethnic Communities' Council of Victoria (2006). *Cultural competence. Guidelines and protocols*. Carlton. Victoria. Ethnic Communities' Council of Victoria.

Fisher, J. P., & Glenister, J. M. (1992). *The Hundred Pictures Naming Test*. Hawthorn: Australian Council for Educational Research

Dahms, H. (2011). *The vitality of critical theory*. Bingley, UK. Emerald.

Dudgeon, P., Kelly, K., & Walker, R. (2010). Closing the gap in and through Indigenous health research: Guidelines, processes, and practices. *Australian Aboriginal Studies*, 2, 81-91.

Edith Cowan University (ECU) (2010). *Conduct of ethical human research*. Retrived from http://www.ecu.edu.au/GPPS/policies_db/tmp/ac023.pdf

Fisher, J., & Glenister, J. (1992). One hundred picture naming test. Retrieved from <http://eric.ed.gov/?id=ED346503>

Fletcher, A., & Hunter, A. (2003). Strategies for obtaining parental consent to participate in research. *Family Relations*, 52, (3), 216-221.

Foley, D. (2000). Indigenous research, differing value systems. *The Australian Journal of Indigenous Research*, 28 (1), 17-30.

Forster, P. (2003). Ethical pitfalls and political perils of class-room based research. *Issues of Educational Research*, 13,(1), 53-65.

Fredericks, B. (2007). *Which way health research? Reflections on the past, Present and Future*. Aboriginal Health Research Unit, Flinders University, SA.

Fredericks, B.(2008).Making an impact researching with Aboriginal and Torres Strait Islander Peoples. *Studies in Learning, Evaluation, Innovation and Development* 5(1), 24-33.

Frawley, J., Nolan, M., & White, N. (2009) *Indigenous Issues in Australian Universities: Research, Teaching, Support*. Charles Darwin University Press.

Gerring, J. (2007). *Case Study Research: Principles and practices*. New York, USA. Cambridge University Press.

Godfrey, J., & Galloway, A. (2004). Assessing early literacy and numeracy skills among Indigenous children with the performance indicators in primary schools test. *Issues in Educational Research*. 14 (2), 144-155.

Gower, G., & Byrne, M. (2012). Becoming a culturally competent teacher: Beginning the Journey. In Beresford, Q., Partington, G., & Gower (2012) (Eds.). *Reform and Resistance in Aboriginal Education* (pp.379-402)..Crawley. University of WA Press.

Government of WA (1999). *The occupational safety and health act*. Retrieved from [http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:17384P/\\$FILE/OccupSftyAndHealthAct1984_04-00-00.pdf?OpenElement](http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:17384P/$FILE/OccupSftyAndHealthAct1984_04-00-00.pdf?OpenElement)

Giroux, H. (1983). *Theory and resistance in education: A pedagogy for the opposition*. London: Heinemann.

Greenhill, J., & & Dix, K. (2008). Respecting culture: Research with rural Aboriginal community. Liamputtong (Ed.). *Doing cross cultural research: Ethical and methodological perspectives*. Dordrecht, Netherlands: Kluwer Academic Publishers.

Grote, E. (2008). Principles & practices of cultural competency. A review of literature. Canberra. DEERW.

Griffiths, M. (2010). Australia second most multi-cultural country. Retrieved from <http://www.abc.net.au/news/2010-11-17/australia-second-most-multicultural-country/2339884>.

Harslett, M., Godfrey, J., Harrison, B., Partington, G., Richer, K. (1999). *We learn a lot from Mr. Hart: A qualitative study of an effective teacher of Aboriginal students*. Paper presented at AARE Conference, Melbourne.

Harvard Catalyst (2010). *Cultural competence in research*. The Harvard Clinical and Translational Science Centre. Retrieved from <https://catalyst.harvard.edu/pdf/diversity/CCR-annotated-bibliography-10-12-10ver2-FINAL.pdf>

Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Matthews, S., Murakami-Gold, L., Chamberlain, A. (2002). *Indigenous Research Reform Agenda: Changing institutions* Cooperative Research Centre for Aboriginal and Tropical Health. Darwin. CRCATH, IRRA 3, 1-25.

Hindmarsh Island bridge affair. (2003, May 10). *The Sydney Morning Herald*, p.9.

Howe, K. & Moses, M. (1999). Ethics in educational research. *Review of Research in Education*, 24, 21-60.

Human Rights Web (1997). *A short history of the human rights movement*. Retrieved from <http://www.hrweb.org/history.html>

Humphrey, K., (2001). Dirty questions: Indigenous health and 'Western Research.' *Australian and New Zealand Journal of Public Health*, 25, 197-202.

Iacono, J., Brown, & A., Holtham, C. (2009). Research methods – A case example of participant observation. *The Electronic Journal of Business Research Methods*. 7, 1. 39-46.

Liaw, S., Lau, P., Pyett, P., Burchill, J., Rowley, K., & Kelaher, M. (2011). Successful chronic care for Aboriginal Australians requires cultural competence. *Australian and New Zealand Journal of public Health*. 35, (3), 238-248.

Ishtar, Z. (2008). "Living on the ground: Research which sustains living culture. In Liamputtong, P. (Ed.). *Doing cross cultural research: Ethical and methodological perspectives* (pp.161-173) Dordrecht, Netherlands: Kluwer Academic Publishers. doi:10.1007/978-1-4020-8567-3_11

- Janesick, V.A. (2000). The dance of qualitative research design. In Handbook of Qualitative Research. Denzin, N.K., & Lincoln, Y.S. (Eds.) (2nd Ed., pp.379-399) *Handbook of Qualitative Research*. Thousand Oaks, California, USA. Sage
- Jennings, N. (2001). Building bridges in school-focussed research: The Australian experience. In McGinty, S. (Ed.), *The politics and machinations of educational research*, (pp.87-97), New York, Peter Lang.
- Kearins, J. (1988). Cultural elements in testing: The test, the tester and the tested. In Davidson, G. (Ed.), *Ethnicity and Cognitive Assessment: Australian Perspectives*, (pp. 60-70). Darwin: Darwin Institute of Technology.
- Kemmis, S., & McTaggart. (2000). Participatory action research. In Denzin, N.K., & Lincoln, Y.S. (Eds.) (2nd Ed.) *Handbook of Qualitative Research* (pp.567-606). Thousand Oaks, California, USA. Sage.
- Kincheloe, J. L. & McLaren, P. L. (1994). Rethinking critical theory and qualitative research. In Denzin, N.K., & Lincoln, Y.S. (Eds.), *Handbook of qualitative research* (pp. 138-157). Thousand Oaks, CA: Sage Publications, California.
- Kirpalani, S., Bussey-Jones, J., Katz, M., & Genao, I. (2006). A prescription for cultural competence in medical education. *Journal of General Internal Medicine*, 21: 1116-1120. doi 10.1111/j.1525-1497.2006.00557.x
- Kumas-Tan, Z., Beagan, B., Loppie, C., MacLeod, A. & Frank, B. (2007). Measures of cultural competence: Examining hidden assumptions. *Academic Medicine*, 82(6), 548-557.
- Laycock, A., Walker, D., Harrison, N., & Brands, J. (2011). *Researching Indigenous Health: A practical guide for researchers*. Melbourne, Victoria. The Lowitja Institute.
- Liamputtong, P. (2008). Doing research in a cross-cultural context: methodological and ethical challenges. In Liamputtong, P., (Ed.) 2008. *Doing cross cultural research: Ethical and methodological perspectives* (pp.3-20). Dordrecht, Netherlands: Kluwer Academic Publishers.

Mack, L., & Gower, G. (2001). *Keeping the bastards at bay: Indigenous responses to research*. Paper presented at the Australian Association for Research in Education, Fremantle, Australia.

Malcolm, I. (2011). Issues in English language assessment of Indigenous Australians. *Language Assessment Quarterly*, 8 (2), 190-199.

Manderson, L., Kelaher, M., Williams, G., & Shannon, C. (1998). *The politics of community: Negotiation and consultation in research on women's health*. Human Organisation, 5,(2), 222-229.

Martin, K. (2008). *Please knock before you enter: Aboriginal regulation of outsiders and the implications of research*. Brisbane, Australia. Post Pressed.

McDivitt, P.J., & Gibson, D. (2004). Guidelines for selecting appropriate tests. In Wall, J.E., & Walz, G.R. (Eds.). *Measuring Up: Assessment issues for teachers, counsellors and administrators*. (pp. 33-52), NC, Caps Press.

Meadmore, D. (2001). *Uniformly testing diversity? National testing examined*. *Asian-Pacific Journal of Teacher education*, 29 (1), 19-30.

Melville, J., & Rankine, P., (2000). Where to now? Issues in the management of Indigenous research in higher education. *Issues in Educational Research*, 10, (1), 67-76.

Monotti, A., & Ricketson, S. (2003). *Universities and Intellectual Property: Ownership and Exploitation*. New York, USA: Oxford University Press.

Moreton-Robinson, A. (2000). *Talking' up the white woman*. St. Lucia, Brisbane: University of Queensland Press.

Nakata, M. (2004). Ongoing conversations about Aboriginal & Torres Strait Islander Research Agendas. *Australian Journal for Indigenous Education*, 2004, 33,1-6.

Nakata, M. (2007a). The Cultural Interface. *Australian Journal for Indigenous Education*, 36, Supplement, 7-14.

Nakata, M. (2007b). *Savaging the discipline: Disciplining the savage*. Canberra: Aboriginal Studies Press.

Nakata, M. (2013). The Rights and Blights of the Politics. *Indigenous Higher Education, Anthropological Forum: A Journal of Social Anthropology and Comparative Sociology*, 23 (3), 289-303. DOI: 10.1080/00664677.2013.803457

National Centre for Cultural Competence (NCCC) (n.d). *Conceptual frameworks/models, guiding values and principles*. Retrieved from <http://nccc.georgetown.edu/foundations/frameworks.html>

National Health and Medical Research Council (NHMRC). (1991a). *National Statement on the ethical conduct of health research involving humans*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (NHMRC). (1991b). *Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (NHMRC). (1999). *National Statement on the ethical conduct of health research involving humans*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (NHMRC). (2003). *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Islander research*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (NHMRC). (2005). *Keeping research on track. A guide for Aboriginal and Torres Strait Islander peoples about health research ethics*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (NHMRC). (2007a). *National Statement on the ethical conduct of health research involving humans*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (2007b). *Australian code for the responsible conduct of research*. Canberra: Commonwealth of Australia.

National Health and Medical Research Council (2011). Procedures and requirements for meeting the 2011 NHMRC standard for clinical practice guidelines. Version 1.1.

Retrieved from

https://www.nhmrc.gov.au/files_nhmrc/publications/attachments/cp133_nhmrc_procedures_requirements_guidelines_v1.1_120125.pdf

Ober, R., & Fasoli, L.(2008). Indigenous researchers reflect at the indigenous research forum [online]. *Ngoonjook*, No. 32, 95-98. Retrieved

<http://search.informit.com.au/documentSummary;dn=889235215284562;res=IELAPA>>

ISSN: 1039-8236.

Partington, G. (2000). *Strategic Partnership with Industry, Research and Training Scheme (SPRIT) grant application*. Unpublished research application.

Partington, G. (2003). *Research at arm's length: The risks of doing research in remote locations*. Paper presented at AARE-NZARE Annual Conference, Auckland, NZ.

Pecukonis, E., Doyle, O., & Bliss, D. (2008). Reducing barriers to interprofessional training: Promoting interprofessional cultural competence. *Journal of Interprofessional care*, 22(4), 417-428. doi: 10.1080/13561820802190442

Provincial Health Services Authority in BC (n.d.). Indigenous cultural competency training program. Retrieved from

<http://www.cultural.competency.ca/>

Ranzjin, R., McConnochie, K., & Nolan, W.(2008). *Psychology and Indigenous Australians: Foundations of cultural competence*. South Yarra, Australia: Palgrave McMillan.

Reich, S.M., & Reich, J.A. (2006). Cultural competence in Interdisciplinary collaborations: A method for respecting diversity in research partnerships. *American Journal of Community Psychology*.38 (1-2), 51-62.

Rigney, L-I. (1999). Internationalization of an Indigenous anti-colonial cultural critique of research methodologies: A guide to Indigenist research methodology and its principles. *Emergent Ideas in Native American Studies*, 14(2), 109-121.

Rigney, L-I.(2006). Indigenous Research and Aboriginal Australia. . In Kunnie, J.E., & Goduka, N.I., (Eds) *Indigenous peoples' wisdom and power. Affirming our knowledge through narratives*. (pp.32-48). Surrey, UK: Ashgate Publishing Ltd.

Social Policy Research Centre (2008). Indigenous Research Strategy: Working better with Aboriginal and Torres Strait Islander people and communities. University of New South Wales.

Schnarch, B., (2004). Ownership, Control, Access, and Possession or Self-Determination Applied to Research: A critical analysis of contemporary first nation's research and some options for first nations communities. *Journal of Aboriginal Health*.1(1),80-95. Ottawa, Canada: National Aboriginal Health Organisation.

Selby, J.M.(2001). Child care in remote Indigenous Australian communities: Empowerment and intervention. In McGinty, S. (Ed.). *The politics and machinations of educational research*. (pp 155-166), New York, Peter Lang.

Smith, F.N. (1997). Indigenous research ethics: Policy, protocol and practice. *The Australian Journal of Indigenous Education*. 25(1), 23-29.

Smith, L.T., (1999). Decolonising Methodologies Research and Indigenous peoples. London: Zed Books.

Smith, L.T. (2000). Connecting pieces: finding the Indigenous presence in the history of women's education. In Weiler, K. & Middleton, S. (Eds.) *Telling Woman's lives. Narrative inquiries in the history of women's education*. (pp. 60-72), Buckingham, UK: Open University Press.

Social Policy Research Centre (2008). *Indigenous Research Strategy: Working better with Aboriginal and Torres Strait Islander People and Communities*. University of New South Wales.

Silverman, D. (2000). *Doing qualitative research: A practical handbook*. London. Sage Publication.

Sue, D.W. (2001). Multidimensional facets of cultural competence. *The Counseling Psychologist*, 29, 790-821.

Taylor, R., & Ward, G., (2001). Ethical research and Indigenous Australia. *Kaurna Higher education Journal*, 7, 15-22.

Thackrah, R. & Thompson, S. (2013). Refining the concept of cultural competence: building on decades of progress. *The Medical Journal of Australia*, 199 (1), 35-38. doi: 10.5694/mja13.10499

Thomas, D., Bainbridge, R., Tsey, K. (2014). Changing discourses in Aboriginal and Torres Strait Islander health research, 1914-2014. *The Medical Journal of Australia*. 201(1), s1-s5. doi: 10.5694/mja14.00114

Thomson, N., (2005). Cultural respect and related concepts: a brief summary of the literature. *Australian Indigenous Health Bulletin*, 5(4), 1-11.

Tripp, D. (1992). Critical theory and educational research. *Issues in Educational Research*, 2(1), 13-23.

Universities Australia (2011a). *National Best Practice Training for Indigenous Cultural Competency in Australian Universities*. Canberra: Universities Australia.

Universities Australia (2011b). *Guiding principles for developing cultural competency in Australian Universities*. Canberra: Universities Australia.

WAAIHEC (2000). *WAAIHEC ethics proforma*.

WAAHEC (n.d). *Western Australian Aboriginal Health Ethics Committee*. Retrieved from <http://www.ahcwa.org.au/index.php/programs/ethics>

Waddington. Neil J. (2000). *Diagnostic Reading and Spelling Tests 1 & 2 (Second Edition)*. Strathalbyn, S.A: Waddington Educational Resources

Walker, R. & Sonn, C.(2010). 'Working as Culturally Competent Mental Health Worker.' In Nola Purdie, Pat Dudgeon and Roz Walker (Eds.), *Working Together: Aboriginal and Torres Strait Islanders Mental Health and Wellbeing Principles and Practice*. (pp.157-180).Melbourne, Australia: ACER Press

Walter, M. (2010). The politics of the data: How the Australian statistical Indigene is constructed. *International Journal of Critical Indigenous Studies*, 3 (2), 45-56.

Watson, H. (2003). *Final report of the national evaluation of the National English Literacy and Numeracy Strategy (NIELNS)*. Retrieved from http://www.google.com.au/search?q=hugh+watson+final+report+of+the+national+evaluation+of+national+english+literacy+and+numeracy+strategy+&hl=en-AU&gbv=2&oq=hugh+watson+final+report+of+the+national+evaluation+of+national+english+literacy+and+numeracy+strategy+&gs_l=heirloom-serp.3...74171.117947.0.119351.125.15.1.94.94.0.272.1527.2-6.6.0...0...1ac.1.34.heirloom-serp..115.10.1630.TwmRQmFt3QM

Weaver, H.N. (1999). Indigenous people and the social work profession: Defining culturally competent services. *Social Work*, 44 (3), 217-225.

Western Australian Aboriginal Human Ethics Committee (WAAHEC) (n.d). Ethics. Retrieved from <http://www.ahcwa.org.au/index.php/programs/ethics>

Western Australian Department of Health (n.d.) *Aboriginal cultural security: a background paper*. Retrieved from <http://www.aboriginal.health.wa.gov.au/htm/aboutus/Cultural%20Security%20Discussion%20Document.pdf>

Weiler, K. (1999). Reflections on writing a history of women teachers. In Weiler, K. & Middleton, S. (Eds.) *Telling Woman's lives. Narrative inquiries in the history of women's education*. (pp 43-59). Buckingham, UK: Open University Press.

Williams, R. (1999) Cultural safety – what does it mean for our work practice?' *Australian and New Zealand Journal of Public Health*. 23(2) 213-214.

Williams, S. and Stewart, I. (1992). Community control and self-determination in Aboriginal education research: The changed roles, relationships and responsibilities of Aboriginal and non-Aboriginal researchers and Aboriginal communities. In White, C. (Ed.), *National Aboriginal and Torres Strait Islander Higher Education Conference Proceedings* (pp.90-98). Toowoomba: University of Southern Queensland.

Woodside, A. (2010). *Case study research: Theory, methods and practice*. Bingley, UK: Emerald Group Publishing.

Vardi, I. (1991). *Phonological Profile for the Hearing Impaired Test*. Perth: Iris Vardi.

Yin, R. K. (2003). *Case study research. Design and methods (3rd Ed.)*. London. Sage Publications.

Appendix A

Research Project on Conductive Hearing loss

Kurongkurl Katitjin: School of indigenous Australian studies

Edith Cowan University

Parents'/Caregivers' consent Form

A lot of Aboriginal children get ear infections. These infections are called Otitis Media and it causes hearing problems for children. A result of the infection is glue ear or runny ears and this affects the children's schoolwork, especially reading. A research project is being carried out to find out the best ways to teach children who have glue ear or have had it in the past.

Your child's ears will be tested by a nurse or health worker to see if he or she has glue ear. We will work out your child's present level of achievement at school and we will get school records of their attendance and classroom behaviour.

Teachers will learn new ways of teaching children with glue ear. We will video tape and/or audio tape lessons in your child's classroom to see how the teacher uses the new methods. Later on, we will compare the children's progress with the information we gathered at the start. These tapes will only be seen and listened to by the researchers. They will not be shown to other people.

We would like to interview you about your child's schooling. The interviews will be tape recorded.

We will keep the information about you and your child confidential. We will write articles about the research but we will not mention names of people in the research or show pictures of them. However, if you give permission, pictures of your child may be posted on the Web or published in a newsletter to show how children work at school. These pictures will not contain any information about your child's performance at school.

The research will continue until sometime in 2003. People who decide not to participate will not be disadvantaged. The research has considerable benefit for Indigenous students and should lead to better learning in schools. The research has the support of

the Department of Education, the Catholic Education Commission and the Aboriginal Independent Community Schools.

Any questions concerning the project entitled **Conductive Hearing Loss and Indigenous Students** can be directed to Associate professor Gary Partington in Kurungkurl Katitjin on 08-93706571; Mr. Graeme Gower, Head of Kurungkurl Katitjin, on 08-93706558; or Dr. Ann Galloway on 08-93706840

Consent for participation in the research

Please tick the parts below that you agree to, and then sign this form

- ☐ I have read the information above and any questions I have asked have been answered to my satisfaction. I know that I can withdraw at any time.
- ☐ I give permission to allow my child/children to participate in this activity
- ☐ I give permission for the researchers to use hearing records and school records of my child/children.
- ☐ I agree that the research data gathered for this study may be published provided I and my child/children cannot be identified.
- ☐ I agree to be interviewed about my child/children's schooling.
- ☐ I give permission for my child's picture and name to be published on the Web and in newsletters and videos provided no information about his/her personal details are given.

Child's name _____ Class _____

Parent's/caregiver's name _____

Date: _____

Parent's/Caregivers's or authorised representative's
signature _____

Investigator _____ Date _____

Appendix B

Research Project on Conductive Hearing loss

Kurungkurl Katitjin: School of indigenous Australian studies

Edith Cowan University

Parents'/Caregivers' consent Form

A lot of Aboriginal children get ear infections. These infections are called Otitis Media and it causes hearing problems for children. A result of the infection is glue ear or runny ears and this affects the children's schoolwork, especially reading. A research project is being carried out to find out the best ways to teach children who have glue ear or have had it in the past.

Your child's ears will be tested by a nurse or health worker to see if he or she has glue ear. We will work out your child's present level of achievement at school and we will get school records of their attendance and classroom behaviour.

Teachers will learn new ways of teaching children with glue ear. We will video tape and/or audio tape lessons in your child's classroom to see how the teacher uses the new methods. Later on, we will compare the children's progress with the information we gathered at the start. These tapes will only be seen and listened to by the researchers. They will not be shown to other people.

We would like to interview you about your child's schooling. The interviews will be tape recorded.

We will keep the information about you and your child confidential. We will write articles about the research but we will not mention names of people in the research or show pictures of them. However, if you give permission, pictures of your child may be posted on the Web or published in a newsletter to show how children work at school. These pictures will not contain any information about your child's performance at school.

The research will continue until sometime in 2003. People who decide not to participate will not be disadvantaged. The research has considerable benefit for Indigenous students and should lead to better learning in schools. The research has the support of

the Department of Education, the Catholic Education Commission and the Aboriginal Independent Community Schools.

Any questions concerning the project entitled **Conductive Hearing Loss and Indigenous Students** can be directed to Associate professor Gary Partington in Kurungkurl Katitjin on 08-93706571; Mr. Graeme Gower, Head of Kurungkurl Katitjin, on 08-93706558; or Dr. Ann Galloway on 08-93706840

Consent for participation in the research

Please tick the parts below that you agree to, and then sign this form

- ☐ I have read the information above and any questions I have asked have been answered to my satisfaction. I know that I can withdraw at any time.
- ☐ I give permission to allow my child/children to participate in this activity
- ☐ I give permission for the researchers to use hearing records and school records of my child/children.
- ☐ I agree that the research data gathered for this study may be published provided I and
- ☐ my child/children cannot be identified.
- ☐ I agree to be interviewed about my child/children's schooling.
- ☐ I give permission for my child's picture and name to be published on the Web and in newsletters and videos provided no information about his/her personal details are given.

Child's

name _____ Class _____

Parent's/caregiver's name _____

Date _____

Parent's/caregivers or authorised representative's
signature _____

Investigator's

signature _____ Date _____

Appendix C

Research Project on Conductive Hearing Loss

EDITH COWAN UNIVERSITY

KURONGKURL KATITJIN (School of Indigenous Australian Studies)

Principal's Consent Form

Edith Cowan University is carrying out a research project to find out about the educational effects of Otitis Media, or middle ear infection, on Indigenous students' learning. A lot of Aboriginal children get this ear infection which causes conductive hearing loss and hearing problems for children. As a result of the infection, children's school work is affected. The Project is being conducted to find out the best ways to teach children who have conductive hearing loss or have had it in the past.

Teachers in the Project receive training in effective ways of teaching students with conductive hearing loss, and lessons are being recorded at regular intervals. Following each recording session a member of the research team interviews the teacher about the children in the class, the teaching practices employed, and the context of the lesson. Data is also collected about students' attendance, behaviour and literacy achievement.

Members of the Project team will also interview principals of participating schools to collect information about the broader school context and factors that impinge on student performance.

The research will continue until some time in 2003. People who decide not to participate will not be disadvantaged. The research has considerable benefit for Indigenous students and should lead to better learning in schools. The research has the support of the Education Department, the Catholic Education Commission and the Aboriginal Independent Community Schools.

Any questions concerning the project entitled **Conductive Hearing Loss and Indigenous Students** can be directed to Dr. Gary Partington in Kurongkurl Katitjin on 08-9370 6571, or Mr Graeme Gower, Head of Kurongkurl Katitjin, on 08-9370 6558.

Consent to participate in the research

☐ I, _____ have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising I may withdraw at any time. I agree that the research data gathered for this study may be published provided I cannot be identified.

Consent to publish photographs and names

☐ I give permission for my picture and name to be published on the Web and in newsletters and videos in conjunction with the research , provided no information about my personal details are given.

Principal _____ Date _____

Investigator _____ Date _____

Appendix D

Kurungkurl Katitjin : School of Indigenous Australian Studies - Edith Cowan University

Research Project:*Teaching Indigenous students with conductive hearing loss in remote and urban schools in Western Australia*

Teacher's/Teaching Assistant's Consent Form

A research project is being carried out about the educational effects of Otitis Media, or middle ear infection, on Indigenous students' learning. A lot of Aboriginal children get this ear infection which causes conductive hearing loss and hearing problems for children. As a result of the infection, children's school work is affected, especially language development. A research project is being carried out to find out the best ways to teach children who have conductive hearing loss or have had it in the past.

Children's ears will be tested by a nurse or health worker to see if they have Otitis Media. For children who have the infection, we will work with you to establish their present level of achievement at school and we will make comparisons of their attendance and classroom behaviour.

Teachers in the Project will receive professional development in effective ways of teaching students with conductive hearing loss. We will visit your class from time to time to record on video and/or audio tape the way you use these strategies. At the end of each lesson that we record, we will interview you about the lesson, the children in your class and your teaching practices. The interview will be recorded on audio tape. You will be sent a copy of the tape(s) of each recording, if you wish to receive them. Later on, we will compare the children's progress with the information we gathered at the start. We will keep this information confidential. Only the researchers will have access to the recordings.

We will write articles in journals and reports about the research but we will not mention the names of people in the research. However, where schools and teachers approve, pictures of participants will be posted on the Web and published in newsletters and in videos we make about the research to show other people good teaching ideas.

The research will continue until sometime in 2003. People who decide not to participate will not be disadvantaged. The research has considerable benefit for Indigenous students and should lead to better learning in schools. The research has the support of the Education Department, the Catholic Education Commission and the Aboriginal Independent Community Schools.

Any questions concerning the project entitled **Conductive Hearing Loss and Indigenous Students** can be directed to Dr. Gary Partington in Kurungkurl Katitjin on 08-9370 6571, or Mr Graeme Gower, Head of Kurungkurl Katitjin, on 08-9370 6558; or Dr Ann Galloway on 08-9370 6840.

Consent to participate in the research

☐ I have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising I may withdraw at any time. I agree that the research data gathered for this study may be published provided I cannot be identified.

Consent to publish photographs and names

☐ I give permission for my picture and name to be published on the Web and in newsletters and in videos produced in conjunction with the research , provided no personal information is given.

Name_____

Class_____

Signature_____

Date_____

Investigator_____

Date_____