# Do no harm: decolonising Aboriginal health research

**Author:**
Sherwood, Juanita Marion

# Do No Harm: decolonising Aboriginal health research

## Juanita Sherwood

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

University of New South Wales

March 2010

PLEASE TYPE

THE UNIVERSITY OF NEW SOUTH WALES
**Thesis/Dissertation Sheet**

Surname or Family name: Sherwood

First name: Juanita                                           Other name/s: Marion

Abbreviation for degree as given in the University calendar: PhD

School: Social Work                                          Faculty: FASS

Title: Do No Harm: decolonising Aboriginal Health research

---

**Abstract 350 words maximum: (PLEASE TYPE)**

This thesis addresses the question: Why has health research not improved Aboriginal health? Exploring this question from an Indigenous perspective required the development of a methodological approach that I personally undertook as a journey, as both a participant and researcher. This methodology was informed by a decolonisation framework, used Indigenous critical theory and required the balancing of two ways of knowing, to grow a new approach to Indigenous health research. It was initiated and guided by Aboriginal Elders.

The thesis critiques the historical, political, social and current context of Indigenous health and well-being in relation to the Western dominance of knowledge production and ongoing colonisation in Aboriginal health research. Positivistic methods used in health research are interrogated in relation to their lack of contextualisation of the objects (Aboriginal persons) studied. A major focus of this study is the problematic constructions of Aboriginal people as a colonial strategy linked to the Invasion doctrine of terra nullius. The replication of this colonial strategy within the Aboriginal health research discourse since the 1870s through to the present and the impact these representations have had and continue to have on Indigenous Australians is examined. The building and maintenance of the institution of the Western Aboriginal health expert is deconstructed in the light of Edward Said's Orientalism and Michel Foucault's discourses on the power of Western knowledge production.

Fieldwork was undertaken in Alice Springs, Northern Territory, where I interviewed participants involved in Indigenous health research. Their stories and my own story in relation to research practices exemplify the maintenance of Western knowledge production problematising Indigenous peoples and treating them as the 'Other'. The consequences of such practice are injury; unethical practice; silencing of Indigenous voices and views; subjugating of Indigenous knowledges and solutions; and production of invalid data that lead to further injury and poor health status. The findings show a way forward, modelled through Indigenous research methods, with ethics and respect at the core of these approaches.

The thesis builds an evidence-based argument that decolonisation is critical to improving the health outcomes of Indigenous people through Indigenous informed health research.

| FOR OFFICE USE ONLY | Date of completion of requirements for Award: |
|---|---|

**THIS SHEET IS TO BE GLUED TO THE INSIDE FRONT COVER OF THE THESIS**

## ORIGINALITY STATEMENT

'I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at UNSW or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.'

Signed .....................................................

Date 29. 3. 2010

## COPYRIGHT STATEMENT

'I hereby grant the University of New South Wales or its agents the right to archive and to make available my thesis or dissertation in whole or part in the University libraries in all forms of media, now or here after known, subject to the provisions of the Copyright Act 1968. I retain all proprietary rights, such as patent rights. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

I also authorise University Microfilms to use the 350 word abstract of my thesis in Dissertation Abstract International (this is applicable to doctoral theses only).

I have either used no substantial portions of copyright material in my thesis or I have obtained permission to use copyright material; where permission has not been granted I have applied/will apply for a partial restriction of the digital copy of my thesis or dissertation.'

Signed ...........................................................................

Date ............... 3 / 8 / 2010 ..........................

## AUTHENTICITY STATEMENT

'I certify that the Library deposit digital copy is a direct equivalent of the final officially approved version of my thesis. No emendation of content has occurred and if there are any minor variations in formatting, they are the result of the conversion to digital format.'

Signed ...........................................................................

Date ............... 3 | 8 | 2010 . ..........................

# Dedication

This thesis is dedicated to Aboriginal Elders past and present and in particular Aunty Beryl Carmichael and Aunty Rose Fernando.

# Acknowledgements

I would firstly like to acknowledge the Ancestors and Spirits, Elders past and present and Aboriginal and Torres Strait Islander communities of all the lands and countries I have worked and lived in within Australia that enriched my life and ways of knowing, being and doing.

This thesis journey has been supported by many and I wish to recognise their roles in helping me take the steps that have become this dissertation. My supervisors Eileen Baldry, Associate Professor, School of Social Science and International Studies and Michael Wearing, Senior Lecturer, School of Social Science and International Studies. Eileen in particular rescued my journey and helped re-build my confidence to maintain the journey. Her patience and wisdom have been greatly appreciated and are the reasons for why I can finally write this page. Michael has also provided much support and laughter. My Aunties and their families have been there all the way and I am eternally grateful for their love and growing of me. A special thank you to Willurei Kirkbright-Burney for capturing my methods in her illustrations of the models in Chapters 4 and 9.

My friends, extended family and mentors Linda Burney, Janet Mooney, Daphne Hall, Jeff Hulcombe, Jane Ulrich, Alex Brown, Alexis Wright, Danielle Russ, Tahnia Edwards, Donna Campbell, William Tilmouth, Aunty Kathy Abbott, Vanessa Davis, and Denise Foster have been there for me in my best and worst times, thank you.

To my family I am lost for words and so I should be after writing this. You have been my strength all along this life journey and have given me the determination to keep going. Mum you have been my best friend and confidant and always believed I could get there, Stephanie you have pushed me to achieve, Jocelyn you have been my joy and made me always appreciate what was before me, Michael you were a brilliant critic who made me think more deeply, Dad although you were not on this plain I know you helped and Joel thank you for being who you are, and putting up with your mum all these long years.

# Table of Contents

## Contents

# List of Figures

# List of Tables

# Abstract

This thesis addresses the question: Why has health research not improved Aboriginal health? Exploring this question from an Indigenous perspective required the development of a methodological approach that I personally undertook as a journey, as both a participant and researcher. This methodology was informed by a decolonisation framework, used Indigenous critical theory and required the balancing of two ways of knowing, to grow a new approach to Indigenous health research. It was initiated and guided by Aboriginal Elders.

The thesis critiques the historical, political, social and current context of Indigenous health and well-being in relation to the Western dominance of knowledge production and ongoing colonisation in Aboriginal health research. Positivistic methods used in health research are interrogated in relation to their lack of contextualisation of the objects (Aboriginal persons) studied. A major focus of this study is the problematic constructions of Aboriginal people as a colonial strategy linked to the Invasion doctrine of terra nullius. The replication of this colonial strategy within the Aboriginal health research discourse since the 1870s through to the present and the impact these representations have had and continue to have on Indigenous Australians is examined. The building and maintenance of the institution of the Western Aboriginal health 'expert' is deconstructed in the light of Edward Said's Orientalism and Michel Foucault's discourses on the power of Western knowledge production.

Fieldwork was undertaken in Alice Springs, Northern Territory, where I interviewed participants involved in Indigenous health research. Their stories and my own story in relation to research practices exemplify the maintenance of Western knowledge production problematising Indigenous peoples and treating them as the 'Other'. The consequences of such practice are injury; unethical practice; silencing of Indigenous voices and views; subjugating of Indigenous knowledges and solutions; and production of invalid data that lead to further injury and poor health status. The findings show a way forward, modelled through Indigenous research methods, with ethics and respect at the core of these approaches.

The thesis builds an evidence-based argument that decolonisation is critical to improving the health outcomes of Indigenous people through Indigenous informed health research.

# Glossary

'Aboriginal', 'Indigenous', 'Aboriginal and Torres Strait Islander people' are terms that are used interchangeably in this thesis and that refer to the Indigenous status of the first people of Australia. Generally, I have used the term Indigenous to be inclusive of all Indigenous peoples of the world.

**Aboriginal people**

Aboriginal people are the First Nation people of Australia.

**Aboriginal and Torres Strait Islander people**

Are the First Nation people of Australia. Aboriginal people live and maintain the mainland continent now named Australia and Tasmania and its seas, oceans and sky-heavens. Torres Strait Islander people reside in and are maintained the Torres Strait Islands and its seas and heavens.

**Academy**

The academy is defined as the Western model of education and epistemologies that inscribes a Western worldview and ways of knowing. These ontologies are developed and grown in institutions such as schools, universities and other tertiary institutions.

**Balance**

Is defined and used in terms of a holistic model. To take from a source without giving back destabilises the model. It is the essence of traditional ecological survival practised by Aboriginal peoples from time immemorial. Law for and from country defines the reciprocal relationships and activities that must be taken up by people to maintain and sustain balance in their world.

The balance symbolism is a critical dimension of the Dreaming. Reciprocal affiliations through oppositional relationships bring about balance. However if there is a dominance of one relationship of knowing over another, there is no balance. This lack of balance puts the world at risk and will destroy. For example, the over-hunting of an animal species without attempting to replenish the species leads to extinction. The continual mining of the earth's resources will lead to depletion of these resources and destruction of the earth's surface. This may lead to 'pay back' or (reciprocity) by the earth through earthquakes, changes in weather patterns, and lack of water.

13

**Co-generate knowledge**

I have used this term to explain that I have worked with people, Elders, ancestors and literature to develop and grow knowledge. It was not an individual act it was collective and collaborative process.

**Colonisation**

Colonisation was a political and social strategy of British imperialism which established British control of land seized through imperial action. To control the land the colonisers subjugated the original inhabitants, a strategy that established the binarism of coloniser and the colonised who were the Indigenous Australians. Colonisation continues today in Australia and impacts on every Australian's life, as we have all been indoctrinated through a dominant knowledge system about our status and authenticity within this country. The power of this indoctrination is that it re-creates itself and is maintained through the production of knowledge based on this worldview.

**Context**

Context is a term used throughout this thesis to explore the 'critical background information' or 'setting the scene'. This information is important in telling 'the whole story' in order to deliver truths.

**Country**

Aboriginal people have a deep and direct relationship with country, who is "mother" "parent" "care giver" to all Indigenous Nations of Australia. The relationship is deeply respectful and reciprocal as the earth has provided a sustainable nurturing environment and way of life appreciated by the first peoples of this country. Her ways of knowing have been passed on to the people through law to ensure that she is cared for as she has cared for people and animals that have been nourished by her. This caring connection is critical to the lives of all Aboriginal peoples and continues to be the framework of their ways of knowing or worldview.

**Decolonisation**

Decolonisation is used here in a personal and cultural sense as a lifelong process that commences once an individual recognises that they have been colonised. It requires critical reflective

thinking and a balanced appreciation of multiple worldviews and their respective truths. On a cultural level in Australia it necessitates a 'contextualised discourse for re-claiming knowledges informed through a balance of truths and histories. Reflecting upon the cause and effect of past action and its policies' (Sherwood 2009:24) to comprehend and make sense of current circumstances and relationships. This process is ongoing as the colonial ideological constructs are part of the dominant political knowledge production and require unpacking constantly through reflective praxis to prevent further indoctrination.

**Deviant**

A term that denotes the construction of Aboriginality in terms of deviance from a white norm.

**Dis-ease**

Is used to denote the holism of ill health, it is not just a physical body issue but it also influenced by the emotional, spiritual and social body.

**Doing**

Is the utilisation and application of Indigenous knowledge systems.

**Dreaming**

The Dreaming is a metaphysical, spiritual and physical framework that explains the creation, landform development and relationships of all living and non-living beings on this continent. The Dreaming period set down our landscapes and our laws for living. The law is inscribed within these landscapes and connects all living and non-living beings into complex reciprocal relationships that compel ways of knowing, being and doing.

This framework is not static it is for ever changing as is the environment that we live in and it has enabled Aboriginal people to survive through following its guidelines of balance, reciprocity, obligation, respect, relationships and community welfare principles.

**Elders**

Aboriginal Elders are generally the older people who are the most knowledgeable and wise of the community. They have developed their knowledge through both lived and learnt experiences.

Elders have always been the custodians of knowledge, cultural praxis and protocols. Their responsibilities have been to nurture and grow Aboriginal people in their law, education, language, culture, ceremony and philosophy. This is to live as respectful beings accepting of their responsibilities to the physical and spiritual ecosystem.

**Epistemology**

It is the analysis of knowledge and its production using specific methods.

**Eurocentrism**

Dominance and assumed superiority of European Western thought on every level of knowledge construction.

**Gammon**

Aboriginal English term used for something that is not true.

**Growing**

Aboriginal English term for the process of nurturing personal, social, spiritual and educational development for sustainability. Elders grow us up through their instruction and modelling of moral behaviour.

**Hegemony**

A term used within this thesis to explain the domination of Western knowledges and cultural norms on Indigenous peoples. It is also the systems in place to maintain the status quo.

**Indigenous peoples**

First Nations peoples throughout the world who have been colonised by imperial empires of the West and East. I use the term within this thesis to acknowledge the local and international collectives who have struggled with the imposition of an oppressive and controlling dominant colonial regime.

**Indigenous ways of knowing, being and doing**

It is Indigenous philosophy. A holistic rather than compartmentalised approach that has been passed down through Law and the Dreaming for generations supported and taught by Elders. It is informed through Indigenous epistemologies (Knowledge and its application), ontologies (being as informed through Law, Dreaming and relationships) and axiologies (Cultural protocols and ethics informed through law and the Dreaming) that have developed directly through living, observation, experimentation and working with the natural world and its ecosystems to sustain and maintain balance.

**Indigeneity**

The quality of being Indigenous.

**Invasion**

The illegal transgression of a body upon another. Within this context, the transgression was committed through the breach of international law by the British under which they claimed Australia as *terra nullius* and hence ignored the sovereignty of the original inhabitants and their property laws. The violence that unfolded in many areas throughout Australia resulted from the lack of respect for the sovereignty of the countries throughout the nation.

**Law**

Aboriginal Law or Customary Law is radically in opposition with Western law in almost every way (Stanner 1979). The Law was generated through the land by the Dreaming spirits. These laws are concrete and extensive are provide strong directions for relationships with the land, cosmos, animals and people. Unlike Western law, it does not change.

**Listening**

Listening is an active process and method. Listening from an Indigenous perspective requires a person to sit and observe the person speaking, allowing their story or narrative to unwind orally without interruption. This act demands respect of the speaker through a disciplined openness of the person 'listener' who is being provided with privileged information.

**Methodologies**

I have used the term methodologies rather than methodology to acknowledge that many philosophical backgrounds and worldviews have informed my methods within this thesis. A method is an approach used to obtain knowledge, and as indicated I have used multiple methods.

**Mob**

An Aboriginal English term for family and connections.

**Neo-colonial**

I have used this term to suggest that although Australia is considered to be no longer a colonial nation, the colonial structures and practices continue to be replicated by the dominance of Western systems that oppress and subvert Indigenous Australians.

**Orientalism**

The discourse of Orientalism involves the contesting of academic constructions that determined what could and would be said about the Orient and the colonised Other (Said 1995:3).

**Other**

The 'Other' is a term that has been used to explore the displaced and minoritised population that has been colonised. The coloniser defined the other as its nemesis, or oppositional inferior. It is a term widely used in postcolonial studies. The use of western names and terminology denies the names of peoples and the space they occupied prior to colonisation. It also provides the colonisers with a framework to embed other myths upon collectively. It has assisted the colonisers to further extend their authority by naming and owning their subjects of their colonies.

**Past, present, future**

An important holistic continuum that informs an Indigenous worldview. The past is as important and relevant as the present, and continues to inform law, protocols and praxis. The present was yesterday's future and so the continuum of past, present and future have critically informed living the law.

## Paradigms

Paradigms are the aggregate a person or researcher's ways of knowing, being and doing frameworks. Their values, beliefs and worldviews that inform this philosophical premise (Denzin and Lincoln 2000). An Indigenous interpreted framework or paradigm similarly is informed through an Indigenous way of knowing (epistemology), Indigenous way of being (ontology) and an Indigenous way of doing (methodological).

This thesis is a practical application of an Indigenous paradigm. I have utilised Indigenous epistemologies (ways of knowing), Indigenous ontology (ways of being) an Indigenous methodology (ways of doing) to explore our ways of knowing and dealing with health.

## Problematic

I have used this term to suggest that this problem assertion around Indigenous Australians is disputable however it often has negative outcomes and ramifications for Indigenous Australians.

## Problematising

The construction of Aboriginal peoples as problematic by their colonisers. With *terra nullius* as its founding ideology, the very existence of Indigenous peoples has been a problem for white Australia. This founding tension has fuelled the relentless constructions and misrepresentations of Aboriginal people as problematic on almost every dimension and has become a tradition informed by the writings of experts and through the development of policy that has continued in Australia unabated. It is a product of a colonial mindset and hence has become a way of knowing Indigenous Australians.

## Reciprocity

It is a way of doing that supports the notion of balance. Relationships define obligations, relationships are multidimensional and to be sustained they must be balanced. The balance is critical to the continuity of the relationship be it with country, people or animal. The reciprocal process is laid down through law and Dreaming and as such continues to be dynamic in status and accountability.

**Re-search**

The term is used to show that research is a valuable approach in cultural revival and Indigenous well-being

**Research**

Is a process for the building of knowledge around an issue to generally to solve a problem.

**Research practice**

A term used in this thesis to denote Western research, process and its outcomes that often has had negative ramifications for Indigenous people.

**Research praxis**

A term used in this thesis to explain the interconnection of theory and its practice its context within this thesis promotes a positive strategy used in research with Indigenous peoples.

**Respect**

Respect is an overarching value and protocol that is at the core of developing a meaningful and sustainable relationship. This relationship is orchestrated by law, because 'Law belongs to people and to country' (Bird Rose 1996:32). The law and knowledge through respect embody our ethical conduct. Respect, in the Indigenous sense means to **listen and hear and value** what we have to say about ourselves and our experiences, even if what we have to say challenges your ways of knowing. Respect means you are open enough to acknowledge that there are many ways of being in this world and that they all have their own authority.

**Sharing**

The notion of giving as an act requiring respect. When someone shares knowledge or time with you this is act of sharing that requires a respectful response in turn. This is also reciprocity. If what is shared is greeted with annoyance, disbelief or rejection, the giver is hurt or injured which occurs often in research. Researchers need to be mindful that the time informants give to the research process and the knowledge they share is a gift. Most often researchers do not appreciate the value of gifts they are in receipt of from their informants.

**Social Justice**

Social justice is about acknowledging the inequity and disadvantage lived by Indigenous Australians and attempting to alleviate this through social justice packages, rights policies, positive discrimination policies and appropriate services. Michael Dodson, First Indigenous Social Justice Commissioner for Human Rights and Equal Opportunity, affirms:

> Social justice is what faces you when you get up in the morning. It is awakening in a house with an adequate water supply, cooking facilities and sanitation. It is the ability to nourish your children and send them to school where their education not only equips then for employment but reinforces their knowledge and appreciation of their cultural inheritance. It is the prospect of genuine employment and good health : a life of choices and opportunity, free from discrimination (HREOC 1993 :4)

Due to our colonial history and current disadvantage within the dominant environment most Indigenous Australians do not enjoy these basic rights. Social justice aims to enable Indigenous people to live with their inherent rights enshrined within the greater society, currently this is not happening.

**Sovereignty**

The legitimate rule over a people and territory and the ability to make political, social, cultural and economic decisions. The sovereignty of Indigenous peoples over themselves and their countries prior to invasion is now universally accepted. Invasion of the continent did not result in Indigenous Australians giving up their sovereign rights, however it has prevented Indigenous people from having control over their lives and Nations. Indigenous peoples continue to assert their sovereignty by demanding self-determination, land rights and the community control of research.

**Torres Strait Islander Peoples**

The Indigenous and independent peoples of the Torres Strait Islands. Torres Strait Islander peoples have a significantly different history and culture to Aboriginal Indigenous peoples of Australia and as such we are not the same people. However we share the same colonial circumstances which have impacted on all Indigenous Australians' health and well-being.

**Truth**

An Indigenous truth relates to the integrity of the person. Their words are guided by the law and hence what they say is considered to be the truth. This is different from the concept of a truth being a validated fact.

**Us**

This term of relatedness and is used to speak from an Aboriginal perspective and as an Aboriginal person. The use of 'I' is frowned upon in our culture and by my Elders as it disconnects you from your origins and sense of community and it is observed as a Eurocentric way of being and doing.

**We**

See 'us', above.

**Worldview**

Worldviews are paradigmatic, which is to say that they guide and determine an entire mode of living for cultural beings. Worldviews or how one views the world is related to how one makes sense of the world through their respective systems of knowledge or knowing related to their peoples, environment, cultures and experiences.

# Abbreviations

**ABS:** Australian Bureau of Statistics

**ABSAIHW:** Australian Bureau of Statistics and Australian Institute of Health and Welfare

**AIDA:** The Australian Indigenous Doctors Association

**ANTaR:** Australian for Native Title and Reconciliation

**AMS:** Aboriginal Medical Services

**AMSANT:** Aboriginal Medical Services Alliance Northern Territory

**ACCHO:** Aboriginal Community Controlled Health Organisations

**AHMRC:** Aboriginal Health and Medical Research Council

**AIATSIS:** Australian Institute of Aboriginal and Torres Strait Islander Studies

**ARC:** The Australia Research Council

**ATSIC:** Aboriginal and Torres Strait Islander Commission

**ATSIWTFV:** The Aboriginal and Torres Strait Islander Women's Task Force on Violence

**ATSIHRAC:** Aboriginal and Torres Strait Islander Health and Research Advisory Committee

**AVCC:** The Australian Vice-Chancellors Committee

**ERG:** Evaluation Reference group

**CCPAR:** Collaborative Community Participatory Action Research

**CRCAH:** Cooperative Research Centre for Aboriginal Health

**HREC:** Human Research Ethics Committees

**HREOC:** Human Rights and Equal Opportunity Commission

**HRSCFA:** House of Representatives Standing Committee on Family and Community Affairs

**IKS:** Indigenous Knowledge Systems

**MHFA:** Mental Health First Aid

**NACCHO:** National Aboriginal Community Controlled Health Organisation

**NAIHO:** National Aboriginal and Islander Health Organisation

**NAHSWP:** National Aboriginal Health Strategy Working Party

**NHMRC:** National Health and Medical Research Council

**NSW:** New South Wales

**NT:** Northern Territory

**NTDHCS:** Northern Territory Department of Health and Community Services

**OATSIH:** Office of Aboriginal and Torres Strait Islander Health

**RAWG:** Aboriginal and Torres Strait Islander Research Agenda Working Group

**RCIADC:** Royal Commission into Aboriginal Deaths in Custody

**SA:** South Australia

**UN:** United Nations

**WA:** Western Australia

# Introduction

# Why?

## Introduction

My name is Juanita Sherwood; I am an Aboriginal Woman, descendant of the Wiradjuri Nation. I am a daughter, mother, sister, and Aunty and have worked and lived in Aboriginal health and education for over 25 years. These experiences, responsibilities and varied environments have shaped my worldview and my ways of knowing, being and doing. My worldview has informed my approach to this thesis, so this is not an objective account. It is a story of a journey I have travelled, gaining insight into why research has not improved Aboriginal health from an Aboriginal perspective. It is informed by peers, communities, Elders, supervisors and rich Indigenous and non-Indigenous textual dialogues. I have attempted to tell this story in an Indigenous **and** scholarly manner that will assist others to comprehend the continuing appalling state of Aboriginal health.

## Two-way learning

This research journey began approximately ten years ago when ten female Elders sat me down one evening to talk about my future. We were at an event that was celebrating a statewide policy; an outcome of the work I had been involved in the area of otitis media.[1] The women told me that that they were very proud of the work I had been doing and that they had plans for me to learn more. They said the work was an important step in my learning journey and that they urged me to go further on this path. The women recommended a significant Elder they wanted me to spend time with to grow my knowledge and work towards achieving better educational and health outcomes for Aboriginal and Torres Strait Islander peoples. I accepted this directive and moved out west from Sydney to Broken Hill to work with Aunty Beryl.

Aunty Beryl became my teacher and she set up a circle of other Elders from whom I was to learn. Aunty Rose Fernando and Aunty Beryl Carmichael have been crucial to my development

---

[1] Otitis Media is a middle ear disease that can cause conductive hearing loss that has implications for listening and hearing at home and in the classroom

as an Indigenous learner as well as being supportive of me through the academic tenure of developing the thesis.

Aunty Beryl has extensive knowledge in education, health, Law and country. As an emerging learner myself in Aboriginal culture I found this request by the Elders a significant honour. Boori Monty Pryor best explores the honour that I had been given:

> Knowledge is passed on to those who are strong enough to keep it. The Elders have to see that strength in you to know that you can keep the secrets and hold the knowledge. You have to be interested not just through seeing with your eyes or hearing with your ears because that means it can go in one ear and out the other. Most importantly, your heart must be open and free because it is only when all the stories and secret songs can be given in trust (Pryor 1998:197-8).

I had received an enormous gift: the opportunity enabled me to re-search my heritage as well as learn from women who I held in the utmost respect. I valued this prospect however it is and has been a journey that provided complexities and heartache in attempting to be a cultural, relevant and safe researcher.

It was my intention to explore Indigenous paradigms, through research, using a model that would ensure cultural safety and respect. The framework for this research was to endeavour to dignify the real experience and not the perceived experience of Indigenous Australians. My rationale was to develop an approach that was meaningful to the researcher and to the Aboriginal participants and communities. University was recommended as the environment from which I had to gain the necessary knowledge and comprehension of theory to undertake valid and authentic research.

The university is recognised as a site of knowledge production; however it is not the only site, as I came to appreciate through this research journey. The undertaking of courses in research did not provide a model that was safe for Aboriginal people. From the university and its academy came many claims of there being only one way to produce knowledge: it was privileged knowledge; it was Western knowledge. It held little appreciation for or recognition of other knowledge as significant or authentic. However, from this engagement with Western worldviews, it became clear to my Aboriginal participants and me that Indigenous knowledges needed to be acknowledged and substantiated as authentic. I resisted what Hannah Arendt calls

26

'the coerciveness of Truth' (Lincoln and Guba 2000:185), and undertook to make sure Indigenous voices that had been silenced were heard.

The contribution of Aboriginal Elders' guidance throughout this research has been significant and essential to my ways of knowing, being and doing:

> Listening to the old people is a true way of respect. That's the main message I like to get across when I speak about my culture. I say, 'There's three things that you have to remember. Three things that you have to do in life: respect your Elders. Respect each other. And respect the things that are living around you. If you don't do these three things then you're stuffed (Pryor 1998:10).

Undertaking this thesis has been the process that attempts to articulate the critically important Indigenous epistemologies or Aboriginal ways of knowing that are mostly absent within an orthodox Western thesis. As such this thesis is different as it has not followed the tried and tested formula of Western scholarship, although attempts were made to follow that formula.

As part of a means of explaining important concepts, I have used Indigenous story-telling as a method that employs repetition of critical points of reference. In this thesis, I have followed this methodology, reiterating vital points in the narrative. Two of many examples include references to negative Indigenous attitudes towards research, and to knowing, being and doing. In recognition of the foundational importance of these concepts, I have repeated them where they are relevant. The aim is to make the work accessible to Indigenous readers while at the same time introducing this concept to non-Indigenous readers.

## Issue

This thesis offers an Aboriginal perspective on Aboriginal health research. The process of doing the work for the thesis explored Indigenous ways of knowing, being and doing, decolonisation and the re-claiming of knowledge related to me and my community's identity and ways of being. It developed into a work integrating multiple methods and worldviews. The intention has been to explore the nature of Indigenous health research in Australia and develop a model of research that would be framed by respect and reciprocity as well as ensuring benefit to Indigenous Australians in relation to improved health outcomes targeting improved quality of life and reductions in morbidity and mortality. This is necessary because currently Aboriginal & Torres

Strait Islander health continues to be reported as problematic with morbidity and mortality rates comparative to that of 4<sup>th</sup> world nations (Freemantle, Read et al. 2006; SJC 2006 :149; Walter and Saggers 2007). This situation is unacceptable as Indigenous Australians live in a country whose mainstream population enjoys the health status of the rich first world.

Doing research in Indigenous communities is not a god-given right to all Western trained academics, be they Indigenous or non-Indigenous. It requires the researcher to recognise the privilege of such an experience and further to comprehend that with this privilege, comes responsibility and reciprocity. The researcher must also critically examine their motives and purpose for undertaking research. This includes a critical reflective process on the experiences of Indigenous peoples who have suffered as a result of the context of research over the last 200 years.

I have had the opportunity and good fortune to work with a number of Indigenous and non-Indigenous researchers who recognise the importance of working in partnership with Indigenous communities. They have taught me a great deal and encouraged my work in the area of decolonising research as they appreciate the importance of this framework as a new paradigm along with the opportunities of privileging Indigenous ways of knowing about their health and solutions. Their work in this area has informed the steps I have taken on my path of learning. It has been a two-way learning journey informed within research by excellent Indigenous and non-Indigenous researchers who have shown me a way forward.

My aim is take you on that path of a critical reflexive research process, one that I have journeyed to appreciate the steps that are necessary for meaningful and effective research with Indigenous peoples. This journey is explored through the following chapters.

## The Research Journey

This thesis is a method for decolonising Indigenous health research (Smith 1999). It was a journey undertaken by the researcher who also became a participant to understand just what is needed to address the question the thesis asked: why has research not improved Aboriginal health?

Michael Dodson inspired this journey with these words:

> I see Indigenous peoples as having twin projects: at one level, we must understand the motivation behind the historical constructions of Aboriginality and understand why they have such a grip over colonising nations; simultaneously we must continuously subvert the hegemony over our own representations, and allow our visions to create the world of meaning in which we relate to ourselves, to each other, and to non-Indigenous Australians (Dodson 2003:33).

I have taken on both projects aligned to Indigenous health research, in order to appreciate why research was not, from an Indigenous perspective, improving Indigenous health status.

The problematic constructions of Indigenous people today in health research have a historical context. The first three chapters of this thesis explore this context and examine the reasons why. These reasons are many and commence with British invasion and the term used to legitimate it; 'terra nullius', a land belonging to no one. Problematic constructions of Aboriginal peoples were firstly developed as a colonial strategy invested in by scientists to undermine Indigenous humanity; Aboriginal de-humanised status would legitimate the British claim towards ownership of the continent. The problematic constructions continued and developed as the continent was being settled. Aboriginal people resisted the settling of their land and this resistance had to be quelled by ensuring a discourse of their primitiveness and dangerous qualities was used ensuring settlers and armies undertook to rid the colony of the Aboriginal problem. 'Experts' grew from such discourse development and the Aboriginal 'Other' became an important way of knowing Aboriginal people and also knowing who the new Australians were not. Contrasting images of otherness informed through Orientalism or Aboriginalism became a field of study worthy of export and one that built academic careers and institutions (Attwood 1992; Said 1995).

Problematic Indigenous constructions have informed how research was undertaken and how academic institutions viewed and explored Indigenous peoples in further research projects. The replication of problematic discourses and representations is acknowledged in this thesis as colonial indoctrination that was supported by a lack of balanced historical texts and teachings. All Australians suffered from this diet of Western dominated unbalanced histories. This ensured the Western 'truths' written by experts about Indigenous Australians would be accepted unreflectively. This colonial strategy has informed and constructed Indigenous and non-Indigenous peoples' relationships in this country. Essentially, it has informed Indigenous health research praxis and Western health service provision. This thesis provides evidence of this.

Knowing that research of the past has informed the present is critical to informing ways of challenging these approaches that cause harm and injury to Indigenous peoples.

This project's findings have led to a challenge of this Western approach and to the need to inform Indigenous health research through a balance of histories and truths both Indigenous and non-Indigenous. A decolonising method developed though my own lived experience of understanding the colonial past and how it continues to inform the present. This decolonising method is a living method and is a directly related to achieving the second project outlined by Dodson (Dodson 2003).

This method aims to subvert the Western hegemony of how Indigenous people are represented. It has informed my critique of current research, the conduct of Western research institutions and their ethical practice including how health research represents Indigenous people. It is a method that developed a reflective model for decolonising to build respectful relationships between Indigenous and non-Indigenous Australians.

The thesis chapters develop these arguments, methods and theory building.

## Chapter 1    Colonisation, it's bad for your health: the context of Aboriginal health

Chapter 1 establishes, by critically reviewing relevant literature, that the appalling health status suffered by Indigenous Australians has historical, political and social contexts that is related, directly, to colonisation. To support this claim I have contextualised within a historical timeline, specific colonial polices and their practice, outlining the impact they have had upon the health and well-being of Indigenous Australians. I have demonstrated that colonisation continues today both politically and through research in the area of Indigenous health. This is because the context of causal agents that have impacted upon the health of Indigenous Australians have been maintained through problematic constructions of Aboriginal people that were established when the concept of terra nullius was applied to this continent.

The purpose of providing the context of these colonial experiences and circumstances has been to juxtapose the research approach used in positivistic science. Positivistic approaches used in Aboriginal health research do not examine their own Western bias or explore the causal circumstances that have contributed to Indigenous poor health status. Such approaches have

produced legitimated ill-informed constructions of Indigenous people that have enabled political bodies and health professionals alike to blame Aboriginal people for their health status. This research practice has a neo-colonial agenda in that it has been able to control what knowledge will be produced and silence any dissent from Indigenous people. This approach has ensured that research has not improved the health outcomes of Indigenous Australians.

## Chapter 2   Different ways of knowing, being and doing

Chapter 2 explores the divergent ways of knowing and worldviews of Indigenous and non-Indigenous Australians through the writings of Western and Indigenous theorists and commentators. This approach is important as it underpins how these differences inform the manner in which research has been and is undertaken in the area of Aboriginal health. It also underpins differences in the way Indigenous and non-Indigenous people view health, and ways of sustaining well-being.

Indigenous systems of knowledge are explored specifically as they provide an opportunity for balancing two different systems of knowing. The Ngurra-Kurlu Walpiri model is detailed to demonstrate ways to develop and build respectful relationships with Western knowledge systems. Western knowledge systems are also explored, however their practice, linked to the positivistic approach, does not allow balance to occur; rather it has to dismiss or reduce all variables that do not support its frame of reference. This dominant way of truth making about Indigenous peoples is challenged, as it does not support a respectful balance that includes Indigenous voices or views. Instead it, has created the 'expert' whose power is embodied within his or her ability to speak on behalf of Indigenous people; a role critical to and for the colonial strategy. Is an approach that has compromised health improvements through colonised Indigenous health research.

## Chapter 3   Constructing Aboriginal health problems

Chapter 3 explores, through the literature, how the construction of Aboriginal people as different and the contrasting 'Other' developed as a colonial research practice of the past. The practice of problematic constructions of Indigenous Australians by experts in the field of social science and medicine was supported by colonial governments in order to be better able to know how to control and manage these resistant and problematic peoples. Importantly, these ways of knowing

Indigenous Australians as problematic and resistant to Western civilisation have been maintained by 'experts' in the field of Aboriginal health research. The expert's opinion and discourse on the 'Other' was and is highly respected. The knowledge they produced was far more valuable than those offered by Indigenous Australians themselves.

The expert's constructions of the past became imperative to support the research hypothesis of the present. As such, research in the area of Indigenous health continued to be informed by the expert and past evidence, rather than by evidence provided by Aboriginal and Torres Strait Islander peoples. The chapter also evidences how this practice continues to inform Western ways of knowing Indigenous Australians and conducting research and health service delivery of the present.

## Chapter 4   The learning journey

Chapter 4 details the methodological journey I have taken. Demonstrating how different ways of knowing can come together to support the building of reliable and valid data in a respectful approach with Indigenous peoples to inform good Indigenous health research praxis.  Positioning me as both a researcher and a participant. The process has grown an Indigenous research methodology that I consider is a valuable approach to be used in the endeavour of improving the health outcomes of Indigenous Australians.

My journey has required that I explore and examine my own colonised mindset and has taken me down the path of a decolonisation process that is ongoing. An Indigenous critical theory emerged as a result of this decolonisation process utilising critical theory as its foundation, to critique colonial policy and practice and appreciate the importance of balancing histories of all Australians. The praxis is supported by my living cultural method, an Aboriginal model for knowledge generation and growth that is explored both pictorially and articulated through the learning journey.

It was in working through these two ways of knowing and learning that the method of this thesis developed. The method has shown that there are ways to respectively co-generate Indigenous and non-Indigenous ways of knowing to improve health outcomes through collaborative participatory research approaches.

## Chapter 5   Aboriginal health research reform: attempts to shift the agenda

Chapter 5 establishes that Indigenous health research reform is a site of struggle and has been agitated for by Indigenous Australians since the late 1930s. From the 1980s onwards the Indigenous reform agenda has been informed by Indigenous Australians and their organisations who have actively engaged with research bodies and government agencies to improve the outcomes of health research for their respective communities and ensure that research praxis is culturally safe and ethical. The chapter examines both the barriers to and strategies of the Indigenous health reform agenda. It demonstrates, by deconstructing the documented Indigenous research agendas, that the main barrier to reform is the continued hegemonic domination by Western institutions and researchers, who have been unable to shift from a Western research-driven agenda. The results of such approaches are articulated by Indigenous participants as injury.

The strategies for change and research reform are inclusive of Indigenous research methodologies, the building and support of Indigenous researchers, the NHMRC Road maps, and challenging the models and practice of institutional Western research ethics.

## Chapter 6   The good, the bad and the ugly in Aboriginal health research

Chapter 6 explores three stories of Indigenous health research that are drawn from participants, research articles and my own personal experiences. These are examined critically for the presence of the impacts and barriers established as affecting Indigenous health in Chapters 2, 3 and 5. The first story is a study of injury that in turn caused injury; story two is a critique of a health journal research article that has subscribed to the discourse of the problematic Aboriginal person; story three is a personal reflective account of a health research experience that injured research participants and the Indigenous researcher. All three stories demonstrate that the research, in those cases, did not improve Aboriginal health and exemplify the injury unreflective research practice can cause.

The fourth story demonstrates what research can achieve when Indigenous people inform and manage the agenda. The focus of change in this story was not centred on research alone or driven by a research agenda; instead it was observed as tool by communities to build evidence to grow ways of dealing with issues they were concerned about. The outcomes of this process went

beyond a published research article; they brought about change and increased health and education service provision throughout NSW, an approach that worked towards improving both health and educational outcomes for Indigenous children.

## Chapter 7   The grog trial: whose knowledge counts?

Chapter 7 uses a detailed account of a government initiated evaluation process of a 12-month trial on liquor restrictions in Alice Springs, gazetted by the Northern Territory Liquor Commission in 2003, to deconstruct contemporary Indigenous health research practices. The trial was a result of an Indigenous movement through political agitation to reduce the harmful effects of alcohol misuse within the Aboriginal community. The effectiveness of the trial's special measures were to be evaluated and a reference group consisting of government and non-government agencies, known as the Evaluation Reference Group (ERG), was established.

The evaluation of the effectiveness of the grog trial[2] is explored from the two divergent research approaches undertaken to inform the ERG of the broader communities' attitudes regarding the trial. One was a random sample household phone survey undertaken by the Northern Territory Department of Health and Community Services, the other an Indigenous-led research approach that interviewed some 270 Town Camp residents. The report by the Chair of the ERG regarding shifts in alcohol consumption and measures of harm, to the Licensing Commission is challenged. It is demonstrated that ignoring vital Indigenous evidence resulted in a report that did nothing to improve the health outcomes of Indigenous people.

## Chapter 8   Ethics: it's just good manners

Chapter 8 builds a model of safe and respectful ethical praxis in Indigenous health research out of the information provided by Elders and informants and by incorporating findings from the previous three chapters. It first establishes how Western health research ethics developed and became dominant in Indigenous health research. The chapter reveals how ethical guidelines for Indigenous health research are used and treated by researchers, a vital aspect that speaks to the findings of Chapter 6, which reveal that, in the first three research projects examined there had been given ethical clearance through Human Research Ethics Committees (HRECs), but these projects did not adhere to ethical praxis from an Indigenous perspective.

---

[2] Grog: is a colloquial term for alcohol

Unethical research practice has been acknowledged in this thesis as causing harm and injuring Indigenous communities. One of the key concerns highlighted in the findings and literature is the inability of researchers and institutions to listen to Indigenous people. Listening is considered by Indigenous people as an essential value of ethical and respectful praxis. Breaching or ignoring this Indigenous value is considered unethical practice. This is affirmed by Elders who are practitioners and teachers of Indigenous moral and ethical matters.

An analysis of what the Elders, who are the experts in Indigenous ethics, say is good ethical praxis has resulted in the development of a reflective model for decolonisation. This model describes the ethical and reflective steps to be taken by health researchers who want to develop meaningful relationships with Indigenous people. It is a model that aims to build an appreciation of another worldview, be it Indigenous or non-Indigenous. The model requires those taking the steps to be critical reflective learners who are enabled to be open to many truths and hence are able to work respectfully with others. It is argued that adhering to this model can lead to improving health outcomes through Indigenous health research.

## Chapter 9    Discussion and conclusion

Chapter 9, the final chapter of the thesis, brings together a discussion of the findings of the previous chapters. It is through this journey that I have co-generated knowledge and established evidence as to why, and in what way current Indigenous health research needs to shift, if its aim to improve the health outcomes of Indigenous Australians is to be realised.

The journey ensured, through my role as both researcher and participant, that I would effectively grow through the analysis and reflection of evidence built during this process. This growth has been a two-way process acknowledging and respecting Indigenous and non-Indigenous worldviews and ways of knowing. To undertake this research in a respectful manner I had to undertake a decolonising journey, a journey that continues. Along this path my focus on improving health outcomes for Indigenous people through research developed into a model, a model that I have come to exemplify through my own growing on this research journey. The research journey is, in fact, the method. As an Aboriginal woman and researcher I have had the opportunity to appreciate that this is the way forward for healing and preventing injury. It is in this light that I can see research being the tool we will use to ameliorate the consequences of the

past colonial practices, provide representations of Indigenous Australians using information that has not been biased through a colonial Western gaze, and that has the potential of improving health and well-being outcomes for Indigenous Australians.

The thesis builds an evidence based argument that decolonisation is imperative to Indigenous health research and a critical Indigenous theory to explain why 100 years of Aboriginal health research in Australia have not improved Indigenous health outcomes.

# Chapter 1

# Colonisation—It's bad for your health: The context of Aboriginal health

> While Western theories and academics were describing, defining and explaining cultural demise, however, indigenous peoples were having their lands and resources systematically stripped by the state; were becoming ever more marginalised; and were subjected to layers of colonialism imposed through economic and social policies (Smith 1999:88).

## Introduction: remembering the context

Colonisation and positivistic Eurocentric research have entwined to form a negative synergistic context for Indigenous Australians' health. Together they have contributed considerably to the current poor health status of Australia's First Nations and require critical examination. In this examination I use Indigenous critical theory, highlighting the unjust and inhuman acts perpetrated throughout the colonial era on Indigenous Australians. These acts have mainly been ignored and at worst denied by governments, historians, scientists and the broader non-Indigenous community. This has required me to fill in the gaps of knowledge related to these circumstances and histories from an Indigenous perspective, providing the context of a trans-generational Indigenous Australian experience.

The scientific method of positivistic research, informed philosophically through Western reasoning, was a significant and useful tool of colonisation. It aided and abetted colonial activities through its production of knowledge about the Indigenous Australian 'Other'. This colonial knowledge development purposely misrepresented and dehumanised its subject by developing racial stereotypes that continue to be used within the Western culture and the academy today (Said 1995). It was undertaken to support the colonial countries' attempts to legitimise their illegal ways of dealing with their problematic natives. As Albert Memmi put it, the coloniser 'endeavors to falsify history, he rewrites laws, he would extinguish memories – anything to succeed in transforming his usurpation into legitimacy' (Memmi 1965 p.52). This willful forgetting has been called colonial amnesia, the inability to resolve an unpalatable past

(Gandhi 1998). Homi Bhabha argues that memory and the act of remembering are critical steps to be taken for a therapeutic recovery from the aftermath of colonisation (Gandhi 1998, Bhabha 1994). He writes that remembering 'is never a quiet act of introspection or retrospection. It is a painful re-membering, a putting together of the dismembered past to make sense of the trauma of the present' (Bhabha 1994).

This memory provides the context of the lived experiences of those colonised and provides the backdrop of the present circumstances which are often ignored in texts that describe Indigenous peoples' disarray. It is this understanding of context that is essential to the Indigenous health stories of research written today, for without the backdrop of history the problematic nature of complex health issues are disregarded. This chapter offers an attempt to remember this unpalatable past that is ignored in positivistic research.

First, the current circumstance of Indigenous health must be understood.

## Aboriginal and Torres Strait Islander health

Aboriginal and Torres Strait Islander health has most recently been reported to be a crisis (NACCHO and Oxfam 2007); an unacceptable situation in a country that has a 'world-class health system' (AIDA 2009:1). For at least fifty years the status of Aboriginal Australian health has been described and bemoaned as appalling (Stanner 1972; ABSAIHW 2008). Even though there has been much hand-wringing and many descriptive accounts of the burden of disease, poor living conditions, and accounts of continuing injustices, Indigenous health remains, as the NACCHO and Oxfam Report, *Close the Gap: Solutions to the Indigenous Health Crisis facing Australia* states, 'a national scandal' (NACCHO and Oxfam 2007:3). This conceptualisation of a national scandal, suggests that this poor health status is recent. It fails to tell the story of two hundred years of both destruction and neglect of Indigenous health.

NACCHO and Oxfam's report is just one of the most recent of some twenty national health reports that have affirmed that Indigenous health requires appropriate funding and approaches to address the significant disparities experienced by Indigenous peoples in Australia (NAHSWP 1989; HRSCFCA 2000; NACCHO and Oxfam 2007:3). It highlights the divergence in life expectancy, with Indigenous Australians' expected life span being 17–20 years less than non-

Indigenous Australians. This is a gap that has been growing 'over the past forty years' specifically in the Northern Territory, the only Australian jurisdiction that provides adequate Indigenous morbidity and mortality data (Thomson and Ring 2008:106). Despite improvements in respiratory disease and child and maternal mortality, the gap grows, signifying chronic injustice (Thomson and Ring 2008).

In 2008, the five leading causes of death for Aboriginal and Torres Strait Islander Peoples reported by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare (ABSAIHW) were 'diseases of the circulatory system' systemic heart and vessel disease; 'external causes' inclusive of physical injury through accidents, homicide, assault and suicide; 'neoplasms' malignant and benign cancers; 'endocrine, nutritional and metabolic disease', inclusive of diabetes and 'diseases of the respiratory system' (ABSAIHW 2008:161). This burden of disease has been estimated to be 'two and half times greater' than for non-Indigenous Australians (AIDA 2009:1). These fundamental discrepancies in Indigenous health status justify comparative descriptions of third and fourth world positioning (Bhatia 1995).

Disparities in health are indicators of a disproportionate affliction of disease within a population group (Adelson 2005:s45).The causal agents of disparities are 'social, economic, cultural and political inequities' (Adelson 2005:s45) developed through a tenure of marginalisation created under the policy of colonisation (Murray, Bell et al. 2003). These inequities have taken a heavy toll upon individuals and their communities (Thomson and Ring 2008). The incidence of co-morbidities, disability and premature deaths are further exacerbated by 'the collective burden of a history of discriminatory practices, unjust laws and economic or political disadvantage' (Adelson 2005:s46).

Furthermore, there is another critical relationship related to the plethora of morbidities suffered by Indigenous Australians and this has been articulated as a stress cycle. This cycle begins prior to birth with the transfer of stress hormones from the mother to child in utero as a result of the mother's historical, political and social circumstances. These stress hormones affect the developing brain and 'They are born vulnerable to patterns of stress reactivity … they over-activate in a sort of emergency mode, and don't switch off' (Professor Sven Silburn quoted and cited in Cresswell 2007:2). This over-reactivity is now appreciated to be linked to the key killer

of Indigenous Australians, cardiovascular disease. Stress is also acknowledged as a common denominator to 'diabetes, obesity, insulin resistance, heart disease' (Cresswell 2007:2). Stress is a killer and is compounded by the lack of acknowledgement of people's sovereignty, rights and traumatic history. As Fiona Stanley argues, 'self-esteem and acknowledgement of history is an extraordinarily powerful preventative factor for health' (Fiona Stanley quoted in Cresswell 2007:3). It is in this light that I have used the term 'injury', following Raphael's definition of 'trauma, psychological injury' (Raphael, Delaney et al. 2007:338) to explore the ongoing nature of harmful experiences that Aboriginal people deal with in health research.

Western health policy has focused upon the responsibility of the individual to control their personal health fate, with disease causation being largely attributed to high risk behaviours and proximate causes of diseases such as hypertension and diet. These notions have largely ignored what puts people at risk (Link and Phelan 1995). The causal agents are linked to people's social environment and, in most circumstances, are not individually chosen. Hence the fate of health status is not entirely a choice but the product of many historical-political-social determinants that are often not elaborated within the discourse of medicine (Kelm 2005; Saggers and Gray 2007).

Prior to European invasion and settlement, Aboriginal Australians enjoyed a non-sedentary life-style that concentrated upon maintaining and sustaining their country, relationships and ecosystems. 'Pre-contact health care systems' (Anderson 2006:4) were focused upon the inter-relationships of land, people, the living and non-living entities and creator beings. If the land was not cared for, it got sick, and so would all other beings related to the land, including the people (Yunupingu 1997). Tenure of management dictated by Law passed down through the Dreaming and Ancestors and was practised to ensure balance and to maintain health. The balance ensured a variable access to nutritional diets high in protein and complex carbohydrates (Mackean and Watson 2004). Lifestyles limited the spread of endemic diseases or injury related to mental distress (Saggers and Gray 1991; Trudgen 2000). Documentation of the first fleeters highlighted that Aboriginal people were in 'good health and free from disease' (Franklin and White 1991:3).

**The context of ongoing colonisation**

Today the burden of disease, poor socioeconomic status and severe disadvantage of the First Australians is a testament to a history of colonisation and its continuation (Mitchell 2007). The

practice of colonisation targeted Aboriginal people in a 'deliberate and calculated' manner which aimed to 'displace and distance people from their land and resources' (Sinclair 2004:50). To achieve this aim, Aboriginal culture had to be destroyed, firstly through hostilities and in more recent times through 'mainstreaming' policies. Canadian First Nation researcher, Raven Sinclair argues 'almost every contemporary social pathology or health issue in Aboriginal communities' (Sinclair 2004:50) is a result of colonisation.

Colonisation has been practised for millennia but in the context of this thesis it refers to the period of European expansion from the 1500s to the 1900s in which Britain and its European neighbours invaded and subsequently settled or exploited large proportions of the rest of the world (Smith 1999). The philosophical underpinnings of colonisation 'provided the means by which concepts of what counts as human could be applied systematically as forms of classification' (Smith 1999:25) utilised through political action and informed by science 'to shape relations between imperial powers and indigenous societies' (Smith 1999:25). This colonised and colonising mindset continues into the 21$^{st}$ century.

The current status of the health of Australian Aboriginal people is directly linked to this history of harmful policy (Reid and Lupton 1991; Saggers and Gray 1991; Kunitz 1996; Murray, Bell et al. 2003; Ring and Brown 2003; Mitchell 2007). The health of Aboriginal and Torres Strait Islander peoples, though, is far worse than other Indigenous peoples living in Canada, United States and New Zealand (Kunitz 1996; Murray, Bell et al. 2003; Ring and Brown 2003). Although their health is still poorer than many of their non-Indigenous neighbours, these First Nation peoples have benefited from somewhat more effective health measures and appropriate policy (Murray, Bell et al. 2003) and through self-determined advocacy and government investment, than have Indigenous Australians.

Aboriginal Health Policy in Australia has failed to improve Aboriginal health, as evidenced by an increase of co-morbidities fuelled by chronic diseases and the flourishing of fourth world diseases (Murray, Bell et al. 2003) such as: failure to thrive, otitis media, rheumatic fever/heart disease, leprosy, tuberculosis and trachoma (Brewster 2003; Couzos and Carapetis 2003; Couzos, Metcalf et al. 2003; Couzos and Taylor 2003; Krause 2003; Zweck, Roche et al. 2003).

All of these are diseases of poverty, are endemic, preventable and continue as a result of a lack of effective political, social and medical intervention.

To try and encompass and analyse the wide sweep of historical-political-social and cultural factors constructing Aboriginal health experience and status, I explore key policy eras targeting Aboriginal and Torres Strait Islander peoples.

## The effects of colonisation

### Dispossession 1770–1885 and 1885–2007

Terra Nullius (land belonging to no one) was a European doctrine used to extinguish the sovereign rights of First Peoples. British Law enabled Australia to be occupied by British citizens, dispossessing original owners without compensation (Reynolds 1987:4). This practice led to the multitudes of injustices suffered by Aboriginal and Torres Strait Islander peoples who held customary ownership of the countries of some 500 Nations throughout the continent. The conception of Australia as Terra Nullius became deeply intertwined with the constructions of Indigenous Australians as inferior and problematic, necessitating the notion of a superior race taking up an empty and untilled land (Reynolds 1987).

Settlement occurred from 1788 not as a single event but as a staggered assault throughout the country over a period of one hundred years (Goodall 1996) originating in the south-east of the country (Goodall 1996) and completed in the Northern Territory around 1870 to 1885 (Haebich 2000; Trudgen 2000). NSW was initially founded as a penal colony, which led to an enterprise of farms, housing and expanding settlement. Within a year of contact, epidemics of smallpox were documented to have wiped out large numbers of Aboriginal people from within the Eora Nation (Sydney) (Reynolds 2001:36). Diseases became the key explanation for decline in numbers of the Aboriginal population, considered to have been between 750,000 and 1,000,000 persons across Australia prior to invasion (Saggers and Gray 1991; Franklin and White 1991). This explanation of demise fits with an ideology of primitive and backward races, effectively whitewashing the impact of 'warfare, dispossession, and demoralisation on health and social organisation' (Anderson 2007:1; Mitchell 2007).

Settlement expansion and encroachment by non-Indigenous populations using many strategies over Indigenous countries (Reynolds 1987; Bird Rose 1991) reduced Aboriginal peoples' access to country, and their ability to maintain societal, legal and religious obligations. European occupation resulted in loss of land critical to the health and well-being of Aboriginal peoples and limiting their access to nutritional resources leading to malnutrition and lowering resistance to infectious diseases. Epidemics of smallpox, measles, influenza, tuberculosis, whooping cough and venereal diseases (Mitchell 2007:43), a decrease in fertility (Rowse 2002; Bird Rose 2004) and deaths resulted, leading to a dramatic reduction in population. The destruction of social and political infrastructures critical to a sense of community well-being was equally important, as will be discussed below.

## Conflict and violence 1788–1928

Settler encroachment of lands met with Aboriginal resistance. The consequences of resistance were violence from both the military and settlers, acknowledged as a sustained period of warfare from 1788 to 1838 (Connor 2003). As the British claimed 'Aborigines were British subjects' they were able to define hostilities 'as civil disorder rather than as a war against a foreign enemy' (Connor 2003:58), ensuring a treaty would not result. Martial law became a standard tactical response during this era, enabling the military to mount attacks without legal retribution (Connor 2003) in NSW, Tasmania and Western Australia (Reynolds 1999), where many lives were lost. In Tasmania from 1824 to 1831 the population was culled from 1,500 to 350 (Reynolds 1999:71). The Frontier warfare escalated once the military had been withdrawn (Connor 2003:120), with numerous reprisals against Aboriginal people, acknowledged as massacres, throughout the country from 1837 (Reynolds 1987).

A number of inhumane strategies were used both by settlers and the police to demoralise Aboriginal communities. Abductions, rapes and the murdering of women (Woods 2002:88) resulted in hostile retaliation from tribal bands (Reynolds 1987). The poisoning of water holes, poisoned food, along with shooting, stabbing and forcing large numbers of Aboriginal people, including children, to jump to their deaths (Elder 1988; Schlunke 2005) were also employed. Massacres, starting not long after invasion and continuing into the 20th century, occurred throughout the nation and resulted in the murder of hundreds of Aboriginal people. The most infamous of these were: at Myall Creek NSW in 1838 where Aboriginal people were decapitated

and hacked to pieces or thrown into a fire alive (Elder 1988; Goodall 1996:31); the Bluff Rock Massacre, NSW 1844 (Schlunke 2005); and the Coniston massacre 1928, Northern Territory (Elder 1988; Haebich 2000).

The scientific community as part of the colonial administration developed constructions of 'primitive, savage natives' who were not long for this world (Wolfe 1999). These constructions supported the 'doomed race theory', encouraging settlers to be active in Aboriginal people's early demise (McGregor 1997; Thomas 2004). Anthropologists in particular promoted a European blindness to the human status of Aboriginal Australians (Stanner 1972). This premise fed 'the psychological disposition to hate and despise those whom the powerful had injured, or wish to injure' (Stanner 1972:108); the instances of massacres highlight this internalised abhorrence. In the wake of such acts the challenge for Western researchers was to ensure they captured every aspect of the dying race, to be preserved in their writings and as specimens for observing, pursued for overseas interests. Prior to the Protection era, this was achieved through shooting, and later, by grave robbing (Turnbull 1997).With these homicidal activities carried out in the name of science, research understandably gained a bad name in Aboriginal communities.

## Protectionism 1838–1970s

Protection was a 'policy of limiting rights and separating Aboriginal peoples from society in order to protect European interests' (Grant, Wronski et al. 2008:3). Although the Bill was passed in England in 1838 to protect the natives' 'just rights and privileges as subjects of Her majesty the Queen' (Ella, Smith et al. 1998:29), it was not enacted throughout the country immediately or uniformly. The Act founded the position of 'Protector of Aborigines' (Ella, Smith et al. 1998:29); however the protectorate was 'abolished in 1849' (Ella, Smith et al. 1998:29). Due to ongoing settler massacres of Aboriginal people, the government, under the pressure from concerned citizens, appointed its own protector in 1882 in NSW, heading a 'Board for the Protection of Aborigines' (Ella, Smith et al. 1998:30). The Board acted without legislative powers initially, sanctioning the enforcement of Aboriginal peoples onto reserves as well as punishing non-compliant Aboriginal families (Ella, Smith et al. 1998:30). This program of management and control was replicated throughout the country (Haebich 1988; Gray, Trompf et al. 1991).

Protection mandated total control over Aboriginal peoples. It controlled where they could live, enforced restrictions on mobility, marriage, employment, education, and nutrition. The bureaucracy and its public service, inclusive of protectors, health professionals, police and welfare officers (Haebich 2000) absorbed Aboriginal wages and entitled allowances (Kidd 2000). This imposed poverty and established the exploitation phase of fraudulent activities by governments and their public servants, and the starving of communities of essential funds for survival (Kidd 1997). The bureaucracy also prevented the purchase of land and the development of economic cooperatives by Aboriginal people (Attwood 2003). Importantly, under this Act, Natives were no longer considered British Citizens; they were now wards of the state. Those surviving the killing times were rounded up onto missions and reserves for 'protection' (Reid and Lupton 1991). This enforced incarceration ensured there was no resistance to further encroachment on Aboriginal countries (Haebich 2000).

Mission/reserve life dictated and enforced welfare dependency (Newfong 1995). Rations consisting of flour, sugar and tea were distributed to adults weekly, a colonial strategy (Rowse 2002:5) promoting 'dependency and demoralisation' (Rowse 2002:7). Poor health conditions caused by malnutrition were exacerbated by crowded living conditions, and deplorable shelters increased the rates of morbidity and mortality (Mitchell 2007). Government underfunding in the area of Indigenous health and housing had become entrenched (Kidd 2000:10).

Health research promoted a 'doomed race theory' with Dr Bruce Cleland prophesying in 1928 the extinction of full-blooded Aboriginals (Mitchell 2007:52). Those suffering leprosy, smallpox and syphilis were chained up by the neck and walked great distances to 'lock-up hospitals' throughout the country (Grant, Wronski et al. 2008), as they were considered dangerous distributors of diseases to white communities (Franklin and White 1991:24). This resulted in Aboriginal people being left to die in these lock-up hospitals (Wolfe 1999) as health provision was mainly in the form of segregated isolation (Anderson 2002). Meanwhile, health researchers focused on descriptive accounts of disease, carried out photographic studies of infected women and men for publication, promoted notions of a disease-ridden population and created the label 'black pox' (Thomas 2004:23) to explain donovanosis, a genital disease. Thomas comments that the photographs are still in circulation, although taking them was an 'abuse of power' that caused those suffering from this disease 'a loss of dignity' (Thomas 2004:23).

45

## Injury through stealing children 1814–1980s

From 1814 onwards, Aboriginal children were removed from their families 'to be educated and civilised' (Ella, Smith et al. 1998:10), although prior to this period they had been kidnapped and exploited as slaves and guides (Ella, Smith et al. 1998:29). From the 1890s, the Protection Board of NSW sanctioned the removal of children to 'training homes', institutionalising their lives (Ella, Smith et al. 1998:31).

In 1937 a Commonwealth Protectors' meeting held in Canberra shifted the agenda of removal for training and civilisation to miscegenation, a scientific rationalisation for breeding out the colour, a policy and practice supported by Protectors Dr Cecil Cook of the NT, A.O. Neville from WA and J.P. Cleland from SA (Haebich 1988; Anderson 2002) to solve the 'half caste problem' (Thomas 2004:63). Protector Neville was concerned with the growing numbers of half-castes, believing Australia would be taken over by this group (Thomas 2004). The Protectors proposed a eugenics policy focusing on biological absorption aimed strategically at having them 'disappear'. It was believed this could only be achieved by their removal and western education (Haebich 2000; Anderson 2002:237; 19). This approach was inhumane and irrational, yet led to future Western political and social constructions that would perpetuate removals through a punitive system of incarceration. As recently as this last decade, these irrational concerns of half-castes taking over the country or running an Indigenous agenda were dealt with by Prime Minister Howard who abolished ATSIC, mainstreamed Aboriginal affairs, and enforced the 'Emergency Intervention' upon Aboriginal Territorians under the guise of 'protecting the children'.

The Protection Act of 1909 in NSW gave the Board the right to take custody of an apprentice 'any child of an Aborigine' (Ella, Smith et al. 1998:41). Simply being Aboriginal entitled removal under the premise of neglect (Haebich 2000). Numbers of removals from 1910 to 1970 are estimated to be 'between one in three and one in ten' Aboriginal children, creating the Stolen Generations (Anderson 2002:239). Neglect was used as basis for removal, and proved to be another construction, developed through policy, that would have a terrible legacy (Haebich 2000:37). Child removal continued in the NT, specifically in Alice Springs, long after the 1970s. Initially used as a strategy to break up Town Camps, the children were offered back to the family if the family left town (Haebich 2000:35).

The direct impact of this policy was the death of hundreds in residential care, due to physical, nutritional and psychological neglect (Kidd 2000:61). Of those who survived their 'care', many self-medicated with alcohol, had their own children taken, lived with violence or suicide, and were further incarcerated (Kidd 2000:61). The Royal Commission into Deaths in Custody (RCIADC) found that 43 of the 99 Indigenous men who died in custody had been removed from their families (Ella, Smith et al. 1998:163). From an Indigenous perspective, this removal policy and practice has been considered a genocidal act, which perpetuated injury transgenerationally (Tatz 1999; Tatz 2001). It is another blemish on white Australian history, the relevance of which has been ignored and denied, yet the scars on Aboriginal families remain. However the policy and practice failed to make Aboriginal people disappear, because the aim of removing Indigenous people did not take into account the nature of Aboriginality, which is not about skin colour but about the identity of the individual, identification by the Indigenous and non-Indigenous community, and spiritual and physical connections to people and place.

## Assimilation 1937–1969

> … all aborigines and part-aborigines are expected to attain the same manner of living as other Australians and to live as members of a single Australian community enjoying the same rights and privileges, accepting the same responsibilities, observing the same customs and influenced by the same beliefs, hopes and loyalties as other Australians (Hasluck 1961:2).

Although this policy aimed to have Indigenous Australians behave as non-Indigenous Australians, government policy continued to control their lives, deny equal wages and employment rights (The Fred Hollows Foundation 2005:2). Aboriginal men, women and children contributed extensively to the growing economic base of the nation (May 1994), but without recognition or compensation. The Pastoral and Cattle Industries of Australia were built on the back of cheap Aboriginal labour (Rowse 2002) and the enforced labour and slavery of stolen children (Kidd 2000:18).

The health research focus of this era was on collecting data on diseases and deficits without intervention (Thomas 2004). Epidemiological research in the 1960s identified that infant mortality was four to six times greater than that of non-Aboriginal infants; and for children under four, mortality was thirteen times greater than for non-Aboriginal Australians (Kidd 2000:12,

32). Malnutrition was the cause of death for 50 per cent of children under three and 85 per cent of children under four on Palm Island in Queensland (Kidd 2000:33). During the 1960s and 1970s, Central Australia was reported to have had the highest infant mortality in the world (Haebich 2000:29).

Governments failed to act on substandard conditions and in fact apprehended maternity allowances, and child endowment payments from 1912 (Kidd 2000:40,47), enforcing poverty and malnutrition. Substandard conditions continued with overcrowded shelters, lack of access to clean drinking water, sewerage and cleaning facilities, all contributing significantly to poor health status (Torzillo and Kerr 1991), as did lack of access to health care, which was denied on the grounds of being Aboriginal until the 1960s (Saggers and Gray 1991:388).

Biochemical definitions of race focused upon research of blood types of Aboriginal Australians from the 1930s to the 1950s and beyond to determine origins and support racial differentials (Thomas 2004:66). Scientific hypotheses were used to explain death tolls and burden of disease for Aboriginal Australians. These included explanations such as genetic factors, inability to cope with civilisation and poor hygiene (Torzillo and Kerr 1991). Health research data collection continues to be used as a tool for blaming the victims for their disease burdens (Mobbs 1991; Mitchell 2007).

## Self-determination 1972–1996

The 1967 referendum, finally establishing Indigenous Australians' full citizenship, raised hopes amongst Indigenous Australians that their status would change. In 1972 the Commonwealth established the Office of Aboriginal Affairs, directing and funding States and Territories to address Indigenous health priorities (Saggers and Gray 1991). Sadly, this policy had a 'top down approach to self-determination' (Maddison 2009:28), focused only upon 'organisational and community management' (Maddison 2009:28) and not the autonomy of Aboriginal communities. Health organisations, land councils and legal services controlled by Aboriginal communities were only established in the 1970s (Murray, Bell et al. 2003).

This was also the era that ran the first national inquiry into Indigenous affairs; the target in 1979 was Aboriginal health. The findings revealed 'low standards of environmental and housing conditions, socio-economic factors, and inappropriate health services' (The Fred Hollows

Foundation 2005:2). These findings have not changed, a result of lack of government investment and goodwill. This is highlighted by the failure to implement the 1989 National Aboriginal Health Strategy (NAHS), the first national Aboriginal health policy (Murray, Bell et al. 2003; Anderson 2007; Anderson 2007).

This political era also saw the documented rise of racial violence within the criminal justice system (O'Shane 1992:2) targeting Aboriginal communities. Indigenous incarceration rates escalated, as did suicide rates, a direct result of racial victimisation (Hunter 2001; Tatz 2001:1). Internalised injury led to a rise in family violence and alcohol misuse (ATSIWTFV. 1999; Brown and Brown 2007). The era of hope was dashed by the continuing irrational and inhumane acts of colonial systems along with the lack of health interventions, particularly in social and emotional well-being treatment (Cunneen 2001).

Colin Tatz argues: 'Much in Aboriginal policy and practice is confusing, contradictory and ambiguous' (Tatz 2001:7), and suggests that ambiguity is a valuable political tool when attempting to assert power and appease calls for action. Policy responses that target Indigenous Australians have been reactive, politically contrived and have had 'serious consequences' (Tatz 2001:7) on their lives. In fact, white solutions for us have become our problems (Sherwood 1999). Stanner's lecture entitled the 'Great Australian Silence' delivered in 1968 offers a reason for problematic government policy. He argued that the government's lack of conscience was a direct result of failing 'to integrate the story of Aboriginal dispossession and its aftermath into their understanding of Australian history' (Manne 2003:1) and its legacy. There has been a willful forgetting of these tragic events, the policies, and the injuries caused. Yet they impart an Indigenous context, not only of Australian history and its denialism, but of the causal agents that created the appalling Indigenous health status that continues unabated.

**Howard Era and beyond: Intervention and Apologies 1996–2010**

In 1996 a Liberal Federal Government was elected with a new Prime Minister, John Howard, who employed denial, deception and ambiguity in Aboriginal policy. By claiming wrongs committed against Indigenous people in the past were not the responsibility of current Australians (Behrendt 2003:3), Howard appeased mainstream Australian guilt. He chose a methodology, which Albert Memmi described in his text *The Colonizer and the Colonized,* of

falsifying histories to imbue the coloniser with importance and superiority (Memmi 1965). Right wing academic allies discounted the works of 'black armband historians' who had chosen to balance the mainstream Australian history stories with Aboriginal accounts and factual archival evidence of unreported warfare (Connor 2003; Manne 2003). Conservative Australians were enthusiasts of these right wing accounts of Aboriginal fabrications of history.

This approach enabled Howard to dismiss evidence based accounts produced in the 'Bringing them home' Report that detailed the shocking results of the Indigenous child removal policy, denigrating and diminishing the impact this policy had on generations of Aboriginal children and their families (Tatz 2001:17). A further act of denial was his refusal to accept the recommendation from the report to offer a national apology (Broome 2002; Behrendt 2003). His successive policy approaches were just as damaging: the abolition of the self-determination policy in 1996; and the abandonment of the collective Reconciliation movement by shifting the agenda to a political funding program, requiring Indigenous communities to share responsibility of government inaction (Behrendt 2003; Manne 2003). He enacted the 1998 Native Title Amendments Act, as a result of pressure from mining companies and national anti-land rights sentiment (Altman 2007). The abolition of ATSIC, a democratically elected body, was supported by a bipartisan vote in 2005 (Altman 2007) effectively silencing Indigenous voices and our ability to represent ourselves (Maddison 2009). His final and most destructive vote seeking policy was the implementation of the Northern Territory Intervention (NTI).

In November 2007 a Federal Labor Government was elected, with Kevin Rudd as Prime Minister. On 13 February 2008 the Prime Minister apologised to the stolen generations. This was a critical and historical event that gave Indigenous Australians a sense of hope that government policy and practice would become more humane and rational. However, the Federal government has not revoked the NT Intervention, instead it has stepped up its discriminatory acts, without any corresponding evidence that such actions are benefiting Aboriginal people. More recently, the government changed the name of the policy to 'Closing the Gap'.

The United Nations' Special Rapporteur on Indigenous Human Rights reported in August 2009 that the NT Intervention 'overtly discriminates against Aboriginal peoples, infringing their right of self-determination and stigmatizes already stigmatized communities' (ANTaR 2009:1). It can

be observed that there is a pattern of such practices and outcomes from government policy targeting Indigenous Australians. Although 200 years have elapsed since the initial conceptualisation of this country as terra nullius we, the First People, are still dealing with governments who aim to appease the mainstream and marginalise us through such actions.

With this brief contextual exploration I have attempted to illustrate the unrelenting injurious effects of colonial policy and its practice on the lives of Indigenous Australians. These effects have occurred over generations and they have also been transmitted intergenerationally (Ella, Smith et al. 1998; Atkinson 2002), resulting in social and emotional well-being co-morbidities that are directly linked to trauma and loss (mhfa 2008; mhfa 2008). Trauma is a normal and predictable response to overwhelming distress resulting from an event which is left untreated or, at worst, ignored. It leads to intergenerational hopelessness and unresolved grief (mhfa 2008:2). Reviewing the evidence, it is clear that it has not been just one act; it has been a sustained and merciless process. Acknowledging this deeply etched impact the last 200 years of colonisation has had on the health and well-being of Indigenous Australians, this process can begin to be appreciated.

The evidence provided here has illustrated that past and present policy decisions have created determinants that influence the health and lives of Indigenous Australians. These 'social and health ills' (Saggers and Gray 2007:5) are the direct result of 'economic and social exploitation' (Saggers and Gray 2007:5). Governments have been the causal agents that have produced the social gradients of health and created the social factors influencing good health outcomes (Saggers and Gray 2007).

However this is not the story that has been told through research to explain the circumstances that have shaped Aboriginal peoples' health. Instead, the data focus upon 'income, employment, education, parenthood, diet and substance abuse' utilising a western model (Tynan, Atkinson et al. 2007:17) of social determinants. This approach promotes an Indigenous deficit model, leading to problematic constructions, rather than reflecting upon the successive 200 years of trauma and injury. 'There is a real tradition in Australian culture of blaming the victim when it comes to Indigenous people' (Howard 2009:31).

## The research context

The above contextual account provides the background for my critique uncovering research that fails to acknowledge these historical, political and social contexts of Aboriginal peoples. Positivistic approaches used in Aboriginal health research have been acknowledged to be unreflective of these contexts (Morrissey 2003; Kincheloe and Tobin 2009).

A positivistic science method is assumed to be an impartial, objective and controlled form of action to define solutions to problems the researcher or funding body has hypothesised (Greenwood and Levin 2000). It has infiltrated qualitative research in its attempt to legitimately re-produce 'scientific applications' (Greenwood and Levin 2000:93) and although critiques have questioned its authority of always offering reliable data, and its unsuitability in many research settings, it remains overwhelmingly supported by universities and funding institutions (Greenwood and Levin 2000:92; Sanson-Fisher, Cambell et al. 2006).

It is worth noting here that Indigenous critical theory uses the term 'positivism' or 'positivistic' interchangeably and in a broader sense than does the Western tradition of philosophy. 'Positivism' in Indigenous critical theory does not mean 'logical positivism', nor is it a direct response to Comte (Comte 1972 ), the Vienna Circle (Schlick 1974) (Popper 1972) or other philosophers who seek to find a solid logical foundation on which to ground the philosophy of science. On the whole, Indigenous critical theory is more concerned with the ideology implicit in the practice (and praxis) of science.

'Positivism' is used in this thesis, and in Indigenous critical theory more generally, to refer to Western science's obsession with artificially isolating its objects of study – decontextualisation – and its fixated agenda of objectivity. It is also used to refer to the belief that this is the only legitimate approach to rigorous scholarly investigation. This is particularly awkward in the fields of health and social science research. If the object of study is an Indigenous population artificially isolated from its connection with history, country, Dreaming, their social and political circumstances, their relationship with the researcher, the cause of the 'problem' being studied can only be internal to that Indigenous population and/or whatever other 'outside' variables have also been artificially isolated as suspected causal factors. In quantitative methodologies these important contextual factors are called 'error' (Popper 1972). Qualitative research has not been

immune to this decontextualising practice either, failing to reflect on the lived experiences of their objects of study along with ignoring the importance of a safe relationship between researcher and researched. So 'positivism' scientifically constructs Indigenous Australians as the causal agents of their own injury.

Most importantly, positivist social science methods are problematic for Indigenous peoples as they were the methods that historically contested Indigenous sovereignty and their political, social, and spiritual ways of being, successfully usurping their status as First Nations peoples.

> From an Indigenous perspective Western research is more than just research that is located in a positivist tradition. It is research which brings to bear, on any study of indigenous peoples, a cultural orientation, a set of values, a different conceptualization of thing such as time, space and subjectivity, different and competing theories of knowledge, highly specialized forms of language, and structures of power (Smith 1999:42).

Academics used positivist objectivity to emphasise their own superiority while making known the inferiority of Indigenous peoples worldwide (Kincheloe and Tobin 2009:520). This form of cognitive oppression 'continues to operate despite' (Kincheloe and Tobin 2009:520) Indigenous attempts to thwart it.

> Research methods are not created in a vacuum. They come out of a historical context, represent a philosophy or worldview and are created in a specific social context. Beneath each culture of inquiry, there is an entire world view and a belief about the nature of knowledge and truth (Kenny 2004:24).

Lester-Irabinna Rigney argues that this 'positivist orthodoxy remains entrenched in the social and natural sciences' (Rigney 2001:3), and its authority within the field of health research has been reaffirmed by the premise of evidence based research (Guba and Lincoln 2005). The problem arising from this method is that what can't be explained is either ignored or explored as problematic, and this 'promotes particular worldviews, and often harms individuals who suffer marginalised status' (Kincheloe and Tobin 2009:513). The article *Healthy Country, Health People Exploring the health benefits of Indigenous natural resource management* (Burgess, Johnston et al. 2005) provides an exemplar of how Indigenous health can be improved, if researchers listen to Aboriginal people, encompassing their beliefs and their ways of viewing

health. This requires the researchers to be open to Aboriginal ways of knowing health and broaden their own perceptions of the social determinants of health that compromise Aboriginal health status. If the researchers had maintained a positivist approach they would have not been open to expanding upon the western health determinant approach and hence would not have witnessed improved health outcomes as a result of Indigenous health knowledge systems, it would simply have been ignored.

Unfortunately, this way of doing research on Aboriginal people is so embedded within the culture of the Academy that its oppressive and de-humanising nature is 'often invisible to researchers and those who consume their research' (Kincheloe and Tobin 2009:513). This is because Western epistemology and ontology implies its science is 'authoritative, neutral and universal' (Rigney 2001:3) ensuring valid and reliable data. Its power is historical in that it has always foisted 'so-called "facts" and "half truths" about Indigenous peoples' contributing to 'hegemonic colonial construction of Indigenous identities' (Rigney 2001:3).

## Conclusion

The purpose of this chapter has been to provide a brief overview of some of the historical, political and societal circumstances that have impacted on the lives of Aboriginal people since invasion, that Stanner espoused as 'The great Australian silence' (Stanner 1979:207). This history, the policies and their consequences have framed the precipitous decline in Aboriginal health status, however they are often ignored or omitted in health discourses that use positivism as a method for knowledge production.

> Aboriginal people need the opportunities to tell their stories. Their ability to express their feelings and experiences however requires an emancipatory framework. The stories of racism and the ability to remain quiet while listening to the pain and the victory underpin healing in the broadest sense (Lavallee and Clearsky 2006:5).

In order to improve the health outcome of Indigenous Australians through research, positivism must be challenged in relation to its unsafe and distorting constructions of data and evidence, as must the ethnocentric philosophy that supports and maintains this form of knowledge production, and that leads to injury of Indigenous Australians.

The following chapter will explore the divergences between Indigenous and non-Indigenous ways of knowing are important to be reflective of in Indigenous health research. Appreciating that ways of viewing health for Indigenous and non-Indigenous Australians are divergent and are a result differing worldviews, is an essential premise of this thesis. It also informs some of the reasons for shifting the current research agenda that is dominated by a Western way of knowing research.

# Chapter 2

# Different Ways of knowing, being and doing

A body of knowledge differs when it is viewed from different perspectives (Battiste 2008:504-5).

## Introduction

Chapter 2 explores the notions of difference between Indigenous and Western ways of knowing, being and doing and the manner in which Western reasoning has dominated Australian shores since invasion, 'infiltrating all spectrums of mainstream society' (Sherwood 2009:s24). As Western ways of knowing have subjugated Indigenous peoples through the silencing of their voices and ways of knowing about themselves. This action has caused trauma and injury to Indigenous Australians, a theme that will be explored throughout the following chapters. The dominance of Western worldviews inclusive of its epistemology and ontology has focused on having to know and name what is different about Indigenous Australians through research and its translation (Said 1995). Resulting in the Western 'expert' who holds dominion over both the subject, Aboriginal People, and the nation (Said 1995).

Importantly, there are divergences in our knowledge systems and worldviews and they continue to impact on how research is undertaken today and how it has been used in the past when focused on Aboriginal peoples. I have taken the approach of exploring the divergences of worldviews specifically to examine issues of concern related to Aboriginal health research, in particular to provide an Aboriginal appraisal of how colonial knowledge production became entrenched within the research agenda. I have also used this chapter to explore Indigenous ways of knowing to highlight their relevance to Indigenous health research.

Aboriginal people have recognised that non-Indigenous Australians think and know another way. Muta, a Murinbata man, explained this to W.E.H. Stanner who wrote about it in his text *White Man Got No Dreaming* (Stanner 1979). Many attempts have been made by Aboriginal people to share their ways of knowing, being and doing with non-Indigenous people. Some non-Indigenous people have listened and learned, many have not. This has had profound consequences for Indigenous Australians who, in their marginalised position, have been oppressed and injured by Western mainstream ways of knowing, being and doing. This chapter

offers an opportunity to explore how different ways of knowing could, if given the chance, build new knowledges to improve outcomes for all Australians.

## Worldviews

'You can't see things through a black man's eyes … it's difficult for [whites] to think black' (Doug  Nicholls cited in Attwood 2003:183). This different perspective is informed by an Aboriginal worldview, a result of life experience, learning and being a member of a now marginalised population. Nicholls stresses an argument that is well known by Aboriginal Australians, as this has been their lived experience. Our people have felt that mainstream society is unable to come to terms with the fact that we know things, that we have solutions for ourselves, and that our ways of knowing, being and doing were and are very successful in maintaining our livelihoods, our countries and our well-being (Grieves 2009).

A 'worldview' has been referred to as 'knowledge systems', 'life-world' (Schultz 1974), and 'cognitive systems' (Marglin 1990; Banuri 1993), and is the context for the processing of knowledge, its understanding and explanation (Studley 1998; Aerts, Apostel et al. 2007). Worldviews are learnt from a young age and consolidated through our life experiences within our cultural group (Ranzijn, McConnochie et al. 2009:15).

The hypothesising of sociology, anthropology and psychology has provided the theoretical foundation to support the notion of 'worldview' (Weber 1930; Mead 1934; Durkheim 1951; Geertz 1973; Dumont 1977; Banuri 1993; LaDuke 1998; Brown 1999).

Worldviews are frameworks for interpreting and exploring the world, supporting the way we act and relate to our world (Sire 1988; Phillips 1991; Solomon 1994). 'They offer a model that allows us to coordinate different aspects of the world in a meaningful way' (Aerts, Apostel et al. 2007:6). Worldviews have a number of characteristic components: they are substantiated by evidence, are generally consistent, allow us to develop explanations of the way things work, and centre us safely in the world we live in (Solomon 1994; Aerts, Apostel et al. 2007). Our assumptions, experience and what we observe as truths are all linked to such reference points.

Worldviews are paradigmatic, which is to say that they guide and determine an entire mode of living for cultural beings. Perspectives, however, can be considered to be more personal, less objective or concrete than paradigms (Denzin and Lincoln 2000). However, perspectives can share some essential elements of a paradigm, especially in relation to scientific discourse and specific epistemologies (Denzin and Lincoln 2000). Paradigms incorporate four key concepts:

ethics (axiology) – how do I act as a moral person?

epistemology – how do I know the world?

ontology – what are the authentic and fundamental elements of my world?

methodology –what is the best way for me to learn about the world? (Denzin and Lincoln 2000:18).

All 'truths' produced by worldviews are necessarily biased and incomplete (Denzin and Lincoln 2000). However, different paradigms in combination can provide richer and more variable outcomes (Denzin and Lincoln 2000; Aerts, Apostel et al. 2007).

The following provides an example of such difference: Indigenous peoples believe they have lived in Australia for a period of time we consider to be forever. Western archaeological evidence through the carbon dating of pollen and charcoal in the Lake George Basin suggests occupation predating 120,000 BP (Reconciliation and Social Justice Library 1998:1). There is, however, speculation by Western scientists that Indigenous peoples migrated to Australia before that time. This is contested by Indigenous Australians and as yet has not been proven by Western research (Malezer 2003). Indigenous peoples maintain that their origins were established during the Dreaming, an era of creation – marking the time that Aboriginal occupation commenced in

Australia (Stanner 1979). This episteme is universal to Indigenous groups throughout the country (Pawu-Kurlpurlurnu, Holmes et al. 2008; Ranzijn, McConnochie et al. 2009). Galarrwuy Yunupingu, a previous Chairman of, the Northern Land Council, asserts 'Our ancestors have been here since the beginning of time' (Yunupingu 1997:1). Aboriginal people were created through the life-force of their Dreaming ancestors along with their respective lands, flora and fauna. Each Aboriginal person, no matter what colour, has, as a result of this creation, a metaphysical and geographical relationship with all of the living and non-living beings of their respective Dreaming creators (Hume 2002).

This way of knowing has informed Aboriginal peoples' worldviews and is distinctly different from a Western way of knowing our history.

The West and their scientists since invasion have attempted to tell their own stories about Indigenous Australians based upon their own truths (Dodson 2003). The 'doomed race theory' is one such myth (McGregor 1997). This has been a site of conflict as Western reasoning has created an image of inferiority and primitiveness of their Indigenous 'Other' to support their claim of terra nullius (Wolfe 1999).

> [m]any Australians have avoided accepting, or even attempting to understand, that at the time of their arrival this continent already had been discovered. It was already travelled, known, and named; its places were inscribed in song, dance and design; its histories were told from generation to generation; its physical appearance was the product of specific Land management practices; its fertility was the product of human labour which had been invested in the Land (Bird Rose 1996:18).

Eurocentrism meant that Europeans believed that only their way of knowing could uncover or discover their truth or facts in their ever-expanding imperial world (Ranzijn, McConnochie et al. 2009). In many senses this belief system has been sustained in approaches to producing knowledge about the 'Other', and in continuing a dominant way of knowing (Said 1995; Smith 1999). This dominant or Eurocentric approach to knowledge production is maintained in most systems that define truths, facts and ways of knowing the 'Other' within First Worlds (Said 1995). It is this universal and dominant approach that Indigenous people argue cannot effectively

appreciate their issues or solutions, as at its very origin is its preoccupation to colonise and exploit the 'Other' in a manner that elevates the West's superiority and legitimacy (Smith 1999).

Indigenous health research fits within this concern as Indigenous Health report after report has stated that Aboriginal and Torres Strait Islander Health status is far worse than that of other Australians (Stanner 1972; NAHSWP 1989; RCIADIC 1990; TaskForce 1990; Public Health Association Special Interest Group 2000; NATSIHC 2004; A&TISISJC. 2006; ABSAIHW 2008). The Health and welfare of non-Indigenous Australians has improved dramatically over the last 100 years (ABS 2003), yet the same cannot be said for Indigenous Australians. Although Indigenous health research has, over the last 50 years aimed at health improvement (Thomas 2004), this has not been achieved throughout the country for most Indigenous Australians.

Why? This is a crucial question in the light of the health improvements for Indigenous populations of other First World Nations throughout the world (Durie 2003; Durie 2003; Ring and Brown 2003; Durie 2004). It is important to ask why the process of research in relation to Aboriginal health is not achieving results. The *Health is Life* report's committee 'believes that many of the difficulties come down to these differing world views about health' (HRSCFCA2000:vii). These differences will be examined throughout this chapter.

## Indigenous worldviews

Indigenous worldviews are holistic, integrating the past, present and future through the layering of knowledges and lived experiences; hence they are not static but are ever-changing, shifting from historic/traditional to contemporary. Alfonso Ortiz, a Tewa Indian academic explores the notion of an Indigenous worldview:

> The notion "world view" denotes a distinctive vision of reality which not only interprets and orders the places and events in the experience of a people, but lends form, direction, and continuity of life as well. World Views provide people with a distinctive set of values, an identity, a feeling of rootedness, of belonging to a time and a place, and a felt sense of continuity with tradition which transcends the experience of a single lifetime, a tradition which may be said to transcend even time (Alfonso Ortiz cited in Royal 2002 :24).

This notion effectively explains our Aboriginal Australian realities as well as our notions of a living cultural continuum; that is the 'past, present and future', in a cyclical model that is continuously re-informing our ways of knowing, being and doing. This signifies that our knowledge systems are dynamic as they continue to shift and grow, accommodating new phenomena, ensuring survival, balance and sustainability persists to drive the essence of Indigenous worldviews. It is this Indigenous holistic paradigm that informs our ways of knowing Aboriginal health and it represents the significant divergence in the ways Western health has worked on us (NAHSWP 1989). This distinguishing feature and other unique components of Indigenous worldviews will be examined in this section to draw out what centres Aboriginal people safely in the world in which they live (Aerts, Apostel et al. 2007).

## Relationships and country

A characteristic feature of Australian Indigenous worldview is the deep and intense connection to country/land, the importance of relationships and collectivity (Yunupingu 1997; Walsh and Mitchell 2002; Smallacombe, Davis et al. 2007; Pawu-Kurlpurlurnu, Holmes et al. 2008; Grieves 2009). This feature is universal to some 500 separate and heterogeneous Nations that co-existed in Australia prior to European invasion, and remains so, although not all Nations remain in existence today. Bird Rose (1996) affirms the interconnectedness of Indigenous knowledge and the importance of respecting this knowledge and its restrictions:

> Law belongs to country and to people. It is embedded, of course, in society and culture, and is intellectual property, which is not freely available to all. Essentially, if knowledge is constituted as evidence of relationships among persons and between persons and country, then it is most assuredly not available to all and sundry. Such a system is subverted through any form of 'freedom of information'. If there is one thing that is absolutely not free, in Aboriginal tenure systems and in Aboriginal politics, it is knowledge (Bird Rose 1996:32).

This system of knowing has not been valued by the West, its governments and academics. Instead, Aboriginal nations have been viewed as homogenous and treated as such. However the Law embedded in country and people articulates the diversity of each different Nation group. This knowledge holds power in that it maintains balance that is essential for survival and sustaining collective relationships. Those who have the responsibility of holding this knowledge

are Elders who pass it on only to those deemed to be ready to receive it, as knowledge handed out to the naive and ignorant can and has resulted in disaster.

Through the process of colonisation, many Indigenous people and their respective Nations were annexed from their land tenure and caretaking roles. This colonial process also took place in New Zealand, the United States, Canada and Africa. Universally, Indigenous peoples yearn for reunification with their land to regain balance of their natural world (Royal 2002). This consideration informs the epistemological basis for decolonisation as a strategy of and for reclaiming Indigenous sovereignty, dignity and well-being. Recognition of Indigenous worldviews as distinct ontological and epistemological traditions from those of the West is essential in relation to Indigenous health research. The way Indigenous people have experienced the world has been different, as the following model demonstrates.

## A model of knowing, being and doing: Walpiri model

This way of knowing will be explored using a contemporary Warlpiri model, namely 'Ngurra-kurlu' (Pawu-Kurlpurlurnu, Holmes et al. 2008). The lead author Wanta Jampijinpa Pawu-kurlpurlurnu describes this as a living model, it explains his journey of learning and discussion with Elders that has encompassed decades (Pawu-kurlpurlurnu, Holmes et al. 2008). His aim was to 'find the relevance of ngurra-kurlu to modern community living' (Pawu-kurlpurlurnu, Holmes et al. 2008:5). Ngurra-kurlu is a guide, and protocol for those working with Warlpiri people and 'when it is supported, promotes the healthy functioning of Warlpiri people and Warlpiri country' (Pawu-kurlpurlurnu, Holmes et al. 2008:5). Ngurra-kurlu is the term that embodies the five fundamental characteristics of Warlpiri ways of knowing, being and doing. These are 'Land (also called country), Law, Language, Ceremony, and Skin (also called kinship)' (Pawu-Kurlpurlurnu, Holmes et al. 2008:1).

All of these fundamentals are interrelated and are all critical to this model and methodology informing the 'whole of Warlpiri culture' (Pawu-kurlpurlurnu, Holmes et al. 2008:1). Although the term ngurra-kurlu is a framework of Warlpiri culture, this model is relevant to many Australian Aboriginal Nations. Ngurra-kurlu has benefits for Warlpiri and those who choose to comprehend it and work with Warlpiri peoples. These are:

- An efficient pedagogy (way of teaching)

- A process for building identity and self esteem
- A way of looking after the health of people and the health of country
- A framework to create successful projects that are relevant to Warlpiri people (Pawu-kurlpurlurnu, Holmes et al. 2008:1).

Ngurra-kurlu is a contemporary model that encompasses the relationships that have for time immemorial been laid down through Jukurrpa (the Dreaming) highlighting both the sustainability of this model as well as its ability to be relevant in an ever-changing world. The model was developed by Warlpiri people to work with non-Indigenous Australians in a manner that respects the 'core values of Warlpiri identity' (Pawu-kurlpurlurnu, Holmes et al. 2008:2), to prevent injury to Warlpiri people.

Wanta Jampijinpa Pawu-kurlpurlurnu's goal of looking after the health of the people and country is at the core of this model and is at the core of Indigenous Law throughout Aboriginal Australia.

> Warlpiri law and culture once provided people with stability, self esteem and direction. It can still do this if it is reinterpreted in the context of community living. Said another way, Wanta is promoting the message that it is 'OK to be Warlpiri'. He states that by maintaining a strong identity Warlpiri can have good lives and opportunities to engage with the rest of the world, without being smothered by it (Pawu-kurlpurlurnu, Holmes et al. 2008:9)

Validating Aboriginal identity is critical to the self esteem and well-being of people and their respective countries throughout Australia (Dodson 2003). This requires a deeper appreciation of Aboriginal worldviews, ways of knowing, being and doing in a manner that can produce harmonious and balanced relationships. Ngurra-kurlu affirms connection to land, the living and non-living ecosystem that are reliant upon the balance of these systems through a healthy land/country and peoples. The values, beliefs, ethics, reality and knowledge development of Indigenous peoples are all linked to managing and sustaining this balance. The model for achieving balance works on multiple levels and requires the living and non-living community, the flora and fauna to work together as assigned through intricate and unique reciprocal relationships. Sharing is an Aboriginal strategy or pedagogical activity that maintains this sustainability through the cultural protocols defined within relationships that are reciprocity and responsibility. Although there has been a critical interruption for many Indigenous Nations in the

maintenance of land and ecosystems, there continues to be, in this contemporary era, the use of Indigenous ways of knowing and worldview to ensure resiliency and survival (Royal 2002; Martin 2007). The Ngurra-kurlu model has been developed to achieve this encompassing relationship with the non-Indigenous population. Critically, the West has not developed a model to encompass the sharing and balance that is essential to building relationships.

Accepting the critical divergences of worldviews of the academy and Indigenous peoples, there is an opportunity to learn how best to work with these two ways of knowing (Pawu-kurlpurlurnu, Holmes et al. 2008), rather than presuming that there is only one way of knowing and being. In order that these stories can be listened to and heard, it is also important that researchers stand back and review their own worldview. With openness there is an opportunity for meaningful exchanges and learning to occur (Kovach 2005).

Connection to land continues. Even when there has been annexation, Indigenous peoples can come back to country and be recognised by country as coming from that geographical place. This is an Indigenous worldview conceptualisation that continues to inform the Indigenous political agenda for reparation of land through land rights (Behrendt 2003). Land is life, and plays an essential role in the well-being of Indigenous Australians; it is an important clue to improving Aboriginal health in the framing of Aboriginal health research agenda (Burgess, Johnston et al. 2005).

## Western worldviews

Unlike the collective and holistic natures of Indigenous cultures, Western cultures are considered to be individualistic, competitive, direct, assertive and self-assured (Ranzijn, McConnochie et al. 2009:22-23) as a result of religious, political and academic warfare over many centuries. The conflict that arises between Indigenous and Western worldviews is historical and political and is embedded within Western Eurocentrism (Cruickshank 2000). Ethnocentrism has an epistemic positivism that holds its truths based upon its own discrete facts, ensuring there is no space for contestation (Cruickshank 2000:4). Since Invasion, the invader's approaches to Indigenous Australians have been based on assumptions of their own Western worldview's superiority. This Eurocentric and empirical assumption led to and continues to result in 'cultural misunderstanding and cultural incompetence at best and oppression, persecution and even genocide at worst'

(Ranzijn, McConnochie et al. 2009:17). Bent Flyvbjerg suggests that the basis of this practice is a 'context-dependent common worldview and interests among a reference group' (Flyvbjerg 2001:101). Although this Western reference group should be aware of other worldview groups' different interests, they have failed to either be reflective or respectful of these differences. Hence, ethnocentric behaviour commonly ignores the right of others as they are not considered normative resulting from their difference. This has resulted in their guilt-free ability to oppress and subjugate. This has been their 'historically conditioned context' (Flyvbjerg 2001:101) and has indeed been the case in Australia.

Michel Foucault critically contextualised the establishment and authority of institutions such as medicine, prisons and psychiatry (Foucault 1961; Foucault 1980; Foucault 1980; Foucault 1989; Foucault 1994). His central concern was the 'destructive powers of Western rationality' (Gandhi 1998:37) which he interrogated through his work on knowledge and power. His *Archaeology of Knowledge* (Foucault 1989) delivers an examination of how 'historically conditioned contexts' developed into a imperialistic Western worldview. In particular, his works, *The Birth of the Clinic: An Archaeology of Medical Perception* (Foucault 1994) and *Madness and Civilization* (Foucault 1961), provide an in-depth appreciation of how knowledge and its discourse are established. These studies highlight the multiple dimensions or contexts of knowledge production and its discursive praxis. Critically, these contexts argue against a positivist theorem of universality, objectivity and ahistorical knowledge development. Knowledge about Indigenous peoples were not independent epistemologies, but rather they were shaped by a political economy and practice of multiple colonial professionals such as police, doctors and anthropologists and doctrines developed within the Dispossession and Protection eras in Australia (Foucault 1989:201).

This approach relates to the philosophy of Western science, informed strongly by the Cartesian–Baconian–Newtonian–Comte paradigms, framed as positivism, scientism, rationalism and modernism (Berkes 1998:176; Harper 2000; Kincheloe and Steinberg 2008), driving Western scientific method towards seeking universal truths. This paradigm has conceptualised that knowledge is generated only through the observation and experiments of the scientist.

Francis Bacon, considered a founding father of positivist philosophy, critiqued the theological traditions of the Medieval period (Dunbar 1995). His concerns were with verification, where truths could only be confirmed through discrete empirical observation and formal experiments (Dunbar 1995; Flyvbjerg 2001). Bacon believed that the data formulated through empirical acts were only the starting point for theoretical development. In this he stands at the beginning of modern empiricism, derived from rationalist 6th century B.C. Greek Philosophy (Harper 2000:717).

Auguste Comte in the 1820s mandated Bacon's paradigm for use in the field of social sciences (Harper 2000). This marked the emergence of 'Comtean positivism' (Kincheloe and Tobin 2009:515), establishing a tradition that 'assumed the natural and social world could be understood and improved by using reason and systematic observation' (Kincheloe and Tobin 2009:515). Foucault explores this period as the Classical age, initiating the development of the classical episteme where the discourse of signs were developed for analysis and calculation (Foucault 2002).

Foucault's deconstruction of positivism offers an appreciation of the limits of this approach, as the signs were simply instruments that enabled a language 'to search for origins and calculability' (Foucault 2002:69). This system aimed to link all knowledge to a unitary language, replacing all languages through a language 'of artificial symbols and operations of a logical nature' (Foucault 2002:69-70). The system required a dual theory of what was to be known and understood through 'duplicated representation' requiring a binary arrangement (Foucault 2002:70.), a significant shift from the theorising that had remained since the 'first Greek Grammarians' (Flyvbjerg 2001; Foucault 2002:71). This shift of formulating knowledge towards analytical rationality ignored the context, and focused on the singular episteme and techne (Flyvbjerg 2001:56). Aristotle's science had encompassed both techne and episteme along with phronesis to craft truths; 17th century science dispensed with this 'practical common sense' (Flyvbjerg 2001:56). So signs became no longer a method for knowing; they were now

> … co-extensive with representation, that is, with thought as a whole; they reside within it but they run through its entire extent. Whenever one representation is linked to another and represents that link within itself, there is a sign; the abstract perception from which it has been formed. (Foucault 2002:72).

This system holds authority today with the ideology of binarism as a foundational and 'philosophical justification' for 'general analysis of all forms of representation' (Foucault 2002:74). It became a fundamental scientific law for the exploration of the most basic elements to the most complex and abstract, such as race (Foucault 2002). Classical episteme foundations were focused upon ordering knowledge. Representation using signs, required a 'taxinomia' which implied an evident order of things (Foucault 2002:80) within a continuum. Empirical rationalism sought to shift a perception of the 'experience of the same' to establishing and formulating order to operate on 'identities and differences' (Foucault 2002:80). This way of knowing tried to unify a theory of science in the fields of physics, psychology and social science, and logical positivism, scientism, pragmatism and behaviourism became popular methods to achieve this taxinomia (Chalmers 1990:4; Foucault 2002; Kincheloe and Tobin 2009:515). Such rational ideologies endorsed that objective facts were established through the researcher's observation as a result of following these formalised rules (Chalmers 1990).

Importantly, this ideology grew from a science focused upon producing valid and reliable results regarding inanimate objects. It is considered problematic when the practice of ordering things scientifically focuses on human beings. This way of knowing has been challenged over the last one hundred years by multiple 'interpretative paradigms' (Denzin and Lincoln 2000:6) of Marxism, critical theory, feminism and constructivism (Denzin and Lincoln 2000:6). This is a monological approach that suffers from a lack of reflection and hence inscribes its own cultural worldview values onto its 'knowledge production in often an undetected manner' (Kincheloe and Tobin 2009:519) upon its subject/object through an undisclosed subjective gaze (Denzin and Lincoln 2005).

## Western practice and techne

The knowledge shift that occurred in the Enlightenment period engaged science in the governance of the state (Foucault 1980). The state began to fund more research and to control the release of some data for the good of the society (Feather 2004). Scientific discoveries enhanced the economic development of the state, and multiplied the techniques used to manage the population (Foucault 1991). The Western world has increasingly relied on science and technology to become more efficient and cost effective (Kenny 1994). Evidence-based approaches used in research to support health and political governance in the field of public

health exemplify this approach. What is considered to be unhealthy practice, and incurs greater government health expenditure, is condemned by health professionals. This is of concern when Indigenous health constructions continue to promote Indigenous Australians as the root cause of all their health problems. Smith argues that science is the tool of imperialism (Smith 1999) with the Indigenous 'Other' in colonised countries an essential subject. Science, using its laws, formalised and racialised the 'Other' as distinctly different and aberrant from the West (Said 1995; Smith 1999).

The Spanish invasion of the Americas in the 16$^{th}$ century informed an approach to the 'Other', influencing future doctrines and practice born from those deemed to be Liberal thinkers (Parekh 1997). The Spanish believed the Indians to be of human form yet lacking criteria of the civilised European. The claim of uncivilised related to their lack of 'script', inappropriate dress and heathen religion. The term 'savage' was used to demonstrate their disturbing differences (Parekh 1997). Christian doctrine defined the Spaniards' ethnocentric consciousness of humanity and morality, a worldview not shared by the Indian 'Other' (Parekh 1997:174-5). This ethnocentric worldview enabled guilt-free conquest and genocide of the American Indians (Parekh 1997).

The Liberals of Britain some two hundred years later were considered 'enlightened' and secular humanists, yet remained ethnocentric. They planned to dismiss the premise of Indigeneity as not human. Ideologically, they distanced themselves from the Spanish religious-conservative logic and its 'barbarism', using a different but equally damaging, secular ideology fuelled by a political and economic agenda (Parekh 1997). Liberalism was basically secularised Christianity and effectively 'Christianised Liberalism' (Parekh 1997:181), supporting a civilising mission of colonial territories and their Indigenous peoples. This political program and rationality were designed to promote rational and civilised beings as God had ordained (Parekh 1997:181).

Locke, Hume and Mills developed a number of doctrines that supported racial theorising and 'colonial exploitation' (Said 1995:13). John Locke promoted the view that all mankind was human. However, if the 'Other' was observed as not 'Industrious and Rational' (Parekh 1997:182), then their property would be appropriated (stolen), ensuring England was following God's 'conditions', that is the enslavement and tillage of land (Parekh 1997). Locke's theorising instigated a belief that 'the English were not only at liberty to, but also had a duty to take over

the 'surplus' Indian land and to interfere with their way of life' (Parekh 1997:183). This duty to interfere required acts upon 'the savages' by the civilised, and established a number of beliefs and practices, namely racial theorising and the supporting of slavery. These became part of the civilising colonial agenda (Said 1995:13).

The Western liberal agenda did not attend to the rights of minority Indigenous populations (Fuery and Mansfield 2000:149). The Western liberal ideology of universality pertains only to Western humanity and different cultural worldviews are only tolerated when they are effectively controlled. If and when Indigenous differences are constructed into images that contradict the universal sets of values and principles of the West, they are hunted down and persecuted (Fuery and Mansfield 2000:149) or silenced.

## The colonial agenda

It is here that theorising of extinction becomes apparent, well before the theorising of Charles Darwin's *Origin of Species* and *The Descent of Man* (Brantlinger 2003:1 and 177). Although Darwinism fashioned the dialogue on primitive races and their impending demise, there were other forces at play establishing a discursive practice of 'natural history, political economy and early ethnology or race science' (Brantlinger 2003:13).

It is important now to deal with the constructions and representations of Aboriginal Australians based on race because these constructions became the tools of the colonisers, not just as a discourse, but as a method of informing colonial practice.

The colonial agenda, observed to be the light of civilisation, ordained the destiny of those viewed as uncivilised and savage. The discourse of 'the savage' explains the demise of Indigenous peoples as a result of Western civilisation. It censored acts of genocide and enhanced the 'ghostly twin' of 'the noble savage' which was 'the self-exterminating savage' (Brantlinger 2003:3). The extinction discourse, Brantlinger argues, was a discursive practice used by colonial professionals such as public servants, doctors, police, the media, scientists and others, promoting a self-fulfilling prophecy.

> The belief that savagery was vanishing of its own accord from the world of progress and light mitigated guilt and sometimes excused or even encouraged violence towards those deemed

savage. Even when savagery was not identified as causing its own extinction, it was frequently held that some races could not be civilised and were thus doomed to fall by the wayside no matter what customs they practiced (Brantlinger 2003:3).

Race and racism provided the semiotics of colonisation, signposting what and who were uncivilised, unequal and degenerating (Brantlinger 2003). The academy developed sciences to further substantiate these differences, utilising a taxonomy or hierarchy of order to buttress the superiority of the civilised Western man over all other races. Those who were deemed 'Other' were to be controlled through methods developed in the fields of science, medicine, sociology and anthropology (Said 1995).

Science and medicine assisted in establishing Australia's 'racial agenda' (Anderson 2002:1) focusing on the protection of the new white settlers. Public health doctors, informed by bacteriologists 'had fashioned natives as biological reservoirs of germs' (Anderson 2002:125), a racialised biology casting whites as vulnerable and in fear of their lives. Aboriginal people would not simply be observed and represented as primate savages they were now considered pathogenic and this required colonial action. Quarantining of reserves, considered to be 'riddled with disease' (Anderson 2002:145), and the utilisation of lock up hospitals served as successful approaches to controlling the Aboriginal menace. These discrete scientific facts were published and 'rapidly entered the Australian public consciousness' (Webb 1998:67), highlighting the significant differences between the superior and clean European and the primitive, disease ridden and declining Aboriginal (Anderson 2002). By the late 1800s this scientific practice was informed by natural selection, providing 'white Australian colonists the justification' for taking nature into their own hands. Science's racial ordering constituted the rationale for committing genocide and mayhem, a political colonial strategy recognised and condemned by Indigenous peoples worldwide (Memmi A 1965; Marglin 1990; Saggers and Gray 1991; Said 1994; Kunitz 1996; Kidd 1997; Smith 1999; Loff 2000; Reynolds 2001; Ermine, Sinclair et al. 2004).

Modernism remained Eurocentric in its perspective and values (Fuery and Mansfield 2000). The Liberal theoretical framework elevated humans above all other living things. It focused on man in the role of definer and controller of the natural world (Fuery and Mansfield 2000). A critique of Western ways of knowing, that is mastery through domination, considers it 'a violent epistemology' seeking to 'possess the Earth like a master owns a slave' (Kincheloe and

Steinberg 2008:151). This provides a model for explaining how Indigenous people have been studied and known; seeking mastery over the nature of the way knowledge about the object of study is gathered enables 'complete control' (Godfrey-Smith 2003; Kincheloe and Steinberg 2008:151).

These philosophical traditions arose in a symbiotic relationship with Western imperialism. Many of these perspectives are maintained, not just by Australia's non-Indigenous population, but throughout the colonised world as a Neo-liberal agenda (Giroux and Giroux 2008). Although Parekh (Parekh 1997) claims Liberalism has changed significantly since post-war times, it remains inflexible on the point of considering the value of 'Other' in contrast to the pursuit of industrial and economic modernity (Smith 2005). Although Liberalism ideologically promotes the rights and choices of the individual, this universal doctrine from an Indigenous perspective only relates to the normative rationalism of 'white is right'. The actualisation of cultural identity in a form that differs from and competes with liberal doctrines is ignored or suppressed (Fuery and Mansfield 2000:149). This is how inequality is sustained: by breaching human rights through the imposition of an identity as inferior, in order to oppress within the modern neo-liberal era (Cruickshank 2000:15). So imperialism continues.

## Western ways of knowing Aboriginal Australians

Foucault's notion of discourse frames the relationship between power and knowledge production (Foucault 1980). The colonial strategy used in Australia set about producing knowledge of Aboriginal Australians in order to know, dominate and manage their subjects (Attwood 1992). This project established a number of academic disciplines enabling a profession of political support and development resulting from their voyeurism, comparison and dissection (Said 1995). Importantly, these discipline methodologies were formulated through their Western-ethnocentric liberal philosophies which informed their selection and use of scientific positivistic methods to construct their social truths (Kincheloe and Tobin 2009).

Orientalism shaped a 'body of theory and practice in which, for many generations, there has been a considerable material investment' (Said 1995:6). Said argued that imperialism and colonisation are not simple acts of amassing and possessing, rather they are 'ideological formations' (Said 1994:8) providing a rationale that certain peoples should be usurped and dominated physically

71

and literally through terms such as 'inferior, primitive and dependent' (Said 1994:8). These literal formations, became the way the 'West' came to know and describe the 'Other'. Said's *Orientalism,* published in 1978, shifted the paradigm in making sense of the historical event, colonialism, by exploring Orientalism as a study of the imperial and cultural domination of the Orient (Arabs and Islam) by the Occident (Said 1995 :12) and demonstrating how the Orient has been described through a Western cognizance or gaze.

Attwood discusses (Attwood 1992; Said 1995:i), in depth, a theory of 'Aboriginalism' that holds the essence of Said's critique of 'Western conceptions of the Orient' (Said 1995). Attwood describes Aboriginalism as a field of study and political consideration born of the Enlightment era informing imperialism and its discursive field of colonisation.

Colonisation relied on a discursive practice, targeting the colonised as a means of:

> [d]ealing with it by making statements about it, authorizing views of it, describing it, by teaching it, settling it, ruling over it: in short, Orientalism as a Western style for dominating, restructuring, and having authority over the Orient (Said 1995:3).

Attwood argues this investment through Aboriginalism continues to live in a number of forms. Firstly as a field of study, 'Aboriginal studies', that necessitates the 'teaching, research or display' (Attwood 1992:i) of Aboriginal people by the European expert. These experts claimed that their role of representing Aboriginal people was essential as they knew 'more about Aborigines than they know about themselves' (Attwood 1992:i).

This way of knowing resulted from what Said termed 'fantasy' discourses of the West (Said 1995:6). Gillian Cowlishaw sets the discipline of colonial anthropology within this discursive fantasy field. Anthropology's science, framed within 'evolutionary paradigms', focused upon essentialising the Aboriginal race as 'living evidence of a universal human past' (Cowlishaw 1992:21). Brantlinger argues that the discipline was pressed by colonial activity from the 1830s on to focus upon comprehending the behaviours of the Indigenous 'Other' (Brantlinger 2003). Anthropologists supported the administration of Aboriginal people, enhancing the 'controlling and effecting modifications in native life' (Elkin, 1934, p.2 cited in Grey 2007:2). By the mid-19th century the discipline focused on the representation of the 'physical, mental and hierarchical differences' (Brantlinger 2003:18) of Aboriginal Australians, ranking them at the lowest rung of

the evolutionary ladder (Webb 1998). At the same time the exotic and influential study of the 'Traditional Aboriginal' became the focus, ignoring those considered less authentic, the urban Aboriginals (Cowlishaw 1992). This knowledge production was influential internationally and informed the writings of authors such as Durkheim and Freud (Stanner 1979; Cowlishaw 1992).

Study of the 'Traditional Aboriginal' led to further marginalisation and silencing of Aboriginal peoples (Cowlishaw 1992). A field of experts was now positioned to claim who was authentic and who was not, through their studies (Cowlishaw 1992). These ways of knowing informed anthropological discourse and continue to be used, as there remains a belief within mainstream Australia that the real Aboriginals live in the Northern Territory and those of the south-east of Australia are less authentic (Grey 2007).

Indigenous criticism targeting the problematic nature of the 'expert' defining and fixating Aboriginal identity, in a paradigm of the past, has contributed to the questioning of whose testimony counts (Rowse 1995). Said suggests that the strategy of Orientalism is reliant upon its 'flexible positional superiority' that continues to place the Western academic in a number of 'possible relationships with the Orient without ever losing him the upper hand' (Said 1995:7). It is this position of power or hegemony that maintains its currency in constantly reinventing discursive activities of experts to promote 'European identity as a superior one in comparison with all the non-European peoples and cultures' (Said 1995:7).

Similarly, Attwood argues that the second feature of Aboriginalism is:

> [a]s a style of thought which is based upon an epistemological and ontological distinction between 'Them' and 'Us' – in this form Europeans imagine 'the Aborigines' as their 'Other', as being radically different from themselves (Attwood 1992:i).

Barry Morris explored this positioning specifically in relation to the hostile encounters of frontier violence and the 'truths' and 'realities' constructed by colonial governments, media and the academy (Morris 1992). Colonial agencies legislated on and promoted the distinction of racial and moral difference, notably the inferiority of their Indigenous subjects (Attwood 1992). This was coupled with allegations and representations of Indigenous treachery and animality establishing and affirming fear and anxiety amongst the settlers residing on Aboriginal lands

(Morris 1992). Morris viewed these representations 'as a constitutive form of violence, and violence in itself mediated and constituted by representation' (Morris 1992:72).

These images produced as 'truths' were and are reliant upon power, which is part and parcel of the colonial process (Attwood 1992; Morris 1992). Importantly, these representations created a knowledge base 'that rendered them knowable' (Morris 1992:74). Foucault explains that knowing within this historical era of Enlightment required a process of examination focused upon 'proof by comparison' (Foucault 2002:61).

> It will not be accepted until its identity and the series of its differences have been discovered by means of measurement with a common unit, or, more radically, by its position in an order (Foucault 2002:61).

This led to the development of a taxonomy of the 'Other':

> [the] 'self' or the group is fashioned through the construction of an 'Other', which is outside and opposite, and that the making of an identity rests upon negating, repressing or excluding things antithetical to it (Attwood 1992:iii).

Colonisers reduced all thought patterns of the beings they colonised, to savagery, bereft of knowledge, sense and morals (Brantlinger 2003). Research was engineered to develop this hypothesis, with Australian scientists measuring empty skulls, a method called craniology. They used seeds and marbles, to 'prove' that Caucasian skulls had a larger brain space than Indigenous skulls (Brantlinger 2003). R.J.A. Berry was one such scientist who had, prior to WW1, studied 9000 Indigenous skulls.

> According to Berry Aborigines were simply another group of small-headed people, and therefore might be classed, with white delinquents and criminals, among the feeble-minded (Anderson 2002:206).

The taxonomic framework used by Eurocentric institutions to define Indigenous persons presented Indigenous knowledges as static, devoid of the ability to cope with change and inferior to their comparative Western models (Brantlinger 2003). Their nets of description were not fine enough, failing to capture the nuanced material, and their theorising reduced what they did glean to useless and homogenous material. For example, many non-Indigenous writers have written

about the "Dreaming" as myths and legends, primitive religions, rites of passage and walkabout stories. From an Indigenous academic perspective, these writers lacked the authority or philosophical grounding to report on these aspects of the Dreaming, and they ignored the important matter of Indigenous ownership of this knowledge. Colonial descriptions devalued the critical importance of how and why Aboriginal people lived, with Stanner arguing that the expert commentaries only darkened the study they sought to enlighten (Stanner 1979:151).

Aboriginalism required the 'Othering' of Indigenous Australians, providing the new settlers and their governments with a sense of who they (rather than Aboriginal peoples) were, as they had transplanted their own identities upon a country they did not know. Through the construction of the primitive and problematic 'Other', the colonisers were complicit in creating an identity of British superiority and Aboriginal subordination (Morris 1992). Othering formulated nationalistic truths that legitimised the killing times as well as establishing a framework for administering the natives (Attwood 1992; Brantlinger 2003)

> … as a corporate institution for exercising authority over Aborigines by making statements about
> them, authorizing views of them, and ruling over them (Attwood 1992:i).

The discipline of Anthropology and various professions used the discourse of extinction, mourning the imminent demise of the Noble Savage (Brantlinger 2003). As discussed previously, the professional experts considered the Aboriginal peoples of the south-east as inauthentic and 'non-traditional'. Those who were able to maintain a nomadic hunting lifestyle were considered traditional; those who were being controlled by government legislation were simply descendents of a traditional past displaying only the physical attributes of Aboriginality. For these anthropologists, these less authentic specimens were not worthy of study or contemplation (Berndt & Berndt, 1988, p.615 cited in Grey 2007:16). This standpoint remains in that it is commonly believed that only Aboriginal people living in remote areas of the Northern Territory, Western Australia, South Australia and Far North Queensland can claim authenticity.

Although colonial anthropologists observed directly the impact of frontier violence and political policies and the fact that some Aboriginal people survived (Grey 2007), they failed to recognise or represent this resiliency. They believed their roles to be apolitical in solving the Aboriginal problem and 'viewed themselves as scientists using a methodology implicitly based on a neutral,

value-free science, above and beyond politics, which could provide benefit to government, mission, settler and Indigenous people alike' (Grey 2007:23). Importantly, this work required the use of Western scientific values which had effectively constructed a subjective racialised Other, and the solutions born from such theorising did not bode well for Indigenous Australians (Grey 2007:23).

Bain Attwood argues that this was Aboriginalism at its finest, disempowering Aboriginal Australians 'as objects of knowledge' (Attwood 1992:ii), over which the expert had full control and 'as the dispensers of truth about their needs and requirements' (Attwood 1992:ii). This power of control enabled the expert greater authority as they could now produce the reality they had hypothesised. They had the ear of governments and influenced their 'policies and practices which have, in turn, determined Aborigines' term of existence – racialising the aboriginal social body and so making Aborigines of the indigenous population' (Attwood 1992:ii-iii). The role of the expert in Aboriginal Affairs has not changed as the sense of power that it creates for the wielder is too great to relinquish.

The legacy of Aboriginalism marginalised and excluded Aboriginal people in Australia, who continue not to have the opportunity to impact upon the social body as their expertise is dismissed by mainstream experts and governments (Attwood 1992). Non-Indigenous academics often presume they are the authorities, castigating Aboriginal people who question their knowledge or attempt to represent themselves and their experiences. However:

> All production of knowledge about the other involves an act of translation which distorts the lived experience and worldview of the other, and, at worst such accounts barely refer to the object of inquiry (Attwood 1992:xiv).

It is the fantasies of the research expert that have led to the challenges by Indigenous peoples worldwide to incorporate into the research agenda our voices, our knowledges out truths and our directions (Rigney 1997; Smith 1999; Dodson 2003) to guide our self-defined destinies.

## Indigenous knowledges

The following section explores a number of the differences between Indigenous knowledge systems and those of the Western tradition. This has been undertaken to raise awareness of the

distinguishing features of Indigenous knowledges which must critically inform any researcher working with Aboriginal peoples. It is important to state up-front that '[a]ll knowledge is first of all local knowledge' (Okere, Njoku et al. 2005:3) to establish that there is an originary moment that is in common to all forms of knowledges. Local means more than a geographical environment, it refers to a system of 'organising principles' (Okere, Njoku et al. 2005:3) such as 'linguistic, socio-cultural, economic, ecological, technocratic, historical, religious' (Okere, Njoku et al. 2005:3) relative to ways of generating self-sustainability that are constantly adapting and linked to the processes of their Ancestors (Okere, Njoku et al. 2005:3). The roots of local knowledge relate to cultural groups', 'unique genius' and 'distinctive creativity' (Okere, Njoku et al. 2005:3). These distinguish a group's 'singular context and history meaningfully developed as knowledge, epistemology, metaphysics, worldview' (Okere, Njoku et al. 2005:3). From this beginning it can be appreciated how Indigenous knowledges have been transgenerationally organised, remaining context-focused rather than content-orientated (Smallacombe, Davis et al. 2007:7). This is divergent to the Western knowledge traditions.

Western science failed to appreciate that its own originary moments were based upon local cultural knowledges (Semali and Kincheloe 1999:29) when it focused upon subjugating Indigenous knowledge systems and describing them as inferior and inadequate (Deloria 1997; Rains 1999; Semali and Kincheloe 1999; Smallacombe, Davis et al. 2007). The denigration of Indigenous ways of knowing is not to be viewed in isolation from the imperialist attitudes and actions of the colonists (Semali and Kincheloe 1999:29). Western science advanced a hierarchical view of knowledges and production, advocating that its own linear approach was superior and hence dismissed 'questions of context that provide information with meaning and potential application' (Semali and Kincheloe 1999:29). The West's knowledge production was focused upon power and profit (Memmi 1965; Langford 1983; Smith 1999; Dodson 2003; Ermine, Sinclair et al. 2004; Okere, Njoku et al. 2005). Universally, Indigenous people know this; they have lived it.

The Year of Indigenous Peoples, 1993, was the year I attended my first International Indigenous Conference on Education in Wollongong. It was there that I had the opportunity to meet and share with my Indigenous brothers and sisters from around the world. We were all connected and close, although we personally did not really know each other. We became 'us', a term that

'includes you, me, all of our relationships, taking place in our various personal, social, political, cultural, physical and spiritual contexts' (Harris and Wasilewski 2004:6). Coming together, 'our identities' (Harris and Wasilewski 2004:6) were honoured because we all valued the importance of relationships, our connection to mother earth, responsibility and reciprocity (Harris and Wasilewski 2004). Indigeneity, the paradigm we all shared, is focused upon 'sustainability, spiritual interconnectedness and co-existence – of *convivencia* – of living together' (Harris and Wasilewski 2004:6). Our ways of knowing are inclusive of praxis around 'relational politics' (Harris and Wasilewski 2004:6) which requires the balancing of diversity through acceptance and relating to it, rather than attempting to destroy it. This praxis is divergent to a Eurocentric scientific approach, that to verify one truth must eliminate all others' truths. Indigeneity is and has always been communally orientated, requiring methods for successful co-existence. Indigenous notions of respect, responsibility and reciprocity are critical foundations for co-existence relying upon 'the ability of all peoples' voices being heard' (Harris and Wasilewski 2004:6). Without this approach, balance cannot be achieved. Balance is about survival, not about dominance, silencing or exclusion. It requires the inclusion of difference to be achieved (Harris and Wasilewski 2004).

Indigenous ways of knowing are also secular, with the Dreaming and land/country being the foundations of knowledge development requiring spiritual and cultural practices and praxis for the maintenance and survival of all beings (Bird Rose 1996; Deloria 1997; Yunupingu 1997; Viergever 1999; Battiste 2002; Burgess, Johnston et al. 2005). In the Australian Aboriginal context, Indigenous knowledges systems are regulated through Aboriginal authority that is constituted as 'roles, responsibilities, modalities of power and influence, governance structures and processes' (Smallacombe, Davis et al. 2007:7) that are critical to its 'formation, maintenance and transmission' (Smallacombe, Davis et al. 2007:7). These systems, known as Indigenous Traditional Knowledges are not isolated. Rather they are enmeshed within ways of knowing, being and doing as 'meanings, values and practices' (Smallacombe, Davis et al. 2007:7) of Aboriginal cultures. As such, Indigenous ways of knowing, being and doing are best explored as an Indigenous paradigm. This paradigm's philosophical framework enmeshes epistemology, axiology, methodology and ontology through a multi-dimensional, layering approach and hence becomes a system.

Critically, the context of the system relates to how it is managed and then translated as Fred Myers illustrates in his explanation of the Pintupi model for looking after young men (men's business).

> Knowledge derives from the Dreaming and is passed from "all the old men" (*tjirpli tjurta*) to "all boys" (*katjapirti*), from "older" to "younger," from "before" to "after," endlessly through the generations (Myers 1986:240-1).

This management and translation of knowledge is firstly to build the autonomy of young men and secondly to enable men to 'look after' (Myers 1986:240) their community by 'carrying and passing on the Law' (Myers 1986:240). It important to acknowledge that throughout Australia, Aboriginal women and men 'control separate and secret domains of knowledge and action, usually referred to as 'business' (Bird Rose 2000:28). Knowledge brokerage by Elders, male or female, is vital to cooperative management and survival as First Nation author Marlene Castellano highlights:

> Knowledge is not a commodity that can be purchased and exploited at will. Because knowledge carries with it power to do good or ill to the knower and the community, many Elders decline to have their knowledge recorded in writing or electronic media. They want to be assured that the seeker is properly instructed and compliant with the ethical obligations that will be assumed (Castellano 2004:12).

First Nations scholars Marie Battiste and Youngblood Henderson explain the intricacies of Indigenous ways of knowing that are shared amongst Indigenous peoples world-wide.

> Indigenous ways of knowing share the following structure: (1) knowledge of and belief in unseen powers in the ecosystem; (2) knowledge that all things in the ecosystem are dependent on each other; (3) knowledge that reality is structured according to most linguistic concepts by which Indigenous describe it; (4) knowledge that personal relationships reinforce the bond between persons, communities, and ecosystems; (5) knowledge that sacred traditions and persons who know these traditions are responsible for teaching "morals" and "ethics" to practitioners who are given the responsibility for this specialized knowledge and its dissemination; and (6) knowledge that an extended kinship passes on teaching and social practices from generation to generation (Battiste and Henderson 2000:42).

The key to these knowledge systems is people's connection to land and nature (Hunter 2004) described by Sefa Dei as 'grounded in a people and a place' (Sefa Dei 2002:5). This definition qualifies as ngurra-kurlu under the description by Wanta Jampijinpa Pawu-kurlpurlurnu, as it takes in the laws, 'relationships and obligations to look after the biophysical environment and how these actions are inherently the same as those that look after people' (Pawu-kurlpurlurnu, Holmes et al. 2008;24). This model illustrates specifically how the Warlpiri are grounded in a people and a place.

> Skin refers to the principles of relatedness that creates obligations and responsibilities. Country is thought of as both the natural environment as well as all the relationships that make 'home' and therefore create a powerful sense of belonging for Warlpiri people. The Law is all the guiding principles that determine the correct way to live. Language is what people speak but also all the various registers that enable different elements of ngurra-kurlu to communicate. Ceremony is Warlpiri education and is also the symbolic heart of the culture (Pawu-kurlpurlurnu, Holmes et al. 2008:24).

All of these elements are intertwined with each other in a holistic model that focuses upon the relatedness of all. For example to know country you must know its Law, its skin, the language for and of the ceremonies (Pawu-kurlpurlurnu, Holmes et al. 2008).

Dr Daes states in the *Report on the Protection of the Heritage of Indigenous peoples* that Indigenous knowledge is 'a complete knowledge system with its own concepts of epistemology, philosophy, and scientific and logical validity' (Daes 1994 para.8, cited in Battiste and Henderson 2000:41). Indigenous knowledges:

> Can only be fully learned or understood by means of the pedagogy traditionally employed by these peoples themselves, including apprenticeships, ceremonies and practice (Daes cited in Battiste 2000:41).

Most importantly, she states that land is the 'central and indispensable classroom' (Daes cited in Battiste 2000:41), where Indigenous knowledges are taught and nurtured. These factors contribute to the difficulty of defining Indigenous knowledge. Their origins have not been set within timeframes or historical eras rather they are observed as always existing and coming from the same source. This source is:

> … the relationships between a global flux that needs to be renewed, the people's kinship with other living creatures that share the land, and the people's kinship with the spirit world. Since the ultimate source of knowledge is the changing ecosystem itself, the art and science of a specific people manifest these relationships … (Battiste and Henderson 2000:41-2).

The land is alive and provides information 'for those who have learned to understand' (Bird Rose 2000:225). This ability to comprehend, and read the signs offered by different beings and act accordingly illustrates the ever-changing and dynamic nature of Indigenous knowledge systems. These systems remain intact and vibrant as they are enmeshed within a 'living cultural tradition' that has also survived. Aboriginal cultures continue even though they have been dealt a tremendous blow from colonial powers. Their strength lies within the ways of knowing, being and doing that are 'constantly validated, reaffirmed and renewed' (Smallacombe, Davis et al. 2007:9).

Indigenous knowledge systems are essential to Indigenous cultures survival and well-being. They always have been and always will be, as they are at the heart of who we are as Indigenous people. These ways of knowing, being and doing are sovereign to us. Denying their existence and importance, violates Indigenous peoples and further exacerbates the injuries meted out through colonisation.

## Paradigmatic disparities

Over the last thirty years in the field of social science knowledge building there has been an explosion of paradigms and their respective methodologies (Denzin and Lincoln 2000; Guba and Lincoln 2005) challenging the hegemony of positivist research and its knowledge constructs. This episteme with its logical tenants of producing 'uncomplicated and validated knowledge that is generalisable' (Kincheloe and Tobin 2009:519) without being subjectively influenced by the historical and social context, is irresistible to the rational scientist. Critically, this approach plays to the ethnocentric researcher who believes that 'their knowledge production that follows the step-by-step methodology of positivism is a certified reflection of the way the world really is' (Kincheloe and Tobin 2009:519). Importantly, non-positivist paradigm developments are critical to building richer and more diverse realities of the many rather than a Western monologue speaking on behalf of all (Semali and Kincheloe 1999).

Truth or truths that relate to an individual's worldview are reliant upon the lived experiences of the society in which that worldview is embedded, the society that it shapes and that shapes it. Indigenous peoples are particularly concerned with concepts of truth and have developed a strong ethical and empirically based approach to consciously assessing the reliability of truth claims (Battiste 2002). These judgments or principles relate to appreciating the validity of personal experience over second-hand assertions, which are the rich data of much Eurocentric research. But Indigenous peoples are hesitant to quibble or assert their truths over others (Bird Rose 2000). Indigenous Law formulated through and from the Dreaming holds truths for Indigenous Australian peoples and is much older than the Western legal system, a system used to dominate and discriminate against Indigenous ways of knowing, being and doing (Stanner 1979; Bird Rose 2000; Pawu-kurlpurlurnu, Holmes et al. 2008).

Indigenous peoples, along with many marginalised people, have been liberated by postmodern paradigms enabling their voices to be heard and legitimised in using their own realities, ontologies and epistemologies (Guba and Lincoln 2005). Yet in the area of health inquiry focusing upon Australian Aboriginal people, positivism remains hegemonic. Although internationally there is recognition of the importance of deriving 'from community consensus regarding what is 'real', what is useful, and what has meaning' (Guba and Lincoln 2005:197), Western medical scientists justify their approaches as producing valid, objective truths using a rigorous method (Semali and Kincheloe 1999). This thinking comes with a legacy of descriptive prose used historically to manage the Aboriginal problem (Grey 2007).

The aim of health research is to formulate approaches to improve health outcomes. I view Indigenous health research in the same light that is undertaken to explore ways of improving health outcomes for Indigenous Australians. Currently in Australia there is no 'agreed mechanism to evaluate the contribution of research to improving health outcomes' (Sanson-Fisher, Cambell et al. 2006:502). This is problematic in attempting to observe the contribution research of the past has made to health improvement. In an attempt to define the mode of research that produced health improvement outcomes, Sanson-Fisher et al. investigated publications that related to Indigenous health for Indigenous Nations in Australia, New Zealand, America and Canada, and selected 1763 publications from 1987 to 1988, 1997 to 1998 and 2001 to 2003 (Sanson-Fisher, Cambell et al. 2006:502). Their analysis of data highlighted a

'dominance of descriptive research' (Sanson-Fisher, Cambell et al. 2006:502), a core product of positivist research (Sanson-Fisher, Cambell et al. 2006). There has been a marked increase in research articles on this topic within the time period 2001–2003 in Australia (Sanson-Fisher, Cambell et al. 2006), yet 78 per cent of those were descriptive (Sanson-Fisher, Cambell et al. 2006). These findings suggest that research into Aboriginal health in Australian remains ' "research-driven" or "fundamental" ' (Sanson-Fisher, Cambell et al. 2006:505).

> [this] long-standing pattern requires both commitment and action from a range of stakeholders including researchers, research organisations (including universities), research funding agencies, governments, Aboriginal organisations and communities (Sanson-Fisher, Cambell et al. 2006:505).

The authors recommend shifting the long-standing pattern of research on Aboriginal health (Sanson-Fisher, Cambell et al. 2006). This issue will be further explored in Chapter 5.

The problem with this recommendation is that the respective research stakeholders, excluding Aboriginal organisations and communities, have been unable to appreciate that Indigenous people have their own paradigms and ways of knowing, being and doing that are at very core of developing solutions for themselves. Rather, the truth or authenticity of Indigenous claims is often, as Hassel argued, not valued through academic fundamentalism, as disciplines assert their own truths and are unable to appreciate a truth that does not obey the rules of their tradition (Hassel 2004). The academic tradition constructed through Western gaze as is their tradition remains an authority over and on what is considered to be authentic Indigenous perspectives (Kincheloe 2000).

## Conclusion

Indigenous knowledges, like Indigenous peoples, were colonised and silenced (Smith 1999). Colonisation of Indigenous truth claims and knowledges have been injurious to Indigenous peoples' well-being both in Australia and internationally (Smith 2005), as has the dismissing of their ways of knowing as viable ways of viewing the world (Kincheloe and Steinberg 2008). The devaluing of Indigenous reality has contributed to the current poor status of Indigenous health in a number of ways (Kelm 1998; Pawu-kurlpurlurnu, Holmes et al. 2008). The maintenance of

Eurocentrism in the fields of science, philosophy, culture and political power persists in marginalising Indigenous people and reducing their health, education and economic status.

It is also argued that research praxis requires a reflective and contextual framework to better inform the Indigenous health research agenda. To further inform this shift of long-standing Western research practice requires a greater recognition of Indigenous worldviews as a distinct ontological and epistemological tradition (Ermine, Sinclair et al. 2004). This necessitates being inclusive and respectful of Indigenous peoples and their worldviews in all Indigenous health research. As Indigenous ways of knowing have grown and further conceptualised to accommodate the significant changes colonisation creates.

Essential to this growing is our challenging the hegemony of Western knowledge production about us, and developing relevant and safe approaches to represent ourselves. These approaches are inclusive of our ways of knowing and are also respectful of Western knowledge systems. Our request is the acceptance and acknowledgement in research that there are many truths and that 'a body of knowledge differs when it is viewed from different perspectives' (Battiste 2008:1). This chapter's evidence has highlighted the differences between Indigenous and non-Indigenous worldviews and how they contribute to the way we view and perceive knowledge. These divergences are important in appreciating how research, as the building of knowledge can improve Indigenous health outcomes.

The following chapter will examine how ignoring these divergent ways of knowing can contribute to problematic constructions that influence the way research will be undertaken and health service provision will be provided.

# Chapter 3

# Constructing Aboriginal health problems

> Since their first intrusive gaze, colonising cultures have had a preoccupation observing, analysing, studying, classifying and labelling Aborigines and Aboriginality. Under that gaze, Aboriginality changed from being a daily practice to being 'a problem to be solved' (Dodson 2003:27).

## Introduction

For some 150 years research has focused on 'knowing' Aboriginal Australians and only in the last fifty years has the emphasis shifted to improving health outcomes for Aboriginal peoples (Thomas 2004). Although there has been a shift of focus, it has not delivered effective outcomes for improving the health and well-being of Aboriginal Australians (Burgess, Johnston et al. 2005). Some of the reasons research has not delivered will be explored in this chapter. This chapter argues that science and medicine in their support of the country's colonial agenda used their research to focus on objectifying and displaying a problematic Native people destined for demise as a result of their own mental and health deficits. These ill-informed assumptions have remained intact through the writings of health experts and have influenced health research and its translation, policy, funding, service provision and attitudes of health professionals. The colonial agenda had a method, for which Edward Said coined the term Orientalism, and it is this method that has been used by the academy, governments and science to promote the superiority of Western ways of knowing, being and doing over those it usurped (Said 1995). This method created the 'expert', whose view of the native was considered a truth, and become the legitimate way of knowing and writing about Indigenous Australians.

This approach has led to ill-informed research practice, colonial amnesia and poor Aboriginal health status. Indigenous researchers and communities have challenged these methods, and are working towards ameliorating the impact colonisation continues to have today together with informing the academy of relevant, safe and meaningful research methods. Scientists have argued that when a research paradigm is proven to be ineffective, there is generally a shift within the scientific community to develop methods that will produce effective outcomes (Kuhn 1962). This has not been the case in Australia in the field of Aboriginal health research; rather it

continues to work on its own past assumptions, inadequate data and universal Eurocentric truths. Indigenous researchers have worked towards shifting the research paradigm in order to address these old ordered traditions to produce research that ensure better outcomes for Aboriginal peoples (Ermine, Sinclair et al. 2004). Chapter 3 will also explore their development

## Evidence- or problem-based research

The previous chapter explored the divergence between Indigenous and non-Indigenous knowledge systems, worldviews and how truths were formulated from the different ways of knowing. These differences have impacted upon the development of relations between Aboriginal nations and non-Indigenous Australians. The key players in promoting such irrevocable differences were the colonial scientific 'experts' who wrote about and defined Aboriginal people as the 'Other'. This section will examine the power of the expert in constructing Aboriginal people as objects of difference and hence problematic to mainstream society.

Othering became a Western truth, a way of knowing Aboriginal people, it indoctrinated a one-way colonial agenda that had to establish Indigenous people's life-worlds as inferior and deviant. These truths developed in the field of Aboriginalism, informed generations of non-Indigenous Australians about Aboriginal Australians, and the ways to treat an Aboriginal person when they met one (Attwood 1992). Schools used these expert sources to teach about the primitive first people of Australia. Media leapt at any opportunity to support the experts' ideologies of the savage Aboriginal (Langton 1993; Manne 2003; Thomas 2004). This is how non-Indigenous Australians without meaningful contact with Aboriginal Australians got to know all there was to know about their primitive Other.

Health professionals and researchers also learnt this way and would have received limited exposure to and appreciation of 'the diversity, complexity, and richness of Indigenous cultures' (Hurst and Nader 2006:294). This lack of knowledge and limited exposure is problematic on a number of levels. Firstly, as it speaks volumes about the lack of a balanced Australian historical education provided in Australian primary, secondary and tertiary sectors (McConaghy 2000). Secondly, it positions health professionals in a state of unease and unknowing, which will inevitably have an impact on their level of confidence and competence when working in the area

of Aboriginal health, be it rural, remote or urban (Mobbs 1991; Larson, Gillies et al. 2007). Thirdly, this unease is transferred onto their Aboriginal clients, who respond with a reciprocal unease (Hurst and Nader 2006; Paradies, Harris et al. 2007; McCoy 2008). Finally, these experiences of dis-ease open a floodgate of misleading information for both clients and health professionals to accept as truths, regarding each other (Memmi 1965).

The resulting lack of access to knowledge and understanding of Aboriginal Australians and their diversity has led to problem-based constructs of Indigenous peoples (Smith 1999). Hurst and Nader argue:

> [t]he cultural and medical framework that has defined Indigenous health and delivery in many countries continues to be fraught with misrepresentation of Native people by Eurocentric scholars (Hurst and Nader 2006:294).

Having worked in the area of Aboriginal health for the last twenty-five years, I have observed 'how ill-informed constructs continue to be utilised in problematising Aboriginal peoples' (Sherwood 2009:24). This directly impacts on the health service provision they are delivered. In many cases these misrepresentations have been developed in the guise of shifting the blame from the service provider or system to the victim (Humphery, Weeramanthri et al. 2001). Although there is prevailing evidence to suggest that Aboriginal health is appalling throughout the country, individuals are admonished for their health problems by insensitive systems which are unable to contextualise Aboriginal people's histories and circumstances. This mainstream treatment contributes to the non-utilisation of Western health services by Aboriginal people, which further exacerbates their poor health status (Humphery, Weeramanthri et al. 2001). The resounding cry from the health profession is that Aboriginal clients are non-compliant (Humphery, Weeramanthri et al. 2001), again failing to acknowledge the insensitive, and unsafe care they have received in the hands of the Western health system. The cycle continues, our mob gets sicker and the health system keeps blaming them (Trudgen 2000).

What is not appreciated by the health system is that this naming and blaming in research processes injures people. These are constructs that Aboriginal people internalise. They are fully aware of the lack of respect they receive within the system and that hurts too, but the ongoing misrepresentations of Aboriginal people in health services and the broader society causes trauma

to both the individual and community (Phillips 2003). To live this cycle of ongoing trauma inevitably causes 'psychological injury' (Raphael, Delaney et al. 2007:388).

There is a reason why the system fails to acknowledge or deal with its institutionalised racism; it is because it has always done things this way. Medical studies of the past contributed significantly to the current perceptions of Aboriginal people as problematic, as discussed in the last chapter. They chose to write disparagingly about Aboriginal people and their health as early as the 1870s in the *Medical Journal of Australia* (Thomas 2004:9). This influenced the Western health profession and its researchers and in no way did they attempt to shift the 'doomed race' theorising or its knowledge base. Rather, research became the site for justifying the belief in the dying savage. The following account, 'Insanity in the Australian Aboriginal and its bearing on the evolution of mental disease' exemplifies this pattern:

> Contact with civilization, phthisis and other diseases, mixed breeding and general racial decay are the order of the day. In a few years this line of research will be closed forever. Whatever may be one's sentimental views on the passing of the primitive peoples, from the scientific or even the utilitarian aspect it will be more than unfortunate if our records are not completed before they vanish (J.Bostock, 1924: 459-464 cited in Thomas 2004:521).

Bostock's perspective of Aboriginal Australians was influential and shared by other leading health professionals and scientists of his era. His writings were considered important and provided insight into the demise of a people he believed lacked the mental fortitude to suffer real mental health issues that the 'higher order' white male suffered (Murray 2007:1). Perhaps the inference was that as Aboriginal peoples lacked the mental health sensitivity of their superior white colonisers; they would not suffer greatly during their own demise.

Research undertaken in Australian during the late 19th and early 20th centuries aimed to prove scientifically that social evolution was not simply a theory but was empirically factual. Baldwin Spencer, a revered anthropologist, scientist and writer speculated that 'Aborigines represent the most backward race' (Anderson 2002:191). His scientific assumptions were backed up by Darwin's theorising on evolution and by other scientists, such as Howitt, who chose also to depict the 'Aboriginal' as the ultimate primitive precursor of modern man (Anderson 2002). This era of research, known as scientific racism, asserted that racial cultures were biologically

determined, with Aboriginal Australians supposedly providing evidence to support the assertion of being the most primitive beings on earth (Thomas 2004). At the other end of the spectrum was the declaration that white Caucasians were biologically the most superior race, and hence superior to black people (Breen 2003). The evidence, drawn from the research on Aboriginal Australians, inferred they were a doomed race, and held minimal intellect and morals. This, in turn, informed the medical profession and health service providers, who focused upon the impact of infectious diseases caused by Aborigines with public health measures intentionally developed to reduce contact with the non-Indigenous populations (Anderson 2002; Thomas 2004).

This mentality is exemplified by Doctor Waite in his discussion of a hookworm eradication program in 1918, who wrote of Aboriginal people:

> They are, however dangerous from a public health viewpoint as distributors of disease among the white communities (Franklin and White 1991:24).

Aboriginal Australians' health status was considered by many health professionals to be a threat to the mainstream population's health, and punishing measures were taken to restrict movement and incarcerate Aboriginal people suffering from contagious diseases onto reserves, missions and hospital lock-ups (Austin 1997; Anderson 2002). Scientific racism focused on difference and biomedical and health research was used to support this premise. Treatment rationales provided by health professionals for Indigenous Australians were also different from those provided to non-Indigenous Australians. In many states this segregationist approach and lack of treatment did not change until the late 1960s.

## Objects of science

The critique of historical scientific discourse focusing on Aboriginal people's health has been understated, as Ian Anderson and Kim Humphrey note:

> … the development of a historical focus on Aboriginal health is relatively patchy. It is quite a paradox that a field so often framed historically has had such a poor uptake in academic history (Anderson and Humphrey 2007:1).

The authors continue that there have been 'some significant exceptions' (Anderson and Humphrey 2007:1) to this statement. David Thomas is one such writer. Thomas, a non-

Indigenous doctor with a working history in Aboriginal health, was concerned about the impact that doctors' reporting of research can have when written or read unreflectively (Thomas 2004:1). This concern led him to review articles of research on Aboriginal health published by the *Medical Journal of Australia* (*MJA*). The review provided specific accounts of research undertaken by doctors and others that was stereotypical, exploitative, racist, entirely ethnocentric and injurious to Aboriginal peoples (Thomas 2004).

Thomas's analysis of Aboriginal health publications in the MJA from 1870 to 1960 provided a listing of research and researchers (Thomas 2004). Their approaches to research were informed by a Eurocentric worldview and the belief that they were the 'experts' describing Aboriginal conditions and circumstances as well as formulating solutions based upon their belief that the population was doomed for extinction (Stanner 1979). They went out to explore and study the unique diseases of Aboriginal people for research, but not to administer treatment (Thomas 2004:49). Rather, their focus was to build upon the collection of data of the exotic as well as to reduce the likelihood of disease transference to the white population (Thomas 2004). Medical scientists claimed the research they were undertaking was imperative, as their data group was dying out fast, and this knowledge would be lost forever (Thomas 2004:77). The concern of the scientific community over:

> [t]he possible loss to science from an Aboriginal demise often seemed as important to the researchers as their concern over the loss of human lives. Whilst there were references to the value of science in helping Aboriginal people, this dying race was of much more of interest as objects of science rather than as the potential recipients of benefits of medical research (Thomas 2004:28).

Thomas analysed the work undertaken in the area of Aboriginal health research and its impact upon Aboriginal people in the light of 'the way researchers have chosen to write about them' (Thomas 2004:1). Reflecting on research of the past he stated that he had 'somehow long known that this research was bad: that it was racist' (Thomas 2004:2). His work was a result of taking seriously the concerns of Indigenous and non-Indigenous peoples and especially the distrust Aboriginal people hold of research past and present. Thomas's aim was to provide a history, not to be rejected but to be engaged with, to learn from so that 'oppressive practices of the past' are not continued in the research into Aboriginal people and their health (Thomas 2004:2).

Thomas relates a familiar dialogue that researchers in the present day are ill at ease with exploring their own objectivity enshrined within their own cultural, historical and political values (Thomas 2004:2).This genre of scientific discourse is believed within the health arena, to be above politics. However, as Thomas asserts, the 'conventions of scientific writing tend to obscure or diminish the social, political and ethical elements of the medical research being described' (Thomas 2004:2). This unease within medical research is a barrier to changing the Western approach ensuring research continues to promote in the area of Aboriginal health, its objectivity in the search for data-driven truths. As Thomas notes, 'objective truth can be produced by deeply subjective people' (Appleby, j; Hunt, L; and Jacob, M, 1994: 185 cited in Thomas 2004:3). We must critically reflect upon the writings of those that deem their truths have been developed in this manner. This is perhaps best summed up by W.E.H. Stanner:

> In the past we were wrong – in some respects grotesquely wrong – about the Aborigines. We thought that they could not possibly survive; that they had no adaptive capacity; that there was nothing in their society of other than antiquarian interest; that there was nothing of aesthetic value in their culture. We could be as wrong about the future (Stanner 1979:382).

Thomas's review exposes the less than charitable activities of medical scientists prior to the 1960s and argues that today scientific racist representations should no longer be used in the descriptions and practice of Aboriginal health research (Thomas 2004). Yet medical scientists have been unable to resist building evidence to support the premise of an Aboriginal problem with the causality resting in Aboriginal hands or bodies (Kelm 1998), rather than the legacy of 200 years of colonisation and the lack of appropriate health service delivery (McCoy 2008). Focuses continue to rely on comparative studies of Aboriginal people versus non-Indigenous people although contextually there has never been a level playing field (Morrissey 2003). We must all become critical readers of 'doctor's writings' that continue to omit the structural, historical, and political contexts of a people they critique and silence.

Thomas's most important contention is that of the power past research continues to hold over Aboriginal people. He writes: 'I have not always had the heart to tell them (Aboriginal people) what my mob has most recently written, and I have read, about their mob' (Thomas 2004:1). This point is critical to my own line of thinking and theorising. As an Aboriginal health professional and researcher I have experienced firsthand the impact past research has on health

91

service provision and research of today. These consequences 'have led to the compounding of injury and poor health status for Indigenous Australians, communities and the Indigenous health workforce' (Sherwood 2009:24). These experiences have led me to take this thesis journey to explore ways of improving Indigenous health research through decolonising research approaches. Indigenous critique has been ignored or downplayed by current researchers. As Thomas suggests:

> These researchers, like most people, find it easier to see the politics, values and traditions of other people (in this case past researchers) than their own (Thomas 2004:3).

This inability to recognise the impact of a Western dominant health authority describing and affixing health deficit to a marginalised and silenced minority remains reminiscent of past research traditions. The tradition needs to acknowledge that there are indeed Indigenous researchers that critique their writings as well as their process, we have witnessed and been injured by their practices, and we have been writing back, speaking back and developing our ways of research to ensure that our people are not silenced, represented as health deficits, and continue to suffer from the 'doctors' writings' of the past. I agree with and support Thomas's following statement:

> I believe that future Indigenous health research would be strengthened by confronting, rather than evading, this social and political context, just as I have argued for a similar engagement with historical context (Thomas 2004:3).

The historical, social and political contexts are critical variables within the Aboriginal health research equation, as are the unstated political, historical and social ideologies in the dominant discourse held by those who undertake the research. Vital too are the financial viability of the institutions that promote the uptake of research and the understanding of these variables on the part of funding bodies that dictate the research and knowledge production agenda.

## Western ways of doing research

Knowledge about research methodologies of the past is essential to appreciating the debate between Western systems of knowledge and the silenced and often invisible Indigenous systems of knowledge (Rains 1999). Scientific knowledge has remained in the privileged domain of the Western academy (Semali and Kincheloe 1999). However, Indigenous researchers are attempting

to deconstruct this knowledge (Rigney 1997). This requires the critical perusal of Western systems of knowledge collection, codification, rituals, construction and language, and subjecting them to a decolonising analysis (Rigney 1997). To begin such a process, a comprehension of knowledge systems is necessary, as explored in Chapter 2, from which we are aware that a 'system of knowing' (Ladson-Billings 2000:257) is connected closely to a worldview and is enmeshed within specific cultures. Worldviews dictate the way in which inquiry will be undertaken and how meaning and actions will be accepted out of the inquiry process (Ladson-Billings 2000).

The Western worldview has developed over centuries out of a European tradition and more latterly America's traditions of knowledge dating from the 17th century. This worldview is the prevailing paradigm for the construction of knowledge in the West and has, to a greater or lesser extent, ensured countries colonised by Britain, France, Holland, Germany and more recently the USA have had their ways of knowing subverted (Ermine, Sinclair et al. 2004). This Western reasoning is taught in schools, universities and regulates health services, housing, judicial systems, welfare orientation, public works and infrastructure. It controls societally conceived norms as well international norms (Ladson-Billings 2000; Lafrance and Bastien 2007).

Western epistemology has silenced Aboriginal voices and subjugated their knowledges, as a calculated project (Ermine et al., 2004, Memmi, 1965, Smith, 1999, Battiste, 2000, Battiste and Henderson, 2000). As research subjects, Aboriginal peoples were and continue to be defined, objectified and othered (Smith 1999). 'The hegemony of the dominant paradigm makes it more than just one way to view the world – it claims to be the only legitimate way to view the world' (Ladson-Billings 2000:258) and has become the legitimising framework for research and inquiry (Lincoln and Guba 2000). As argued in earlier chapters, the representations that arise from this authority of positivism are problematic, as they are premised by thick descriptions of problems to be solved.

These representations inform a schematical construction of knowing the Other, which continues to raise problems:

> A construction once formed is likely to maintain itself … Constructions are self-sustaining and self-renewing. Constructions, like other forms of knowing such as theories, are able to 'wall off' contravening evidence, by their very nature (Guba and Lincoln 1989:145).

The self-sustaining nature of problematic constructions remains ever-present for Indigenous peoples, informing research and policy targeting communities, even when there is rational evidence affirming the constructions are false (Guba and Lincoln 1989). These constructs have been argued to be developed by the colonisers to authenticate invasion, and the systematic gaining of control of land, resources and peoples through imperialism (Memmi 1965; Denzin and Lincoln 2008). Linda Tuhiwai Smith argues that there are a number of ways of describing European imperialism: 'as economic expansions, as the subjugation of "Others", as an idea or spirit with many forms of realisation and finally as a discursive field of knowledge' (Smith 1999:21).

## Othering

Othering is the discourse of Orientalism, a means by which the 'West', a discipline of European culture, colonised the 'Other' via a process of management and imaginative production (Said 1995). Said asserts: 'European culture gained in strength and identity by setting itself off against the Orient as a sort of surrogate and even underground self' (Said 1995:3). The Orient and its Oriental are manmade constructs, discursive formations of the West that Said argues were '*essentially* an idea, or a creation with no corresponding reality' (Said 1995:6). This:

> … is not an airy European fantasy about the Orient, but a created body of theory and practice in which, for many generations, there has been considerable material investment. Continued investment made Orientalism, a system of knowledge about the Orient, an accepted grid for filtering through the Orient into Western consciousness, just as that same investment multiplied – indeed, made truly productive – the statements proliferating out from Orientalism into the general culture (Said 1995:6).

The colonial literary endeavour became a key agency for the academy; 'for display in the museum, for reconstruction in the colonial office, for theoretical illustration, in anthropological, biological, linguistic, racial, and historical theses about mankind and the universe' (Said 1995:7). The West undertook this task to exemplify its 'cultural leadership' (Said 1995:7) or 'cultural

hegemony' (Said 1995:7). Orientalism was simply producing knowledge that would continue to exemplify the notion of the West's superiority.

In Australia, there was significant investment, in both time and funding by the academy to create this 'body of theory and practice' (Said 1995:6), over approximately 150 years. The speculation continued to develop a 'system of knowledge' (Said 1995:6) about the Other that became 'an accepted grid for filtering through' (Said 1995:6) the Other or Aboriginal Australian 'into Western consciousness' (Said 1995:6). The investment proved profitable in that it became a growing academic body of theorising as well as authorising accounts of Aboriginal Australians for non-Indigenous people to accept as truths known as Aboriginalism explored in Chapter 2. Marcia Langton argued that from Invasion onwards, Aboriginal people were ' the most consistent and prized of Australia's intellectual exports' (Langton 1998:25). Sociologists such as Durkheim utilised reports written by Australian researchers about Aboriginal Australians to develop sociological notions that remain part of the repertoire of analytical tools of the social sciences (Langton 1998:25). I suspect such theorising and the tools developed would be heavily contaminated by the colonial myths of Western ways of knowing the Indigenous Other.

Said asserted there has been a proliferation of academic disciplines whose focus was to describe, analyse and exhibit their 'Western findings' of their subjected Indigenous object. The Australian academy in an attempt to assert itself as a site of credible knowledge production within the West focused upon Aboriginal Australians as a unique and informing subject matter (Cowlishaw 1992). In many ways this was the forging of the country's own credibility through the utilisation of variable academic disciplines, discoveries and findings. It signalled its entry into the competing spectrum of Western knowledge production. This venture was significant as Australia was considered to be an incarceration colony only and not a site for the development of new knowledges. Visiting scientists such as Darwin and the uptake of data by Durkheim indicated that Australia the nation and its academy were worth taking seriously (Brantlinger 2003).

This discursive context of colonisation is vital to the current story of Aboriginal health research. Said argued that the theory and practice of a Western way of knowing, asserting its truths upon the 'Other' implied that Western power was synonymous with scientific truths (Said 1995:46). The development of concepts about Aboriginal people relied heavily upon these ways of

knowing the Other developed through the European Imperial movement and its colonial scientists (Said 1995:50).These knowledge systems of the Other remain intact today, as they were passed down through a system of Western privilege, promoting egocentrically the superiority of the Western mind (Said 1995). This is the tradition of Western knowledge development and in particular, health and medical knowledge regarding the Indigenous Other informed by a colonial mandate highlights the urgency of decolonising this site and field of production.

## Authenticity

This section will explore how scientific racism informing research of the past continues to have ongoing agency in political strategies of governments in dealing with their Indigenous peoples. Sissons (Sissons 2005), a First Nation scholar, maintains that the colonial agency continues to describe and construct the Indigenous Other. The construct of the authentic Indigenous person requires Indigenous people to live up to the representations developed by experts about them. The construct of 'biological and cultural authenticity' (Sissons 2005:39) is now an economic strategy used by governments of colonial states to further reduce those they usurped. The inauthentic is the binary of the authentic: educated, living in urban dwellings, impure, not black, and effectively stripped of their identity. The inauthentic is a product of colonial policies of the past in Canada, America, New Zealand and Australia (Sissons 2005). A body of peoples not worthy of study, or to be written about by experts, and hence are 'not known'. Rather than acknowledge this lack of knowledge, further actions were taken by governments to reduce identity connections on the basis of blood quantum to reduce funding to Indigenous communities which is still carried out in the USA and Canada (Sissons 2005).

These actions of the past and present have injured communities and individuals, dislocating peoples from their sources of well-being, critiquing their ways of knowing themselves, attacking their identity (Sissons 2005:40). Aboriginal authenticity has, at its root, colonial scientific racism, which was prescribed through notions of blood purity. Australia, the United States, Canada and New Zealand all participated in this scientific approach to define, exclude and act upon those considered inauthentic (Anderson 2002). In the United States and Canada a lack of blood purity excludes people from identifying themselves as members of Nation groups as well as excluding them from land repatriation (Sissons 2005).

In Australia blood quantum was also used to qualify authenticity for Aboriginal peoples. Terminology abounded such as: full-blood, half-caste, quadroon and octoroon to order the race. Blood group research arose in the 1930s in both Australia and North America upon their Indigenous subjects (Thomas 2004:56) following a similar focus of the 1920s in Germany (Thomas 2004). It was speculated that studies of serology and blood groupings could identify individuals and ethnic groups (Thomas 2004:57). The outcomes of such work instead of affixing a primitive blood group status, highlighted that there was a racial affinity between the European and Aboriginal races (Thomas 2004:61). This medical research informed Dr Cleland's argument for biological absorption of Aboriginal Australians into the non-Indigenous population. The aim of breeding out the colour was considered achievable without; ' "throw-backs" to Aboriginal type' (Thomas 2004:61). This racist and medicalised ideology backed up by medical research demonstrates the concerns Aboriginal people hold about Western derived scientific truths and the power they held and hold in informing policy.

## The power of the expert

This section examines the power of the expert whose constructions of Aboriginal people are influential as they are replicated as truths in the discourse of Aboriginal health research, instead of the critical voices and views of Indigenous peoples who are the experts of their own reality.

The field of Indigenous health research is littered with experts who write from a cultural hegemonic approach. One such expert, Peter Moodie, has been recognised and highly acclaimed by his peers for his important role in the area of Aboriginal health research (Saggers and Gray 1991; Thomson 1991). Appreciating the extent of his readership, it is important to critically reflect upon the constructs and representations, Moodie developed in his text *Aboriginal Health* (Moodie 1973). These ways of knowing Aboriginal people are transmitted onto Aboriginal people by those who accept Moodie's discourse.

To elucidate this discourse I have reviewed a number of statements made by the author highlighting an unexamined Western authority, subjectivity and superiority. His statements, published in 1973, mirror the theorising of Doctor Cilento in the 1920s who believed it was critical to bring the Aboriginal object out of the museum, and display it instead as a biomedical specimen, as a 'modern disease threat' (Anderson 2002:145). Cilento believed that Indigenous

people's problems with health were due to their minimal capacity for behavioural change, especially in the area of hygiene (Anderson 2002:147). I am suggesting that Moodie was influenced by the writings of this Indigenous health expert Cilento, and that this cycle continues through the power experts who simply reassert the continuing of the scientific and racist research discourse of the past.

It is critical to challenge these ways of knowing us, especially in the area of health research:

> Challenging research hegemony involves understanding colonial history, and ensuring that research has practical applications that empower and liberate the people through practical and ameliorative results; which, in contemporary Indigenous contexts means engaging in a decolonisation agenda (Ermine, Sinclair et al. 2004:16).

Ermine, Sinclair et al.'s statement is critical to and informs the arguments underlying this thesis. It aims to shift the research approach from an oppressive and injurious regime to a process that is ameliorative and informed through a balance of context and Indigenous people's voices and views. This is a critical agenda as Indigenous health data highlight, and hence the following critique identifies what must be challenged.

Moodie's *Aboriginal Health* has been widely read and appears to have informed the next generation of health scientists, whose formative writings could have been built upon his theorising. This is of concern when reading Moodie's first sentence in the text's introduction:

> The principal aim of this study has been to identify, classify, evaluate, and interrelate current Aboriginal 'health problems' (Moodie 1973:5).

Moodie's opening line states an empirical positivist method for a descriptive account of Aboriginal health problems. The terminology used identifies the 'Aboriginal' as an object included in this study by virtue of 'health problems'. The language used in the principal aim of the study's four's actions are examples of the most disturbing pseudo-scientific racism, setting the scene in the research of the past, where Aboriginal bodies and skulls were identified and classified to support the Western notion of inferior and primitive status (Thomas 2004). The purpose of the term is to create a belief that research can bring order and hierarchies by using 'empirical reality' (Said 1995:47) on Aboriginal health problems, and more so the object.

98

It was from this study in particular that gaps in Aboriginal health status data were first identified. Moodie claimed that the gaps prevented a competent analysis of status, morbidity, mortality and trends. Saggers and Grey affirm Moodie's findings and claim that:

> Moodie's comprehensive study of Aboriginal health was largely based upon the limited official statistical collection available, and upon epidemiological and clinical reports, as well as his own research in New South Wales (Saggers and Gray 1991:5).

Their account of Moodie's work is important, as he provided the first snapshot of the National health status of Aboriginal people. He tellingly asserts the lack of data is in itself a factor of the Aboriginal 'health problem' which contributes to misrepresentations, invalid assumptions with consequential effect (Moodie 1973). However, armed with this knowledge, Moodie unfortunately did not question his own assumptions derived from the inadequate data.

Moodie concluded his text with a chapter titled 'Prognosis of the Aboriginal Health Problem' (Moodie 1973:265), a title befitting the claims made to explore the poor health status of Aboriginal people and the gap in mortality and morbidity between Aboriginal and non-Aboriginal Australians. Moodie asserts that the differential exists because of Indigenous Australians' 'cultural handicap' (Moodie 1973:266) that prevents them from enjoying the same good health non-Indigenous Australians share. His reasoning is that:

> [t]hese handicaps arise from aspects of belief systems, value systems, behaviour patterns that act as barriers to preventative or therapeutic medicine by blocking contact with the health care delivery system. The failure of Aborigines to acquire behavior patterns suited to healthy high-density living, or the urge to modify their domestic environment (poverty notwithstanding) to minimize the transfer of communicable diseases, can be seen as a basic reason for the exceptionally high morbidity from infections to malnutrition (Moodie 1973:267).

I argue that Moodie's statement is strongly informed by a number of assumptions:

1. Orientalism or Aboriginalism that highlights the significant difference between cultures and promotes the superiority and strength of the West inferring the inverse for the Other (Said 1995:44-5).

2. Failure to be healthy is a result of Aboriginal values and life-styles or 'disorderly defects' (Said 1995:47) as well as an inability 'to conform to white standards' (Dr Cecil Cook cited in McGregor 1997:162).

3. The 'problem' relates directly to the Aboriginal state of primitiveness and considered lack of Western belief and value systems (Anderson 2002).

4. Colonial amnesia of Aboriginal people's colonial experiences that created their current standards of living and health (Mitchell 2007).

5. Western belief systems have 'the status of scientific truth' (Said 1995:46).

Moodie's expert conclusion supports the concept 'of filthy black camps', a term used despairingly to indicate squalor:

> A particular handicap of this kind arises from the lack of early personal contact of Aboriginal and part-Aboriginal women with the domestic skills and 'household values' of urban society – skills and values which have been 'traditional' among white women of all social classes since long before Australia was settled (Moodie 1973:267).

It is a statement that promotes the imperative of colonisation and civilisation for cleanliness and godliness. His hypothesis draws from a normative knowing of Aboriginal people juxtaposed with the civilised and classless status of the non-Indigenous woman. Importantly, his statements have informed other health scientists who have accepted into their consciousness notions of Indigenous behaviour patterns as barriers to Indigenous well-being articulated in many health research articles of more recent times (Ewald, Hall et al. 2003).

Representations take on a life of their own and often re-used although they may be fanciful and ill-informed opinions by other writers and researchers (Smith 1999:79). Moodie's ill-informed opinion regarding Aboriginal belief systems blocking Aboriginal people accessing health services has become another strongly held belief system held by the health profession. Alford, a more recent researcher, illustrates the maintenance of these representations:

> Rural doctor shortages are compounded by a long-term and persistent reluctance by Indigenous Australians to access mainstream services. This is reflected in their low utilisation of general practitioner services compared with non-Indigenous people in all geographical regions, even when mainstream services are available (Alford 2005:79).

Whilst Alford's statement, reported in 2005, demonstrates the influence of the established discourse, the Australian Bureau of Statistics and Australian Institute of Health and Welfare (ABSAIHW, 2008) refutes it.

> While data on general practitioner encounters reveal that the rates at which Indigenous people visit general practitioners are similar to those of non-Indigenous people for many conditions, Indigenous people are somewhat underestimated in this data set and thus the true GP encounter rates for Indigenous people are likely to be much higher than those reported (ABSAIHW 2008:15).

Although the ABSAIHW assert that data related to Indigenous peoples use of health services have been undercounted, claims such as Alford's, are made with the authority of the Office of Aboriginal and Torres Strait Islander Health, as in their following consultant Reports *Aboriginal and Torres Strait Islander Primary Health Care Review: National Strategies for Improving Indigenous Health and Health Care* (Dwyer, Silburn et al. 2004), *Aboriginal and Torres Strait Islander Primary Health Care Review: Investment Analysis of the Aboriginal and Torres Strait Islander Primary Health Care Program in the Northern Territory* (Beaver and Zhao 2004)). The point being made is that assumptions and evidence based upon poor data collection continue to inform policy directions.

The most injurious statement written by experts such as Moodie and Alford is the inference that Aboriginal people are the cause of their health problems. Chapter 1 identified the many causal agents that have led to the current poor health status of Aboriginal Australians. Personal choice is certainly a contributing factor but does not explain the critical disparity of morbidity and mortality observed in this country between Indigenous and non-Indigenous peoples. Promoting Aboriginal people as the sole cause of their health status is a belief system based upon an Australian health science discourse that has problematised Aboriginality. This discourse shifts the blame from lack of action by health professionals and governments onto the Aboriginal people. The pathologising of Aboriginal people as reservoirs of disease has been an old health and government strategy used to reinforce the ideology of Indigenous Australians lack of Western civilised attributes. These respective agencies' methods of dealing with this belief system have simply imposed more problems related to their health status for Aboriginal peoples

(Sherwood and Edwards 2006:185). In every sense these medical discourses are informed by Orientalism. The most recent example of such practice has been the NT Intervention.

## Who is the problem?

This section explores how problematic constructions formulated by experts in Aboriginal health have influenced the practice of health professionals. This practice exacerbates Indigenous poor health status and further contributes to the burden of trauma and injury experienced by Indigenous Australians.

Leonie Cox's paper: *Fear, Trust and Aborigines: The Historical Experience of State Institutions and Current Encounters in the Health System* (Cox 2007) illustrates the problems for Indigenous people living with ill-informed constructions of themselves and their health issues created by experts. Cox undertook an ethnographic study in Cherbourg Queensland (1995–6) on how race relations impacted on health service providers' relationships with Aboriginal peoples and the level of care they received. The importance of this study is its methodology, which the author states 'was grounded in phenomenology focusing on the world of everyday experience and on how people explained their situation to themselves' (Cox 2007:1). It was grounded in Cherbourg's colonial history by exploring the dynamics of race relationships formulated from the past that remain problematic today. One of Cox's research questions asked:

> What dynamics occurred in the borderlands of institutional and community life to perpetuate the persistent, depressing statistical profile of Aboriginal health in terms of low life expectancy, higher morbidity for various chronic disease and a marginal status across a number of social indicators such as education, income, employment, housing and so on (Cox 2007:1).

Cox's findings are refreshing in that they acknowledge both Indigenous communities' experiences as well as that of their respective health professionals. These findings resonate with the experiences I have lived and observed, and as they are contextualised within the backdrop of a problematic colonial history, blame is not placed on the individual. Rather, it critiques a history and system that perpetuates a dynamic that maintains the 'persistent, and depressing statistical profile of Aboriginal health' (Cox 2007:1).

Cox's findings gave voice to the experiences of Indigenous peoples, an experience so often hidden in research on their health problems. These findings tell a story not often told, but one well known by Indigenous peoples. Cox found two factors that influenced the Cherbourg community access to their local hospital:

1. Prior government policy using health agencies to control and subvert Aboriginal populations; and
2. the continuing inequitable race relations (Cox 2007:1).

These inequitable relations were more recently played out in 2006 when a twenty-five-year-old Aboriginal woman died in the car park of the hospital and another Aboriginal woman in her sixties was turned away by her local hospital and had to hitch-hike to access medical care, dying in the process (Cox 2007:2). From an Indigenous perspective these experiences are regularly played out. As Cox comments, 'each instance consolidates the fear, resistance, shame and avoidance historically associated with the health system' (Cox 2007:2).

Cox also explored Aboriginal peoples' experiences and memories from the past stating:

> The town's residents shared their memories of absurd government policies that took them from their country, then from their parents, and into a dormitory system (Cox 2007:3).

What Cox discovered was the dominant and explicit role the health services and the police played in the implementation of these government policies. The agency of health, as an institution, had been a site where 'punishment, degradation, humiliation, intimidation and control were practiced on Aboriginal people' (Cox 2007:4). She goes on:

> The health system cannot improve the health status of Aboriginal people without some attempt being made to heal the historical rifts between the two. Unfortunately these rifts are frequently reinforced by contemporary practice (Cox 2007:6).

This is because, as Cox discerns, the negative treatment is not simply a thing of the past. Cox identifies many stereotypical beliefs held by health professionals that influence their respective actions. For example:

Some hospital personnel allowed their fear and negative judgements to figure prominently in their clinical decision making … The assumptions made by health professionals about Aboriginal people's use of alcohol contributes to high levels of morbidity through misdiagnosis and/or alienation of people from the hospital (Cox 2007:7).

While living in Western NSW I personally observed a situation that resonated with Cox's analysis. A good friend of mine had been admitted to a hospital with severe abdominal pain. He was having an x-ray when I came to visit him so was not in his bed. However a young resident doctor, who was caring for him, approached me, seeing I was waiting for this patient. As I had a health identification tag around my neck I think he assumed I was there to see the patient in a professional capacity. The doctor took it upon himself to tell me the reason the patient was unwell was a result of him being Aboriginal and a drinker. I assured the doctor that the patient was not a drinker and had not drunk for some 20 years. The doctor glared at me and said 'Everyone knows they are all drinkers'. This friend's care of his undiagnosed condition continued to be compromised by the doctor's belief system. Sadly, when my friend died of stomach cancer a couple of years later, his medical specialist confirmed that he may have had a chance if he had been referred earlier (Authors experience, 1999, 2004).

Cox claims Indigenous people's critical narratives of health services are important, as they provide an opportunity to have a sense of control over their respective lived experience of a dominant system which has left many 'profoundly powerless' (Cox 2007:8). It is also important to examine the maintenance of ongoing constructs and assumptions which 'inform the attitudes and actions of many mainstream health staff, who express dominant value systems in their daily work at health services' (Cox 2007:8). These assumptions, Cox argues, relate to the plethora of health data and their respective problematic constructions that health staff read, 'activating stereotypical ideas about Aboriginal people' (Cox 2007:8). Cox's argument affirms my own standpoint in that the writings of past experts continue to inform the consciousness and practice of health professionals today.

Perhaps Australian social scientist, W.E.H. Stanner's reflections clarify the problematising nature of research in the area of Aboriginal health.

My interest in Aboriginal health goes back a long time. I could not but think of this the other day when I read in an official paper: Aboriginal health is distressingly poor. Evidence of malnutrition is widespread; infant and maternal mortality is many times greater than the Australian standard; respiratory diseases, gastro-enteritis, ear diseases and deafness, trachoma and other serious eye infections, hookworm and leprosy are markedly more common than among other Australians (Stanner 1972:136).

Stanner remembers the time some 40 years before where he had written a piece that held the same depressing statistics as the summary he had just read. Stanner explores the reason for remembering the paper he wrote in 1937 and it has a great resonance today:

What are the constants that allow a problem stated in 1937 to be given an almost identical statement in 1972 (Stanner 1972:135)?

He goes on:

I have noticed, increasingly of late, a type of comment, sometimes official, which is worth examination. There is an admission that our efforts in the health field are not succeeding as well as we had hoped, but the admission is coupled with a suggestion that the Aborigine himself is the prime cause of failure (Stanner 1972:136).

Stanner takes his audience back to the failed experiments on Aboriginal peoples, to mission living, assimilation and unsustained funding as the causes of poor health and not Aboriginal people. He argues it was policy and lack of action by governments that should be targeted. In particular, the protection policy that practised incarceration and overcrowding became an 'ecological hazardous concentration' (Stanner 1972:136) resulting in epidemics of disease and deaths. By comparing the traditional life-style of Aboriginal people, who lived in smaller and mobile groupings to the government policy of overcrowding hundreds together in small confined spaces, he asks 'Who is the problem?'

Linda Tuhiwai Smith argues that the problem rests within Western policy, which enforced incarceration onto reserves and missions. It is here the discourse of 'the indigenous problem' (Smith 1999:90) was extended, resulting from Indigenous resistance to colonial policy and practice. Indigenous people resisted Western notions of civilisation as this practice directly contributed to Indigenous health disparities. However, problematising of Indigenous Australians

was now established as a fact in policy, and academics accepted this discourse to validate their assumptions, which Moodie's work exemplifies. It has been this approach of problematic constructions that has led to report after report affirming Aboriginal and Torres Strait Islander health status as far worse than that of other Australians (RCIADIC 1990; Bhatia 1995; Bartlett 1998; ABSAIHW 2001; AIHW 2002; NATSIHC 2004; A&TISISJC. 2006; Australia. 2007; NACCHO and Oxfam 2007; ABSAIHW 2008).

## Paradigm shifts

In this section I will explore Indigenous resistance to the discourse of problematic constructions focusing upon the dominant positivist research knowledge and paradigms that inform Aboriginal health research praxis. The legacy of 'experts' from a Western worldview who explored, probed and emphasised inferior status of Indigenous peoples' lives and culture has led Indigenous people worldwide to challenge the Western research community (Smith 1999). As Ermine et al. assert:

> It is inconceivable that dominant research can meet the needs and aspirations of Indigenous Peoples because of the unresolved issues of Western self-perpetuation and its self-enclosed system that recreates and diffuses Western hegemony (Ermine, Sinclair et al. 2004:24).

Indigenous critique has a central aim of asserting an Indigenous agenda and resisting problematic constructions of the past in order to undertake research embodying self-determination. This requires a paradigm shift. This new paradigm values Indigenous voices, perspectives and achieves positive outcomes as negotiated with Indigenous peoples (Ermine, Sinclair et al. 2004). The objective is the 'dismantling of an old order of research practice' (Ermine, Sinclair et al. 2004:9), a practice Denzin and Lincoln suggest remains intact within medicine and health sciences as a colonial strategy to control the 'deviant, or troublesome Other' (Denzin and Lincoln 2005:2). As the health discourse continues to focus on control through official forms of surveillance, health management and then problematic representations when communities fail to be healed by such measures. It is this discourse and sentiment that requires critical reflection if the aim of health research is to improve health outcomes of Indigenous people.

The positivist/traditional research paradigm is a principal method used in health research that compels an Indigenous critique. It has been a method that 'prescribed a static and fixed subject'

(Denzin and Lincoln 2008:33) of colonised Indigenous peoples, dismissing their perspectives and knowledges. Positivistic research is theorised to provide an 'objective, value-free and scientific process for observing and making sense of human realities' (Smith 1999:164) which on the whole remains fixed on non-Indigenous realities. Smith explains the importance of method 'as the way in which knowledge is acquired or discovered and as a way in which we can 'know' what is real' (Smith 1999:164). This is the foundational principal, that lies at the crux of conflict around whose cultural knowledge viewpoint or worldview 'counts' and who can decide what is valid and reliable. Utilising this method, from a Western worldview (methodological and epistemological foundations) to examine and explain the 'human behavior and human condition' of Indigenous people is to be challenged in the light of past research. Decolonisation frameworks challenge these 'hegemonic accounts of indigenous/colonized' (Denzin and Lincoln 2008:33) victims of their own poor health behaviours. This approach requires contextualising the causal agents of Indigenous poor health status as undertaken in Chapter 1. Hegemonic accounts of poor health deficit and blame will continue until these critical contributing determinants are recognised as core consequences of Western colonisation and oppression that remain in situ.

Positivism has been a foundational paradigm in both qualitative and quantitative research that holds an interpretive focus using tools of 'representations' (Denzin and Lincoln 2005:3), to deliver observations on phenomena. Within this traditional paradigm of quantitative research modern epidemiology arose (Pearce 1996). A tool of public health that has shifted its focus of analysis from peoples to the person, that 'blames the victim, and produces interventions that can be harmful' (Pearce 1996:678). This research approach set within a positivist and reductionist model has neglected the 'social, economic, cultural, historical, political and other population factors' (Pearce 1996:678), which I have argued in Chapter 1 are the essential context for framing Indigenous health and its research. In order to make sense of the phenomena being studied, within a naturalistic locale, ignoring what has contributed to the phenomena and how that holds meaning to those being studied, is problematic (Denzin and Lincoln 2005). Epidemiological research is a method used to explore the 'measurement of disease occurrence' (Pearce 1996:679). Methodologically, it lacks 'distinctive theory to permit an understanding of the population patterns of disease' (Pearce 1996:679), the analysis of disease occurrence, can lead to findings that 'blame the victim' (Pearce 1996:679). The consequences of such findings targeting individuals 'will merely move the problem rather than solve it' (Pearce 1996:680).

This shifting of a problem, and individualising the discourse within the new epidemiological paradigm has been acknowledged in the data recording Aboriginal and Torres Strait Islander morbidity and mortality. There have been achievements in reducing infant and child mortality, yet this gain has shifted the loss of life to the 'young and middle-aged adults' (Bartlett 1998; Thomson, Murray et al. 2003:55), with life expectancy 20 years less than for other Australians, a trend that impacts upon the economic, political and social emotional well-being of the family and community (Thomson, Murray et al. 2003). Ben Bartlett argues that the 'public health paradigm' tends to implement health action through 'what "experts" consider good for people' (Bartlett 1998:10). This medical dominance relates to 'the histories of colonisation that involved the colonisers' dominance over the colonised' (Bartlett 1998:14). Bartlett argues that this ongoing colonial dominance is 'part of the cause of persisting poor health in Aboriginal communities' (Bartlett 1998:14). The last two chapters have explored the discourse of experts in health research on Indigenous Australians whose opinions are often ill-informed, or are informed by other ill-informed experts rather than Aboriginal people. Deriving health solutions for Aboriginal people based upon biased assumptions and prejudicial belief systems has done a great deal of harm to Aboriginal Australians. The ethical implications of doing harm in research will be examined in Chapter 8.

Michael Morrissey, a social epidemiologist and advocate of a social determinants approach, found that the application of a 'cross-sectional, positivist poverty research' (Morrissey 2003:28) within Aboriginal health agenda had significant limitations and argues for a change in approach to Aboriginal health research. Morrissey's findings suggest that comparative analysis using variables such as income gradients are ineffective in appreciating the gap in health status for Indigenous Australians and the non-Indigenous Australian population. He argues that; 'poverty is only one element in a complex social process which cannot be 'captured' by cross-sectional quantitative techniques' (Morrissey 2003:27) , this suggests that other determinants will also be unable to be explained or explored using this methodology. This point is significant, underlying the need for a shift in research paradigms that will enhance a critical and more comprehensive understanding of the complexities of Aboriginal health. As Pearce puts it:

> To understand the causation of disease in a population, it is essential to understand the historical and social context and to emphasize the importance of diversity and local knowledge rather than only searching for universal relationships (Pearce 1996:682).

The historical, political and social experiences of Indigenous peoples previously explored in Chapter 1 is critical to framing the context of disease causation and ongoing injury. Context provides the critical feature of a counter hegemonic critique in Aboriginal health research, shifting the blame from Aboriginal people onto the causal agents.

## Whose knowledge counts?

Paradigmatic controversies exist over the concepts of validity (Guba and Lincoln 2005:191). Qualitative paradigm moments have shifted mainly towards a non-positivist approach, supporting a premise that 'Inquiry methodology can no longer be treated as a set of universally applicable rules or abstractions' (Guba and Lincoln 2005:191). This shift led to the moments of 'the modernist or golden age' and 'blurred genres' (Denzin and Lincoln 2005:3). Simultaneously, a number of innovative analytic methodologies arose, including 'hermeneutics, structuralism, semiotics, phenomenology, cultural studies, and feminism' (Denzin and Lincoln 2005:3). Critical theory surfaced, supporting a new approach towards 'researching and analysing the construction of individuals' (Kincheloe 2000:304). The critical researcher is one who uses their work to critique the social, cultural and political environment. This approach is mediated by a standpoint claiming:

> [m]ainstream research practices are generally, although most often unwittingly, implicated in the reproduction of systems of class, race, and gender oppression (Kincheloe 2000:304).

This standpoint has informed my research endeavour of redressing social injustices rather than concentrating upon the amassing of knowledge (Kincheloe 2000). The tradition requires 'self-conscious criticism' (Kincheloe 2000:305) or critical reflective practice in that the researcher analyses their own subjectivity and 'normative reference claims' (Kincheloe 2000:305). This action is critical for reflective learning practice and has been crucial to my own research journey. Critical theory fits well within my own attempts of ameliorative liberation, as a discourse for disrupting the dominant ways of knowledge acquisition and production (Kincheloe 2000:310). It has been informed by a number of disciplines such as poststructuralism, feminism, cultural

studies, postcolonialism and Indigenous research methodologies as emancipatory critiques (Kincheloe 2000; Smith 2005). The borrowing or utilisation of such theories among diverse branches of learning is defined partly by the term *bricoleur* (Denzin and Lincoln 2005:3) in qualitative research. Decolonising Indigenous methodologies critically do 'not constitute a single agreed-upon set of guidelines of methods' (Denzin and Lincoln 2008:33) and as such their use of other methods depends on what the focus of the research is. This point is critical, as emerging Indigenous research approaches can ill afford to comply with the essentialist and legislative approaches of Western disciplines, as they failed to be open to other ways of knowing. Indigenous research methodologies are emerging in the wake of the constraints created by the authoritative powers of knowledge production. This resistance to one disciplinary paradigm has informed my approach to developing an Indigenous research methodology that celebrates many voices and views.

The 'blurred genres' moment (1970–86), a period when 'local knowledges and lived realties became important' (Smith 2005:90), was the moment that Indigenist research came into its own. This occurred in unison with the escalation of 'indigenous political activism' in Australia, New Zealand, America and Europe (Smith 2005:90). The decolonisation agenda was established within this era to disrupt and destabilise the oppressive Western Academic dominance, as a peaceful movement (Smith 2005). Although this approach is pacifist, Smith believes it can be viewed as threatening, political and confronting as it 'requires a major change of worldview, that forces a society to confront its past and address it at a structural and institutional level that challenges the systems of power, is indeed political' (Smith 2005:91). I am able to affirm Smith's statement having witnessed over many years the reactions of Western researchers, whose hackles immediately rise on the neck when questioned about the efficacy of their research approaches and methods focusing upon Aboriginal health research.

The 'postmodern, a period of experimental and new ethnographies (1990–1995)' and 'post experimental inquiry (1995–2000)' and the 'methodologically contested present (2000–2008)' (Denzin and Lincoln 2008:4) are the moments when Indigenous scholarship stood its ground. This coincided with the decade of the World's Indigenous Peoples (1993–2003) celebrating survival and resilience and challenging the legitimacy of Western research methods and

epistemologies (Denzin and Lincoln 2008:3) that remained colonising agendas. It is this era that inspired my own questioning of the hegemony of Western research and practice.

Lester Irabinna Rigney, an Australian Indigenous scholar, argued that 'Indigenous people now want research and its design to contribute to self-determination and liberation struggles as defined and controlled by their communities' (Rigney 1997:1). This statement is valid and reliable, as I have observed it is shared by Aboriginal and Torres Strait Islander researchers I have met throughout this country. The way we do this is to 'analyse and critique epistemologies that are common place in higher education' (Rigney 1997:1). This requires Indigenous academics to translate and transform Western ways of knowing and doing into relevant and meaningful methods for Aboriginal research. It also necessitates a critical reflective review of research of the past and present, pinpointing its hegemonic process that injures Aboriginal communities yet generally remains invisible to the Western eye.

Rigney has also questioned the legitimacy and honesty of the Western academy in its practice of appropriating Aboriginal knowledge, accepting copyright of that knowledge and then building careers from this looting (Rigney 2006). These thefts have also been articulated by Indigenous Lawyer Terri Janke in her Report on *Indigenous Cultural and Intellectual Property Rights* (Janke 1998). It is these unethical practices of stealing, misrepresenting, and problematising by Western researchers that has assisted in giving research a bad name for Aboriginal people and ensured it is a 'site of contestation not simply at the level of epistemology or methodology but also in its broadest sense as an organised scholarly activity that is deeply connected to power' (Smith 2005:87). It is this conceptualisation of power and the control over Aboriginal people that Indigenous scholars are challenging by engaging in research, critiquing inappropriate methods and methodology and supporting their communities in negotiating safe processes for research that focus on outcomes community have determined.

Rigney recommends a key strategy for influencing and improving Aboriginal research in Australia requires 'a rich field of Indigenous Australians intellectual theorising of research epistemologies on which to draw' (Rigney 1997:109). This has not been the case up until now because, as he reminds us, Indigenous access to universities is only a recent phenomenon, a result of past historical political marginalisation (Rigney 1997; Rigney 2006). Rigney's own

research journey's purpose is to grow that Indigenous Australian intellectual community through the sharing of his 'Indigenist methodology' and by promoting discussion in the movement of 'liberation epistemologies' (Rigney 1997:110). The basis of these epistemologies, Rigney argues, are informed through his 'anti-colonial cultural critique' of the historical and lived experiences of Indigenous peoples within Australia's colonial past and present (Rigney 1997:110). This positioning enables strategic development for the decolonising of existing epistemologies in order to establish more effective ones (Rigney 1997:110). From my perspective this critique provides the critical context of the historical, political and social Aboriginal experience of colonisation, which will enable us to respond to Martin Nakata's question 'how do we speak to what is known about us, written about us and not owned by us' (Nakata 1998:4). We must critique these statements, using a context of balanced histories to inform the political underpinning of such statements to explore why they were written about us and by whom. Nakata's question inspired my critical approach to contextualising the causal agents of Indigenous health status.

I believe Nakata, like Rigney, was rousing us as Indigenous people to develop an 'Indigenist methodology' that holds as its basic assumption the rights of Aboriginal peoples to have control in the manner they are represented (Rigney 1997:110). Indigenist research can offer a process for examining our experiences of colonisation; seeking to inform the dialogue of self-determination and de-colonisation; address the maintenance of colonisation, racism and marginalisation in our own lands. It also strives to redress the injury caused, heal the intergenerational trauma and build our confidence of and within our cultural ways of knowing, being and doing (Rigney 1997:116-117).

Linda Tuhiwai Smith's *Decolonizing Methodologies (1999)* highlighted this moment, inspiring Indigenous scholars worldwide to challenge, critique and disrupt the Eurocentric tradition of problematising Indigenous peoples. Indigenous scholars were only too aware of the shortcomings of such a tradition, and were highly motivated to undertake and develop 'methodologies and approaches to research that privileged indigenous knowledges, voices, and experiences' (Smith 2005:87). Smith's writings have been influential to me in the exploration of other liberating methodologies, that draw strongly upon the necessity of re-visiting and re-

membering our colonial past and present to draw upon methods that will assist us as Indigenous researchers in undertaking research that is relevant, safe and meaningful for our communities.

As Indigenous researchers, we need to be cognisant that we 'are in receipt of privileged information' (Smith 1999:176) and perhaps treat this information even more confidentially as a result of our insider status. Western researchers have not appreciated this responsibility, and through their use of 'covert ideological frameworks' they were able to 'distort, make invisible, exaggerate' and built assumptions on data they manufactured that were never factual (Smith 1999:176). We must not go down this road, our journey must be scrupulous, we must not hide out values or ethics. They need to signposted. We are in a strong position of co-generating important data with our communities to assist our communities in changing their status quo. We, like other researchers, 'have the potential to extend knowledge or to perpetuate ignorance' (Smith 1999:176).

## Conclusion:

This chapter explored how problematic neo-colonial research and expert knowledge constructions of Aboriginal people impact upon their health and well-being. These constructions have been developed through a Western gaze in research of the past and have been maintained by informing approaches to research today. These constructions or representations have a historical and political context that evolved out of Western ways of knowing the 'Other'. As explained in previous chapters, these ways of knowing were built upon a problematic relationship that commenced with Invasion and has been played out since then through oppressive regimes to control and subordinate Aboriginal law and resistance.

Western social and medical science has been used to substantiate this problematic view of Aboriginal peoples. In more recent times research in the area of health science in particular has promoted the idea that current health disparities of Aboriginal Australians result from their inability to accept Western normative behaviours. This scientific paradigm has not provided agency for Aboriginal Australians. Rather, it places the blame for their circumstances on the people. It has been devoid of all contexts that provide the essential causal agents of current Aboriginal health status. It is this way of knowing Aboriginal Australians and the treatment they

113

receive as a result of this knowing that has engendered Indigenous researchers to develop methods and approaches to shift the current research agenda.

This has involved a decolonising framework and it is one to be shared with all researchers, Indigenous and non-Indigenous, as we have all been colonised. This framework is about re-claiming our knowledges and histories that were hidden in order to contextualise our discourses and balance our ways of doing and being together (Sherwood 2009). The following chapter will explore this process in greater detail.

# Chapter 4

# The learning journey

White man got no dreaming,
Him go 'nother way.
White man, him go different.
Him got road belong himself.
– Muta, a Murinbata, cited in (Stanner 1979:iv)

## Introduction

This chapter explores the processes of crafting this thesis requiring the articulation of its methods and methodologies. Its aim is to explain why I chose to use the tools described in the following pages. These tools have emerged in my attempt to ensure the research I undertook was respectful of my participants and my Aboriginal worldview and culture, safe for those who would be involved in sharing their knowledge with me, and responsible to our Indigenous communities throughout Australia in the sense of authentic and truthful representation and development of meaningful research outcomes. My endeavour was to ensure that this was not research for research's sake. Instead, it has been about providing relevance and value to our communities and my Indigenous researcher peers as an act of reciprocity for the knowledge and friendships that have been shared with me along this collaborative learning journey.

These specific priorities just articulated relate to Indigenous people's concerns about research and to my aim of shifting the current research agenda in Aboriginal health, using a decolonising research approach that is inclusive of Indigenous critical theory. Research has a bad name amongst Indigenous peoples worldwide, resulting from its Eurocentric focus and its continuing close connection with colonisation (Rigney 1997; Ermine, Sinclair et al. 2004; Smith 2005). Research 'rooted in western positivistic beliefs' (Lee 2008:127) has objectified, oppressed, blamed and devalued Indigenous peoples through the bias of its Western worldview origins (Struthers 2001:127). It has appropriated knowledges, exploited and misrepresented its subjects, informed prejudices and racism, as well as created power imbalances with benefit afforded only to the experts (Struthers 2001; Smith 2005; Van der Woerd and Cox 2005; Lee 2008). Indigenous researchers like me are attempting to counter this approach through the development of methods and praxis that celebrate the resilience, make visible the silenced, respect people and

115

their cultural protocols and ensure benefit is an outcome of the change we are all collaboratively working towards (Smith 2005). This counter-approach requires that the Indigenous researcher be cognisant of Western ways of knowing, being and doing as well as decolonising themselves.

The research I have undertaken for this thesis has focused upon Indigenous health research, examining Indigenous and non-Indigenous perspectives of improving health outcomes from such research. Through discussions with Elders and Aboriginal community members from New South Wales, South Australia, Western Australia, Tasmania, Northern Territory and Queensland, I came to appreciate that the term 'research' was directly related to past and present experiences of colonisation. Contrary to the altruistic claims of the academy, funding bodies and researchers that research aims to achieve positive outcomes for those being researched through the building of knowledge about them, it does not reflect the injury research of the past has caused. It is this history of research in Australia and its current approaches used in health research in dealing with Indigenous communities that concern Indigenous Australians.

I have reviewed this history through literature reviews and have exemplified how this research practice was a central colonial activity focused upon producing knowledge about Indigenous Australians commencing in the early 19th century and maintained throughout the 20th century. This research, undertaken using a Western systematic approach of building knowledge about their colonised 'Other', used methods informed through ethnocentric logic to support their colonial hypothesis. The definitive answers developed were, as argued in Chapter 1, that Aboriginal people were a problem to be solved. Research rendered Indigenous Australians voiceless and cast them as primitive, necessitating controlling political and medical regimens to protect non-Indigenous settlers from these unruly and deviant peoples. Research was a central tool of the colonial authority which, in turn, empowered fields of science to authorise colonial views of Indigenous Australians.

Research continues to be supported through the academies and fields of science that were historically implicated in authorising colonial constructions of Indigenous Australians. These institutions remain focused upon building Western knowledge and Western experts **on** Indigenous Australians. Research and its quest of knowledge production is viewed to have paramount importance over the needs and concerns of Indigenous Australians, as exemplified by

Studdert et al. 'the goal must be a reasonable balance between the accommodation of local [Aboriginal communities] concerns and a level of efficiency that does not stymie valuable research' (Studdert, Vu et al. 2010:278). The context of this comment relates to Indigenous health research ethics and the many constraints health researchers argue Human Research Ethics Committees (HRECs) place on researchers, constraining the all-important knowledge production over the rights and concerns of a marginalised and problematised Indigenous population. It is from this vantage point that it becomes clear how the colonial authority is maintained within the Aboriginal health research agenda. The ideological reasons for undertaking research may have changed, but what has not changed is the paramount importance of the Western scientific gaze over the needs and concerns of their objects of study. It is this way of thinking and acting about research that continues to concern Indigenous Australians.

I chose to examine how this past practice continues to inform Indigenous health research of the present through: exploring my own past research encounters; interviewing participants I have researched alongside; and interviewing participants who have worked in separate Indigenous health research projects or were concerned about Indigenous health research and its lack of positive outcomes for Indigenous communities. The interviews commenced in 2005 and were completed by 2008; however the discussions with Elders commenced in 2000 and continue today. The projects discussed and reflected upon ranged in time from 1990 through to 2004. It has been through this personal reflexive practice that I clearly observed and experienced the maintenance of colonisation and hegemony within the Aboriginal health research agenda. This approach to Aboriginal health research I believe has failed to improve health outcomes as supported through the litany of health data over the last thirty years, because it continues to position Aboriginal people as voiceless, describe us as the problem, and ignore our concerns about appropriate safe praxis and respectful and valid representation. These approaches do not deliver Aboriginal peoples truths and hence tell the same old story, that we are a problem to be solved by people who do not listen to us.

As such, it has been important that I chose approaches that aimed to shift the current approach to Aboriginal health research so as to:

1. highlight the importance of respecting Indigenous ways of knowing, being and doing

2. develop and promote a research methodology that has at its core respect for Indigenous peoples and their ways of knowing, being and doing

3. recognise Indigenous strengths, resilience and wisdom, rather than problematise them.

The thesis has become a methodological journey highlighting different approaches to formulating Indigenous truths. Out of this process has emerged an Indigenous research methodology relevant to health research. The methodology is the result of the coming together of Indigenous and Western ways of exploration balancing and privileging neither intellect over emotion or experience nor the objective over the relational. The authoring of this thesis work positions me as both researcher and participant through a journey of learning.

## Methodological framework

The methods explored throughout this chapter do not flow in a linear manner. Rather, they flow like parallel streams that sometimes entwine and then separate (not unlike a double helix), informing ways of knowing, being and doing from a multitude of different worldviews. They then come together again, reflecting common themes, feelings and experiences but again part because the stories, although similar, do not tell the entire story. I have attempted to tell a story that holds truths for the Elders and participants who gave me their stories to respect and nurture in a safe way.

## Decolonising methodologies

This section, which is crafting my methodology, is somewhat discursive. I use a range of critiques and theorising to build an approach, a framework that accommodates my personal decolonising journey, my role as insider and outsider researcher, and the foundational place of both Indigenous ways of knowing and of critical theory to challenge the hegemonic Western health research methodology. I draw on Indigenous and non-Indigenous theorists, from Sartre to Habermas to Smith and, in a Indigenous approach to knowledge development, return to and build on positions and arguments already explored in the previous three chapters, to accomplish this.

Reading *Decolonizing Methodologies* by Maori academic Linda Tuhiwai Smith greatly inspired me and became a significant turning point in life and work as an Indigenous researcher. Her words were those I held in my heart and she unleashed my passion to re-claim my stories, history

and identity. I was encouraged at my first Indigenous Research Conference, held in Adelaide 2000, by Martin Nakata and Errol West to write down my feelings about Indigenous research. This declaration was important after meeting up with Linda Tuhiwai Smith and Lester-Irabinna Rigney, at the conference. In every sense it was the beginning of:

**My Research Journey**

I cringe at the texts that disregard and misrepresent my identity

I'm embittered by the data that confounds my notion of social justice

I weep at the reckless abuse of ignorance and power

I reject the consciousness of superiority and prejudice

I reflect on the despair of my brothers and sisters

I rejoice in the empowerment of my people's voices

I dance on the mother as she responds to our growth

I claim my inheritance of resisting oppression

I write my story to counter misbeliefs and encourage understanding

And I will my story to nurture a place for safety and respect of our cultures and our peoples
(Sherwood 2001:28).

Smith's text is essential reading for all researchers working in the area of Indigenous peoples (Porsanger 2004), especially Indigenous researchers like me who were overwhelmed by the debilitating power of Western research and its silencing paradigms.

Smith articulated the essential context of the immense and mostly negative impact Western research has had on Indigenous peoples historically, politically, economically, spiritually, collectively and personally, tracing the obsessional behaviour of the West to 'problematise the indigenous' (Smith 1999:91). Smith's work and Lester-Irabinna Rigney's (Rigney 1997; Rigney 1999; Rigney 2001) writings were indeed liberating, speaking our truths in our language in a genuine and meaningful manner. Both authors critically informed my journey, providing the hope and courage necessary for shifting the health research agenda. Chapters 1 to 3 testify to this critical approach.

Importantly, Smith declared her positioning as 'colonized' (Smith 1999:1) and it is within this space that she writes of the 'the term "research"' (Smith 1999:1), acknowledging its link to 'European imperialism and colonialism' (Smith 1999:1). This positioning provides the

framework for exploring 'research as a significant site of struggle between the interests and ways of knowing of the West and the interests and ways of resisting of the Other' (Smith 1999:2). It is this position of being colonised that I acknowledge and chose to take the journey of decolonising myself and my research praxis.

Research is a term held in most Indigenous peoples' minds with suspicion and scorn (Rigney 1999; Atkinson 2002; Martin 2007). This argument is highlighted both through my participants' experiences and my own in later chapters of this thesis. Knowing and appreciating the scepticism with which research is viewed by their communities and their own researchers (Smith 1999), Indigenous people may be deterred from undertaking research. However, as Smith argues, research is also the site from which 'something more' (Smith 1999:3) can be done through the use of a 'decolonization framework' (Smith 1999:3). This framework is imperative to both the challenging of knowledge collation related to Indigenous peoples that has 'reproduced particular social relations of power' (Smith 2005:88) and to endeavouring to refocus the 'institution of research' (Smith 2005:88). Smith calls for a review and rethinking of 'the deep underlying structures and taken-for-granted ways of organizing, conducting, and disseminating research and knowledge' (Smith 2005:88). This shift is esential within the broader research institution in its attempt to yield relevant and improved outcomes for Indigenous peoples through research as well as accommodating Indigenous researchers safely within the academy. This safe inclusion has the possibility of transforming the research agenda, because:

> [w]hen indigenous people become the researchers and not merely the researched, the activity of research is transformed. Questions are framed differently, priorities are ranked differently, problems are defined differently, people participate on different terms (Smith 1999:193).

I have directly experienced how the research approach shifts when Indigenous people become the researchers, territory which is explored specifically in Chapter 7. The research process and praxis were transformed through important insider knowledge. Aboriginal researchers with like-minded non-Indigenous researchers are able to shift the paradigm of research from one that silences and problematises to a praxis that is safe and respectful and encourages informants to share their wisdom, since they know they will be heard. From such praxis the process becomes a two-way sharing and learning encounter that contributes to the building of valid and meaningful data.

The decolonisation framework is inclusive of 'deconstruction', the 'taking apart of the story, revealing underlying texts, and giving voice to things that are often known' (Smith 1999:3) by Indigenous peoples as a means to redress the constructs used by academics and governments. Countering problematic constructs involves a deeper appreciation of how and why we were defined in this manner and recognising how this method holds power within the mainstream community. It also requires that we view ourselves in a different light from that of 'passive victims' (Smith 2005:87) of research. Instead we must recognise our worth through the recovery of 'our own stories of the past' (Smith 1999:39) and present and become activists 'engaging in a counterhegemonic struggle over research' (Smith 2005:87). This struggle is entwined with our recovery of well-being through our self-determining of 'what is really important about the past with what is important about the present' (Smith 1999:39). Utilising these knowledges and praxis as methodologies in research about ourselves can present a counterhegemonic argument against the populist dominant paradigms of problematic constructs and more importantly articulate the changes necessary for 'self-determination and liberation' (Rigney 1997:109). These ideals are promoted and worked towards through critical theory research.

Smith and many Indigenous academics argue that social justice, self-determination and decolonisation are spaces that we can take up as methods to change the maintenance of political and discursive colonisation (Smith 1999; Lui-Chivizhe and Sherwood 2000; NAHO. 2003; Smylie 2003; Porsanger 2004; Sinclair 2004). The Indigenous experience of living through colonialism and imperialism provides another dimension to the praxis of anti-postcolonial times (Smith 1999; Smith 2005). This experience is unique to critical theory and herein lays the claim for Indigenous critical theory.

Smith maintains that decolonising traditional research method and theory is not an act of rejecting Western knowledge. Instead, it is about examining and critiquing its authority to reflect an Indigenous worldview (Smith 1999). Academia established the essential tools for reducing and implicating the 'Other' or 'Aboriginal', and this has been implicit to the colonial process and its discourse enabled the actual expropriation of Australia (Turnbull 1997; Wolfe 1999; Langton 2002). Colonisation needed the academy and the academy became the site to inscribe the rule of colonial discourse related to Aboriginal people's representation and reproduction (Wolfe 1999). The discourse disciplined and restricted the content and context of the 'Other' (Said 1995).

The discourse of Orientalism involves the contesting of academic constructions that determined what could and would be said about the Orient, after colonialism (Said 1995:3). This is relevant to the concerns Indigenous scholars raise about the old order of research and writing that does not allow the Other to distinguish their own literary identity (Ermine, Sinclair et al. 2004). Importantly, Orientalism provides some of the key tenets of colonisation and its aftermath.

> Orientalism can be discussed and analyzed as the corporate institution for dealing with the Orient – dealing with it by making statements about it, authorizing views of it, describing it, by teaching it, settling it, ruling over it; in short, Orientalism as a Western style for dominating, restructuring, and having authority over the Orient (Said 1995:3).

Orientalism informs part of the Australian Indigenous people's story of colonisation, however it does not capture the lived outcomes of such literary endeavours or the means by which these are reinscribed further than the academy. Sartre's perspectives on colonisation capture a more rights-based conceptualisation, and assist in appreciating the lived experience.

> Colonialism denies human rights to human beings whom it has subdued by violence, and keeps them by force in a state of misery and ignorance that Marx would rightly call a subhuman condition (Sartre 1957; Memmi 1965:xxiv).

Sartre's focus on the relationship between the absence of rights and the presence of violence in the context of colonisation and its broader consequences describes and analyses, in a very real sense, the Indigenous Australian experience. The current context of rural and remote Aboriginal people's circumstances resulting from the lack of basic service infrastructures and rights such as schools, police, employment, housing, economically nutritious food, sewerage, clean drinking water and primary health care service provision, exemplifies this condition.

Said also argued that scientific research and academic writings about the 'Other' were undertaken specifically to support the colonial doctrine (Said 1995; Bhabha 1999), asserting that knowledge developed within the political activity of colonisation about the 'Other' cannot be accepted as "true" knowledge' (Said 1995:10). Fanon and Memmi argued that the colonists falsified knowledge in order to maintain their authority, superiority and legitimacy (Memmi 1965; Fanon 1999). Sarup takes this position further by questioning the orthodoxy of academic

institutions set up by the coloniser that privileged Western ways of knowing the 'Other' (Sarup 1996).

Both Said and Fanon assert that the dehumanising project of colonisation upon the colonised has been successful in creating psychological injury to the individual and their respective nation's identity (Said 1995). Fanon's analysis demonstrates this injury: 'I am talking of millions of men [sic] who have been skillfully injected with fear, inferiority complexes, trepidation, servility, despair, abasement' (Fanon (Black Skin, White Masks) cited in Caute 1970: 7). His text, *Black Skin, White Masks,* explored and captured the consequences of racism and colonisation upon the colonised (Caute 1970). It is Homi Bhabha who re-members and reflects on Fanon's brilliance to articulate 'the complexity of psychic projections in the pathological colonial relation' (Bhabha 1989:142). This position has great relevance to Indigenous social and emotional well-being, which has been injured as a result of the ongoing campaign of colonialism through marginalisation, oppression and racism in Australia.

This line of argument is contested by the West; however Indigenous researchers recognise that it is the lived experience of Indigenous peoples worldwide.

> Reclaiming a voice in this context has also been about reclaiming, reconnecting and reordering those ways of knowing which were submerged, hidden or driven underground (Smith 1999:69)

Reclaiming Indigenous ways of knowing and asserting their legitimacy is the challenge (Bishop 1998; Battiste and Henderson 2000; Ermine, Sinclair et al. 2004). The United Nations Sub-Commission on the Elimination of Discrimination and Protection of Minorities have declared and affirmed the *Principles and Guidelines for the Protection of the Heritage of Indigenous People* (Daes 1995), developed by Indigenous scholars and human rights experts (cited in Battiste 2002:2). Battiste states that 'They acknowledge that the heritage of an Indigenous people is a complete knowledge system with its own concepts of epistemology, and its own scientific and logical validity' (Battiste 2002:2).

Indigenous knowledges and Knowledge Systems are terms used to relate to a complex set of knowledge and technologies existing and developed within Indigenous communities in a particular geographical area (Foundation. 2002; Hunter 2004; Smallacombe, Davis et al. 2007).

Indigenous Knowledge Systems (IKS) encompass the terms of traditional knowledge, Indigenous knowledge, local knowledge, cultural heritage, Traditional Environmental Knowledge and what Western academics have named myths or folklore (Berndt and Berndt 1996; Berkes 1998; (ICIPT). 1999; Bird Rose 2000; Hume 2002; Scott 2002).

> Indigenous scholars discovered that Indigenous knowledge is far more than the binary opposite of western knowledge. As a concept, Indigenous knowledge benchmarks the limitations of Eurocentric theory – its methodology, evidence, and conclusions – reconceptualizes the resilience and self-reliance of Indigenous peoples, and underscores the importance of their own philosophies, heritages, and educational processes. Indigenous knowledge fills the ethical and knowledge gaps in Eurocentric education, research and scholarship (Battiste 2002:5)

Reclaiming Indigenous knowledge systems is paramount to our healing and well-being and offers the essence of who we are as peoples. These ways of knowing have tenure that out outspans Western theory by thousands of years yet they have been subjugated through these dominant Western knowledge systems. I have been guided through Indigenous philosophy to appreciate that our ways of knowing can co-exist with western systems of knowledge and have worked towards balancing both ways of knowing. Balance and survival are at the core of Indigenous philosophy and balance requires the respectful accommodation of difference. Importantly, dominance destroys balance which, in turn, impacts on survival. Being inclusive of Indigenous philosophy in Aboriginal health research is critical to improving health outcomes as well as an essential practice of decolonising methodologies. This is also because:

> It is unconceivable that dominant research can meet the needs and aspiration of Indigenous peoples because of the unresolved issues of Western self-perpetuation and self-enclosed system that recreates and diffuses Western hegemony ( Deloria, 1980 cited in Ermine, Sinclair et al. 2004:24)

This is why Said's discourse on the Western representation of the 'Other' is important to this thesis. It supports an Indigenous critical theory for re-reading health research articles, histories and policies (Said 1995) and a decolonising framework. Said's exploration of the Western worldview's epistemology and ontology that focused on having to know and name what is different mirrors health research accounts that will be explored in Chapter 6. The Orientalist, in this case the Western positivist researcher, must explore, research and write about the Orient,

that is Indigenous Australians, in order to become the expert and to control and rule over it (Said 1995:197). This activity sets up an iniquitous and unharmonious relationship between Aboriginal people and the academy, fuelled by power and arrogance (Sarup 1996), a power relationship informed by Foucault's 'notion of discourse' (Said 1995:3). This relationship provided the colonisers with their own sense of importance, superiority and identity (Said 1995). It also provided a myriad of employment opportunities in literature, research, public service, policing and the military for the Orientalist. These professions institutionalised their dominance and hegemony through research about the Other informing law making, history writing and development of knowledge about the 'Other' (Said 1995).

I have come to appreciate that the hegemony and discourse of Western research in Aboriginal health has a broader discourse than Orientalism. It is a discourse that health science has and continues to uphold that Aboriginal people are the problem in relation to their health status. This discourse is important in that it shifts the blame from governments and the health profession on to the Aboriginal people. This is a discourse that must decontextualise its research, otherwise it may incur the blame for Indigenous health status. This is why many Indigenous scholars claim that colonialism continues through research methods that silence Indigenous peoples' voices and ignores their issues of concern further corroborates this claim (Ermine, Sinclair et al. 2004; Sherwood and Edwards 2006).

Decolonising methodologies offer hope of shifting the research paradigm and our positions of being framed within a Western worldview as problematic (Smith 1999). Through the utilisation of Indigenous research methodologies privileging Indigenous ways of knowing, being and doing we become the brokers of our solutions, self-determining our ways forward and de-colonising our representations and hence our minds. The framework explored is complex and requires that research, researchers and its institutions must acknowledge that their approaches towards Indigenous peoples have been 'historically and institutionally contrived' (Sherwood 2009:24). This Western reasoning is no longer valid or beneficial for anyone (Kincheloe and Tobin 2009). Decolonisation within Australia 'requires a contextualized discourse for re-claiming knowledges informed through a balance of truths and histories. Reflecting upon the cause and effect of past action and its policies' (Sherwood 2009:24) is required, instead of continuing to construct

Indigenous Australians as problematic. I have taken this approach to provide an Indigenous perspective on why research has not improved Aboriginal health.

## Indigenous research methodologies

Wendy Brady (1999) heralded Aboriginal research reform in the wake of the rise of Indigenous academics and researchers within the academy. Brady maintained that Indigenous researchers would not be happy to be merely tokens within the research agenda. Their role was to advocate for and promote the interests of their communities (Brady 1999). Lester Rigney led the charge for an anti-colonial critique, asserting that 'Indigenous people now want research and its design to contribute to the self-determination and liberation struggle as defined and controlled by their communities (Rigney 1997:109). Rigney declared that Western research methods continued to colonise Indigenous peoples, through their 'cultural assumptions' and 'dominant epistemologies' (Rigney 1997:114), which led to research being a tool only of the West. Rigney's call for libratory epistemologies informed by feminist research laid out the critical foundations for Indigenist research methodology.

Feminism provided an important gendered critique of positivistic research in the area of women's studies. Feminist critiques highlighted that knowledge construction was 'not value neutral and is filled with competing interests' (Rigney 1997:116). Hence scientists' claims of objective research producing valid data are questioned in regard to producing truths. Truths in the field of research with women required women's experiences to be at centre of research. This strategy was established to resist the patriarchal oppression women had suffered through history (Rigney 1997:116). Similarly, Indigenous people have experienced colonial oppression meted out by Western colonial patriarchy. Rigney respectfully acknowledges this feminist framework as the foundation of his Indigenist model; a model informed by his lived experience, epistemology and community.

The Indigenist model is a research method 'which gives voices to Indigenous people' (Rigney 1997:119). The privileging of Indigenous voices in research immediately shifts the paradigm from object to participant/expert. This model acknowledges Indigenous knowledges along with the right to be heard. This is liberation in action.

Linda Tuhiwai Smith's work has informed most Indigenous academic/researchers as it speaks of the struggle that many of us have witnessed and been part of as the 'colonised' and as a 'problem'. Her text states that research can make a difference to Indigenous peoples as it can be a site for decolonisation that shifts our positioning in our worlds through our own constructs of ourselves (Smith 1999). Both Rigney and Smith's work embody Indigenous research methodologies. Their work has influenced my research journey and has informed my own decolonisation project. I believe research is a process that can achieve the outcomes Indigenous people voice and view is important for them. Research can become a word that is valued by Indigenous communities, providing opportunities for employment, the sharing and co-generation of knowledge, contextualised representation, and transfer of shared knowledge back to communities to be used for their own advocacy projects.

An Indigenous Research Method (IRM) is a model for undertaking research **with** and not **on** Indigenous communities, in order to provide outcomes and benefits as negotiated by and with respective communities. This methodological approach is different from an empirical positivistic model in that it recognises and acknowledges the importance of Indigenous people's knowledges, worldviews, ethics and protocols as well as their historical, political, and socio-economic contexts (Rigney 1999; Smith 1999; West 2000; Smye and Browne 2002; Fredericks 2003; Smylie 2003; Castellano 2004; Ermine, Sinclair et al. 2004; Porsanger 2004; Sinclair 2004; Martin 2007). IRMs have emerged only latterly in the 'qualitative research era' spanning over 100 years originating from traditional 'positivist' foundations (Denzin and Lincoln 2005). This era encompasses overlapping traditions described as:

> ... the traditional (1900–1950); the modernist, or golden age (1950–1970); blurred genres (1986–1990) the postmodern, a period of experimental and new ethnographies (1990–1995); postexperiential inquiry (1995–2000); the methodologically contested present (2000–2004); and the fractured future, which is now ( 2005–) (Denzin and Lincoln 2005:3).

IRMs appear to have come into view in the final two historical moments. It has been my experience, however, that the postmodern and postexperiential inquiry moments have informed their underlying philosophy. IRMs' emergence has been essential to Indigenous people's survival, as well as ensuring research undertaken provides valid and reliable data explicit of

Indigenous people's perspectives providing the critical outcomes to remediate the consequences of colonisation.

The emerging methods have been developed by Indigenous scholars to resist positivistic research practice of the past and present. IRM distinguishes itself from this approach focusing upon the importance of subjectivity, worldview perspectives versus the notions of universal one truth and objectivity. A universal one truth approach invalidates other ways of knowing and multiple truths which IRM respects. Objectivity, a notion used in positivistic research suffers from undisclosed assumptions, values and motives that are not acknowledged by researchers but permeate their respective findings. This is because research is not a neutral project and can no longer promote this objective perspective as 'Class, race, gender, and ethnicity shape inquiry, making research a multicultural process' (Denzin and Lincoln 2005:20), which Chapter 3 in particular highlights.

IRMs have emerged in response to the consequences of past research and are vital to ensuring that this process is not replicated.

IRMs require researchers to reflect upon their knowledge or lack thereof, motives and purpose for doing research. This process is perhaps the most difficult, as it requires a great deal of work and critical reflection for the researchers, acknowledging the impact of past research, the history of colonisation in Australia and the impact ongoing colonisation has on their ways of thinking, being and doing. Another critical difference is that IRM does not seek to replicate its approach. Rather, it appreciates the importance of variation, variables, histories, environments, countries and law. This feature again shifts the focus of research methods from a one-size-fits-all to recognising the importance of context and essential local-based solutions. IRM is highly cognizant of the power differentials created in research projects especially related to Indigenous communities. It aims to shift this power through a collaborative approach that builds capacity of all involved, not simply the researcher. This is the paradigmatic shift that is necessary for changes in research outcomes for Indigenous people.

## Indigenous critical theory

Indigenous critical theory has become part and parcel of my decolonisation framework, and has become essential to my position as a critical reflective learner. In this section I will explore how I came to refine critical theoretical approaches to meet the specific needs of this thesis for

decolonising Indigenous health research. This theoretical tradition derives from the 'Frankfurt School of Social Theory' (Giddens 1985:121), whose founders were, in the main, Marxists, believing that Marxism was a flexible and variable 'critical approach to the study of society' (Giddens 1985:121). Max Horkheimer, a member of the Frankfurt School and founder of critical theory, defined it as 'a form of theorization motivated by a deep concern to overcome social injustice and the establishment of more just social conditions' (Kemmis 2006:125). Jurgen Habermas, a devotee, recognised that capitalism had shifted, and Marxism's approach required modernising to ensure its relevance to societal critique (Giddens 1985:122). Habermas's key contribution to this reconstruction of Marxism as a science was to introduce the importance of ' "self-reflection', or 'reflexivity' " of human agents' (Giddens 1985:125), a perspective ignored within positivism.

Habermas's work 'Hermeneutics a theory of Interpretation' explored the use of languages in science (Kim 2005). In particular, he argued that the Positivists claimed that the language of 'analytical-empirical sciences' (Kim 2005:74) was self-explanatory and did not require contextualisation. He was concerned that the institution affirmed scientific truths rather than the processing of data, believing the scientific community was 'manipulating the external world' (Kim 2005:75) by their own closed language system. Habermas argued that to develop truths required a 'feedback-regulated observation' (Kim 2005:75) or reflexivity. Reflective critique, Habermas argued, commands a 'social process' not a solo event, that can result in 'intersubjective agreement, mutual understanding and unforced consensus' (Kemmis 2006:127). Collaborative Community Participatory Action Research (CCPAR) provides such a setting for reflective activity that is not focused upon a forced consensus (Denzin and Lincoln 2005), and is an approach used in this thesis.

Charles Lemert was concerned that critical theory must move beyond its Western language games and become a method for doing, along with opening to other ways of knowing, being and doing that are not of the West, to provide the liberation it seeks (Lemert 2005:xi). The concept of critique within critical theory requires the researcher to examine the context of a situation to appreciate how certain standpoints, society and its practice have created 'irrational, unjust, alienating or inhumane' acts upon certain groups (Kemmis 2006:125). This approach has led me to explore the historical, political and social factors that have constructed Indigenous poor health

status. I have called this the Context. It is an Indigenous critique that attempts to fill in the gaps of knowledge of the events from an Indigenous perspective informed by Elders and historians and is explored as such in Chapters 1, 2 and 3. My critique has located aspects of irrational and inhumane practice that I believe require acknowledgement, and has highlighted these acts or mainstream social processes as causal agents of continuing poor health status of Aboriginal peoples.

> Unless Western knowledge orthodoxies are interrogated, the basis of their power will continue to reproduce the colonised as a fixed reality, including the subtext of Indigenous *intellectual nullius.* The struggle for Indigenous intellectual sovereignty is to move our humanness, our scholarship, our identities and out knowledge systems from invisible to visible (Rigney 1999).

I have followed Rigney's direction by critiquing the underlying aspects of Western epistemology and ontology in order to defend an Indigenous research framework. Chapters 1 to 3 have initiated this critique and Chapters 5 to 9 explore explicitly the research stories that exemplify the research approach in Aboriginal health that necessitates such critique. Western axiology has also been critiqued as it relates to Indigenous rights and philosophy in Chapter 8.

## Auto-ethnography/story-telling:

Auto-ethnography is a method that enables me to write and research so that I put on show the many layers of consciousness that relate to my person and my culture (Ellis and Bochner 2000). This method supports my role within the Collaborative Community Participatory Action Research method as I have been able to describe the 'experiences and interaction with other participants as vital parts of what is being studied' (Ellis and Bochner 2000:741). I have also been able to incorporate my personal experiences into the research and have done so to firstly provide illuminating stories, and secondly to not undertake research for research's sake alone (Ellis and Bochner 2000). According to Ellis and Bochner (Ellis and Bochner 2000), I hold a dual positionality as an Indigenous researcher, an insider/outsider, and as I am concerned about the representations and interpretations of past research I have focused upon myself as a research subject.

My 'evocative narratives' (Ellis and Bochner 2000:744) have breached 'the conventional separation of researcher and subjects' (Ellis and Bochner 2000:744). This action was driven by

Indigenous ethics of knowingly doing no harm to people, country and all living and non-living things (Weber-Pillwax 2004; Wilson 2008). It is also aligned to reflexive writing that has its emphasis on process, which Greenwood and Levin claim provides the generalisation necessary for validation (Greenwood and Levin 2000). It is assumed that if research methods are not able to be generalised for comparative approaches then validity is questionable. However Greenwood and Levin maintain it is essential to appreciate the conditions in which knowledge was generated which 'contextualizes the knowledge itself' (Greenwood and Levin 2000:98). Cora Weber-Pillwax substantiates this point stating 'any research that is carried out with people is carried out within the context of an existing community' (Weber-Pillwax 2004:80). Failing to appreciate this context places the data collected through the research questionable. The contexts of Indigenous communities' experiences are imperative to any research praxis and the development of meaningful and valid data.

The application of this knowledge in a different setting requires an appreciation of the new setting's own context and conditions (Greenwood and Levin 2000). Applying this new generated knowledge on another setting without appreciating the local context will reduce the generalisational validity and worse, injure those subjected to the method. Reflexive writing ensures that context-bound generated knowledge is described and situated within its local Indigenous knowledge. This is an ethical praxis that follows the cultural principles of working with non-homogenous Indigenous communities (Weber-Pillwax 2004).

Story-telling, in every sense, is auto-ethnography, as it enables the researcher 'to write in a highly personalized style, drawing on his or her experience to extend understanding about a social phenomenon' (Wall 2006:1). It is also an Indigenous methodology and is utilised by Indigenous scholars in research (Weber-Pillwax 2004). Story-telling is a 'potent research tool' (Lekoko 2007:83) for Indigenous people in that it is a methodology not considered Western; rather it is used in everyday Indigenous interactions and has been used from our beginnings. This approach is important when undertaking collaborative community-based research as everyone has a story to share, and is a methodology that respects Indigenous ways of knowing, being and doing (Lekoko 2007). Most importantly, it is an approach that recognises 'ordinary people as the hub of knowledge' (Lekoko 2007), instead of approaches that can demean their informants. Collaborative story-telling enables multiple voices to be heard emphasising their 'complexities

131

rather than commonalities' (Bishop 1999:6). This notion of reflecting complexities is oppositional to the praxis of traditional research where the aim is to synthesise and simplify aspects of truth (Bishop 1999:6). Yet in Indigenous research it is an approach people are comfortable with, enabling participants to 'recollect, reflect and make sense of their experience within their own cultural context' (Bishop 1999:6). Their value is that many truths are shared instead of one overriding version.

Stories are not just for entertaining, they hold power in knowledge transmission (Dion 2004), inclusive of Indigenous cultural protocols of respect, reciprocity, active listening and responsibility promoting powerful social agency. They are told to '[e]ducate the listener, to communicate aspects of culture, to socialize people into a cultural tradition' (cited in Royal Commission on Aboriginal Peoples, Canada 1996 vol.1: 3 Dion 2004: 61) and such story-telling also supports sharing. Indigenous cultures recognise story-telling's methodological and ethical perspectives, in that listeners have a responsibility to listen and hear the story being told and appreciate 'what is expected of them in the storyteller/listener relationship' (Dion 2004:62). The story-teller also holds responsibility in telling the story, to ensure that the story is relevant and appropriate to the listener (Bishop 1999; Dion 2004; Archibald 2008). I have used story-telling based on this premise in the thesis and in my teaching.

Elders provide opportunities for learning this skill within our culture and in other Indigenous Nations throughout the world, and are observed as the authorities for transmitting such knowledge that is both spiritual and sacred (Archibald 2008). They also pass down the protocols in regard to the responsibility inherent in story-telling, that encompass 'appreciating the significance of and reverence for spirituality, honouring teacher and learner responsibilities' (Archibald 2008:x). Once the listener is taught how to listen to stories, there is a reciprocal expectation by Elders that the learner will use this knowledge to share with people (Archibald 2008:3). This maintains the strength of this approach and its cultural importance. This expectation is, in part, the telling of the thesis, that the Elders have instructed me to share. Their knowledge has been shared with me and, as Jo-ann Archibald highlights,

> If one comes to understand and appreciate the power of a particular knowledge, then one must be ready to share and teach it respectfully and responsibly to others in order for this knowledge, and its power to continue. One cannot be said to have wisdom until others acknowledge an

132

individual's respectful and responsible use and teaching of knowledge to others (Archibald 2008:3).

Knowledge sharing maintains law and is considered a reciprocal act.

> Knowledge transmission is based on law and the Dreaming, respect is inscribed in how we teach and how we relate to each other. It has to be connected to the Dreaming otherwise the story is empty. Our way is holistic the way we listen, teach and talk, we have to give that back to our communities to support their well-being (Aunty Beryl).

As a collaborative learner I have taken on this responsibility of sharing what has been entrusted to me in relation to knowledge around research for this thesis and in other research experiences.

## Collaborative Community Participatory Action Research (CCPAR)

CCPAR method is best described as a mixed methodological approach inclusive of critical cultural Indigenous protocols that I consider the right way to do research with our communities. The collaborative community relates to our communities who hold and bring their critical ways of knowing, being and doing to the research that is about them and for them (Brands and Gooda 2006). Importantly, it provides the perfect setting for story-telling as a data collection approach and the sharing of knowledge to be reflected on and acted upon (Bishop 1999). The research aim of illustrating and dealing with the problems of community members must be inclusive of these members as co-participants (Denzin and Lincoln 2005). Community collaboration and contribution is critical to the value/relevance of the research being undertaken and to the validity/rigour of the data being revealed (Brands and Gooda 2006). The praxis and process is focused on 'practical, reflective, pragmatic action – directed to solving problems' (Denzin and Lincoln 2005:34) as identified by the collaborative community. This is in contrast to the positivist approach, in which the researcher narrates the problem and solution commonly without community involvement or context.

CCPAR is both a method and pedagogical praxis used in this thesis. For example, the Elders' Circle made up of female Elders provided a community that was collaborative and participatory, spurring action in the area of research. Their mutual sharing of knowledge, their pragmatic

guidance, enhanced my reflective feedback and subsequent actions. Their role is further explored in the living method section.

CCPAR matches an Indigenous pedagogy of ethical praxis for knowledge searching and research because 'the researcher is accountable for the effects of the research project on the lives of the participants' (Weber-Pillwax 2004:80). Without collaborative participation of community members, the Indigenous researcher is unable to ensure benefit. The Indigenous researcher is not the 'boss' of the research, instead they support the development of objectives and directives with community, ensuring the process is safe and promoting opportunities for the building of capacity, and employment if possible.

CCPAR's method has existed for a millennia connected to the knowledge brokerage praxis held by Elders. Simply stated, it is how we do business in our communities as confirmed by my Elders' Circle. The praxis involves collaborative discussion, participatory planning and decision making and is 'actually determined by the parameters set by ethics and principles' (Weber-Pillwax 2004:88) of the Aboriginal community that you are working with. Indigenous notions of CCPAR incorporate collaborative action, the building of relationships and benefit balanced for all involved (CRCAH 2008). I have followed this premise both in this thesis and in other research encounters.

Action Research (AR) as part of CCPAR is flexible and has many variations: collaborative enquiry, participatory research, co-generative enquiry, emancipatory or liberating research and contextual action research (Masters 1995; O'Brien 1998; Greenwood and Levin 2000; Kemmis and McTaggart 2000). O'Brien states it is 'learning by doing' (O'Brien 1998:3) and shifts the traditional position of the researched or subject to one of joint researchers/participants. The focus of the doing is the solving of contextual problems by those who experience those lived realities (Greenwood and Levin 2000). The process of AR is iterative and commences with a problem to be solved that participants have identified; a plan is developed to take action; action is evaluated or reflected upon regarding the need for further planning and action (Kemmis and McTaggart 1990; Stringer 1999). The process has a number of spiraling steps, which produce a cycle of continuous reflective action. Schon (1991) suggests that this 'continuity of inquiry entails a continual interweaving of thinking and doing' (Schon 1991:280) using a range of theoretical

frameworks to inform learning and deepen reflective and collaborative action. The CCPAR method is distinguished from positivism in that its focus is connecting practice with theory, creating praxis; participants provide the context of their situation to research; the actions that are taken are decided upon collectively; the knowledge created comes about through co-generative inquiry; and the reflections of the researcher are incorporated in her/his living worldview (Greenwood and Levin 2000).

I chose this method because of the focus on collaboration and hence the re-positioning of the researcher as a joint learner rather than the expert. It recognises Elders as knowledge holders and teachers and my role as both researcher and participant. It responds to The Health Is Life Report (HRSCFCA 2000) which recommends that research in the area of Aboriginal health: 'must also be developed and conducted in conjunction with the Indigenous community' (HRSCFCA 2000:126). As Sarantakos contends, the research process is based on the political passion of the researcher to take action by means of investigation and involving participants in focusing on social issues that require solving (Sarantakos 2005). CCPAR is about solving problems, aiming to improve praxis through inclusive action of researchers and participants (CRCAH 2006).

CCPAR is a method of 'insider research' (Kemmis and McTaggart 2000), as the participants shift between two ways of thinking: firstly as insiders who are able to clearly explore and have dialogue on their issues with their insider knowledge; and then as outsiders reflecting on the knowledge provided (Kemmis and McTaggart 2000). Importantly, 'The insider(s) will have a role as a long-term member of the setting [community] when not involved in the study, where as the outsider(s) will not' (Bartunek and Louis 1996:3). The insider has to live with the outcomes of research which Patrick Sullivan argues makes their contributions more meaningful (Sullivan 2006). Contributions require the skill development of participants so that they have equity in the collaborative equation (Kemmis and McTaggart 2000; Sarantakos 2005; Sullivan 2006).

Kemmis and McTaggart (2000) assert that, in order to effect change you have to research the practice. Changing the practice 'requires changing not only behavior or intentional action (including the way the practitioners understand the practice and the practice setting) but also the situation in which the practice is conducted' (Kemmis and McTaggart 2000:585). To make the shift in Aboriginal health research practice, Aboriginal people's participation is vital.

## Thesis process

Although this thesis is methodologically driven by an Indigenous critical approach, it nevertheless had to conform to a more traditional 'Western' process exemplifying the two ways together that are an Indigenous reality in Australia. A brief account of this thesis process follows.

## Ethics

Ethics approval for this project was obtained from the University of New South Wales in November 2005 and the Central Australian Ethics Committee in September 2005. The specific scientific merit of this study was to articulate an Indigenous research health methodology. The primary ethical considerations of the study related to respectful and culturally relevant approaches to informed consent and interviewing methods. As an Aboriginal woman grounded in an Aboriginal worldview I believe Indigenous ethical considerations are critical to safe, relevant and beneficial research for Aboriginal communities. These considerations are: respect, reciprocity, balance, responsibility, and listening. The researcher requested a circle of female Elders to be advisors to the research process as well as to provide critique of the writing up of data to ensure my approach was at all times reflective of Indigenous law and ethical considerations. This was considered by the Elders as 'right way research'. The method of data collection using storytelling is culturally relevant, and was a method taught to me by the Elders to respectfully capture the stories of the participants in this study.

## Literature review

Concerns regarding Indigenous research have been effectively articulated by Linda Tuhiwai Smith in her text *Decolonizing Methodologies*, as discussed in Chapters 2 and 3. Smith's work encouraged me to develop an Indigenous Research Methodology focused upon emancipation, participation and improved health outcomes. Smith provided sources of important literature as well as further information being examined from academic, grey and internet literature. The focus of my searches have been: Indigenous health, Aboriginal health research, Indigenous ethics, Indigenous paradigms, Aboriginal Traditional Knowledges, Indigenous Worldviews, Indigenous models for research, Indigenous researchers, Decolonisation, Colonisation, Postcolonialism, Postcolonial theory, Orientalism, Postmodernism, Humanism, Enlightment,

Western Science, Western worldviews, and Positivist research. This literature reviewed help to inform the analysis of Chapters 5 to 9 that follow.

## Community/Informants

Approximately fifteen semi-structured and sometime free-flowing exchanges constituted the informal in-depth interviews I undertook. The participants included Aboriginal Elders, Aboriginal and non-Aboriginal people who have worked in Aboriginal health research with whom I had long-standing, trustful and reciprocal relationships. The interviews were audiotaped, transcribed and kept on computer with restricted access through a password only I knew. All participants were given their transcripts to ensure I had captured what they had told me. Some participants made changes to their stories after further reflection and their revised versions have been used in the thesis. The data collected through the interviews have been analysed thematically and grounded in an Aboriginal way of knowing, privileging Indigenous voices. The data have been maintained in a narrative style.

The participant's stories provide a direct and personal representation of Aboriginal health research experiences that have not been available in texts reviewed. The informants were selected because of their knowledge and experience in the area of Aboriginal health research and were identified from long personal and professional relationships with me. This sampling frame is of itself, an Indigenous methodology.

## Elders

Aboriginal Elders are the holders of knowledge and law within Aboriginal communities. They provide teaching through the use of Indigenous epistemology, ontology and axiology. Their role is essential to the development of Indigenous paradigms as they practise Indigenous ways of knowing being and doing. The mentoring of this way of knowing, being and doing enables paradigms to be developed to meet the needs of Aboriginal peoples. Elders are pivotal to and part of Indigenous Research Methodologies (Wilson 2008).

The process of commencing and working through this thesis has been guided and overseen by a 'Circle of Elders', to ensure safety, growth and relevance. Linda Smith argues that Insider research requires 'a purpose-developed support group' (Smith 1999:139) and Elders 'act as a

guardian of the researcher, mediating their journeys through the community and through the research' (Smith 1999:139). The Elders provided their guidance through storytelling as well as critiquing and overseeing the process of the research journey. Their faith and belief in this journey has kept it and me going.

## Insider research

An insider/outsider perspective is provided through the personal stories of my experiences of Aboriginal health research, both good and bad. As an Indigenous researcher I am considered to have both 'insider' and 'outsider' status (Weber-Pillwax 2004; Lee 2008). I am an Aboriginal community person with connections to multiple Indigenous communities (Insider) and in the position of research trained and working within a Western academic organisation (Outsider) (Lee 2008:128).

This enabled me to provide situational stories in Aboriginal health research and reform, explored and critiqued using Indigenous reframing: 'Reframing is about taking much greater control over the ways in which indigenous issues and social problems are discussed and handled' (Smith 1999:153) and representation: 'Representation of indigenous peoples by indigenous peoples is about countering the dominant society's image of indigenous peoples, their lifestyles and belief systems' (Smith 1999:151). This approach is focused on developing solutions for the 'real life dilemmas' (Smith 1999:151) Indigenous communities experience, in a meaningful way. These stories are documented in Chapters 5, 6, 7 and 8. I have chosen health research projects to demonstrate the underlying issues that arise in Indigenous health research using the critique of Indigenous critical theory and story-telling. Some are projects I worked on as an Indigenous researcher, others are taken from the research literature. These stories highlight the dilemmas and tensions of insider/outsider status in research, where personal and community conflicts arise from unsafe Western research practice.

It is at this point important to acknowledge that 'Most indigenous researchers who work with indigenous communities or on indigenous issues are self-taught, having received little curriculum support for areas related to indigenous concerns' (Smith 1999:135). This has been my experience and is why the Elders have been so important to my undertaking of this project. As Smith notes, 'Insider research has to be as ethical and respectful, as reflexive and critical, as outsider research.

It also needs to be humble' (Smith 1999:139). This is because the Indigenous researcher is from the community and has 'a different set of roles and relationships, status and position' (Smith 1999).

The insider positioning is a privileged one that comes with great responsibility to community (Weber-Pillwax 2004). It is this responsibility that has driven me to focus on shifting the dominant institutional paradigms of current and past health research on Indigenous peoples. This shift is essential for changing the research agenda as I bring evidence to this thesis of direct experiences of academic colonisation. These experiences have dominated the landscape for me in the field of research and in the articulation of Aboriginal peoples' concerns about their health. I believe this research journey encapsulates the political and contested spaces of and for Indigenous researchers. It is a journey I have travelled and been supported in by Elders and peers, although the process has been somewhat uncharted. However, it has positioned me to be able to unravel this process and share the steps for future Indigenous researchers.

## A living cultural method

Indigenous knowledges are alive and well and have a key function 'as part of a living cultural tradition' (Smallacombe, Davis et al. 2007:9). Our ways of knowing, being and doing were passed down through law within the Dreaming and are 'constantly renewed and re-enacted through cultural and social practice within, among and between Indigenous people' (Smallacombe, Davis et al. 2007:9). Their transfer and accommodation relate to the multi-faceted processes that are in place within a lived social/cultural system. Indigenous cultural protocols provide the methods and methodologies as every community has its own protocols related to law and country, for such knowledge transference that are in every sense inter-disciplinary (Weber-Pillwax 2004; Lee 2008), Essentially these ways of knowing, being and doing have informed my approach as I too am part of this social/cultural system:

> It is [also] important to emphasise the ongoing vibrancy of Aboriginal culture and its ongoing embrace of new technologies and practices. These are the ways Indigenous knowledge is constantly validated, reaffirmed and renewed' (Smallacombe, Davis et al. 2007:9).

The accommodation and enculturation of these new technologies and practices have led many of us to work towards creating research methods that support and validate our knowledge systems.

It has been a challenging task to write about and pull out a theoretical framework from the way you naturally or instinctively do things. This is a story/journey that has been lived and continues to been travelled. It is different from a Western methodological approach regarding Indigenous health research. This is because a different worldview influences my life and living as the following model highlights.

*Figure 1*: **The Model: A living method**
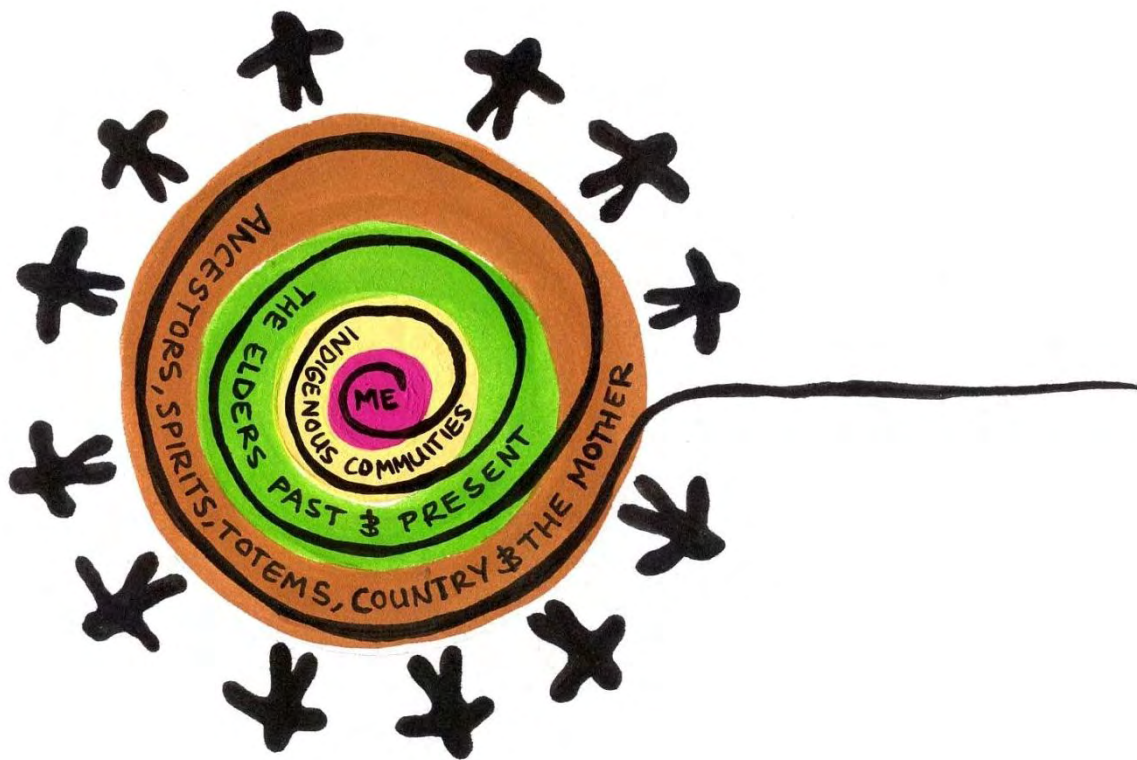


**Illustrated by Willurei Kirkbright-Burney 2010**

This method has been pictorially developed to illustrate the multiple Indigenous sources of co-generational knowledge transmission. They are represented in a series of concentric circles to show the connection and synergy within each layer of sources. The centre circle encompasses me, the collaborative cultural learner (I listen to and work with all layers to co-generate knowledge, praxis and change); the following encircling layer represents Indigenous communities and participants who provide the contemporary living knowledge related to power differentials and law; the next layer represents the Elders who provide the practical knowledge,

transmitting and translating the metaphysical and spiritual knowledge from the outer layer, into Aboriginal ways of knowing, being and doing; the outer layer represents the metaphysical realm of Ancestors, Spirits, Totems, the Land our Mother, Animals, and the living and non-living beings who transfer knowledge through dreams, visitations and messaging through animals.

Circles are symbols used within Indigenous cultures to illustrate the holistic nature of our ways of knowing being and going (Archibald 2008). The spiral in this model starts within the first circle and spirals out through the layers. This symbol indicates that the system is not closed or static, highlighting the ongoing process or processing required to comprehend and then co-generate knowledge. It also symbolises my learning journey. As this is my method of learning and growing, I am centred as the very small and central circle informed by the many layers surrounding and holding me on the journey of decolonisation. This is a journey that is never completed it is the continuum of living in two worlds.

## My learning journey

It is important to claim my position as an Aboriginal woman and researcher as the core of this research learning journey. I have done so because this is Aboriginal protocol, and is supported by the writings of Aileen Moreton Robinson (Moreton-Robinson 2004), Margot Weir (Weir 2001), Bronwyn Fredericks (Fredericks 2003) and Karen Martin (Martin 2007). This establishing is important within a research context because, '[t]here is an increasing reluctance to accept research from seemingly objective observers who do not reveal their human identities as part of their research activities' (Kenny 2004:7-1).

As an Aboriginal woman I bring to this story my knowledge and lived experiences. This knowledge is from my insider/outsider context from working in health, education and research for some twenty-five years. From this context I bring a number of stories of Indigenous health research to be explored. I believe my story as a researcher provides an insight into the current health research agenda as well as into the maintenance of academic colonisation.

> Many Indigenous researchers have struggled individually to engage with the disconnections that are apparent between the demands of research, on one side, and the realities they encounter amongst their own and other indigenous communities, with whom they share lifelong relationships, on the other side. There are a number of ethical, cultural, political and personal

issues that can present special difficulties for indigenous researchers who, in their own communities, work partially as insiders, and are often employed for this purpose, and partially as outsiders, because of their Western education … (Smith 1999:5).

I have experienced a number of ethical/moral dilemmas doing research that have placed me in positions that are just not appreciated by my Western colleagues. I have resisted and spoken up to deaf Western ears and these stories will be shared in Chapter 6, to ensure the safety of Indigenous researchers of the future.

I also bring the stories of Elders, Indigenous and non-Indigenous peers that are intertwined with my own story. Aunty Beryl claims 'it's about telling a story, ours and mine'. 'We want you to tell the story from a Black woman's perspective; you are our vessel to make sure it happens', stated Aunty Rose. Telling your own story Aunty Beryl argued establishes who you are, who your mob[3] is, and what you have learnt along the way which essentially provides your authenticity and authority. Bronwyn Fredericks supports this notion:

> Our stories are powerful learning and teaching tools. It is in the listening to someone else's story as a human being that we can give honour to the journey someone else has travelled (Fredericks 2003:66).

As a researcher my role is to tell a story and provide a picture that relates to the socially constructed environment as the basis for knowledge development (Foltz and Griffin 1996). This is where I have co-generated data and this positioning has led also to 'self-discovery' as was the expectation of the Elders (Foltz and Griffin 1996:303).

## Community/Participants

Indigenous and non-Indigenous people's voices and knowledge have provided important lived information related to Indigenous health research. Their stories are a product of in-depth interviews which have been left intact as they were spoken in a narrative format. The spoken word is provided, as it should be listened to, heard and understood; as it is considered offensive and disrespectful to attempt to re-interpret its message. The words uttered by Aboriginal people have a context of meaning that is significant to Aboriginal people, as does the pattern of utterance or story. This way of knowing and its transmission has been embedded as truths within

---

[3] Mob: Family and extended family connections.

the land and is known as Law. Initially, I was not keen to ask anyone other than Elders to be part of this project as I knew very well the distrust Aboriginal people hold around research and was really surprised when people asked me to tell some of their story.

## Aboriginal Elders

Aboriginal Elders are respected and selected for their knowledge, wisdom and integrity. Developing wisdom through both lived and learned experiences physical and metaphysical. Eldership does not become acknowledged for those of a certain age, rather it is earned. Elders have always been the custodians of knowledge, cultural practice and protocols as passed down from the Dreaming. Their responsibilities have been to nurture and grow Aboriginal peoples in their law, education, language, culture, ceremony and philosophy. This is to live as respectful beings accepting of their relationships and responsibilities to the physical and spiritual ecosystem. Teaching through mentorship, their role requires them to be both strong and sound in their ways of knowing, being and doing.

Elders are responsible for assessing who is ready to access knowledge. This is different from the manner of transferring knowledge within the academic tertiary knowledge system, where knowledge is considered available to all if you can afford it. It is important to appreciate the knowledge transmission process is very different to that of didactic tutoring. My growing[45] under the Elders clearly demonstrates this. In the beginning of my journey with the Elders I was provided with many stories to simply listen to. Initially, I questioned how this was going to assist me in working through the answers I thought I was looking for. I had a great deal to learn, I had to learn to listen respectfully, not question, but simply sit and allow their words to wash over me. They were sharing their souls with me and in the first instance I was unable to appreciate the gifts they gave me. I had been taught within the Western system to question and affirm what I knew. This approach is highly disrespectful of the storyteller. I had to decolonise my ways of learning. I was no longer able to push and prod for answers, I was simply asked to be. I believe it

---

[5] Growing: building knowledge and ethical praxis through mentoring.

took me a good year to shift my questioning approach. However they were all very patient with me, they never growled[6] me, they just kept telling the stories.

I learned to listen and hear, I was not directly given advice, I was becoming an active learner in an environment I was attempting to write about. The Elders' first lesson for me was imperative and perhaps one of the simplest: if you don't listen, you can't hear. My journey of learning progressed in this manner, deconstructing approaches I had taken up in my western education, to enable me to be open to the sharing of wisdom I was receiving.

The Elders provided opportunities for me to act on what I was learning in ways that were relevant to our communities. For example, take a project that I was working on that had, due to its State ethics policy, effectively cut out an opportunity for young Indigenous women's education in the area of women's health. Aunty Rose argued that they were most in need of this information sharing, and that I had to find another way of dealing with this issue. I contacted the school and requested that I provide an education session on Women's health with the Elder and other health providers. The school endorsed the need and sent consents out for the young women to attend this session. Aunty Rose said that the young women regularly thanked her for this session.

My relationship with the Elders of learning/teaching was based on reciprocity. I had a responsibility to ensure that, whenever I could, I would follow up on whatever they thought was to be actioned. This went both ways. When I moved to Alice Springs to work, one Elder prepared me for the trip with a smoking ceremony specifically to protect me and ensure the sprits in Central Australia would recognise who I was and why I was there. The rest came to visit me, as they were worried about me being away from home and the power of the country. They had to see for themselves that I was coping. They were relieved to observe that things were fine, but they regularly reminded me of the importance of returning home.

Our communication approaches obviously adapted to my distance from them. We talked and laughed a lot on the phone and I would make trips to see them at least once a year. I also started sending them the beginnings of chapters. They provided a very strong framework for me to bring things up to discuss with them. They did not provide answers to questions that arose, rather they

---

[6] Growled: Aboriginal English term for being told off.

encouraged me to be reflective and think through a way forward. Once I had undertaken a course of action, they would either agree with the approach I had taken or they would tell me to go back to the drawing board.

The sharing of chapters written have been politely viewed and responded to in a positive manner. However what has been important is how I have actually acted upon this knowledge. Everyday scenarios that either resemble or reflect the issues explored in the chapters have been shared with the Elders. They have requested that I tell them these stories and then they have provided feedback on how I have dealt with them. On most occasions I have had them in fits of laughter as they responded 'You've got it girl, we were worried about that academic language, but you get what that means now and you're doing it, right way'. They were particularly excited about a course that I was able to prepare and run on Indigenous research methods at Nura Gili.[7] To all of them, that was what this learning was all about, and I was actioning my teaching to others to be respectful of our ways of knowing, being and doing. They still growl about the language we have to use and how I have to have things backed up by sources that they believe are irrelevant to what they know as law. Ermine et al. (2005) support this perspective as 'Elders are scholars in their own right within the First Nations knowledge system' (Ermine, Sinclair et al. 2005:14) and, as such, they do not require validation from other knowledge systems. Importantly, within an Indigenous framework of knowledge development and brokerage we as Indigenous people are unable to claim this knowledge as our own, instead we want it acknowledged that we are 'part of a participatory mind and social product of that knowledge' (Ermine, Sinclair et al. 2005:14).

The translation process of knowledge co-generated from an Aboriginal worldview into knowledge required for a Western thesis was perhaps the most difficult and frustrating. Aunty Rose in particular was unhappy about the type of language I was using and subsequently was not happy to read the chapters. To translate the work I had written to have meaning for her was essential to my journey. This translation they had already taught me was to simply provide examples back to them through story-telling. Aunty Rose wanted to see if I had captured her message in our ways of knowing, being and doing. This process of translation is as it should be, back to our ways of doing. Aunty Rose was pleased that I was using this method and she said that she could now observe my progress more effectively. These stories related to learning

---

[7] Nura Gili is an Indigenous studies and student program at UNSW.

experiences and their outcomes, both good and bad and, their content and context were critical to the delivery in order to assess their truths.

In a sense, Indigenous researchers simply relay this knowledge. We are conduits grown through knowledge brokerage under our Elders to transfer these ways of knowing being and doing. It is not a new model; it has always been so. However, what is new in this method is that we must be able to translate this knowledge in a meaningful way for it to be respected by other knowledge systems.

During the last years of my thesis I was fortunate enough to help nurse Aunty Rose up to her death and provide support to her family in the way she had always given to me. This was a special gift for me and it would not have happened if I had not returned to Sydney, which is what she had been growling me to do. It is important to stress that my growing under these women did not simply relate to the writing and preparation of the thesis. Their guidance was far broader than that.

## Ancestors, Spirits and the Land our Mother

The Ancestors and their spirits created The Dreaming, which encompasses Land, Law and Life. The Dreaming is a knowledge commodity that has been described by outsiders as nothing more than 'mythology' or a name that suggests a purely fictitious story to explore natural phenomena. To us it is our 'Law' framework and provides us with detailed explanations of our relationships with all living and non-living beings within our universe. The Dreaming period set down our landscapes and our laws for living. The law is inscribed within these landscapes and connects all living and non-living beings into complex reciprocal relationships that compel ways of knowing, being and doing.

These laws have been passed on through our own legal specialists, Elders chosen for this role who teach the Law on many levels to all community members.

The Dreaming can also be explored as our scientific theory of universal laws. This theory is unlike others transformed into text. It is a relative theory that like the universe is undergoing constant flux and explores the development of change in many modes of descriptions, such as art, song, dance, land forms, dreaming spirits, and narrative descriptions.

146

## Conclusion

An Indigenous framework for research is informed by Indigenous ways of knowing, being and doing and is different from a Western framework in that it must be first 'and foremost accountable to our indigenous community' (Kahakalau 2004:19). Second, it must be of benefit to the community in the ways they have voiced (Rigney 1999; Smallacombe 1999; Smith 1999; Sherwood, Gentle et al. 2003; Kahakalau 2004). Third, it must be harmonious with Indigenous communities' protocols and values as defined by them to ensure the process is safe and respectful (Smith 1999; Sherwood, Gentle et al. 2003; Kahakalau 2004; Martin 2007). Using Indigenous ways of knowing develops a strong sense of respect and ensures that the praxis and language used is safe to Indigenous peoples. Fourth, information collated through the research must be presented back to the community in a manner that makes sense to them and is useful. I was personally told by community members of a thesis undertaken in their community by a French scholar who did send them a copy of his completed thesis but in French. Community feedback is considered reciprocal knowledge sharing, is ongoing and is a responsibility Indigenous researchers are ethically obliged to maintain. Research must be a focus for change in areas such as social justice, health improvement and self-determination, and finally 'must be sophisticated and scholarly to convince academia that they are of equal scope and breadth as established Western ways of research' (Kahakalau 2004:20).

Smith and Kahakalau, both Indigenous scholars, reason that contemporary Indigenous methodologies are a blend of Indigenous ways of knowing, being and doing and existing methods (Kahakalau 2004). This blending relates to Indigenous researchers' experiences and training within academia along with their knowledge and community responsibilities that come with their insider status. These enhance the ethical nature and benefit of the research (Smith 1999; Kahakalau 2004). The pathway I have followed has been rigorous, however it is not viewed by Indigenous peoples as developing new knowledge rather it is a balance of existing knowledges.

Methodology used in research 'is important because it frames the questions being asked, determines the set of instruments and methods to be employed and shapes the analyses' (Smith 1999:143). My methodology has been informed through an Indigenous philosophy and lived experience, and has also been guided by Aboriginal Elders. My research question is political in

that it questions the validity of Western research practice that is focused upon continuing to problematise and de-humanise Indigenous Australians. Of course not all Indigenous health research does this, but there continues to be a great deal of research that does, as will be explored in Chapters 6 and 7. The approach has been justified through the evidence explored in the stories of Indigenous and non-Indigenous Australians in Chapters 6–8, which follow. I have used 'a mix of existing methodological approaches and indigenous practices' (Smith 1999:143) as a praxis for balance and to ensure my findings would be valued as valid outcomes of such research praxis. My intention has always been to improve health outcomes through respectful and safe research using the wisdom and knowledge systems of both Indigenous and Western peoples.

Subsequently, the methodology/method for this thesis is the journey and the journey is the method; a collaborative learning journey, influenced by multiple ways of knowing, being and doing that are Indigenous and non-Indigenous. A learning journey is never completed from an Indigenous perspective; it is the continuum of living. However, it is important to recognise and reflect upon what you have learned along the way. This learning journey and resulting thesis captures the reality of issues that arise in an attempt to articulate another way of knowing. In other words, what I have attempted to explore has become a real lived experience. This thesis is the how, why, what and when of working through both an academic and a cultural expedition.

It has been a two-way learning experience for me, the researcher, who has accommodated a western education process alongside an equally important Aboriginal pedagogical approach to learning. This two-way approach is the very essence of the method developed within this thesis. It holds that two ways of knowing can co-exist, but there must be trust, respect, balance and a process of decolonisation for them to do so.

Margaret Kovach asks the question 'Is there a uniquely Indigenous methodological approach to research?' (Kovach 2005:1). This journey thesis argues that there are many and they reflect the context of each Indigenous issue and community. With respect to Australia, where this searching is focused, there are many Nations, and therefore many ways of knowing, being and doing. This has been a guided learning journey travelled with Elders, which positions it fundamentally as an Indigenous method.

The theoretical approaches underpinning this thesis have been selected to articulate the following:

- Respecting the position of Indigenous ways of knowing, being and doing

- The importance of decolonisation of the researcher and the research process

- The undertaking of health research in a manner that is respectful of Indigenous ways of knowing, being and doing

Kovach and Kahakalau state that emerging Indigenous methodology is a lived experience. This has been the way this thesis journey developed through experience to analysing and theorising (Kahakalau 2004; Kovach 2005).

My role as an Indigenous researcher and storyteller comes with significant responsibilities that are born from my culture and worldview and from being positioned in accommodating two distinct worldviews and their respective ways of knowing. This positioning creates an ethical dilemma: one traditional and orthodox 'Western' code of conduct breaches and essentially denies and rejects the 'Other' Indigenous code of conduct-Law and protocols. Ellis and Bochner (2000) contend that this requires me to look inward, 'exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations' (Ellis and Bochner 2000:739). Telling these stories enables a process for reflection. They are also empowering in the telling as they provide an opportunity for relating the issues using an Indigenous way of knowing, relating issues that are problematic to be shared with a reader or listener (Dion 2004).

This two-way learning experience is the very essence of the method developed for this thesis. The approach I have taken has necessitated listening, observation and lots of talking together. It also required reflection individually and collectively with the Elders, community participants and the broader community. Not all participants collectively share one voice about a given subject. However, I believe this is where the collective reflection is important as this achieves an outcome that respects all community views. I have observed that there is a fine line regarding balancing perspectives and philosophies and it is not about overwhelming these with a 'theory of praxis' as spelt out by academic methods. Rather, it is about balancing a number of ways of knowing through a safe process. It is in fact the process that is the most important component of

valid and ethical Indigenous research because if the process is respectful, collaborative, safe and reflexive, there will be benefits for participants and communities.

# Chapter 5

# Aboriginal health research reform: attempts to shift the agenda

> … We ask you to study the problem, in the way that we present the case, from the Aborigines' point of view. We do not ask for your charity; we do not ask you to study us as scientific freaks. Above all, we do not ask for your "protection". No, thanks! We have had 150 years of that! We ask for justice, decency and fair play. Is this too much to ask? Surely your minds and hearts are not so callous that you will refuse to consider your policy of degrading and humiliating and exterminating Old Australia's Aborigines (Ferguson and Patten 1938:56).

## Introduction

This chapter examines the attempts made to shift the Australian Indigenous health research agenda from the Western academic obsession with defining, describing and problematising Indigenous people, over the last three decades (Henry, Dunbar et al. 2004). Approaches taken to reform the Indigenous health research agenda have come from Indigenous Australians and have more recently been supported by non-Indigenous peoples. This has partly been in recognition of the poor outcomes from past research and the maintenance of poorly informed constructs misrepresenting Indigenous Australians within health research. Parallels can be seen in the international literature (Said 1995; Smith 1999; Battiste and Henderson 2000; Battiste 2002; Ermine, Sinclair et al. 2004), but it has been insufficiently researched in this country. The purpose of this chapter is to illustrate that Indigenous health reform is an issue of concern for Indigenous Australians, as discussed in Chapter 4. Reform actions or responses of the last three decades in Indigenous Health research continue to be based on a Western research framework that remains non-compliant with the Indigenous philosophy of self-determination and control over their own affairs.

Instead, Western academic imperialism has maintained its practice of silencing Aboriginal people's voices and agendas. Research continues to be funded through a Western mechanism of research power authorised to speak of and for Aboriginal peoples about what is best for them.

Although this approach has not improved Indigenous health, health researchers and their institutions continue not to listen (Henry, Dunbar et al. 2004). So:

> The current order of research established from archaic modes of thought requires more than a gentle nudge of a radical paradigm shift. This shift in consciousness will not and cannot be manifested through the lenses of Western thought alone. It will require models of new knowledge from different worldviews. For the West, not only must the discourse of intolerance be allowed to implode under the weight of their own reasoning, but alternate venues of expression have to be offered in the place of their own deficiencies. Alternate paradigms that envision higher standards of human creativity are required (Ermine, Sinclair et al. 2004:45).

Indigenous health reform requires a balance of worldviews as argued in Chapter 4. A shift of consciousness is far more comprehensive than changing a research method; it requires the adoption of a decolonising framework. Shifting Western worldview dominance in Indigenous health research will entail an in-depth and respectful dialogue with Indigenous peoples along with developing an appreciation and being inclusive of their different ways of knowing, being and doing. In every respect this thesis journey attempts to provide a way forward for this shift to occur in Australia. This chapter examines the barriers that have prevented meaningful Indigenous health reform for Indigenous Australians.

## Challenging the paradigm: Indigenous researchers

Aboriginal Australians have argued for research reform from the 1930s to today. Their concerns were then as they are today; research problematises Aboriginal people. William Ferguson and Jack Patten of the Aborigines Progressive Association accused researchers of creating 'scientific lie[s]' (Ferguson and Patten 1938:60) to mislead the mainstream population into beliefs about Aboriginal primitiveness that ensured marginalisation, through systemic racism and breach of rights. Their critique remains pertinent today.

> At worst, we are no more dirty, lazy, stupid, criminal, or immoral than yourselves. Also, your slanders against our race are a moral lie, told to throw all the blame for your troubles on to us. You, who originally conquered us by guns against our spears, now rely on superiority of numbers to support your false claims of moral and intellectual superiority (Ferguson and Patten 1938:60).

Aboriginal critique of research escalated from the 1970s onwards, with the rise of political activism resulting from an inherent distrust of the mainstream government and academic elites. Research was observed to be 'intimately bound up with histories of colonisation' (Humphery 2001:197) and its maintenance without reform would continue to colonise Aboriginal peoples. The focus on Aboriginal people as merely objects of study and those who studied them acknowledged as experts required an Indigenous-led revolution to shift the research agenda (Henry, Dunbar et al. 2002) from oppression to emancipation (Rigney 1997).

Still not heard, from the 1980s onward Aboriginal people, communities and their organisations articulated the need for shifting the research agenda to one in which communities have their rights recognised and advocated meaningful and relevant outcomes (Brands and Gooda 2006). These assertions have been actioned through debate, partnerships, framing of ethical guidelines for researchers and the development and utilisation of Indigenous research methodologies (Brands and Gooda 2006).

Those who have challenged the paradigm include Indigenous Australian academics/researchers, activists and Aboriginal organisations. Marcia Langton (Langton 1982; Langton 1993) and Rosalind Langford (Langford 1983) provided an appraisal of the Western research practice that failed to respect Aboriginal peoples. This agenda was taken up in 1987 within health by the Central Australian Aboriginal Congress (CAAC) in the development of research guidelines promoting participation and control of Aboriginal health research as well as the development of culturally safe methodologies (Liddle and Shaw 1983; Henry, Dunbar et al. 2002). This marked the activation of research reform. Research guidelines developed at the Camden Workshop in 1987, observed as ethical guidelines, established the rights of Aboriginal people in research building on the CAAC guidelines promoting 'a needs based approach to research be adopted' (Humphery 2001:200) along with the skilling up of Aboriginal people as researchers.

In 1996 Ian Anderson took the reform agenda further to promote the value of research for those being researched, rather than those doing the research (Humphery 2001:201). This argument interrogated 'notions of priority and benefit in Indigenous health research' (Humphery 2001:201) which shifted the debate from simply adhering to ethics to real action. This empowered many Aboriginal organisations to state that there would be 'no survey without service'. However, this

153

required reform within the funding arena for Aboriginal health research, and a methodological approach that privileged Indigenous voices and praxis.

Many Indigenous and a number of non-Indigenous academics have contended that Western methodologies continue to misrepresent and define Australian Aboriginal peoples as the problem (Langford 1983; Brady 1992; Langton 1993; Dodson 1997; Rigney 1997; Nakata 1998; Rigney 1999; Moreton-Robinson 2000; West 2000; Cadet-James 2001; Martin-Booran Miraboopa 2001; Nakata 2001; Sherwood 2001; Atkinson 2002; Blair 2003; Briscoe 2003; Fredericks 2003; Bissett 2004). As discussed in-depth in Chapters 1 to 3 this critique has also been made by many Indigenous and colonised peoples worldwide about their experiences (Freire 1989; Said 1994; Fanon 1995; Said 1995; Bishop 1997; Deloria 1997; Bishop 1998; Bhabha 1999; Smith 1999; Battiste and Henderson 2000; Battiste 2002; Smylie 2003; Durie 2004; Ermine, Sinclair et al. 2004; Sinclair 2004). The critiques argue for models of self empowerment and healing to replace the colonial ideology.

## Indigenous Health reform

The Links Monograph Series undertaken within the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) provided considerable documentation of what 'underpinned the apparent ineffectiveness of research in terms of addressing Aboriginal health' (Brands and Gooda 2006:28) utilising an Indigenous framework. This series critically articulated what was required to shift and create reform within the health research agenda.

- Indigenous control of the research agenda
- Indigenous control of the research process
- Improved processes for quality control
- Improved process for consultation and negotiation of research; and
- Improved processes for transferring research findings into policy and practice (Dunbar, Arnott et al. 2004:ix).

The CRCATH's aim to improve the health of Aboriginal communities through research required further uptake of 'research transfer and capacity development' (Brands and Gooda 2006:28). Research transfer meant developing stronger relationships between the users and stakeholders of

research as well as dissemination of findings in a relevant manner with an emphasis on brief, simple and meaningful communication. Capacity building focused on the development and training of both Indigenous and non-Indigenous researchers.

These initiatives proved to be successful highlighting the importance of 'shared learning' (Brands and Gooda 2006:29) between Indigenous and non-Indigenous researchers, leading to the creation of effective Indigenous-informed methodologies, with positive outcomes. Although these research encounters confirmed the importance of Indigenous frameworks providing outcomes communities requested and required, they were too few to have shifted the agenda (Dunbar, Arnott et al. 2004).

The barriers that continue to impede reform in Aboriginal health research are:

- the power difference between Indigenous and non-Indigenous research participants
- the entrenched privileging of western research traditions
- the under-valuing of Indigenous knowledge and perspectives
- the widespread influence of 'investigator driven' approaches to research (Dunbar, Arnott et al. 2004:53).

These barriers ensure that Indigenous frameworks are not employed. Importantly, balanced partnerships are unattainable when essential pre-planning with communities regarding capacity development and relevant time frames are not factored into the research or the funding of the project (Dunbar, Arnott et al. 2004).

It is significant that the CRC for Aboriginal Health has attempted to address many of issues raised by its predecessor in its Links Monograph Series for Indigenous Research Reform Agenda. It is doing this by shifting from the traditional research agenda to one that aims to 'ensure that research provides benefits to Aboriginal people and is controlled by Aboriginal people' (CRCAH 2006:1) and establishing a cooperative prioritisation for research projects through the building of relationships in health, community controlled health, government and the community (CRCAH 2006).

## The National Health and Medical Research Council (NHMRC)

> The committee considers that the National Health and Medical Research Council (NHMRC) should review its priorities and ensure that Indigenous health is given a much greater focus, including a significantly increased share of available funding. There should be revised guidelines which differentiate research in this area from normal scientific research, and which take into account the need for community involvement, as well as the need to involve researchers best suited to the task (HRSCFCA 2000:126).

The following section tells the story of Indigenous health reform orchestrated from within a powerful Western health research body, namely the NHMRC. This narrative offers an appreciation of the concerted efforts made to challenge the colonial agenda of Indigenous health research and highlights the fact that these efforts would have been more effective if they also required a shifting of consciousness from the dominant research approach to being more inclusive of Indigenous people's concerns.

The NHMRC is a Western research body which has taken a number of steps to improve funding of Indigenous health research and support Indigenous participation within this shifting agenda. However, it also continues to control the agenda of what and how research will be funded. The mechanisms of funding and review have not shifted and remain biased towards researcher-driven approaches. This has been highlighted within the review and will be discussed further in Chapter 8.

The history of NHMRC involvement in Indigenous research commenced in the 1950s in the Northern Territory. Harry Giese, Director of Welfare for Aboriginal people, objected to health researchers targeting Aboriginal communities for blood specimens without the Board's consent and saw no benefit in these collections to the Board's guardians (Thomas 2004). Giese attempted to negotiate with the researchers for individual consent of Indigenous peoples without coercion to become subjects of these studies (Thomas 2004).

Giese's response followed a long history of blood collection by scientists throughout the Northern Territory (NT), which appeared to be of no value to either the NT administrators or the Aboriginal population. With a great deal of the research focused on blood collection used to 'answer questions unrelated to Aboriginal people's health' (Thomas 2004:104). Aboriginal

communities were observed as 'a convenient bulk reservoir from which samples could be drawn' (William Refshauge, Director-General of Health cited in Thomas 2004:104). At a meeting between the researchers and the NT Administration, Kirk, one of the researchers, stated that Giese 'tended to see the problem purely from the point of view of the aborigines' and that 'because of his concern for the people Mr Giese tended to over emphasize the human rights angle' (Thomas 2004:104).

Giese's recommendation was observed by the researchers as shifting the power from their hands to the administration and possibly even granting Aboriginal individuals some sense of control over their lives. This was not to be contemplated. Instead, it was proposed that all future research targeting Aboriginal peoples would be assessed by the National Health & Medical Research Council (NHMRC) as to its scientific relevance (Thomas 2004:105). This though did not appear to have benefit for the health outcomes of Indigenous Australians.

> Whilst the representations of Aboriginal people and their health may have been influenced by this change in the researcher's power, there was as yet not much evidence in the scientific publications beyond the researcher's effusive acknowledgements (Thomas 2004:105).

The NHMRC remained the mechanism for approval of scientific research on Aboriginal people until 'The Workshop on Priorities to Improve Aboriginal Health' was held in Alice Springs in 1986. There it was argued that an Aboriginal presence in the research agenda was a priority (Humphery 2001). The Indigenous Community Controlled Health Organisations took the opportunity to speak on behalf of Aboriginal and Torres Strait Islander Australians regarding their rights in the health research agenda, in what up until that time had been an exploitive project (Paul and Atkinson 1999). Importantly, the NHMRC had recognised:

> … the fact that past research into Aboriginal health has failed to address this poor level of health adequately, but has often concerned itself primarily with matters of interest to science or to white Australians (NHMRC 1989:4).

Many recommendations came from this workshop with a plan to develop an interim NHMRC Guidelines focused on Aboriginal and Torres Strait Islander Health research. The Guidelines encompassed critical focus areas for community consultation, confidentiality, community involvement, community employment throughout the research process and, most importantly,

ownership and publication of research data (Humphery 2001; Henry, Dunbar et al. 2002). Paul and Atkinson asserted that in the wake of these guidelines, research into Indigenous health had still not engaged with the rights of Aboriginal research participants:

> [guidelines] are frequently ignored in both the process of research and the papers which are produced as a consequence (Paul and Atkinson 1999:31).

Paul and Atkinson claim that Aboriginal health research has failed to provide, or even explore a fundamental understanding of the causation of health inequalities, although the NHMRC Infrastructure Review stated that 'Aboriginality is itself a health hazard' (cited in Paul and Atkinson 1999:32). This position absolved the 'health mechanism' of blame for its failures in preventative or public health measures, because it suggests a change in health outcomes could not be achieved because of people's Aboriginality. In the light of past policy, practice and research, it is possible to appreciate how this thinking has been promoted, resulting in mainstream health systems maintaining a systemic ideology that Aboriginal a person's health status is directly related to their primitive and deficient morality. Death and disease are seen as manifestations of people's inability to be caring worthwhile citizens (Foucault 1980), and morbidity and mortality data are used to define Indigenous peoples' situation. Denzin argues that problematising Indigenous cultures is part of a neo-liberalist agenda, with a strategy to 'blame its members for the problems that the members of the culture experience' (Denzin 2003: 4). It is in this setting and political climate that Indigenous issues will continue to be promoted as a problem due to their perceived and constructed 'deviance' and lack of compliance to mainstream ideology and health care.

## The Road map

Steps have been taken, specifically in the last decade, by the NHMRC to promote Indigenous health research reform. As a body it has significant influence on health research and has worked towards increasing its own funding for Indigenous health research. The catalyst for change was directed through the *Health is Life: Report on the inquiry into Indigenous health* (2000) as well as via an analysis of National expenditure that established that 'there is no evidence of where the money's been spent' (Leon de la Barra, Redman et al. 2009:13) in relation to Indigenous health improvement. The *Health Is Life* report brought to light issues around the continuing structural deficit that is Aboriginal health services and health research in stating:

158

The committee believes that many of the difficulties come down to these differing worldviews about health, about how it should be defined and about the sorts of services needed for good health (HRSCFCA 2000:vii).

The committee recommended a shift in the research focus:

While the committee appreciates the need for pure research it believes that the current state of Indigenous health does not allow for any luxury in this regard (HRSCFCA 2000:125).

This shift required that:

[t]he National Health and Medical Research Council (NHMRC) should review its priorities and ensure that Indigenous health is given a much greater focus, including a significantly increased share of available funding. There should be revised guidelines which differentiate research in this area from normal scientific research, and which take into account the need for community involvement, as well as the need to involve researchers best suited to the task (HRSCFCA 2000:126).

Such a paradigmatic shift necessitates decisive involvement of Indigenous peoples in the framing, process and methods of the research. Research founded on these principles needs to be driven by an Indigenous worldview. This is the shift that has been fought for over the last twenty years by the Community Controlled Health sector, Indigenous researchers and their respective communities (Humphery 2001).

In 1997, the NHMRC established the Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG), a joint project with the Office of Aboriginal and Torres Strait Islander Health (OATSIH) (RAWG 2003). In 2000 the NHMRC invited a sole Indigenous representative onto the council to provide advice, and to support the work of the Indigenous Health Research panel (Cunningham, Reading et al. 2003). The Special Research Development Committee (SRDC) is a principal committee of the NHMRC. RAWG was formed as a subcommittee of the SRDC. RAWG provided critical leverage into the policy reform of the NHMRC to focus on funding research that would improve the health outcomes for Indigenous Australians. It had 'historically almost exclusively funded investigator-initiated research with little capacity to strategically target funding to specific areas' (Leon de la Barra, Redman et al. 2009:5).

In 2001 RAWG put into action the development of the Road map Strategy, which effectively targeted funding to Indigenous health research, after the release of the *Health is Life* report, to identify and codify National Aboriginal and Torres Strait Islander health priorities (RAWG 2003). In line with the Report the NHMRC acknowledged:

> In the last triennium, the SRDC (Special Research Development Committee) recognised that Aboriginal and Torres Strait Islanders are overwhelmingly the most disadvantaged group in Australia, and that health research in this area did not appear to be contributing to an improvement in health status (NHMRC 2003:1).

In 2002–3, a Road map for Indigenous Research was developed under the guidance and funding of RAWG. The Road map was adopted by the NHMRC's Council, which agreed to implement the strategy at its 144th Session in October 2002 (NHMRC 2008). This could be considered to be the development of the new guidelines as recommended by the *Health is Life* report. However, RAWG recommended that the Road map be developed to support the NHMRC to:

> advise Aboriginal and Torres Strait Islander communities throughout Australia, on the achievement and maintenance of the highest practicable standards of public health, and to foster research in the interests of improving those standards (RAWG 2003:3).

Despite changes recommended by the *Health is Life* report, the NHMRC's advisory position to Indigenous communities in the area of health reform and research appears not to have shifted a great deal. As Humphrey's has argued, the control of 'traditionally entrenched research bodies' (Humphery 2001 :201) on Indigenous health research makes it difficult to craft real change and hence the reform could be observed as merely rhetoric (Humphery 2001).

The NHMRC's Strategic Framework for Improving Aboriginal and Torres Strait Islander Health Through Research (NHMRC 2002) and its accompanying document, Final Report of Community Consultations on the NHMRC Road map (RAWG 2003) provides some of the discussions from the four workshops supporting the Strategic Framework (RAWG 2003). RAWG developed the Strategic Framework for research through 'a series of workshops and meetings' (RAWG 2003:3) as well as incorporating knowledge from the 'communities it represents' (RAWG 2003:3). The Strategic Framework is the Road map and its following six themes promote the 'processes

necessary to identify Aboriginal and Torres Strait Islander health issues' (RAWG 2003:3) along with the research methods that 'should be given priority for funding' (RAWG 2003:3):

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

> 2. A research focus on the factors and processes that promote resilience and well-being; in particular but not exclusively, during the periods of pregnancy, infancy, childhood and adolescence and form the basis for good health throughout the life span.

> 3. A focus on health which describes the optimum means of delivering preventative, diagnostic and treatment-based health services and interventions to Aboriginal and Torres Strait Islander peoples.

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

> 5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities.

> 6. Development of the nation's Aboriginal and Torres Strait Islander health research capacity (including training Aboriginal and Torres Strait Islander researchers) and health research practice in relation to Aboriginal and Torres Strait Islander communities.

> These six theme areas are consistent with the functions which the National Health and Medical Research Council is charged with under the 19992 NHMRC Act (NHMRC 2002:3-4).

Theme number one has beoame a priority area of funded Indigenous health research with the levels of descriptive research increasing dramatically from 2003 (Sanson-Fisher, Cambell et al. 2006) despite it being the bulk of research over the past century. This is a research focus that does not and has not delivered health improvement outcomes for communities researched; it has, however, continued to build knowledge on the level of health deficit suffered by Indigenous Australians. This is not the reform Indigenous people have agitated for. The subsequent five themes have received attention through research funding. On the whole, however, theme 1 dominates the Indigenous Health research agenda.

Along with these themes are a number of principles that underlie the RAWG way forward in Indigenous health research on and for Indigenous peoples. These are:

- Health being conceived of as "… not just the physical wellbeing of the body but a whole of life view, which embraces the life, death, life concept."
- Community involvement in the development, conduct and communication of the research.
- Communication of research plans, progress and results.
- Ethical research aiming to be of practical value to Aboriginal and Torres Strait Islanders peoples and their service providers.
- Research support including the enhanced development of skills, knowledge and capacity in the Aboriginal and Torres Strait Islander research workforce.
- A focus on identifying 'positive models' or examples of success (RAWG 2003:4-5)

These principles are in line with, and are comparable to those developed for the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003) endorsed by the Australian Health Ethics Committee council at its 148th Session in June 2003; these were the result of the revision of the Interim guidelines of 1991 (NHMRC 2003) (explored further in Chapter 8). Although the above principles reflect Indigenous involvement, they do not in any sense reflect community control that is promoted by the CRCAH whose manifesto is 'With strong and effective Aboriginal input and control, we will conduct high quality and strategic Aboriginal health research' (CRCAH 2008:cover) to improve health outcomes. From an Aboriginal perspective, the RAWG of the NHMRC was unable to strategically implemented critical reform as evidenced by the following statement:

> Whilst there is a requirement for ongoing consultation and review with Aboriginal and Torres Strait Islander people around the research process and annual research priorities, some potentially beneficial research will continue to emanate from research driven processes (RAWG 2003:5).

This statement attests to the paramount importance of a research-driven agenda, above and beyond the needs of Indigenous Australians and provides a way around the requirement to have Aboriginal controlled health research. The reform was unable to shift this way of thinking within the NHMRC body, or in the ways it funded Aboriginal health research discussed further in

162

Chapter 8. However, it must be acknowledged that the Road map was an important step left and forward from the robust dominant Western research agenda. Indigenous health research and Indigenous researchers were highlighted as priority areas for the scientific academy and funding. This in itself was a significant shift, along with the recruitment of Indigenous researchers and participants to inform this agenda. In every sense it has created the opening necessary for Indigenous dialogue; it is a beginning that requires further building to balance the priorities of Indigenous Australians within the agenda.

The following section examines the review process of the 2003 NHMRC Road map strategy, an informative evaluative step necessary for guiding future reform.

## Road map Review

Warwick Anderson, the NHMRC CEO, established an Aboriginal and Torres Strait Islander Health and Research Advisory Committee (ATSIHRAC) to advise the CEO 'on strategies to improve the effectiveness of the NHMRC's response to Aboriginal and Torres Strait Islander health issues' (Anderson 2008:1). The ATSIHRAC conducted consultative workshops (in Sydney, Melbourne, Alice Springs, Perth and Townsville) for the review of the Road map in May and June 2008. The facilitators and authors of the Report were Judith Dwyer and Kate Silburn.

The review asked its 134 participants (Indigenous and non-Indigenous) the following questions:

- Has the Road map been used?
- What has the impact been?
- Are the Road map themes still relevant?
- Proposals for the future (Dwyer and Silburn 2009:4-7).

The responses to these questions were collated from all workshops and nine written submissions and are explored below. The approach used to facilitate discussion involved a 'world café' method, with participants 'invited to engage in discussions in small groups on questions that matter to them' (Dwyer and Silburn 2009:4). The Indigenous experience of this process is elaborated upon by a participant at the Alice Springs workshop:

I felt it was very orchestrated and the group work they got us to do was very academic, which excluded the very few community people who did come. The group work was aimed at supporting the NHMRC it did not provide opportunities to question its focus (Participant 5).

**'Review question 1: Has the Road map been used by individuals or organisations to develop and implement research projects? If not, why?'** (Dwyer and Silburn 2009:11)?

Respondents acknowledged that the Road map had led to a greater focus on Indigenous health research. The development of the NHMRC *Values and Ethics* statement (NHMRC 2003) and *Keeping Research on Track* (NHMRC 2005) were viewed as important resources to support this greater focus. Importantly, the degree of its impact was difficult to ascertain due to a lack of knowledge by participants attending the workshop about the Road map. The authors suggest that many participants did not realise that there was a relationship between the research being undertaken in communities and the Road map (Dwyer and Silburn 2009:4). This suggests that the organisation of the workshops was inadequate and that communities are not being kept abreast of who is doing research and why research is happening but is an important finding in and of itself as to the inadequacy of the Road map's implementation in communities.

One participant highlighted the poor organisation of this workshop:

The review process did not ensure community involvement. The audience consisted of academic people and not community members, community voices were once again excluded due to poor planning. As an individual I offered to go out to the community and inform them of the meeting and why it was being held. It is important community members are told the reason for why these things are happening. My offer was ignored until 24 hours before the meeting. This was disrespectful to the community and gave me no time to effectively organize any information sharing. I was able to talk to a few people who did attend but on the whole I was disappointed (Participant 5).

**Concerns raised by participants at the review:**

Participants felt that the NHMRC document *Keeping Research on Track* (NHMRC: 2005) had not been promoted nationally or evaluated.

The following account by a workshop participant provides a more detailed account.

I spoke up about the document 'Keeping research on track' a document produced for communities. The NHMRC showed goodwill in funding and producing this document for the Aboriginal communities. But it has not been rolled out into the communities. The NHMRC did not fund the rollout to the community. Instead the NHMRC requested that Indigenous researchers through their work dispense this document to Aboriginal communities. This is wrong as it is critical that community know their rights (Participant 5).

The preceding comments indicate the lack of support provided to Aboriginal and Torres Strait Islander people and their communities in relation to health research and research ethics. As the participant states, it is imperative that communities know their rights as this is a key element of Indigenous health research reform. However, this element has been only partly implemented. The fact that this document is available on the web on the NHMRC site does not make it accessible to communities.

A key concern raised was the ' "traditional" grant assessment processes' (Dwyer and Silburn 2009:12), which fundamentally limited projects to those 'in line with the Road map's vision' (Dwyer and Silburn 2009:12). The traditional process supports and benefits those with industrious track records as a measure of competence, 'a measure which reflects neither community engagement nor the extent to which the work has made a difference in communities' (Dwyer and Silburn 2009:12). Some researchers have gained their industrious track record by riding roughshod over Indigenous communities in research encounters. They do not have, and do not believe they require skills such as 'cultural skills, the capacity to speak the language and communicate well with Indigenous communities' (Dwyer and Silburn 2009:12), considered to be important in Indigenous research.

This approach is problematic as the following participant explains:

Now we must now fit into their research framework to do funded research for our communities (Participant 5).

Although there are additional funds to undertake Indigenous health research, the agenda for what research will be funded remains in the control of the NHMRC. The NHMRC established an Indigenous Health Research Panel (IHRP) in 2003, ensuring in most cases, that Indigenous health research grants are appraised by Indigenous and non-Indigenous Assessors. However, the

research framework remains within a Western dominant model that is not inclusive of specific Indigenous community issues or approaches.

The funding process remains biased towards what Western research bodies consider to be the experts who hold senior roles in most research projects.

> This also means that we have to have an industrious track record, which we simply do not have. We are used as research assistants, we are not given the opportunity to run projects the way communities want them. We have been forced to stay in the background and help the white experts, and the roadmap made sure of this as well (Participant 5).

These concerns raised are vital to informing the Indigenous health research agenda and require addressing, especially in the light of building expertise in the area of Indigenous health research and researchers.

Another point raised by participants about the assessment process was that many organisations had fraudently obtained funds 'by 'using' the names of Indigenous researchers (Dwyer and Silburn 2009:12) on their project grants without effectively employing those researchers or discarding them after the grant has been obtained. It means that research is not informed through an Indigenous culturally informed approach and limits the opportunity for skill development of Indigenous researchers.

**'Review Question 2: What has been the impact of the Road map on research and researchers'** (Dwyer and Silburn 2009:13)?

A highlight of the impact has been the valuing of Indigenous knowledges along with recognition of the need to develop research processes that engage with and focus on capacity building. Participants believed that there had been a shift in research 'on' to research 'with' Indigenous communities. They were also pleased that the Road map stressed that research should be process- rather than outcome-focused (Dwyer and Silburn 2009:13). Capacity building grants were observed to have had a good impact, especially in the area of developing a 'critical mass' (Dwyer and Silburn 2009:13) of Indigenous researchers.

**Concerns raised by Participants**

There were still barriers that limited advancement in the recognition and valuing of Indigenous knowledge systems, the engagement of communities and capacity building including 'systemic bias against Aboriginal and Torres Strait Islander people', 'racism and paternalism in research' (Dwyer and Silburn 2009:13) and lack of acknowledgement of Indigenous knowledges. It was also noted that there continues to be ignorance around the role of Indigenous researchers in relation to their dual accountability to their communities and their organisations with greater dialogue needed in this area.

Positivist science was considered to be too narrow an approach to effectively address the needs of improving health outcomes for Indigenous people. The model and its application limit solution development by failing to engage with communities and failing to approach health issues raised by communities holistically. Chapters 1 to 3 also argue this point, and my method chapter promotes approaches that focus on legitimate community collaborative participation that inform the research process in its entirety. This approach supports the review participants' statement that research should 'start with the community and end with the community' (Dwyer and Silburn 2009:14).

Ethics was raised by participants who claimed that the process did not ensure communities were informed. They were concerned that plans to streamline the ethics process would exacerbate this problem.

> The NHMRC also want to streamline the Ethics process in Aboriginal health research. This is unjust, immoral, unethical and inappropriate. It means if an academic organisation in Victoria wants to do a National reaching research project they only need approval through their State ethics committee. This means they can come to Alice Springs and do their research without going through our local ethics committee. I am really concerned that other people will be making decisions of what they think is ethically sound for a population group they don't know, how is that ethical? They do not have to live with the outcomes, they are not living with the Interventions as we are, that have already taken away our rights, and this is just another step (Participant 5).

Generally when research ethics are discussed, they are not explored using an Indigenous framework and context. If they were, this streamlining approach would never be considered, as

every Aboriginal Nation has their own laws related to their country, as the participant states it would be highly unethical to undertake this approach.

**'Review Question 3: Do the current Road map themes and questions have ongoing importance? If not, what changes to the Road map are desirable'** (Dwyer and Silburn 2009:16)?

On the whole participants believed that the Road map did need to be more explicit and strategic (Dwyer and Silburn 2009).

**'Future Proposals: Road map 2 as a strategic plan for action'** (Dwyer and Silburn 2009:18).

The Road map 2 proposal was to be inclusive of a number of matters:

1. Indigenous knowledge, leadership, values and ways of seeing the world must be central to the research endeavour.
2. 'Road map 2' should build on the Road map, by articulating a strategic action agenda, as well as a framework.
3. The NHMRC should develop a program of commissioned research, and should make other changes in the way Aboriginal and Torres Strait Islander health research is assessed and funded, in order both to address priority research questions and to recognise particular requirements in the timing and methods of research in this area.
4. Research transfer should be a major priority.
5. The NHMRC's work in Aboriginal and Torres Strait Islander research should be built on a strategy of community engagement.
6. A research agenda should be outlined, with a focus on social determinants of health and illness, health services/health systems research and identified priority health areas. Research should be inter-disciplinary and cross-sectoral.
7. The NHMRC needs to adopt strategies for building more active linkages with other important contributors and stakeholders in Indigenous health research.
8. The NHMRC should take an active role in Closing the Gap.
9. There should be renewed effort in capacity building for Indigenous health research (Dwyer and Silburn 2009:19-24).

The review emphasised the need to increase the focus on Indigenous communities and Indigenous researchers in the area of capacity building, skill development, as well as a recognition of the unique roles Indigenous researchers hold. This acknowledgement will undoubtedly increase community engagement, through research methods that are relevant and safe along with further use of Indigenous knowledge systems to inform solution development.

A key element discussed throughout was the need to reform the 'traditional' grant application mechanisms to support the priorities established in Road map 1 as well as provide the outcomes the NHMRC agreed to undertake in its 144th session. The Committee recognised that radical action was needed to effect reform:

> The Committee notes that the NHMRC has been trying to improve its efforts in this regard over a number of years, but given the enormity of the problem does not believe that anything less than a radical restructuring of the way Indigenous health research is managed will achieve what is needed (HRSCFCA 2000:126).

## Critique

> [t]here remains a need for further reform to optimise research outcomes for Indigenous people from research (Leon de la Barra, Redman et al. 2009:2)

The NHMRC's journey of Indigenous health research reform has been significant in relation to expenditure and its Road map for strategic research direction. However, its underlying philosophy remains traditional in its assessment of applications that tend to favour and sustain the old order approach to research **on** Aboriginal people rather than **with** them (Street, Baum et al. 2009). In this sense the NHMRC reform has not achieved a paradigm shift, which is essential in achieving health outcome improvements for Indigenous Australians. The traditional Western research paradigm has remained dominant but has clearly failed to bring about significant improvements (Ermine, Sinclair et al. 2004; Leon de la Barra, Redman et al. 2009). It is recognised that for a real change to occur, there needs to be an institutional transformation. This is tricky ground as the entrenched traditional approaches and their structures have profited from the way they do research (Henry, Dunbar et al. 2002). There has also been strong opposition to the methodological shifts that have been argued for by Indigenous researchers and communities

aiming to incorporate benefit for those researched rather than for the researcher (Henry, Dunbar et al. 2002). The NHMRC has acknowledged in the past:

> … the fact that past research into Aboriginal health has failed to address this poor level of health adequately, but has often concerned itself primarily with matters of interest to science or to white Australians (NHMRC 1989:4).

Leon et al.'s review of NHMRC policy reform highlights the fact that NHMRC policies on research funding could effectively inform research methodology, and yet this has not occurred (Leon de la Barra, Redman et al. 2009), despite the NHMRC being the 'major funder of health research' (Leon de la Barra, Redman et al. 2009:2). Perhaps this relates to Street et al.'s argument that Indigenous health research reform requires a different approach from its current funding mechanisms, because academic peer review of researcher-driven research continues to place the power of 'decision-making in the hands of the researchers' (Street, Baum et al. 2007:372) and generally the community and other stakeholders are avoided. Currently, many Aboriginal organisations are unable to access funding through the NHMRC as they do not qualify as a health or academic body. As already noted, the criteria restrict the research of community driven priorities and solution development and reinforce the power of an 'investigator-driven approach' (Street, Baum et al. 2007:372) that fails to incorporate an Indigenous worldview or Indigenous solutions (Larkin 2006:22).

Positivism's ontology and axiology used in Western medical research is heavily influenced by its own cultural framework that dominates and 'constructs the world we live in – named it, discussed it, explained it' ( Scheurich & Young 1997:8 cited in Larkin 2006:22). It validates its own bias and reproduces evidence to support its own cultural practice, hence the maintenance of descriptive research exploring disease and deficit. This point has been established in Chapter 3 in the section on experts informing experts. A Western way of knowing is different from Indigenous Australians' ways 'because of their divergent structural positions, histories and cultures' (Larkin 2006:22), resulting in research that tells a non-Indigenous story, but rather reflects its own cultural bias and history.

However, evidence-based positivist research has the backing of governments, which are also unreflective of their own cultural bias in their approach to Indigenous affairs. Larkin believes

that research outcomes will only improve when 'marginalised and disempowered groups' (Larkin 2006:24) promote their own needs through their own cultural worldview which will provide 'culturally sensitive evidence-based' (Larkin 2006:24) data devoid of 'racial political oppression and racist ideology' (Larkin 2006:24).

In this light, it is important to explore the most meaningful shift the NHMRC has undertaken in Indigenous health research, that is the increase in expenditure on Indigenous research of 5 per cent as recommended by the *Health is Life* report. However, the research funded through the 'People Support Awards' (Leon de la Barra, Redman et al. 2009:8) since the Road map was implemented continues to process descriptive accounts of disease and avoid Indigenous community engagement. The good news is that the 'Capacity Building Grants in Population Health Research' (Leon de la Barra, Redman et al. 2009:9) have increased Indigenous researcher participation, suggesting that more funding needs to be allocated to support collaborative approaches that build the capacity of Indigenous researchers and their communities. Evidence from Australia and overseas affirms that research is most effective in improving health outcomes when it evaluates what is actually going on with the involvement of Indigenous researchers and their communities instead of further descriptive accounts of disease and mayhem (Leon de la Barra, Redman et al. 2009).

Another NHMRC practice deemed inappropriate for Indigenous health research is the peer review model (Street, Baum et al. 2009:1). Research undertaken for the CRCAH through a literature review and semi-structured interviews examined the impact of peer review within the grant assessment process for Indigenous health projects. This approach continues to undermine the principle, from their own reform agenda, 'that Aboriginal people should control research about Aboriginal issues' (Street, Baum et al. 2008:1). Indigenous control of research is and has been strongly contested by the researcher driven community (Street, Baum et al. 2008:12). Because those researchers are supported by their peers in the grant assessment process, they are more than likely to get approval than projects that promote Indigenous community control. This is a vital issue when reflecting on the ethics, benefit and outcomes of research, and is discussed further in Chapter 8.

The literature highlights the fallibility of the current peer review process, suggesting its effectiveness is sketchy and problematic. Peer review structures remain shrouded within traditionalist frameworks that 'reinforce the existing power structures and research priorities' (Street, Baum et al. 2008:11) and peers are able to maintain this order through their selection of grant winners. It is a competitive regime focused upon researchers' track records rather than beneficial outcomes for those researched and is in direct conflict with the Indigenous research agenda (Street, Baum et al. 2008) as 'it incorporates belief models of first world societies' (Street, Baum et al. 2009:2). This essential Western bias supports the notion of research driven 'decision-making to researchers' (Street, Baum et al. 2009:2), which undermines the principles of Indigenous research reform. Although this process has been argued to be in the support of research rigour through excellence and track records, these requisites have often failed to provide the outcomes necessary for Aboriginal health research. Rather, these aspects, considered to be essential, can work to the detriment of those being researched in that the processes critical to outcomes are often ignored by the researcher such as capacity building within communities and transfer of findings. It is also the case that research is not rigorous if it fails to engage the people it is researching. This aligns with the Indigenous notion of respect: no respect means no rigour or validity.

Another failing of the NHMRC's Road map is that it has not incorporated a mechanism for measuring its impact. This makes it complicated to observe the recommendations that the NHMRC has implemented (Leon de la Barra, Redman et al. 2009:7). Hence:

> [t]here remains a considerable way to go before Australia could be said to have in place strategies that optimised the research effort in improving the health of Indigenous people. Government, the community and researchers should continue to advocate for improved funding and for the development of new models reflecting international best practice (Leon de la Barra, Redman et al. 2009:10).

## Indigenous dialogue

> NHMRC's commitment to improving the health of Aboriginal and Torres Strait Islander peoples is being implemented through a strategic approach based on priorities identified by Indigenous people themselves, and delivered within the context of a whole-of-government approach to Aboriginal Affairs (NHMRC 2008:1).

To what extent though were these priorities identified by Indigenous Australians? My own experience of participating in the Darwin RAWG workshop makes it difficult to appreciate that such identification occurred. The workshop I attended was not Aboriginal friendly or safe in that it relied upon a limited time frame, an inadequate and restricted consultative process, and was weighted towards non-Indigenous health academics, who outnumbered Indigenous participants, and constantly spoke over Indigenous people. As a participant in the Darwin consultation, my observation was that the agenda had been set, and that the consultants simply led key experts to discuss this agenda, which became the Road map. If the strategy's aim was to improve the health outcomes of our communities, injuring the community messengers is not the way to achieve this. Once again, people spoke on our behalf, determining our futures and theirs, ignoring the opportunity to learn from us, and appreciate our worldviews.

I did not attend the workshop in Sydney as my experience in Darwin had made me wary of being involved in such a process again. When I reviewed the participants who did attend, I saw that I was not the only Indigenous researcher who had given it a wide berth.

The national review report does appear to have acknowledged critical issues raised by Indigenous peoples this time round. Nevertheless, the Road map process was injurious to Indigenous participants:

> It makes you sad you get de-spirited by the process. Research does determine our future whether we like it or not and there is a lot of denial about that (Participant 5).

The bottom line in this NHMRC research agenda is explored by Participant 5:

> NHMRC still determines who will be researched and what will be researched and what will funded and not. The community once again is excluded from the process (Participant 5).

## Conclusion

Research and its reform is a site of struggle, as highlighted in this chapter. For Indigenous Australians, it is about the right to represent ourselves in a meaningful way in order to ameliorate the ongoing impact of colonisation. This requires funding bodies and researchers to recognise how colonial power structures continue to maintain Western privilege within this agenda, circumventing meaningful reform. Reform is necessary, and many steps have been taken towards

this; however, to shift the locus of control and power and to change radically how Indigenous Australians are represented and treated demands a significant philosophical shift:

> We are having to argue all the time about the rights of community. It is exhausting and injurious to us all. Lack of recognition of Indigenous peoples' rights remains a problem in this country and it's also a big issue in health research. Non-Indigenous Researchers keep trying to treat us all the same; they ignore what we say and ignore what we want. They fail to appreciate that we have country to protect and that we have to work within two sets of rules. So the roadmap does not take this into account either, it just continues to colonise us and aims to assimilate us (Participant 5).

There has been a great deal of goodwill, energy and hard work undertaken to reform Indigenous health research by Indigenous and non-Indigenous researchers, organisations and communities and this must be acknowledged. However we have not yet achieved what we have tirelessly been asking for: respectful engagement and to be heard. This lack of respectful engagement causes injury and will be explored further in the following chapters. Injury resulting from Indigenous health research does not build positive health outcomes. Ideologically, Indigenous health research reforms should focus on delivering improved health outcomes, however:

> Significant health gains for Aboriginal and Torres Strait Islander people cannot be achieved without strong Indigenous leadership and ongoing input into health research (CRCAH 2008:9)

Chapter 5 has explored and deconstructed the strategies of and barriers to Indigenous health research reform, evidencing that barriers highlighted in Chapters 1 to 3 remain in situ as a result of institutionalised colonialism. These barriers and the strategies to overcome them offer a basis for appreciating the ongoing conflict and problems that arise in Indigenous health research. These matters will be explored in the following chapters.

# Chapter 6

# The good, the bad and the ugly in Aboriginal health research

> Imagine how you would feel if every time you opened the newspaper your culture was denigrated and attacked. Imagine how you would respond if your self-esteem was constantly maimed and abused. When I read attacks on my Aboriginal culture, my soul is sickened at the very root (Bamblett 2006:1).

## Introduction

Chapter 6 explores the maintenance of cultural hegemony within Aboriginal health research via three reflective stories. Analysis of these three stories allows for critical consideration of the way Western health knowledge and theory continues to 'under-value Indigenous knowledges and perspectives' (Dunbar, Arnott et al. 2004:53).

The stories highlight the barriers, discussed in Chapter 5, to achieving positive health outcomes for Indigenous communities. These barriers emerged from analysis in Chapter 5 as: the imbalance of power between Indigenous people and the non-Indigenous researchers; the unshakable privileging and power of Western research practice; dismissal and omission of Indigenous ways of knowing, being and doing; the maintenance of descriptive research accounts that focus upon the problematising constructions and deficits of the Aboriginal Other; lack of ethical practice by researchers in the field; maintenance of power of funding bodies stipulations on what knowledge will be considered valid and meaningful; and the lack of acknowledgement of the impact of bias, paternalism and racism in research (Denzin 2003; Dunbar, Arnott et al. 2004; Dunbar and Scrimgeour 2006; Dwyer and Silburn 2009).

A fourth and final story examines an Aboriginal informed counter-approach to those highlighted in the first three stories.

## Story One: *Injury Study*

### Issue

Aboriginal and Torres Strait Islander people's injury and trauma levels are disproportionately higher than those of non-Indigenous Australians, some 2.8 times higher (Wenitong 2008:s37).

There has been a 'historical neglect of this area of public health' in Australia continuing to add to the burden of disease and injury for Indigenous Australians (Ollapallil, Benny et al. 2008:s3). The causes of injury are comparable to those of non-Indigenous Australians, 'suicide and transport accidents' (Wenitong 2008:s37), however Indigenous Australians suffer higher mortality arising from 'interpersonal violence and burns' (Wenitong 2008:s37); with a higher and sometimes fatal serious injury relating to 'interpersonal violence, falls and transport accidents' (Wenitong 2008:s37). Injury is one of the key causes of death and disability in Central Australia (Ollapallil, Benny et al. 2008:s8). Prevention of such high rates of injury and trauma requires a contextualised response informing the current 'gaps in knowledge of Indigenous injury' (Wenitong 2008:s40) and its different configurations.

The following story was such an opportunity to provide a contextualised account of Aboriginal injury in Central Australia.

## The story

This is an account of two researchers, working on a research project on Aboriginal injury in Central Australia funded by the NHMRC. The aim of the research project was to examine the impact injury was having on Aboriginal communities (Hulcombe 2006) with the key objective to 'determine community perceptions of the causation of injury and what to do about it' (Wright,2001:1 cited in Hulcombe 2006:1). The project included an:

> epidemiological assessment of injury in the region; an evaluation of the effectiveness of the Tangentyere programs [in injury protection]; an exploration of community perceptions of injury; and an ecological study in order to document policy and intervention priorities for injury prevention and to design one or more proposals for such interventions (Gray 2006:9).

It was established as a collaborative partnership amongst Tangentyere Council,[8] the Centre for Remote Health (CRH) and Research Centre for Injury Studies (RCIS) (Gray 2006:9).

The conventional approach of research funding from national health funding bodies requires that the Principal Investigator (PI) has a track record in the field of research and a published history in their field of expertise (Dunbar and Scrimgeour 2006). The PI, who worked alongside another

---

[8] Tangentyere Council is an Aboriginal organisation established to support Town Camps and their residents.

'expert' in Aboriginal health research who drove the project, was considered an expert in Aboriginal injury. The PI's injury expertise consisted of data collection and its analysis within a traditional positivist epidemiological epistemology. This way of knowing injury was an essential underpinning to the success of the grant application.

Indigenous injury conceptualised through a Western way of knowing has mostly focused upon de-contextualised data that have been collected through health services and other agencies and continues to be fragmentary and uncertain (Vos, Barker et al. 2007:i). On the whole, these data fail to provide the context in which the injury was sustained and its further consequences. It has been this conceptualisation that informs much research and further descriptions.

There is another way of knowing injury from another field of experts who are Aboriginal people experiencing injury (Gray 2006) who highlight that the Western conceptualisation is incongruent with 'Indigenous concepts of health and the generation of injury as a whole' (Hulcombe 2006:2). Rather than the Western view, Indigenous participants' contribution to and of this project required an Indigenous conceptualisation of:

> concepts of mental, spiritual and social injury since health is seen as involving physical, mental, affective and social functions and any impairment of these functions is seen as injurious (Hulcombe 2006:2).

These ways of knowing are aligned and in keeping with the National Aboriginal Health Strategy (NAHSWP 1989: x) definition of Aboriginal health. They also correlate with the social determinants of Aboriginal health, namely colonisation as defined by Joan Vickery et al. (Vickery, Faulkhead et al. 2007). This determinant is 'collective trauma' that remains part of a National Aboriginal community memory and lived experience (Vickery, Faulkhead et al. 2007:23). Judy Atkinson explores this notion:

> Collective or communal trauma refers to traumatic experiences which are experienced by large groups of people, who may therefore share some of the psychological, cultural, physical, spiritual, social and mental distress (Atkinson 2002:53)

These experiences of trauma have been meted out through colonisation as genocidal policies, massacres, warfare, dispossession, slavery, stolen generations, racism, and unrelenting grief and

loss (Atkinson 2002; Raphael, Delaney et al. 2007; Vickery, Faulkhead et al. 2007). The literature in Aboriginal defined injury is not extensive; however it is critically being developed through the work of Indigenous academics such as Judy Atkinson and Gregory Philips (Atkinson 2002; Phillips 2003) and acknowledged as a determining feature of Aboriginal health as argued by Tom Calma, the Aboriginal and Torres Strait Islander Social Justice Commissioner (A&TSISJC 2009).

The Injury project PIs employed two Aboriginal women and a non-Indigenous male to undertake the field research work with Aboriginal communities and develop the literature review on Indigenous Injury. The Indigenous author of the first draft of the literature review was regularly told she was pushing an Aboriginal agenda which failed to appreciate the Western science of de-contextualisation. Essentially, she was told to stop blaming the white fellas. From my own reading, her draft documented much of the qualitative data related to colonial injury of Indigenous people worldwide and she was attempting to explore these universal phenomena as a direct result of Aboriginal Australians' colonial experiences. Her review also canvassed the multiple reports on petrol sniffing in Central Australia that continued to promote more research, rather than abating the injury occurring.

> You know millions of dollars would have been spent on all those reviews and hardly any money hit the ground for those kids and when you think about it, it is just millions of dollars spent on people researching (Participant 7).

The PIs were insistent that this was the approach they wanted to take, and that more research was necessary, because:

> There's still these same people and others that are still doing the same research and where do they get the money from and why and who is the research for; that is the question, who is it for? (Participant 7)

So they handed the draft over to a non-Indigenous researcher who was told to re-write the literature review properly as the last author was unable to write it effectively or to their specifications. This rejected author went on to win the Miles Franklin Award for a novel she was writing during this project. It came to pass that there were many authors of this draft literature review, because it continued to tell a story the PIs were not happy with and in the end it was

never completed because it failed to support their expert non-Indigenous hypothesis on Aboriginal Injury that required more research.

The two researchers' experiences have been shared to explain the problems they had working on the project as well. They both undertook fieldwork, running focus groups and in-depth interviews in remote communities and Alice Springs. The data co-generated[9] with communities were collated and presented back to communities through workshops. One workshop held in Alice Springs resulted in the participants' painting the story of injury for themselves. Unfortunately the PIs did not appreciate this form of data.

The Injury report has not been completed or published as a result of the ongoing conflicts arising from whose story counted (the research expert's or the community's). However, the project's findings were released in a discussion document presented at the Centre for Remote Health Alice Springs Seminar Series in 2006. Participants interviewed from this project were simultaneously undertaking research for the Injury project as part of the research survey on the Grog trials in Alice Springs that will be explored in the following chapter.

The key problem with this project was that the funding body and research experts had defined the research problem and question rather than asking the Aboriginal communities how they would define them. The site of conflict was the research objective to 'determine community perceptions of the causation of injury and what to do about it' (Wright 2001:1 cited in Hulcombe 2006:1). The conflict was between the Principal Investigators (PIs) and the researchers conducting the reviews and interviews. The traditional approach and way of knowing used in undertaking this project differed significantly from the ways of knowing of the researchers and Aboriginal communities. The PIs' task had been set out by the funding body's guidelines, which required them to satisfy the funding body's criteria. This direction in itself would determine whose perceptions determined the causation of injury for Aboriginal communities and what would be done to alleviate it.

This approach is problematic for Indigenous people because, as Smith argues, it is critical that the methodology and methods fit with the issue being examined to ensure research findings are reliable and valid (Smith 1999:173). If the perceptions and concepts driving the methodology are

---

[9] This is a term used throughout the thesis for the process of the collaborative growing of knowledge.

outside and dismissive of an Indigenous lived worldview it will undeniably produce invalid data about Aboriginal people (Dunbar and Scrimgeour 2006). This is an issue of 'construct validity' embedded in cultural knowledge. This point is summed up by Hulcombe regarding the methodological approach:

> To my mind the theme that needs to be stressed most is that injury, in any context, cannot be studied fruitfully through the lens of biomedical reductionism. Injury does not just 'happen' (Hulcombe 2006:1).

Such expert determinations have been problematic for Aboriginal peoples, as previous chapters have outlined. Hulcombe articulates the reason for this concern:

> In the diagnosis and alleviation of injury, it is critical that the understandings of the cause of injury for Aboriginal people are remedied from their perspective. To do otherwise is to mistreat the ailment and compound the pain (Hulcombe 2006:3).

Previous research into and conceptualisations of Indigenous injury have failed to encapsulate what Aboriginal people believe is the cause of their injury resulting in solutions that fail to address what communities want addressed.

> This limited and ill-defined view has too much of a "victim blaming" connotation attached. It also has the effect of limiting parameters of policy and programs to an ineffectual level (Hulcombe 2006: 2).

This is at the heart of undertaking research from an Indigenous methodological approach. It requires changing the ideology held by decision makers through the narrating of Aboriginal stories and truths. By sharing Indigenous truths, Indigenous people are seeking to shift the current constructions of them as problematic to resilient (Atkinson 2002:260). This story highlighted that:

> All phases of the project indicate that 'injury' is a construct whose meaning is heavily influenced by the culture of whoever happens to be defining it (Hulcombe 2006:2).

The researchers knew that solutions for Indigenous injury necessitated Aboriginal people defining what injury was to them and their community. This was another site of conflict. Both

180

participants I interviewed believed that the agenda for outcomes had been set by the funding body and the experts. The following statement illustrates the Indigenous researcher's frustration with the expert investigator driven approach.

> I feel such sadness, like its all gammon[10].
>
> Starting with this project I can see that research, whatever it is, is not making any difference really, well not for the people who are the research subjects.
>
> Before this job I hadn't much experience with research really, and in the beginning I had big expectations for this project, I thought wow things are going to happen and I am going to do all this stuff. But then within the first month everything was shattered. Within the first month we had meetings with the boss and someone from Adelaide, and it woke my eyes up to what was really going on (Participant 1).

Aboriginal researchers believe the work they agree to undertake will make a difference to their communities and build up sustainable solutions. They are promised they will be taught skills, and that this research will make a difference.

> They make it all glitz and glam and the people are just hanging out for some real difference (participant 1).

Effective and competent workplace supervision of Aboriginal researchers means being honest about the benefits for the community, the researcher and the team (Laycock, Walker et al. 2009:68). This was not the case. The workplace failed to respect the researcher's 'Indigenous knowledge and worldview' (Laycock, Walker et al. 2009:68) and dismissed their contributions along with their ways of knowing of working with the communities and 'this is where a lot of tensions comes from' (Dianne Walker cited in Laycock, Walker et al. 2009:15). This left the informant to state:

> I was really devastated, I was. I was just seeing things never change, they just get worse, sometimes they get a little better, better in the sense that the town gets cleaned up so you can't see anything, but it is still happening, but then it will when they don't listen (Participant 1).

The experience of working on this project led that researcher to identify who was benefiting from the research, and it was not the communities.

---

[10] Gammon: is made up, not true.

Their career is getting accelerated, their names are getting on the journals and they are getting invited to these conferences to give big speeches with big experts on this and that. But they're not experts on fixing things, they are just experts on making themselves into something. That hurts me. I was naïve, I really thought people, professionals in these areas had a heart, and some kind of sympathy to make a change and help people (Participant 1).

Both researchers were concerned that the PIs' approach would change the essence of what had been communicated by a number of Aboriginal Central Australian communities regarding 'injury amongst Aboriginal people and injury to Aboriginal people' (Hulcombe 2006:2).

When I hear them talking I felt shame because, how come these guys got their hands on this, and I sit there thinking about what's gammon, what can we do, and off the top of their heads they say "Oh look, this is what you have to do." How can they know how it is going to be? They haven't even thought about it or talked about it, it is just off the top of their head, like this is the answer (participant 1).

The process became injurious to the researcher who stated 'I felt shame because I don't know what to do. I know it's not going to work' (Participant 1). The experts dominated the solution development and prevented the researcher from effectively participating and being heard. Knowing that the outcome would not benefit communities and perhaps lead to further injury resulted in this feeling of shame and being 'inferior' (participant 1). To feel inferior and shamed is injury, a product of expert superiority and cultural incompetence (Laycock, Walker et al. 2009).

The project's aim was not being achieved. Rather than uncover the determinants of injury, it appeared that the experts were causing injury. This occurs also when community members and their organisations are not heard in the research process causing people to lose 'confidence, feel hurt, anger and suffer stress when their view of injury and what is required to adequately challenge the issue is either ignored or given token recognition' (Hulcombe 2006:3). These 'feelings of hurt, anger and stress are then multiplied when the program meets its inevitable conclusion' (Hulcombe 2006:3). The inevitable conclusion is invalid data as a result of unsafe processes that will undoubtedly further problematise Aboriginal communities. This is injury to those (Community) people; and may manifest itself as injury amongst themselves' (Hulcombe 2006:3). This is why research has a dirty name for Aboriginal communities. Further injury

results from injurious research that 'could be in the form of substance abuse, failing health or a decision not to try again. With program failure there is also the inevitable ongoing injury amongst the targeted group, which was not effectively addressed and therefore continues unabated' (Hulcombe 2006:3-4). This is the succession of neglect that can result from unsafe research approaches.

Hulcombe is critical of the turnstile of promises that never eventuate, after communities have invested in research projects with their time, knowledge and hearts. Often the investment leads to despair as the community waits for the promises that never arrive, let alone the findings of the research undertaken on them, filled with their intellectual property and hope (Hulcombe 2006). Participant 2 explores this notion as a result of contacting a remote community:

> I go down to one of them and they say "Sorry we don't want to talk to you mob, we've had enough of talking, nobody supports us, we don't want to talk about anything anymore". They've had it. They were hurt! (Participant 2)

There are numerous problems highlighted by the researchers of this project that relate to maintaining the integrity of the Aboriginal people who gave of themselves. However the PIs failed to recognise the importance of Aboriginal ways of knowing for its direction, process and outcomes, creating another barrier to effective Indigenous health research (Dunbar, Arnott et al. 2004). This causes injury:

> What I've learnt or felt people have tried to explain to me over time is that for those issues that occur on their land, for all those things that affect people, that they have their own authority to speak, and that to articulate that to someone else and in the academic manner to frame it within someone else's theoretical framework or whatever … worldview, was not to present the evidence as it stood so to speak. The evidence was that people's voice has its own authority, and it has its own source of authority even more so. To deny that was to deny the person, and to challenge their wellbeing, which is what is happening (Participant 2).

Failing to acknowledge Aboriginal people's perspectives, the researchers argued, was injurious to the Aboriginal communities and themselves. Paredes (1994) claims 'the parallels between the dispossession of native people's land and dispossession of their intellectual products are riveting' (Paredes (1994:v) in Ermine 2000: 75). Much of this intellectual product is information given by

communities to researchers in the belief that change will occur. Participant 2 discusses what the gains are in enabling Aboriginal control of the process:

> I am new to research, but my experience from my short time here is that that authority and voice and the knowledge it holds is just being totally shoved aside. And when people try to listen they totally misinterpret it or can only act in a limited way because there are all these other structural restraints that occur and that crop up. There is just no letting go. And that comes up against I guess that universal truth (Aboriginal Law) we were talking about earlier on, because, if you are able to let go there is no danger there, there is actually benefit to be derived, because you are actually fitting in with the truth. You'll start to, you actually start to gain that knowledge and that's a plus (Participant 2).

Alienation of Indigenous knowledges from people's own lived context is problematic, raising concerns regarding the validity of such results. It is insinuated in the injury project under discussion that research must be grounded within a Eurocentric framework to be considered valid. This obsession is fraught with further development of invalid data and remains the problem Aboriginal people have with research (Smith 1999; Ermine, Sinclair et al. 2004). For the PIs, the data developed from hospital breakdowns of injury occurrence held greater meaning than the community's exploration and ownership of their issues and concerns through a medium that holds authority for them. The community used a well-known and authorative medium of painting to explore their injury story.

> Well in this research we have presented people's knowledge as they present it and we have tried to value it for being what it is, tried to demonstrate that at a practical level so in a sense we have the information from the 'horses mouth'. I was at a meeting recently where the question was raised "Do we have any academic literature which explains what these paintings are about just so these people won't think we are pulling it out of air?" I was a bit dumbfounded about that (Participant 2).

It is this lack of insight held by many researchers (be they Indigenous or not) that ensures only data they consider meaningful will be utilised. The result of such actions again can lead to invalid and unreliable data (Smith 1999). It causes injury to those who shared their knowledge, breaching respect of what was given without a reciprocal outcome (NHMRC 2003). Participant 2 argues that the continual engagement of sharing knowledge in research is injurious:

184

Well, I haven't seen a lot of research per se…..yeah, I have seen the boot end of it so to speak, and it's totally destroying. I get amazed how people keep wanting to engage! I know it is having a disastrous effect on a lot of people but there is still willingness and a wish to engage … And that's the whole injury thing (Participant 2).

The participant was concerned about the ethical nature of the project's process. Tight timing is defined by funding bodies and makes thorough consultation difficult. The timing establishes an approach that rushes people, something Participant 2 believes is disrespectful. Clearly articulating an approach that people observe as disrespectful to themselves will cause injury. Many Indigenous researchers are placed in a position that they feel is unethical, because they know they are breaching the values and protocols of the community they are working with. This in turn causes injury to both the researcher and the community they are working with. As Participant 2 explains:

What position was I put in!? And to go out to the remote communities – that was prior to the town communities – and they didn't know [about the project] someone may have wrote a letter approving it two years earlier – so where was I left!?

I feel disappointed because … I feel like I was set up.

You know in Rugby Union with the suicide pass I think it's called now days, but in my days it was called 'sold the dump', where someone passes to you and everyone is there waiting to tackle you. That's how I feel a bit, I feel like I got sold the dump (Participant 2).

Sadly, these issues are generally considered to be insignificant to the outcome of the all-important report. Participant 1 articulates this, stating they believed that their voice during the research process along with communities being interviewed 'had no power, no authority, no nothing' (Participant 1). When the Aboriginal researchers tried to steer the project to be respectful of community protocols, the experts were annoyed.

They just put up a tension that they were annoyed that they were put in that position. I could see that they were scared that the project may be taken on a path that they don't want it to go. I could feel that, and I don't have any experience with this, but I could see it. And I thought, so how do the people that this project is going to influence or control get to have a say? This project will have some recommendations, or policy, that will influence their lives and they didn't even want

them involved in the process of actually developing the project and that hurt me. It scared me away from this kind of thing (Participant 1).

Participant 1's concerns are critical and relate to several of the general concerns Aboriginal people have regarding research today. It also illustrates how research of the past controls the ways of knowing and doing Indigenous research. The crisis highlighted in this project is that the traditional paradigm of doing health and medical research, in particular on Aboriginal people, remains inflexible to the very needs of the people they are researching.

That is what cuts me up, doesn't anyone care? And all those Aboriginal people out there caring, nobody wants to support them, and they are getting injured. The cycle starts with them, the researchers (Participant 1).

Indigenous research methodologies seek to change this by challenging the paradigm and way of knowing held by experts that produces injury through problematic constructions of Aboriginal communities. It aims produce valid, rigorous and meaningful data using methods and ways of knowing, being and doing that do not cause injury.

## Story Two: 'An evaluation of a SAFE-style trachoma control program in Central Australia'

### Issue

Trachoma is a disease 'caused by repeated episodes of eye infection with *Chlamydia trachomatis*' (Couzos and Taylor 2003:574). Repeated infections of chronic conjunctivitis causes scarring of the conjunctival along with an 'eversion of the eyelid' (Couzos and Taylor 2003:575). This can lead to damage of the cornea from in-turned eyelashes that, if left untreated, will cause blindness. It is a disease that is preventable and remains endemic amongst Aboriginal populations in Australia (Couzos and Taylor 2003). Donna Mak asks 'Why is Australia the only developed country with endemic trachoma' (Mak 2006:487), and it appears that there are a number of reasons: lack of education and training for health professionals (Couzos and Taylor 2003:584); it is simply another neglected public health area as a result of inconsistent health provision from states and territories since the National Trachoma program finished up in 1978 (Mak 2006:487); it is a disease occurring in Aboriginal remote communities (Kaplan-Myrth

186

2004); and lack of will by governments to improve housing infrastructure, a critical determinant of this disease.

**The story**

The following review of a research article titled 'An evaluation of a SAFE-style trachoma control program in Central Australia' by Ewald, Hall and Franks, published in the *MJA* 2003; 178: 65–68, explores why trachoma is endemic in Australian Aboriginal populations.

It reports an evaluation of a program focused on 'trachoma control' (Ewald, Hall et al. 2003:65) prior to and at the completion of minimal housing infrastructural repairs claimed by the authors as 'major environmental health improvements' (Ewald, Hall et al. 2003:65). The treatment and study consisted 'of three elements of the SAFE strategy – community antibiotic programs, facial cleanliness, and environmental health improvements' (Ewald, Hall et al. 2003:65) in a remote central Australian community. The trial of treatment ran over 21 months while some sanitation and housing improvement occurred within the first 12 months (Ewald, Hall et al. 2003). It was hoped that these approaches would reduce trachoma in this community.

Ewald et al. state the elevated prevalence of trachoma infection prior to treatment led to greater than 70 per cent of the community's population being prescribed antibiotics. However their anticipated reduction in numbers of people continuing to have contagious trachoma did not occur. The community's environmental infrastructure improvements, documented as 'major environmental health improvements' (Ewald, Hall et al. 2003:65), in 1999, included the building or renovation of 24 houses (no clarification as to what type of renovations), the installation of 'a reticulated sewerage system and treatment works' (Ewald, Hall et al. 2003:66), 'and the laying of lawn on an oval as well as the sealing of some roads for a population of some 900 Aboriginal residents' (Ewald, Hall et al. 2003). And yet:

> the housing in this community remains inadequate in number, and most homes were inadequate in functionality one year after the housing was occupied' (Ewald, Hall et al. 2003;66).

Overcrowding and environmental causes are considered to be keys determinant of this disease along with poor socio-economic status (Couzos and Taylor 2003:582). However, the authors write:

Population mobility (both within and between communities), inadequate housing and continued crowding (despite improvements), as well as uncertainty about compliance with antibiotic treatment, are the likely factors contributing to the lack of effect of this trachoma control program. Because of high population mobility, a region-wide approach is needed for effective trachoma control (Ewald, Hall et al. 2003:65).

This exemplifies a discourse of problematic constructions with medical compliance arising as another a bio-medical discourse of power that Humphery et al. argue is laden with paternalism and blame, targeting the Aboriginal community in the Northern Territory (Humphery, Weeramanthri et al. 2001).

To cling to the static notion of 'non-compliance' in relation to Aboriginal 'patients' is to cling to a century or more of similarly static, blame directing and unproductive thinking (Humphery, Weeramanthri et al. 2001:vii).

The term continues to be in use in Aboriginal health research articles. However a critical review of National trachoma programs argues that the reasons for non-compliance sit squarely in the hands of governments and health services (Roper, Michel et al. 2008).

The notion that the Aboriginal community continues to be the problem is conveyed even when offered a health treatment program and housing improvements. However Humphery et al. established why this type of discourse is used:

This effectively absolves the practitioners from further exploring and politically engaging with the socio-economic 'causes' of patient non-compliance, beyond that identified through the clinical encounter itself and by way of a rather shallow grasp of 'environmental determinants'. It also effectively precludes a fuller exploration of the ideology and material practice of the medical encounter in terms of its embeddedness within structures of power, authority and social control (Humphery, Weeramanthri et al. 2001:6).

Ewald et al.'s introductory statement highlights the pathologising of Aboriginal peoples that is commonly used in these descriptive research accounts:

In Australia it is now almost exclusively a disease of Aboriginal people. High prevalence rates have been associated with poor environmental health conditions, inadequate hygiene, crowding,

low socioeconomic status and an arid environment. The main reservoir of infection and transmission is among children and those who care for them (Ewald, Hall et al. 2003: 65).

But a completely different interpretation of the findings can be made if a historical, political and social reflective perspective is taken. This is critical to the reading of such articles because, as Cunningham et al. suggest, there is evidence that clinicians can be 'contributing inadvertently to "this treatment gap' because they bring to each consultation 'prior beliefs about the likely nature of the condition' (Cunningham, Cass et al. 2005:505). Unreflective writing of doctors and failing to include the contextualised experiences of their subjects will misinform their readers. Researchers have a responsibility to ensure that their belief and assumptions are stated and not hidden within 'their' findings.

Bio-medical terminology used to explain the incidence of infection lays the blame on the 'reservoir of infection and transmission … among children and those who care for them' (Ewald, Hall et al. 2003). This terminology was used by doctors in the early 1900s to convey the rampant disease-ridden Aboriginal community who were a threat to the health of white populations (Anderson 2002:145). The statement is considered shaming and is not entirely correct as Couzos and Taylor suggest that there is another transmitter of trachoma, the fly (Couzos and Taylor 2003). The expert statement indicates the obsession of health providers to relegate patient behaviours as problematic. This ensures Aboriginal parenting is pathologised as a determinant for poor health status.

Hugh Taylor's assessment of what is required paints a different picture:

> [t]o eliminate trachoma in Australia we need to upgrade the basic services and housing of Indigenous communities in the outback to the same minimal standard that every other Australian enjoys (Taylor 2001:372).

Housing is inadequate and substandard, contributing to a host of health-related issues (Pholeros, Rainow et al. 1994; Bailie and Myfawny 2001; NACCHO and Oxfam 2007). Access to sanitation, clean drinking water, garbage collection and transport are not available to all Australians, especially those in Central Australia (Ring and Brown 2002). These are verifiable causal agents in infection and transmission, rather than simply 'children and those who care for them' (Ewald, Hall et al. 2003:65). The lack of these basic services ensures that a 21-month

program of antibiotic regimes, face washing and hand washing will not contribute much to the treatment of this endemic disease.

Most Central Australian Aboriginal communities do not have access to an environmental health program (HRSCFCA 2000; Ring and Brown 2002). Funding for comprehensive primary health care, including the social and infrastructure needs of Aboriginal communities would ensure more effective assessment, regional treatment and education programs as recommended by the new National guidelines (Mak 2006). However Aboriginal health services as presently funded can only focus on critical health priorities. These are key impediments.

> Structures and processes within governments and professional institutions influence eye health programs. Commonwealth government bureaucrats use the metaphor of a 'filter' to describe the many layers through which eye health policy must pass before programs reach the ground level (Kaplan-Myrth 2004;13).

Yet Ewald et al.'s line of argument suggests that such service provision and housing improvement are not the solution. Instead, they imply that the disease persists because Aboriginal people choose to live in an arid environment, their cultural lifestyle and poor parenting. These associated factors are incorporated in the phrase 'Remote Aboriginal health condition': Aboriginal people living in remote areas are far enough away to be forgotten, or stigmatised with the 'disease of poverty, ignorance and dirt' (Kaplan-Myrth 2004:2). Ewald et al. also stated that the WHO Safe strategy had not been implemented in Australia (Ewald, Hall et al. 2003). There is contravening evidence from the Kimberleys in Western Australia:

> The World Health Organisation SAFE strategy has been implemented since 1996, as described in the Kimberley regional trachoma control guidelines and a peer-reviewed publication (Johnson and Mak 2003:116-17).

Some of the literature I reviewed demonstrates that the SAFE approach is working well and prevalence rates have been reduced (Roden 2000; HealthInfoNet 2001). Hugh Taylor, a specialist in this area argues that that prevalence in Central Australia has remained unchanged for 20 years. He stresses that Australia is the only developed country in the world where blinding trachoma remains a problem (Taylor 2001). In fact it is the cause of 50% of blindness suffered by Aboriginal people (Thomson 1998). The World Health Organisation (WHO) set up the SAFE

190

strategy to eliminate trachoma, and it was agreed under a former Health Minister in 1997 to support the NT in this endeavour. However, very little has happened since this agreement (Taylor 2001), which is not surprising in light of the structural impediments discussed by Kaplan-Myrth. The lack of service intervention related to eye health care is a critical omission of Ewald's study and one that Mak states has been a key barrier to trachoma control (Mak 2006). The NT Health Department is responsible for the provision of this care (or lack thereof), and the Commonwealth for the funding of this care (Kaplan-Myrth 2004). It may have been a more cost-effective research project to find out why SAFE had not been delivered. Kaplan-Myrth writes:

> Primary eye care is a grand idea, but is it effective? Irrespective of the World Health Organization and the Australian Commonwealth government's emphases on primary eye care and community based rehabilitation, in practice most Aboriginal people still do not have access to any form of eye care (Kaplan-Myrth 2004:6).

Research undertaken, in 2000 (Laming et al. (2000), provided evidence of an increase in the prevalence of trachoma in Central Australian Indigenous populations recommending better treatment programs and improvements in living conditions (Laming 2000). Perhaps Kaplan-Myrth's exploration of the National eye health policy and service provision provides reasons for this.

> The complexity of the eye health network and the hierarchy of players within that network exacerbate conflicts and lead to breakdowns of every sort. Even straightforward epidemiological information about the rate of eye diseases is lost in the fray (Kaplan-Myrth 2004:9).

This information is fundamental to explaining what is *not* happening on the ground at both a State and Federal Government level. This fundamental point is not captured in Ewald et al.'s study. What has been further omitted from the study is the fact that a National eye health program has been running for some twenty years in Australia, but it is not funded adequately in the NT (Kaplan-Myrth 2004). Instead of undertaking a critical analysis of the lack of implementation of service provision, Ewald appears to focus on the victims of ineffective health services. This study failed to explore the context of the causal agents of trachoma in this community; instead it takes a narrow, positivistic approach conveying the same old mantra: Aboriginal people are the problem.

**Story Three:** *National Indigenous health evaluation*

**Issue**

Western ways of knowing Aboriginal people's issues continues to inform national health policy and practice. This next story explores whose knowledge really counts in Aboriginal health service provision.

**The story**

I accepted a position as Aboriginal Research Fellow in 2002, funded through Primary Health Care Research, Evaluation and Development (PHCRED), a National health agenda aimed at building the capacity of research in the area of primary health care. I was informed the role would build my skills and capacity in Aboriginal health research, important skills for one focused on Aboriginal health improvement. In most projects I was asked to be on, training or capacity building was not part of the agenda of the organisation or of the Principal Researcher. Rather, my role was setting the projects up, establishing or renewing relationships with Aboriginal communities, undertaking interviews and the administrative necessities of such work. I was excluded from preparation of funding submissions, analysis of data and the final reporting of such data. This exclusion ensured I remained a research assistant rather than growing the skills necessary to be a Principal Investigator. In support of this notion my ex-Manager more recently wrote: 'We have moved away from the idea of the Indigenous researcher as the 'research assistant', collecting data for someone else to analyse and write up' (John Wakerman, Director, Centre for Remote Health, Alice Springs cited in Laycock, Walker et al. 2009:128).

This is an important shift and one perhaps learnt from the loss of several Aboriginal researchers. As a result of this change the researchers now want to 'exploit and learn from the skills and experience that each Indigenous researcher brings to every stage of the research process' (John Wakerman cited in Laycock, Walker et al. 2009:128). Exploitation had always been a colonial strategy. However to learn the skills that each Indigenous researchers brings requires non-Indigenous researchers to respect and listen to their Aboriginal researcher colleagues and value their ways of knowing, being and doing.

The Office of Aboriginal and Torres Strait Islander Health (OATSIH) commissioned an independent review of a National Indigenous health program, funded by OATSIH. The review

required a body of researchers and consultants with experience in Indigenous health to undertake a review for their funding body. The organisation I worked for submitted and won the review project. An Aboriginal researcher was a critical component of this project, and as the Aboriginal research fellow within this workplace I became the essential token for the project.

The National Health project's Principal Investigator (PI) was non-Indigenous, a previous employee of a National Indigenous health body, and friend of my manager. I had a number of administrative roles including the preparation of the information sheet and consent forms for Aboriginal participants and the ethics application. I was also requested to undertake the interviews with the PI in NSW. This required re-establishing contact with Aboriginal stakeholders and communities to ensure they were able to be part of the project in a manner that was meaningful to them.

Aboriginal researcher, Kim O'Donnell, explains this process:

> A lot of time is needed to facilitate and mediate the research process with Indigenous stakeholders. There is a lot of explaining to do, about the project and also about contemporary research practice and how it's different from the past. … As the Indigenous researcher, you need to spend a lot of time talking to people (cited in Laycock, Walker et al. 2009:72).

We spent less than a week in the field interviewing staff and clients of a health service. We visited one clinic and its outreach site. Both sites impressed me with the holistic approach the health service had taken to implement this program. The service focused upon patient-centered care and emphasised a one stop shop for clients who are notably the most disadvantaged within the Australian population (NATSIHC 2004). The team had built up successful partnerships with other related existing services and critically with the community. The only shortfall I observed was funding.

The health service had prepared a great deal for our visit, organising clients and staff to be interviewed and providing a space for us to work. The interviews went well as the service had informed their clients of the reasons for the interviews as well as ensuring staff were given time to participate. We were able to observe the clinics in action and were informed of how the holistic approach had saved a number of people's lives.

On the final day in the field, the PI organised a meeting with the Chief Executive Officer (CEO) and the Program Manager (PM) to discuss the next steps of the project as well as, I believed, to thank them both for their support of the research team in this project. I attended this meeting and it initially went well until the PI provided her perspective of the service. She claimed that the holistic approach was an inappropriate way of providing the program. This assessment confirmed the PI's lack of knowledge and comprehension of Aboriginal health praxis that is linked to the working definition of primary health care, that is:

> ... based on practical, scientifically sound, socially and culturally acceptable methods and technology made universally accessible to individuals and families in the communities in which they live through their full participation at every stage of development in the spirit of self-reliance and self-determination (NAHSWP 1989:x).

This point is important to the manner in which the report of the qualitative data we were collating would be discussed. Without a sound appreciation of the context of community health philosophy the report would miss the vital differentials that are Aboriginal primary health care. As the PI was simply an investigator and not representing a funding body, the critique was uncalled for. The statement, however, shamed both the CEO and the Manager of the Program. I believed I had to interrupt and attempt to explain the notion of holistic health care as well as disarm the aggressive attack on the CEO and Program Manager. The researcher told me to shut up and keep quiet as she was not interviewing me. The tone of her response was aggressive and demeaning and ensured that all in the room were left feeling acutely uncomfortable and injured. Her approach was disrespectful to us all. She ignored my responsibility to this community:

> The role of the Indigenous researcher is often undervalued by investigators ... the Indigenous research brings the substance. If you haven't got support from the Indigenous community, you haven't got the project. We call, talk, explain and build trust in the research. People may not know the research leader, but they will know me (Kim O'Donnell cited in Laycock, Walker et al. 2009:72).

Kim's point is relevant to this situation and to many others. The PI's disrespectful approach immediately lost the NSW project's credibility and trust that I had attempted to build. When the PI left, the CEO and the Program Manager told me that they were deeply offended by the PI's criticism especially in the light of the time and support they had provided. I attempted to

apologise for the PI's behaviour. It had deeply shamed me, especially in the light of having distressed community members. I said I would make an official complaint to my Manager about this PI's behaviour. I personally felt I had let the community down.

On my return I spoke to my Manager regarding the PI's behaviour, requesting an apology for the CEO and PM. I was taken off the project as a result of my actions and an apology was not delivered to the CEO or PM. I considered this lack of response to be indicative of the lack of respect they held and demonstrated for Aboriginal communities and their Indigenous employees. This project illustrated the manner in which ethical praxis in Aboriginal health research is set within a Western worldview fixated on the belief of its own cultural superiority in the attainment of knowledge about the Other.

## Story Four: *Otitis media Redfern*

This story has been presented to explore the importance of Aboriginal community control in Aboriginal health research. The research was a process grounded by Aboriginal people, and it aimed to make changes that would improve Aboriginal children's life opportunities.

### Issue

Otitis media is a middle ear disease that can cause conductive hearing loss. If it damages the middle ear significantly, this hearing loss can be permanent (Sherwood 1997). The prevalence of otitis media disease and its consequences are greater for Indigenous children than for non-Indigenous children (ABSAIHW 2008:90). Damien Howard, an educational psychologist working in this area for over twenty years, believes it is a disease of poverty with associated features of 'crowded housing, poor access to health care and nutrition' (Howard 2009:31). Importantly, this disease:

> [c]an affect Aboriginal and Torres Strait Islander babies within weeks of birth and a high proportion of children will continue to suffer from chronic supprative otitis media (CSOM) throughout their developmental years (Thomson and Ring 2008:103).

This finding is critical as learning to listen and developing speech occurs within these early years (Sherwood and McConville 1994). For children whose first language is not English, attempting to learn another is extremely difficult with a hearing loss (Howard 2009). This is the situation for

an estimated 90 per cent of the Aboriginal child population in the Northern Territory (Howard 2009:31).

**The story**

In 1988 I was employed as a child health nurse at Redfern community health. In this role I screened children in their first year at school in the areas of hearing, otoscopy, visual acuity and speech. I observed an extremely high prevalence of conductive hearing loss amongst Aboriginal students in all primary school grades and alerted the medical officer who I worked with of the rates. The medical officer stated that this had always been the case. As a teacher and Registered Nurse I was aware of the significance of unrecognised and unaddressed hearing loss in relation to learning and behaviour.

By talking to the parents of children with conductive hearing loss I found that there was a familial history of both otitis media and no action. Parents from the Redfern Aboriginal community, Aboriginal Education Assistants and teachers were concerned about numbers of students and the educational impact on them. Due to otitis media's invisible nature and students' coping mechanisms, the hearing loss was not obvious (Sherwood 1993). Yet, as Howard suggests, children's coping mechanisms at school and home were getting them into trouble with many being labelled 'defiant or naughty' (Howard 2009:31) or worse.

A community meeting was organised at the Aboriginal Education Program Unit of Sydney University. In attendance was an Educational specialist from the Menzies School of Health who recommended a small research project be undertaken to chart the prevalence within this urban area. This project was undertaken with the support and consent of the community, and three local inner-city schools. The findings were comparable to prevalence rates of rural and remote communities throughout Australia.

> The study found that 81% of Sydney Aboriginal children's ears appeared otoscopically abnormal, and the same finding was made by Sunderman & Dyer (1984) with Aboriginal children in the Kimberley region of Western Australia. Further, the finding that 13.5% of tympanic membranes of the Sydney schoolchildren's eardrums were perforated is very similar to that by McCafferty, Lewis, Coman & Mills (1985) that 13% of tympanic membranes were perforated in a sample of 6 to 10 year-old children at Cherbourg, Queensland. Around Alice Springs in the Northern

Territory, Quinn (1983) found that the percentage of Aboriginal children's ears having perforations in individual communities ranged from 17% to 57% (Nienhuys 1991:17-18).

Recommendations from this study promoted the need for medical and educational intervention particularly in the light of the finding: 'It is especially disturbing that children were found in the sample with severe hearing losses and who have never received audiologic and special education attention' (Nienhuys 1991:18). To receive services required referrals from a medical officer who did not consider the incidence of otitis media in Redfern as an important issue.

The findings provided vital information for the community to take action. A Redfern Aboriginal Interagency group became a strong advocate for action and invited the NSW Aboriginal Education Consultative Group (AECG) President, Linda Burney, to a meeting to discuss the results of the research. Linda Burney informed the Education Minister who responded quickly and proactively. This resulted in employing teachers of the deaf throughout the State to work with students with conductive hearing loss. A National consultation for the development of guidelines for the management of otitis media (OM) in NSW was funded, a role I won through tender. The consultation project required that I visit each state and territory in Australia to:

> Report on strategic approaches to the educational challenges of Otitis Media amongst Aboriginal and Torres Strait Islander students (pre-school – year 12) in education systems across Australia, and, advise on what is considered to be "best educational practice".

And:

> Suggest strategic initiatives for the NSW education system that would address the educational consequences of hearing loss amongst Aboriginal and Torres Strait Islander students (Sherwood 1992:6)

Educational strategies were collated and taken to the steering committee that took them up with their respective departments. A number of key recommendations were developed and actioned, these being the establishment of an Interdepartmental Committee on Aboriginal Otitis Media, inclusive of:

- NSW Office of Aboriginal Affairs
- NSW Ministry of Education and Youth Affairs

197

- NSW Aboriginal Educational Consultative Group Incorporated
- NSW Department of School Education (Aboriginal Education Unit and Special education)
- NSW Department of Health (Aboriginal Health Unit)
- NSW Office of Juvenile Justice
- NSW Board of Studies
- Aboriginal Medical Services (AMS)
- National Acoustic Laboratories
- NSW TAFE (Sherwood 1992:1)

This was the first interdepartmental committee established in the state to coordinate action in the area of Aboriginal children's health and educational needs. Through the advocacy of the Interdepartmental Committee on Otitis Media and the NSW AECG a number of initiatives occurred. These were: A National OM Conference held in Alice Springs 1994; Aboriginal Community education sessions throughout the State of NSW over a nine-year period; a NSW State wide Health and Education Conference on OM in 1996; Educational strategies through the NSW Department of Education and The NSW Board of Studies (Sherwood and McConville 1994).

The NSW Health Department took up the health challenge, establishing a research committee to develop medical guidelines for the management of Aboriginal children with otitis media as a supplementary edition of the Australian Medical Journal of Australia (Close 1994) and Guidelines for communities (Sherwood 1997). From this collaborative work the Commonwealth funded all Aboriginal Community Controlled Health Organisations throughout the country to provide hearing health screening and interventions for Aboriginal children along with the establishment of Ear Nose and Throat Clinics at many Aboriginal Medical Services. The Aboriginal Health Branch of NSW Health developed an Otitis Media Statewide Strategy completed in1999. The strategy established Otitis Media Health Workers and a State Otitis Media Coordinator.

Key features that ensured successful outcomes for communities throughout NSW were:

- The community was involved at every step of the way and decided to take action through research using the lobbying power of an interagency group

- The research was a tool to validate concerns and provide data for action. Feedback of results to community members ensured they were able to make decisions for change.

- Relationship building, respect and reciprocity were vital to this approach ensuring sustainability of the process.

- Community involvement was extensive and inclusive of an Indigenous interagency, Indigenous health and education agencies, parents, schools, and students. This ensured strategy development occurred from a grass roots level up.

- Transfer of knowledge gained through the research was delivered throughout NSW by Indigenous agencies and methods. This was an iterative process as it provided critical feedback to further inform strategies.

- Ongoing advocacy and building a National and International network through sharing and consultation created pathways for growing awareness and formulating strategies.

- Through ongoing educational approaches otitis media is now acknowledged in all State and National Education Policy.

This project was successful because Aboriginal communities and their respective organisations, using community driven consultative action, recognised that OM was a lifelong barrier, for those with OM, to reaching their potential. The community knew we had to do research to get the data we needed to argue our case; we did the research following community protocols; it was culturally safe and we produced the data necessary to take action. The results were not used to problematise the community, instead they were used to urge action from government agencies, which, on the whole was effective and the communities and their children received the benefit.

When compared with the three projects analysed previously, differences are that the research was not funded through a national body that could control how the data would be used; it was not undertaken purely for publishing reasons. It was about creating change. It was undertaken according to an Indigenous agenda and so observed the problems leading to this health and educational issue from an Indigenous perspective and did not blame the community for the high rates of OM.

The process was about working **with** community and not **on** a community, and listening to and hearing what people believed to be the issues, rather than listening to the experts. Importantly, the experts in NSW did not believe this story initially and it was a challenge to get health departments involved. However we worked together using the Interdepartmental committee and the National findings to effect change and they eventually came around.

I have observed, since this project, that when researchers, be they Indigenous or non-Indigenous, work in partnership with Aboriginal communities using methods that support the sharing and building of knowledge together, the projects are successful. The success is highlighted in the two-way learning outcomes as well as benefit for communities.

## Discussion

There are differences between each reflective story and the final story. The difference is the benefit received by Aboriginal communities. Wand and Eades explain what is necessary to ensure research benefit for Aboriginal and Torres Strait Islander people:

- A collaborative approach between researchers and Aboriginal communities is pivotal to developing a research project consistent with Indigenous cultural values and health concepts, with the potential to improve services and outcomes for Aboriginal peoples.
- Planning and broad consultation can ensure that research is feasible, ethical, culturally sensitive and beneficial (Wand and Eades 2008:584)

Story four encompassed these aspects and was able to bring about benefit to Aboriginal communities and their children. Stories one, two and three did not. Instead, they reaffirmed:

> There is ongoing concerns from Indigenous peoples that communication by researchers is poor, consultation is inadequate, values are violated by inadvertent cross-cultural insensitivity, and the research often fails to benefit the community (Wand and Eades 2008:584).

These concerns highlight why the current research agenda needs to change as discussed in Chapter 5. Although there have been funding shifts and support to grow Aboriginal researchers, their journey in this field can be extremely risky and injurious. Nea Harrison and Carol Watson of the CRCAH recognise the issues Indigenous researchers face:

200

The Indigenous researchers who were employed to conduct interviews as part of a wider research project raised the issue that their personal credibility is at risk if anything goes wrong in the research or the reports produced. They are the people known to the community and they will be the ones held responsible. The researchers reported that they are vulnerable because although they only had responsibility for one aspect of the research or planning process, they would be held accountable by the community for all of it if there are any problems (Laycock, Walker et al. 2009:88).

These issues were raised in story one and three and are risks Indigenous researchers take on when they become part of any research project where they are not appreciated by their non-Indigenous peers. This relates to worldview differences, insider status, ethical values and Aboriginal law. Once you enter into a relationship, you immediately take on a responsibility to maintain that relationship in a manner that is respectful. Once respect is breached, the Indigenous researcher is considered responsible for this breach, since they established the relationship.

Another way to look at this issue is to argue that respect is just good manners when you are in some else's home and is expected by Aboriginal communities. However, we suffer from researchers who believe they are Goldilocks. They walk into our house (country) uninvited, they steal our food (well-being), they break the furniture (law & protocols), and they trash the beds (show no respect), then run away, never to be seen again (with our knowledge for their stories). This is not a respectful relationship and this is why communities expect their own mob to encourage those that come with them to show good manners, and tell their 'truths'.

In stories one and three the Indigenous researchers were unable to ensure the non-Indigenous PIs acted responsibly and respectfully towards the Aboriginal communities, who gave of their time, and shared their knowledge with the promise of change. Although we attempt to ensure that there is no harm, we do not have the power to ensure due process occurs. The result, as explored by all participants is that they felt hurt, injured and believed that they had let their communities down. The Indigenous researcher feels used by the PI to encourage the community to be part of the project. When things go wrong or the researchers are lied to, they are still seen as responsible, while the PIs go home free of this burden. This is because an Indigenous researcher is responsible for the research experience in order to remain strong in a spirit of reciprocity and law.

Many of us view this approach to the community and ourselves as an ethical breach of trust, which simply reinforces our mistrust of research. Dunbar and Scrimgeour discuss these approaches to Aboriginal peoples and their communities and suggest that established researchers tend to resist and resent addressing the specific Aboriginal and Torres Strait Islander Values and Ethical guidelines (Dunbar and Scrimgeour 2006). (Dunbar and Scrimgeour 2006). I suggest this resistance and resentment arises in large part from the colonised mindset we all have and underlines the importance of decolonisation.

This leads to the question: How can we trust research and the experts to deliver on outcomes they promise when they resist following Indigenous protocols of respect, ignore Indigenous knowledges, Indigenous ethical guidelines and injure their Indigenous researchers? In many cases, we can't, as story one, two and three demonstrate. Their lack of partnership building with Aboriginal communities is considered a barrier to Indigenous participation and eventually a impediment to 'scientific rigour and 'scientific truth' (Dunbar and Scrimgeour 2006:185) of the research undertaken. This approach will not deliver benefit to Aboriginal communities.

These concerns were voiced by participants in story one, who argued for greater community control regarding their perceptions of injury. The story also demonstrated the inability of the PIs to support an Indigenous agenda, inclusive of Indigenous concepts and ways of knowing, being and doing. This was further played out in relation to data collection and collation. From an Indigenous perspective, data come from the Aboriginal experts and are explored in ways that are meaningful to their participants, for example in paintings and stories. The non-Indigenous researcher will follow the tradition of data collection in line with established definition of injury, requiring the quantifying of data from numerous sources that are not Indigenous and which remain underreported, for example, hospital breakdowns and ABS data (ABSAIHW 2008). This is despite what Clapham, et al., highlight as data gaps, 'To date, there are few published studies describing the magnitude of injury among Indigenous Australians, and no study provides a comprehensive understanding of the impact of injury on their lives' (Clapham, Mark et al. 2006:217). Story one could have achieved this from a Central Australian context if the PIs had been able to engage respectfully with the community and their researchers.

Story two tells a one-sided account of community failure fitting within a cultural hegemonic approach of Aboriginal health research. Community participation in the project would possibly have provided the vital reasons as to why the project was not successful. Inclusion of community members would have been an opportunity to listen to and hear what the barriers were to successful management of trachoma within their communities. Instead, this article blamed the community for their high rates of trachoma. The project reported did not appear to undertake a collaborative partnership with the community, or to develop the project in line with the cultural values and health concepts of the community to improve health services and outcomes. Story three also failed to demonstrate a collaborative approach.

Another difference evident in the final story was the ongoing communication or sharing of knowledge. This is vital to Indigenous health research and was not acknowledged in story two or three. The data were not recognised as the community's and the community was unable to interpret or use the findings in a way that benefited themselves. Ongoing dialogue between the community and agencies was essential to the success of the otitis media project whereas it was not in the other projects outlined. In story four the research was not seen as the end product. What was done with the information made the difference. The community and its stakeholders were able to use the data shared with them to agitate for change and it worked. In stories one, two and three, research was handed over to the funding bodies or government agencies that did not have the community expertise to interpret or act upon it. Once again, the data were used to manage Aboriginal communities rather than to influence change to improve health outcomes.

## Conclusion

The aim of this chapter was to demonstrate why research has not improved Aboriginal health, using reflective stories of current research practice and praxis. What is considered bad and ugly from an Indigenous perspective has been highlighted as well as what is good in achieving outcomes through research. The crux of conflict is the general disregard for Indigenous experience and knowledge in informing research about ourselves. Instead, we continue to be oppressed by experts, supported by health funding bodies, who write what they believe will solve out problem. Hence:

In Aboriginal health research, there is a legacy of mistrust of researchers, who have often made false assumptions and misunderstood the values and practices of Aboriginal and Torres Strait Islander cultures by approaching them through their own cultural lens (Wand and Eades 2008:584)

This legacy continues and has been demonstrated through stories one, two and three. They illustrate that research methods and methodology of the past continue to inform research practice today. This hegemonic approach to amassing knowledge of the Aboriginal Other in the area of health has failed to improve the health outcomes of Indigenous people. Instead it has contributed to the ongoing neo-liberalist agenda of blaming the colonised for the injurious actions and neglect by the coloniser. This approach cannot offer benefit to Aboriginal communities, rather it further rationalises to the broader community why colonisation was necessary for Aboriginal populations.

This approach has also compounded injury and loss for Aboriginal people, their communities and their researchers. Through the utilisation of ill-informed constructions of Aboriginal people by health professionals, policy makers and funding bodies, the injury and poor health already present are compounded (Sherwood 2009:s24). Colonisation incorporates systemic racism which compounds experiences of hurt, injury and trauma that eventually becomes internalised, and leads to further injury, grief and loss. The most damaging tactic used by researchers is to not listen to these experiences, not hearing and acknowledging what is being shared, resulting in further internalisation of pain (Sherwood 2009:s25). Phillips argues that colonisation has been successful in translating its situational trauma into inter-generational trauma (Phillips 2003:23), and unreflective research has achieved trans-generational trauma (Sherwood 2009:s26) as observed in story one. If unreflective research causes injury, how can research improve the health outcomes of Aboriginal people?

# Chapter 7

# The Grog Trial: Whose knowledge counts?

> I have heard white people say cynically, 'We couldn't clean them up with poison and guns, but watch, we'll do it with the grog' ( Downing, 1973:3 cited in Wright 1997:1).

## Introduction

Chapter 7 tells a story illustrating the barriers to health improvement for Indigenous Australians that result directly from the cultural hegemonic agenda of colonisation used by both governments and the academy in their maintenance and control of their 'Aboriginal problem'. It builds upon the barriers raised in Chapters 3 and 5 in relation to the Western expert along with the practice of silencing Indigenous voices that ultimately causes injury to Indigenous peoples.

The project explored here surveyed Aboriginal community members living in Town Camps in Alice Springs, on the effectiveness or not of the gazetted grog trials held in Alice Springs 2002–3. This analysis of the project demonstrates significant differences in the manner the research was undertaken and reported. It also illustrates how the Western research tradition continues to marginalise and silence Aboriginal people in relation to policy development about them.

It incidentally provides a snapshot of good research using an Aboriginal method and methodology.

## Issue

Alcohol and its misuse is 'a major problem and one of the biggest challenges facing many Aboriginal and Torres Strait Islander communities today' (NACCHO 2003:594) and is a key contributing feature of the burden of dis-ease and early mortality (AMSANT 2008). It is difficult to ignore the harm alcohol presents to Indigenous and non-Indigenous populations. However this chapter illustrates how governments can do this.

Alcohol is 'commonly blamed for Indigenous violence' (Memmott, Stacy et al. 2001:2). There is a consistent representational image describing the relationship of violence and alcohol as common features of Indigenous people's lives (Memmott, Stacy et al. 2001:26). Gregory Phillips believes research examining Indigenous people's perspectives around its use is essential, when:

the most widely stated theory of the relationship between Indigenous usage of alcohol and other substances and trauma is that people are medicating their emotional, mental, physical and spiritual pain – grief and loss – with alcohol or other substances (Phillips 2003:25)

The Indigenous story of alcohol usage is important and must be defined, as Phillips urges, by Indigenous people themselves, otherwise we will continue to be injured by solutions uninformed by our experiences. As alcohol has become a:

collective way of coping with a spectrum of conflicts, contradictions and stressors. Such a coping response has devastating psychological and social costs, and interferes with indeed often precludes, the development of more adequate individual and community coping and problem-solving strategies (Paul Reser, 1990:54 cited in Memmott, Stacy et al. 2001:26).

Aboriginal communities throughout Australia have attempted to address these circumstances through a multitude of approaches such as: creating dry communities, instigating night and day patrols, and promoting liquor restrictions. 'However, their efforts have often been undermined by a lack of support from governments' (AMSANT 2008:1).

## The history of Aboriginal injury in Alice Springs

Alice Springs, Central Australia is the setting of this story. Known as Mparntwe to the Central Arrernte peoples, the custodians and caretakers of this country from time immemorial (Brooks 2003). It is now a township with a history of European occupation dating back to the 1870s that led to Aboriginal dispossession and injury. In the 1880s Alice was charted as a town and the original owners were dispersed onto the fringe into what is known today as 'Town Camps' (TangentyereCouncil 2000:6). By 1891 with the influx of settlers it is estimated that some 1100 Aboriginal people in the area had been killed resisting Invasion (TangentyereCouncil 2000).

1927 saw Spencer and Gillen publish their first ethnographic version of the Arrernte Peoples, The Arunta (Spencer and Gillen 1927), a disparaging research account of an accommodating population Spencer spent time with from the 1890s onwards.

In contact with the white man the aborigine is doomed to disappear: it is far better that as much as possible he should be left in his native state and that no attempt should be made either to cause

him to lose faith in the strict tribal rules, or to teach him abstract ideas which are utterly beyond the comprehension of an Australian aborigine ( W.B. Spencer 1896:111-12 in Rowse 2002:23).

Spencer drew his perspectives from Aboriginal populations who had been dispossessed and severely traumatised by ongoing dispersal, starvation and manslaughter. Yet these representations became the yardstick for knowing the Aboriginal Other. Such constructions encouraged further violence and the passing of draconian laws making them outlaws in their own countries. In 1928 Alice Springs was 'declared a prohibited area for Aboriginal people' (Aboriginal Ordinance 1918), an ordinance remaining active until 1964 (Tangentyere-Council 2000:6). Aboriginal people who were unemployed could be charged and convicted for being found within the two mile 'European residency', an Aboriginal prohibited zone (Rowse 2002:71).

From 1900 onwards the Northern Territory Aboriginal Protection Board removed Aboriginal children from their families and dispersed them throughout the Territory after an initial compounding at the 'Bungalow' (Tangentyere-Council 2000). Aboriginal people came to stay at the fringe camps to be close to their children and seek poorly paid employment. T.G.H. Strehlow in 1937 was an Aboriginal patrol officer who later became the holder of many Aboriginal ceremonial objects. During his tenure as a protection officer he described the conditions of camps:

> The living conditions of natives in the various camps in Alice Springs are deplorable, and probably cannot be improved … The present gazetted area is barren and rocky, devoid of shade and firewood. The huts and tin shacks are disgraceful structures. The surrounding district is practically devoid of any form of game which the natives could eke out their present rations (AA NT CRS F126, Item 37, T.G.H.Strehlow to Chief Protector, 18 March 1937 in Rowse 2002: 72).

Aboriginal people were forcibly removed from the Alice Springs area to outlying missions and reserves. Only Aboriginal persons working on the town sewerage were exempt. This policy targeted all Aboriginal peoples of Central Australia irrespective of their connection to country. For the Central Arrernte people who are responsible for the maintenance of country and law for Mparntwe, this policy was devastating and contradictory, as the Town's ration depots and opportunities of employment attracted countrymen and their families from all over Central

Australia (Rowse 2002). The protection policy of dispersing and exclusionary management ensured Aboriginal resistance to these laws.

> The constant attempt by authorities to evict Aboriginal people from Alice Springs were continually frustrated by the mobility of the population (Tangentyere-Council 2000:7).

In the 1970s fringe dwellers, now Town Camp residents, were able to negotiate with the Territory Government to become incorporated housing associations. These associations united in 1977 to form Tangentyere Council. Tangentyere over a period of some fifteen years, became the primary provider of services and the site of advocacy for the 'Town Camps' by fighting for 'special purpose leases and the securing of funding for housing programs' (TangentyereCouncil 2000:8). William Tilmouth, Executive Director of Tangentyere Council affirms this advocacy position:

> Alice Springs is traditional Aboriginal Land. It is Aboriginal country. With the advent of colonisation, we were displaced on to the fringe of society. From that time on, there has been a contest for space – space to live, space to strengthen culture, space to be Aboriginal. Through the formation of Tangentyere Council Inc., the endeavour to share this space has taken on a united voice in the struggle for equality (Tangentyere Council 2000:2).

This struggle is not over, as demonstrated by the federal Governments plans to take hold of and control the land and housing associations of Alice Springs under their Northern Territory (NT) Intervention strategy.

## Grog in Alice

Grog is considered a significant problem in Alice Springs especially by the Aboriginal population residing in the township. Aboriginal people and their respective organisations have attempted to voice concerns about the ongoing injury resulting from excess alcohol usage. The morbidity and premature death rates within the Central Australian Aboriginal populations are twice those of people living in the Top End of the NT (AMSANT 2008:1). In 2003 the consumption of excessive alcohol contributed to 7% of all Indigenous deaths in Australia and 6% of the total burden of disease (ABSAIHW 2008:140). Governments are armed with these data, yet Alice Springs, home to approximately 27,000 people, has some 45 takeaway alcohol outlets

scattered throughout its precinct (Rosewarne and Boffa 2003). Unlimited access to grog is considered to be a determinant of alcohol problems (AMSANT 2008).

From 1990s on the dilemmas of liquor licensing and Indigenous populations in Central Australia have been documented and deliberated on (Lyon 1991; D'abbs, Hunter et al. 1994; Rosewarne and Boffa 2003). As Pamela Lyons points out, 'the problem' continues to be drinkers 'who are more visible' (Lyon 1991:1), resulting from lack of housing, and being turned away from drinking venues due to 'regulations' (Lyon 1991:1). Data suggests problem drinking is a broader mainstream community issue. As Rosewarne and Boffa affirm, during 1998–99 in Alice Springs, 24 million dollars was spent on alcohol. In 2000 the average alcohol consumption in Alice Springs was 70% greater than the national average with alcohol related harm during this period leading to 1,341 hospital admissions (Rosewarne and Boffa 2003:1). Yet the public face of drinking is considered to be an 'Aboriginal problem' only, and Dr Ian Crundall's solution is based on this approach: 'Some people thought you should put all Aboriginal people in a big hole and bomb it' (cited in Wright 1997:242) affirms this problematic notion.

The issues of alcohol use and mis-use are not clear-cut within Aboriginal communities; however, there is an inherent connection to its use related to internalised injury and anger that is often ignored in the development of solutions (Howells 2008). Maggie Brady and David Martin in their report titled: *Dealing with alcohol in Alice Springs: an assessment of policy options and recommendations for action*, claim that risky Indigenous drinking patterns are opportunistic, related to an available cash flow and that drinking is done socially with a number of people (Brady and Martin 1999). This pattern is considered to be different from the European binge-drinker who drinks to excess in isolation (Brady and Martin 1999).

There is a view held in Alice Springs by many residents that Aboriginal habitual drinkers are the only problematic abusers of alcohol (Brady and Martin 1999). These perceptions have more recently been supported through the NT government's approaches to alcohol consumption in the Territory. For example, Crundall authored a report entitled: *Northern Territory Alcohol Consumption and Related Attitudes: 2006 Household Survey (Crundall 2006).* Crundall's survey states; 'Most of the alcohol problems in the NT are Aboriginal problems' (Crundall 2006:14), which respondents are asked to agree to or disagree to. This closed question elicited majority

agreement by the non-Indigenous NT residents of Darwin, Alice Springs, Katherine, Nhulunbuy and Tennant Creek (Crundall 2006:17). Yet data collected in 2007, a time which alcohol had been prohibited to Aboriginal persons, showed that consumption of alcohol for the NT population had increased to 17.3 litres per person, with the NT recording the 'second highest per capita consumption in the world' (AMSANT 2008). This begs the question 'Who has the problem?'

## Alice Springs Grog Trials

In April 2002 the People's Alcohol Action Coalition (PAAC), a body made up of Aboriginal organisations, was successful in its agitation for a 12-month trial on liquor (grog) restrictions supported by a change in Territory government (TangentyereCouncil, National Drug Research Institute et al. 2003; Hogan, Boffa et al. 2006). The trial was gazetted by the NT Licensing Commission to be held in Alice Springs in 2003 after a long and drawn-out debate imposing restrictions on sale and access of liquor types, as well as special measures targeting Aboriginal community members (Hogan, Boffa et al. 2006).

The trial limited quantities of alcohol that could be purchased, reduced times of sales and established a community reference group to responsibly contribute to the trial's evaluation process. The reference group consisted of 'government departments, commercial interests, health services, Aboriginal organisations and the alcohol industry' (Crundall 2004:1), and was known as the Evaluation Reference Group (ERG). The new measures of alcohol restrictions were packaged with a number of community-based strategies. The measures being trialled were:

- Only light beer to be sold in hotels prior to 11.30 am on weekdays
- Take away opening hours to be from 2pm to 9pm on weekdays
- No alcohol containers larger than two litres to be available

The complementary measures were:

- A drop-in centre for young people and alcohol-free entertainment.
- Introduction of a Community Day Patrol
- Delivery of brief interventions by Primary Health workers

- Targeted interventions with frequent clients of the Sobering up Shelter and an extension of Shelter hours by one day (i.e. Monday) (Crundall 2004:2).

The ERG functions were specific: to ensure information was fed back to the community regarding the progress of the trial and to advise the Commission of key recommendations by the completion of the trial. The key purpose of the ERG Dr Ian Crundall, Chair of the ERG argued, was to provide a reference point to and from the community for the 'evaluation' (Crundall 2004:7) or, as he put it more bluntly, 'the collection and interpretation of information and not deciding about strategies to put into place' (Crundall 2004:8). The organisations involved were:

- Department of Health & Police as agencies dealing directly with health and law enforcement aspects of alcohol related harm
- Alice Springs Town council as the elected body of residents
- Tangentyere Council, as agency responsible for Town Camps
- Arrernte Council
- Central Land Council due to its links to surrounding Aboriginal communities
- ATSIC as having responsibility for Aboriginal activities (an incorrect belief by Crundall)
- Central Australian Aboriginal Congress as the agency primary responsibility for delivering health services to Aboriginal people in town and the surrounding district
- Chamber of Commerce & Central Australian Tourism Industry Association representing the two major commercial sectors of the local economy
- Australian Hotels Association & Liquor Licensees' Association as representatives of directly impacted and suppliers of alcohol
- Alice in Ten Quality of Life which variously represented a range of other community interests connected to alcohol issues (Crundall 2004:7)

Members of the ERG's interests were divergent and this was played out throughout the evaluation process and its aftermath. During the evaluation the supply of fortified wine was introduced by the alcohol industry to replace the 4- and 5-litre wine casks which had been prohibited. This action was observed by Indigenous organisation members of the ERG, as an undermining of the trial by the liquor industry (Bell 2003). Yet Crundall defended this by stating:

> ERG members who wanted significant changes to the trial or its evaluation were referred to the
> Licensing Commission, since it was the authority responsible for deciding the scope and structure

of the trial … Those concerned about the shift to fortified wine, for example, might have initiated outreach work to explain the new risks presented by higher alcohol content drinks and to support new drinking patterns (Crundall 2004:8).

Stephanie Bell, Chief Executive Officer of Congress, Alice Springs, argues that it was Dr Crundall who held the power to take up suggestions for changes to the trial as requested by the ERG to the Licensing Commission (Bell 2003). She stated 'In fact, when Congress requested through the ERG that action be taken on the port issue after six months' worth of data showed a continued large shift to port, it was Dr Crundall who led the argument against such action' (Bell 2003:2). He later 'conceded to the ERG that he had "misread the data" ' (Bell 2003:2). This poor scientific approach led to the failure of the trial and injury to the Aboriginal community (Bell 2003). Dr Crundall's role as chair enabled him to take up recommendations as nominated by the ERG to the Licensing Commission. In fact that was his role. However, rather than accepting that he failed to act effectively in this position, he blamed Indigenous organisations for their inability to effect change, another example of a colonial mindset.

## The Crundall and Moon evaluation

The evaluation consisted of monitoring shifts in alcohol consumption and measures of harm related to alcohol usage, i.e. assaults, homicide, suicide and antisocial behaviour with the establishment of a 'cross-sectional Reference Group to help monitor and evaluate the trial' (Crundall 2004:5). In addition the Licensing Commission was required by law to obtain public perspectives of the trial. To do this the Northern Territory Department of Health and Community Services (NTDHCS) planned to undertake a 'random sample survey of the attitudes of Alice residents to the restrictions' (TangentyereCouncil, National Drug Research Institute et al. 2003:2), although the NT Licensing Commission had commissioned 'an independent, scientific and professional evaluation' (Wakerman 2003:6).

The random sample survey, which became known as the 'household phone survey', excluded residents without household phones, along with residents under the ages of 18 years and those with limited English or requiring an interpreter. This effectively reduced significantly the number of Aboriginal household respondents (Crundall and Moon 2003:8). Crundall argues he had to agree to a phone survey of households 'as a last resort' (Crundall 2003:34) because of

demands being made by the Central Australian Human Research Ethics Committee, but this was not the case. The demands of the Committee were to ensure Aboriginal representation would occur, and the planned documented household survey clearly excluded Town Camp residents. These 'protracted negotiations' (Crundall 2003:34), Crundall contends, led to a reduction in time to undertake a more complete survey. Crundall alleges that when he realised the Town Camps were being excluded he agreed to the Division of General Practitioners funding Tangentyere Council to undertake a similar survey in the Town Camps (Crundall 2003).

Crundall and Moon's evaluation was poorly executed and failed to be responsive to issues raised by its own ERG (Bell 2003). They also failed to provide their report in its entirety to the ERG members, stating the final document and data were 'redundant' (Crundall 2003:30). The result of this inaction led to well founded criticism targeting Crundall's and Moon's methodology, methods and findings (Wakerman 2003). Inappropriately, they stated that the Licensing Commission had no clear objectives for the trial (Crundall and Moon 2003), enabling them to dictate the terms that were to be evaluated and documented. Dennis Gray of the National Drug Research Institute, Curtin University of Technology substantiates this statement, arguing that their lack of direction prevented focusing on reducing harmful alcohol consumption (Gray 2003).

## Town Camp Survey

Through discussions with Dr Crundall it was settled that Tangentyere Council, the National Drug Research Institute, and the Centre for Remote Health as a collaborative working team would undertake a survey of the Town Camp residents' attitudes to the Alice Springs Liquor licensing restrictions (TangentyereCouncil, National Drug Research Institute et al. 2003). The time frame for the survey of Town Camp residents was also limited. However the Tangentyere research team prepared an ethics application according to the requirements of the NHMRC *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003). The application received approval from the Central Australian Human Research Ethics Committee in August 2003.

I have been unable to articulate the approach undertaken by Crundall and Moon as they omitted methodological discussion from their report, apart from establishing it was a household phone survey. However I can describe the Aboriginal approach to the survey undertaken by

Tangentyere Council and its partners as I was part of the research team, and the data and process has been published in its entirety without omissions.

## Tangentyere model

The following model for research established in this project has become known as the Tangentyere research model. It was a model developed utilising Indigenous methods and methodologies in balance with multiple Western methods to ensure research was undertaken respectfully, ethically and safely within the Alice Springs Town Camps. It provides an example of research praxis that successfully collated valid and meaningful data. It also exemplifies how critical community engagement ensured there were positive outcomes for participants.

## Information sharing

Tangentyere Council representatives were concerned about the Licensing Commissions phone survey results singularly informing the trials evaluation:

> We did not think it was fair that Town Campers would not be included in the survey: especially when many people think that Town Campers do not care about the grog problems and they misjudge our opinions and our appearance and our way of living. So Tangentyere Council made the decision to conduct its own survey to make sure Town Campers' feelings about the grog trials were heard (Foster, Williams et al. 2006:4).

Hence the Tangentyere Council, in its role of advocate for Town Camps, undertook the survey and ensured each Town Camp housing association was fully informed about the purpose of the survey and how each camp would be involved.

Information sharing is a two-way process, so a detailed translation/dissemination aspect was built into the survey project to ensure each housing association and their residents were given meaningful and ongoing feedback. A week prior to the survey, flyers about the project were distributed to each camp by their own property management officers. The week of the survey the researchers spent a lot of time explaining to all residents, not just those selected, the purpose and motive of the survey. 'This is very important for Town Campers because they have had bad experiences with research before and we needed to explain that we were going to do the work' (Foster, Williams et al. 2006:8).

## Participatory knowledge brokerage

The research team was selected by Tangentyere council 'on the basis of their ability to relate to people living in the town camps' (TangentyereCouncil, National Drug Research Institute et al. 2003:6) to undertake the survey and interviews. Research team members were representatives of the Town Camps, Tangentyere Council as well as the Centre for Remote Health. They held the languages (Eastern Arrernte, Western Arrernte, Warlpiri, Luritja, Anmatyerre, Katej, Pitjantjatjara, Pintupi, Alyawarre, Pertenne, and others), the cultural expertise, community knowledges, and cognition of the kinship relationships within the diverse camps, and the awareness of the impact grog was having in their camps. Indigenous researchers:

> work within a set of 'insider' dynamics and it takes considerable sensitivity, skill, maturity, experience and knowledge to work these issues through (Smith 1999:10).

A three-day workshop prior to the survey grew the research team. Those who worked with 'growing' the team were also selected by Tangentyere Council, because

> Non-indigenous teachers and supervisors are often ill-prepared to assist indigenous researchers in these areas and there are so few indigenous teachers that many students simply 'learn by doing'. They often get hurt and fail in the process. I have heard this articulated by indigenous researchers as 'being burned' or 'being done over' (Smith 1999:10).

Dennis Gray and Jane Ulrik both non-Indigenous researchers have worked extensively with Indigenous communities and are highly respected by Tangentyere Council. I was selected as the Indigenous researcher to support the training and work in the field with the research team. I held in-depth experiences of the role and the inside dynamics essential in research with Aboriginal people. My role was to ensure these dynamics were not dismissed and were in fact considered to be a core component of the research process.

The training was essential to the process as it enabled time for people to get to talk through the complex issues around the survey and its consequences.

During those three days we explored:

- The survey's purpose, and who would benefit
- The issues for self/researcher and the Town Campers

215

- Issues relating to the Town Camp survey and its aim to inform the broader community and Licensing Commission
- Exactly what the alcohol restrictions were and what they were meant to achieve
- What the special measures were.

Everyone involved became aware of what the trial was about, as there had been limited information or community focused promotion of the trial measures. We all needed to be prepared to answer questions that residents may have posed regarding the measures. The preparation was based firstly upon respecting the people we were interviewing, and ensuring that community members were provided relevant information on which to make decisions a basis of ethical research.

We explored what research was, the impact it has had on our past, why we needed to do it and how we could ensure the community gained the outcomes it needed. The process of discussion and reflection enabled us to build an Aboriginal perspective into the research project, a much richer process than simply having Aboriginal people asking research questions of Aboriginal participants (Brown, Morrissey et al. 2006). Vanessa Davis, research team member reflected on this aspect:

> Research for us is, what is the right question to the right person, when it is ok to ask, keeping information safe, using information properly, learning new skills, providing information, and whether comfortable. It is a process, for us, it was finding answers to questions we had about attitudes of Town Camp residents to the 12 month liquor restrictions (Ulrik, Foster et al. 2005:2).

**The process: It's about respect**

'It's about respect' was the defining distinction between Indigenous research methodologies and that of traditional Western research focused on Aboriginal communities, evident in the Town Camp survey. There was an expectation that the Town Camp survey must follow the line of questioning of the town household phone survey but research team members were concerned that direct questioning would shame participants or be considered offensive (Foster, Williams et al. 2006). The questions were modified to prevent people feeling shamed and to make them more meaningful to the participants. As Foster, Williams, Campbell, Davis and Pepperill argue 'We

are internal experts and know what is appropriate with the wording of questions' (Foster, Williams et al. 2006:6). Vanessa confirms this:

> For us, we are looking for answers. We know our social issues, we know our people, we know our culture, our language, have respect, and we are not just the interpreters, we have strong rules, consent is understood (Ulrik, Foster et al. 2005:2).

Informed consent was considered to be a particularly serious issue. The research team believed that participants needed to be fully informed because 'Informed consent for us is very important because we are answerable to our community' (Foster, Williams et al. 2006:6-7). This consideration is a result of number of issues, the context being:

- Indigenous peoples' research experiences of the past
- The lack of meaningful information Town Campers had received regarding the 'grog trials'
- Building trust
- Reciprocity
- Relationships
- Responsibility
- Law

Smith reinforces the importance of an Indigenous approach to consent seeking which fits closely with the concerns we hold as Aboriginal researchers.

> Asking directly for consent to interview can also be interpreted as quite rude behaviour in some cultures. Consent is not so much given for a project or specific set of questions, but for a person, for their credibility. Consent indicates trust and the assumption is that the trust will not only be reciprocated but constantly negotiated – a dynamic relationship rather than a static decision (Smith 1999:136).

This consideration differentiates the ethical positioning of most research projects undertaken by non-Indigenous researchers. Consent and subsequent signatures on a consent form are obligatory parts of any research; however researchers are generally absolved of any responsibility to communities before they get the participants' signature through the endorsement of an ethics

committee. This is contrary to the position Indigenous researchers hold. They are responsible to the community throughout the process and for ever after (Laycock, Walker et al. 2009).

## Responsibility

Responsibility means more than obligation; it is inclusive of accountability and relates to country, relations, community protocols and law. It holds a number of meanings that are known and felt by Indigenous people (Laycock, Walker et al. 2009). When Indigenous researchers agree to undertake research they agree to take on responsibility for the entire impact the project will have on their people before, during and after the research (Laycock, Walker et al. 2009). Indigenous researchers are Indigenous people, who have and hold significant relationships with their community.

> We know the context that the interview is being conducted in – who else is there, the cultural rules and non-verbal cues. We know how to dress, respect the elders and use appropriate behaviour in the proper way that respects our culture. We also know when 'sorry business' (funerals and mourning) or Aboriginal Law business is being held so that we acknowledge people's loss appropriately and do not do the survey work in Camps at that time. We know when people are home, the days of the week that are best to visit, the time of the week when people would be around and not feel pressured to participate (Foster, Williams et al. 2006:9).

Insider knowledge is critical to ensuring the process is safe for those being researched, it is about respecting Aboriginal ways of knowing, being and doing.

The team worked towards making sure the language was appropriate; questions were modified in a brief, clear and meaningful manner so that each researcher would not be writing too much while talking to the participants. Researchers practised asking questions of each other and changed them round when the wording was not clear. Practising continued until everyone felt the process was safe for Town Camp residents and the researchers (Foster, Williams et al. 2006).

It was agreed that:

> This way of getting consent meant that the responsibility for consent was with the researchers, they would be the one to answer if people later felt that they had not given consent (Foster, Williams et al. 2006:6).

218

The researcher who did the interview had to sign off on the consent sheet which was to be witnessed by an accompanying researcher.

## Training and field work

The sampling planning of Town Camp households was vital to the survey's success. Every researcher learnt about the importance of prior organisation and statistical random selection to ensure camp residents were well represented. This process required critical insider knowledge of households and their population distributions enabling effective planning of research team groupings. Teams of pairs were set up to guarantee:

> … that the members had family connections on the Camps they were to work on, they had both male and female members and had (Aboriginal) language speakers – so that they were acceptable to the residents and could communicate with them (Foster, Williams et al. 2006:8)

This is an Indigenous approach to undertaking research, appreciating the importance of language speakers, their relationships with research team members and respecting those considerations. The team incorporated into the survey a question about how the community wanted results feedback in a meaningful way. This is significantly different from other projects I have worked on in Central Australia, where these considerations are ignored when raised by the token Indigenous researcher. However as the team argued:

> Aboriginal people have been doing research for a long time. That is how we survive. Non-Aboriginal people have been doing research on Aboriginal people for a long time. They have taken information away. The biggest thing for our research is trust. We need to hold on to information about us. It belongs to our people. We need to be able to use that information (Ulrik, Foster et al. 2005:1).

During the planning of the survey we were told that a Camp was in sorry business. The loss of a family member through death requires grieving and this process is known as sorry business. This business is Law and requires respect and time. The team made certain this business was respected and family members residing in other Camps were not included in the survey. Only insider knowledge could ensure that injury was not caused to the community.

All researchers were required to wear Tangentyere Research photo identification so that Camp residents recognised we were the researchers. Each Camp was informed when the researchers would be at their Camps over a ten-day period. This was important in respecting community and it increased participation.

> The method of the way we did it, is we did it on the best days when people are around, we let everyone know what was happening before and during, and we did a lot of things when asked (Ulrik, Foster et al. 2005:3).

The researchers were aware of the intrusiveness of banging on someone's door and demanding to be invited in, by participants who were then expected to give up their time, knowledge and privacy.

> The first thing to do is to wait quietly for someone to see that you are there and invite you to come inside the yard. We introduced ourselves, explained what we were doing and why in a way that the person we were talking to understood, and then asked if they wanted to be part of it. We then encouraged and answered any questions to make sure that consent was informed. We knew that many people did not like signing anything and that just getting a signature on a piece of paper was not getting informed consent; so the researchers signed a form confirming that the explanation had been given and that consent had been received (Foster, Williams et al. 2006:9).

This approach worked well and by the second and third day, household residents would approach the team asking when they could be interviewed. On one occasion we arrived in a camp as a car was driving out. The occupants called out to us to tell us they were going into town to do some shopping but that they wanted to be interviewed and asked us not to forget them. On their arrival back they sought us out again to ensure they were included. This picture is different to the one painted by researchers of the past who complained of the lack of interest Aboriginal people had regarding research. What is different was the way we approached the community.

**Listening**

Through out the ten days researchers came together each afternoon to make sure they had completed the surveys correctly and to plan the next day's interviews. This was an important opportunity to discuss issues arising and debrief. Many residents used the interview process to tell their stories, and we listened. We did not stop participants mid sentence and then ask them

220

the next question; we listened to their entire story. Many stories were overwhelming, but needed to be told, and as Aboriginal researchers, we had a responsibility to listen with respect; this is reciprocity. As the researchers were representatives of Tangentyere Council, they encouraged households to use the interview opportunity to bring up any problems they were having with their housing. These were reported to the council for action.

This approach gave people time to think. I recall a resident coming up to us a couple of days later asking if they could add more to their interview as they had been discussing the survey with their family and they had more ideas about preventative strategies.

> We got a lot more discussion and information from the Town Campers because they feel comfortable with us and can talk and not feel embarrassed or 'shamed'. Many people would not give good answers to non-Aboriginal people, whereas we could talk about a lot of other things to make people feel comfortable and can help people understand more about the questions and allow people to feel proud to be involved. Aboriginal research is done in this way – with Aboriginal people in control and recognizing Aboriginal expertise – the results will be more valid (Foster, Williams et al. 2006:10).

## Putting the story together

The importance of data collection and verification was crucial to the team. The coding, entering of data onto spreadsheets and then on to the SPSS program was done meticulously. This was important because, as Dennis Gray observed, the ERG had misinterpreted some of the data sourced in the Tangentyere survey (Gray 2003). He was able, as result of the careful work done by the team, to qualify the meaning of the survey's results (Foster, Williams et al. 2006:10). Tangentyere Council Executive reviewed the results and funded the production of the reports: one for Town Camp residents, and a technical report by Dennis Gray for the Licensing Commission (Foster, Williams et al. 2006).

Town Camp residents were responsive to the survey process and spoke openly of their concerns related to alcohol misuse. Community people appreciated that their voices were being listened to and they offered a number of ideas for strengthening the restrictions as well as placing further restraint on port sales (Foster, Williams et al. 2006).

The most phenomenal thing about the whole process was the fact that people were very happy to be asked and that was hugely significant because nobody had actually ever bothered to ask them at all and it inspired people. The interviews were long and detailed in depth and hugely rewarding for both the interviewer and the interviewee because it was actually a discussion (Participant 4).

## Outcome

The findings and recommendations of our survey were not considered by the Licensing Commission. Although the process ensured Aboriginal voices were heard, they appeared to be irrelevant to the Evaluator and the Licensing Commission.

So yet again even though we did the process, we did all of that and we had ownership of it and all of that stuff it makes you wonder well what the hell do you have to do to be heard. It was very disappointing but we learnt a lot from it and that process of learning is continually feeding back into how we're going about it (Participant 4: 2005).

It was distressing that Aboriginal perspectives of the trial were ignored, especially when the Licensing Commission was legally required to be responsive to community views, and obliged 'to base their decisions on the available evidence' (Wakerman 2003:7). Effectively, the Aboriginal Town Camp and other Aboriginal householders evidence was considered irrelevant.

The following extract from the Alice Springs News explores the reality of weakening the grog restrictions, a result of the Licensing Commission's decision.

Two senior Aboriginal women are calling for renewed action on grog after the Liquor Commission's weakening of alcohol restrictions in Alice Springs (see last week's issue). Margaret Kemarre, OAM and Margaret Heffernan made their heartfelt call to the Alice News last Sunday. They are shocked that the way is now open for cheap cask wine to come back onto the market, while cheap cask port also remains available. This is what they said:– They are doubling up two casks, the red one [port] and Coolibah [moselle]. Port itself is really damaging. All you people out there, you've got to see this port killing all our families, all my family, all your family, families and families (Finnane 2003:2).

The reality of alcohol misuse is that it kills and this fact is supported by much data (D'abbs, Hunter et al. 1994; Williams 2002; Hogan, Boffa et al. 2006; ABSAIHW 2008). In fact the NT has continued to have the greatest rate of deaths, with 6.4 per 1,000 related to alcohol and

hospitalisation rates of 94.3 per 10,000 from 1992 through to 2001 (Hogan, Boffa et al. 2006:208). Alice Springs from 2003 to 2004 had the greatest 'rate of separations for conditions associated with harmful use of alcohol' than any other region in the NT at 53.9 per 10,000 (Hogan, Boffa et al. 2006:208). Ignoring this fact is negligence (Bell 2003).

## Outcomes of the evaluation

A serious failure of Crundall and Moon's evaluation was its inability to set an objective focused on reducing harm related to alcohol abuse through the targeting of sales and consumption. As the trial prohibited the sale of 4–5-litre casks of wine, Aboriginal drinkers shifted their consumption to 2-litre casks of port, the cheapest substitute. This shift was significant with a 1,000% increase in sales from the commencement of the trial (Hogan, Boffa et al. 2006:207). Hogan et al. consider this to be a 'fundamental flaw' as the scientific literature has established that 'per capita consumption' is a dangerous sign of harm to people (Hogan, Boffa et al. 2006:210). The lack of focus on this indicator may have predisposed the Commission to reintroduce the 4- and 5-litre wine casks (Hogan, Boffa et al. 2006:210).

The evaluation highlighted the positive impact of reduced trading hours, along with a reduction in injury related to alcohol abuse (Hogan, Boffa et al. 2006). Hence, a decision was made to maintain the restricted trading hours. However the Commission reintroduced the sale of 4- and 5-litre casks, ignoring evidence provided by the Tangentyere research.

> Well that was the view of Indigenous people on the very serious issue of alcohol and Aboriginal people had their views on alcohol, and a lot of people didn't want to drink, a lot of people wanted to drink, but wanted to drink only beers, and not the red wine and the cheap coolabahs, you know. And the liquor commissioner totally ignored that – that was evidence based research, and it was research done in a language that people could understand – it was more comprehensive research than anyone has done before. And yet they are still ignoring it…what they are presenting is a myth, and this is the reality (Participant 3).

Dr Crundall's perspective was very different, as the Commission had 'acquiesced to lobbying by the tourism industry and police for the reintroduction of 4- and 5-litre cask wine containers' (Hogan, Boffa et al. 2006:208). These deliberations were observed as problematic by some members (Indigenous organisations) of the ERG:

Not everyone was satisfied with this outcome, particularly with regard to the reintroduction of large containers and the failure to limit access to fortified wines (Crundall 2004:11).

The outcomes were in direct conflict with harm minimisation within the community at large, one that has the 'highest rates of alcohol consumption per capita in the country' (Hogan, Boffa et al. 2006:211), leading to 'deleterious consequences' (Hogan, Boffa et al. 2006:211) with an excessive burden of 'deaths, morbidity and social harms' (Hogan, Boffa et al. 2006:211). Crundall's response:

While racial distinctions alone should never be a determinant for a response and there must always be resistance to any approach that smacks of apartheid, there is considerable evidence that intrinsically links higher levels of alcohol harm to Aboriginality (Crundall 2004:13)

He then asked:

[s]hould Aboriginal people be one of many voices in determining population measures or should they have a special status due to their unique circumstances? If the former approach is taken then Aboriginal people must lobby like any other interest group in matters that affect more than themselves (Crundall 2004:13-14).

Crundall ignored the fact the trial directly resulted from lobbying by Aboriginal organisations and the Town Camp survey was another attempt to lobby the Liquor Commission with voices of Aboriginal people impacted by the harm of alcohol daily. As Participant 3 put it, 'What more has to be done for Aboriginal people to be heard?' A climate where the liquor industry is determined to make a profit and is supported by the government and other important economic industries effectively silences Aboriginal voices (Hogan, Boffa et al. 2006).

Crundall confirmed the trial created a market for fortified wine consumption increasing consumption by 1,000% (Hogan, Boffa et al. 2006). When the trial ended, consumption of fortified wine, bottled wine and mid strength beer had all risen with a critical increase of cask wine purchase 56.7% (Crundall 2004:16). Crundall argued that, although, Aboriginal fortified wine consumption increased he was unable to define the good or bad outcomes to the consumers or the market. This argument in the light of physical harm fortified wine was causing Aboriginal drinkers, is highly problematic for Aboriginal communities. Incredibly, Crundall asks:

> If indicators of harm are reducing or not escalating, is it a problem that a new preferred beverage is in place? (Crundall 2004:16).

The Trial's outcome for the Aboriginal community, Tangentyere Council, its research team and the respective Indigenous organisations of Alice Springs was devastating. We all knew the effect the re-introduction of wine casks and the lack of restrictions on port, now known as 'monkey blood', would have, because we listened to the people, those who were being impacted by the ravages of internalised trauma and injury. This was simply another example of the cumulative trauma of not being heard

The NT government along with the Licensing Commission's approach to the trial reversal undoubtedly ensured injury and harm for Aboriginal communities would continue. This outcome had been established within alcohol abuse literature and the voices of Town Camp members. It affirms that research undertaken in a Western positivistic manner does not improve the health outcomes of Aboriginal people, instead it causes further injury. This positivistic approach, used by the NT government, is argued by Brown et al. to smack of 'racism in the culture of (self-styled) "mainstream Australia" ' (Brown, Morrissey et al. 2006:203).

## Critique of the Northern Territory Department of Health and Community Services (NTDHCS) Survey

This section examines the NTDHCS survey instigated by Crundall that informed in part the ERG Evaluation. It provides an exemplar for 'whose knowledge counts', even when the basis of this knowledge developed is flawed. It was this research endeavour, and its flawed approach that led to the Tangentyere research of Town Camp participants.

The NTDHCS methodology of using a household phone survey discriminated against Aboriginal participation both within the Town Camps and the broader Alice Springs Township and led to poorer participation rates. The surveying of 402 Aboriginal people from a population of 28,500 people providing a statistical coverage of only 1.4% (Brown, Morrissey et al. 2006:204). The Town Camp survey sampled through a planned approach to capture numbers that were statistically relevant; 277 people from an approximate population of just under 2000 providing a more comprehensive coverage of 13.8% (Brown, Morrissey et al. 2006:204). Face-to-face interviewing with language speakers ensured that there were no exclusionary tactics used.

225

The NTDHCS survey was undertaken internally by its own Department and therefore was neither independent (Wakerman 2003) nor scientific owing to misread data analysis. In contrast, a report of the Town Camp survey was presented to the Liquor Commission exploring, in entirety, the survey method and the analysed data. Survey results were fed back to Town Camp residents in a plain English report. Data and findings were provided and explained through community meetings. Hence the survey ensured 'Aboriginal direction, ownership, participation and accountability back to the people' (Foster 2005:1), a method proving to be effective, educational and culturally safe, providing, reliable and valid data (Foster 2005). The NTDHCS survey results were not circulated to the broader Alice Springs community.

Flawed methodology and methods will effectively skew any comprehension of research findings, resulting in invalid data and analysis. Indigenous people are incensed with such approaches that fail to provide a 'sound conceptual understanding' of their situations (Smith 1999:140). These concerns are raised by Participant 3:

> I think too many non-Aboriginal researchers have taken the context out of what Aboriginal people are saying. Have disregarded it and treated it with contempt, and been minor in the whole research when really the essence of what people are saying is all there in the context of cultural meaning that they are talking about. And so as a result of that, culture is ignored as being something outside of research; and so I see that it is a struggle to have cultural context involved in research, when really it is a way of people that live by a certain code, certain parameters (Participant 3).

These reasons reveal why Indigenous people are seeking to undertake their own research. The 'indigenous agenda challenges indigenous researchers to work across boundaries' (Smith 1999:140) of both Western privileged approaches and respectful Indigenous research methods to develop valid and robust data. This is an evolving field that is set within an agenda of revealing meaningful data to improve life chances of Indigenous people.

Much of Crundall and Moon's findings have been questioned regarding their validity, by both the ERG and Dennis Gray (Hogan, Boffa et al. 2006). Dr Crundall's explanation for this lack of scientific rigour was that he was making the report community-friendly, yet it was not circulated to the community of Alice Springs. The process and outcomes of each project reflect the

divergent philosophies and agendas of the researchers. The Indigenous research survey aimed to inform change; the non-Indigenous survey ignored the crucial issues.

As a result of flawed methodology used in the survey and the mis-analysis of data supplied by ERG members, the Evaluation of the Trial carried out by Crundall and Moon provides a study of 'method-induced bias' (Brown, Morrissey et al. 2006:203). The evaluation report, failed to:

- establish a harm reduction focus,
- analyse all the data delivered by the ERG members,
- scientifically and correctly analyse the data collated
- provide a comprehensive sample of Alice Springs households
- ensure statistically appropriate Aboriginal participation,
- be independent

As noted, the evaluation process was considered flawed by many internal ERG members and external academics. Hogan et al. confirm: 'Gray noted that the data presented in the official report had not been subjected to appropriate statistical testing and identified several problems with the findings' (Hogan, Boffa et al. 2006:209). In particular, the survey undertaken through the evaluator's work place, namely the NTDHCS cannot be considered independent, a key directive from the Licensing Commission. Bell claimed the evaluation 'is inaccurate and of poor scientific quality' (Bell 2003:2). Crundall agreed that his analysis of data reported to the Licensing Commission and the ERG was deficient (Bell 2003). Yet it was not retracted.

## Good research

How can Aboriginal researchers achieve health improvements through Aboriginal health research? The Town Camp survey provides insights into the complexities of undertaking relevant, safe and meaningful research that can provide outcomes communities deem necessary. However, there needs to be recognition within the mainstream research community that maintaining a purely positivist approach is racist. This story should be shared to prevent further injury to our communities because, as Participant 3 articulates:

> For too long non-indigenous people have been doing research on Aboriginal people, and when they do their research, the government and its negativity of their histories their white values and

beliefs about how Aboriginal people should and shouldn't live, comes out, and sometimes it is very paternalistic, in fact in times it is very missionary.

In order to change this power dynamic and improve the outcomes of research, he suggests:

> It is a chance for Aboriginal people to do their own research and to come up with better and more comprehensive solutions than what non-Indigenous people can do (Participant 3)

When Aboriginal people set up research with Aboriginal communities to achieve positive outcomes, they know the process requires sensitivity and respect. As Tangentyere's survey focused on Town Camp residents from numerous countries of Central Australia, it was essential that the research team was selected for their expertise in working within these different country men and women. As members of these communities (Insider status), their responsibilities were to ensure that the process was safe, community members were well informed, they collected accurate data, and that no one was shamed.

## Training and trust

The training workshop ran the week prior to undertaking research in the Town Camps and set the space for community collaborative learning. It was the space we all required to develop and build upon our relationships so that we could trust each other. Trusting relationships amongst researchers is as important as building relationships with your respective communities, as illustrated in Chapter 6. We needed to know that we could trust each other, not to shame each other or a camp resident. We also learnt to appreciate each others' strengths and weaknesses. This was important as we knew when to back each other up if we were having difficulties.

Participant 4 explores the additional outcomes of this training:

> We would sit in the training and talk about: Okay we want to find out whether people will think the grog trial was a good idea. And you would ordinarily think that's a pretty easy sort of yes or no sort of thing but people would go home, would discuss it with family, they would discuss it with Elders who would give them a different bent on things, talk to the kids about it, they would discuss it. It also impacted on their own lives and their ways of thinking about it and you might think it was a group of twenty people who came to the training. The flow on effect would have been probably 200 people who were actually involved in various levels (Participant 4).

**Capacity enhancement and reciprocity**

Outcomes of this project relate to the notion of capacity building a fundamental focus of Aboriginal health research (NHMRC 2003). It is important to clarify that this term can be considered a deficit model, with researchers thinking that they must go in and build knowledge within the community. This is significantly influenced from a Western worldview, colonially indoctrinated to believe that Indigenous people remain lacking in the capacity to articulate knowledge and this is why they must speak on our behalf.

However, capacity enhancement from an Indigenous perspective is observed as a two-way process that involves the sharing of knowledge and responding to what is shared respectfully and responsibly. Research is an opportunity to build new knowledge and awareness around a specific issue and in the light of poor access to knowledge translation in Aboriginal communities, it is reciprocal action for the time and knowledge informants give freely. The NHMRC *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003) assert that Reciprocity is a vital component of ethical research with Aboriginal communities: 'Reciprocity requires the researcher to demonstrate a return (or benefit) to the community that is valued by the community and which contributes to cohesion and survival' (NHMRC 2003:10). The Town Camp survey achieved this through its process.

> Because we had to clarify what we meant about a lot of things and it was an educative process not only for us and the non-Aboriginal people but it was a process that filtered throughout those whole communities (Participant 4)

The process was iterative, supplying continuous feedback to communities because people knew the Tangentyere research team was training, talking and consulting prior to the survey date. This was important to camp residents; they were informed, which showed they were valued. This did not occur with the NTDHCS's evaluation process.

As a result of our training focus, our skills grew and strengthened as we felt confident and comfortable working together. Our compatible working relationships were on show and this was necessary to make those we interviewed feel comfortable, respected and safe to talk to us.

> Insider research has to be as ethical and respectful, as reflexive and critical, as outsider research. It also needs to be humble because the researcher belongs to the community as a member with a different set of roles and relationships, status and position (Smith 1999:139).

Indigenous insider status is not appreciated within the mainstream research agenda especially in relation to the reciprocity and responsibility that comes with this role. Indigenous researchers are generally chosen to provide Indigenous representation on a research project and be the link between the research team and the community, they are considered to have inside status. However, their role has been defined by their community, due to this insider status, and this role has significant implications and responsibilities. 'Being part of an Aboriginal research process is a partnership and means working together to research issues that are important to the community you are working with' (Foster 2005:45) and not necessarily that deemed by non-Indigenous researchers. This partnership incurs responsibility and reciprocity that guided the research process. As a result, the responses to the survey questions by camp residents were particularly positive and richly informing, as Participant 4 confirms:

> Very wide, yeah huge and so instead of getting, going back to the yes and no response to whether the grog trial was a good idea or not, what came into those responses was history. People started talking about a lot of stuff about how whitefellas used to pay Aboriginal people in stock camps and these sorts of things, they were paid with grog, rum, these sorts of things. These sorts of discussions came up and instead of anybody else saying oh well that's not particularly relevant, let's move on to the next question, we'll ask you this one, we actually got a deep sense of the attitudes that people had, those attitudes were related to a lot of other issues, we got a lot of discussion about stolen generation stuff. We got health, we got human rights, we got multitudes of stuff …

The researchers who undertook the surveys were respectful of all responses given. This is a defining point to what made this method different. I have observed researchers questioning Indigenous people and when the response they give does not follow exactly the line of their questions, the participant's answer is generally ignored and another question is asked. These actions cause shame, which compounds existing trauma and leads to injury. When the researcher ignores the context provided by informants their data will be incomplete and invalid. As Participant 4 explains:

If people don't feel that they're actually being listened to and heard then people aren't going to tell you anything or they'll tell you anything to get you off their case or who knows there are multitudes of things but when like for us with that survey. If you looked at the responses to 'do people want to keep liquor restrictions and somebody else had of interpreted those results we would have had a far different outcome because when people said, and a vast majority of people said 'no don't keep the restrictions' anybody else would have got hold of that and said 'see told you so, people don't want alcohol restrictions'. But when you looked deeper and you cross-checked it with other responses to other questions, you realised that people are actually saying 'no we don't want those restrictions we want more'

The point made by this respondent is that the results discussed in this statement would have been misinterpreted by many researchers because of their unfamiliarity with the cultural context and the language being used. Many researchers do not listen or observe body language and hence miss many cues. The context of what is being explained and explored by informants is essential to their story in its entirety. This is why it is crucial that Indigenous people are involved in the analysis of such data confirming the importance of Indigenous researchers researching their own people. As Brown et al. argue:

[t]he immense benefits from a research point of view, of admitting the proper place of Indigenous people in the research process and the relative simplicity of doing this once it is recognised that fieldwork research techniques are not particularly hard to learn, whereas the immense cultural and linguistic knowledge of the Indigenous researchers could not possibly be fully acquired by non-Indigenous researchers over many years of 'cross-cultural' and linguistic training (Brown, Morrissey et al. 2006:203).

Foster explains precisely what this requires:

You have to ensure them your trust and confidence and for us to get the appropriate answers from them we had to judge by their body language and expressions on their faces. Some researchers might think that this is not the right way or it introduces bias in gathering the information. That's where we are different, as Aboriginal people are brought up to respect each individual. If you sense these signs and gestures like body language, expressions on their faces, turning their back towards you or even hiding from you then you know that it's not the right time to ask them questions and you have to stop (Foster 2005:13).

Respect is critical to the Indigenous experience in research especially in the light of past negative experiences (Dunbar and Scrimgeour 2006). It is at the core of Aboriginal ways of knowing being and doing (Martin 2007), it's law (Foster 2005) and as such is at the core of Indigenous Research Methodologies. The NHMRC's guidelines on ethical research practice within Indigenous communities highlight respect as a value at the heart of guiding principles for Indigenous health research (NHMRC 2003), affirming that respect must frame 'all aspects of the research process' (NHMRC 2003:12). Respect was encompassed within the Tangentyere project: recognition of sorry business; the importance of ensuring there were language speakers; informed consent; listening; reading people's body language; knowing when to leave people alone; providing information; establishing the context; and working towards benefit for the community.

Participant 3 explores this point further in relation to the building of valid evidence:

> Well the way I see research and the way it benefits Aboriginal people is, firstly it is evidence based information in the sense of the appropriate processes, appropriate questions asked in the appropriate way by having language speakers talk to Aboriginal people and its through that avenue that we can get evidence based information that really should be influencing government and state policies and how services are delivered. And if the services are not being delivered and people are saying so then that, in itself, is evidence based.

Indigenous evidence collected through Indigenous methods is less likely to be misinterpreted or filtered through a framework/worldview that is unable to define its meaning. Appreciating the context is crucial to building reliable and valid information and is a central principal of Indigenous research methodologies. The context of the community must be taken into account and this requires in-depth knowledge of history, policy, country, law and family relationships. If context is not considered then what you state that you have observed or explored has no real meaning or value, as you have removed all the variables that have created what you have observed. It is a naïve approach but one so often taken by non-Indigenous researchers in Indigenous research projects.

The most important thing is context and having a much more in-depth understanding. Tangentyere researchers know the people, live the context, speak the language and understand the complexities of the issues in a way that an external researcher cannot (Foster 2005:10).

The experience of undertaking research and training had numerous outcomes for all researchers and their families. This is the strength of Indigenous research: the process is rich with outcomes along the way and it is not simply focused upon the final product.

It's an eye opener, it's a learning session because people do learn about their own plight, they learn about the issues of alcohol and the issues of kidney disease, heart failure, whilst they do the research. It is a learning process that does empower them to start thinking about, "well gee, this is happening to my family, how can I prevent it, how can I work with my family to get over the illnesses that we face?", but also to empower them because powerlessness is an issue in itself (Participant 3).

The CEO of Tangentyere Council was keen to develop Tangentyere's research capacity and he achieved this despite having suffered the broken promises of researchers from the past and in the present to collaborate and share their knowledge with Tangentyere and the Town Camps. As Tangentyere was not a health body they were unable to apply for funding directly to do research. Instead they needed to connect with a university collaborative body, which does not often bode well for Indigenous organisations, as Participant 3 corroborates:

It's very hard when you have a struggle against the so-called collaborative partners for the kudos of that research, for the ownership of that research, and the ownership of that data. It's once Aboriginal people value the notion that they actually own the stuff that they have the power then to utilise the stuff in a way that they want to. For a lot of universities and researchers it's their money in the bank, and they will fight you to get that kudos, and so that they can do publications.

Although there are funds to develop Indigenous researchers, they remain enmeshed in universities. For many Indigenous people, attending university is simply not an option because of lack of the access to prior education deemed necessary to build the qualifications required for entry. Because it is many years away from community in an environment that is not Indigenous-friendly, it is an option many do not wish to consider. Aboriginal people have the skills to

undertake reliable and meaningful research; it is simply that their skill base is not recognised by Western Institutions (Brown, Morrissey et al. 2006).

Academic institutions remain focused on formulating knowledge about the Other's experience utilising Western doctrine to maintain their position of power. This form of knowledge brokerage continues to colonise and subsequently oppress Indigenous peoples and their knowledges. It is an approach which does not benefit Aboriginal communities or fit with research needed to make changes communities are literally begging for (Dunbar and Scrimgeour 2006), as the Alice Springs grog trials example exemplified. It was a project that had to be done because of political and community pressure but the opportunity to make a real difference was always out of the hands of the Indigenous community. This has parallels with the Aboriginal health research agenda. There is real political pressure to expend funds in a way that makes it appear something is being done. However, those who could make a real difference are not considered being of value because of an entrenched notion of Western superiority.

## Conclusion

This chapter's account of research with Aboriginal communities illustrates the difficulties Aboriginal people have representing their concerns and interests regarding alcohol mis-use and the harm it causes.

> It is accepted that colonisation and its effects are significant factors in the aetiology causes of Indigenous alcohol usage, yet what the literature misses is aetiological theories, explanatory models, strategies for intervention, and strategy evaluation for Indigenous peoples, which are researched and written by Indigenous peoples themselves (Phillips 2003:23).

Philips suggests that it is not that the Indigenous data do not exist, but rather that it is not formulated in the descriptive terminology of Western research that is considered valid and reliable (Phillips 2003). Yet the Alice Springs grog trials research undertaken by Tangentyere Council and partners produced Aboriginal data using a methodological sound approach in a manner that was both meaningful to the informants and the Licensing Commission. Nevertheless, the report was dismissed. The reasons behind the Liquor Commission's failure to respond to the recommendations of Tangentyere's report are not clear. Instead, the Licensing Commission based its findings on Crundall and Moon's evaluation.

Analysis of the Alice Spring's Grog Trial evaluation emphasises the maintenance of a cultural hegemonic agenda held by many bodies in relation to Indigenous peoples and the solutions to the health issues they face. In many ways the response to the Town Camp survey is not unusual, as the NT and its respective governments have failed throughout their tenures to listen to Indigenous voices and support their strategies to reduce harm (AMSANT 2008) and violence (Atkinson 2007) for many decades. This discrimination is not new; failure to listen is not new, blaming Aboriginal people for government failure is not new. 'Innocent intentions' of governments have justified such action in their efforts to address the circumstances of cultural divide and marginalisation' (Hinkson 2007:287).

However at the core of this situation is the consistent belief and construction of Aboriginal peoples as problematic. The NTDHCS's Evaluation and that of governments has been one 'forced to produce the truth of power that our society demands, of which it has need, in order to function' (Foucault 1980:93). Although NTDHCS's findings were challenged, the government accepted the studies 'truths', as they fitted with the views of their voters. In other words, alcohol was an Aboriginal problem, and not one for the rest of Territorians and its tourists. The NT government was swayed by 'powerful commercial interests' rather than doing its job to 'minimise the health and social consequences of excessive consumption' (Saggers and Gray 2001:22).

This chapter highlighted how flawed and unethical research can lead to Indigenous people's injury. It also showed that there are opportunities to grow good Indigenous research models that do not cause injury. These models are informed through Indigenous philosophy and law to do no harm, as well as a critically reflexive approach sensitive to the experiences of those who have been harmed through research. This approach to research did deliver valid and meaningful data, and ensured the data were taken back to the communities in the ways they requested. Although the data were ignored by the Licensing Commission, Tangentyere's approach provides a way forward to inform the research reform agenda.

The following chapter will explore what is ethical praxis within an Indigenous research context.

# Chapter 8

# Ethics: It's just good manners

## Introduction

This chapter aims to contribute to the knowledge on research ethics from an Indigenous perspective. As has been established in Chapter 2, worldviews are paradigmatic and guide how we act as moral people. It was also established that Indigenous and Western worldviews are divergent and, accordingly, the way we view our moral and ethical conduct also differs. Knowing this, we need to reassess the current conduct and articulate specifically what is ethical and moral conduct in Indigenous health research, to prevent further injury and improve health outcomes.

Not surprisingly, ethical conduct in research has been highlighted by participants and through my own experience as a problematic in the area of Aboriginal health research. There is a major concern realised by informants that the current approach to satisfying human research ethics committees does not, in most cases, provide Aboriginal communities with an equitable or safe partnership within the research project. Rather, ethics approved through an institutional ethics committee for research in Aboriginal communities are more about the protection of the researcher, their organisation and the institution than about the communities and their peoples (Smith 2005:96). The process, language and sentiment of such research remains embedded in Western law, values and ethics. Western power is further exhibited through controlling and articulating the manner in which this process occurs.

Indigenous ethical principles and values are divergent to those of Western research institutions (Shibasaki and Stewart 2005:3). In Chapter 3 I highlighted the importance of acknowledging the divergence of Western and Indigenous worldviews. Recognising that that there are many worldviews, knowledge systems and ways of knowing, being and doing is central to ethical research (Smith 1999; Battiste 2008). However, 'most researchers do not reflect on the difference between Eurocentric knowledge and Indigenous knowledge' (Battiste 2008:503). This lack of reflection engenders a 'cognitive imperialism' (Battiste 2008:504) focusing upon establishing universal dominant norms of behaviour (Battiste 2008) in line with the Cartesian

ideology of a Universal Truth. Arguments supporting this approach have been voiced by critical theorists and Indigenous scholars asserting that Western ethical principles and guidelines used in research involving humans are ineffective in protecting those being researched (Lincoln and Denzin 2008:569), as they are derived from a number of Western philosophical traditions that fail to recognise the rights of people of difference, especially Indigenous peoples.

This is why ethics with aim of doing no harm are the core of Indigenous research methodologies. Although Western ethics aim to achieve this goal, the findings from this thesis suggest that research undertaken unreflectively does cause harm. It is this harm that Indigenous people connect with 'research' (Minichiello, Aroni et al. 2000; *Onemda* VicHealth Koori  Health Unit 2008). The preceding chapters have provided an Indigenous perspective on how Western research and its philosophy have caused harm. The theorising, representations and eventual praxis resulting from the research, knowledge production is vested strongly within a Eurocentric paradigm. As such, the modus operandi for research using current ethical guidelines in Aboriginal communities is observed 'as serving the Western model of research that has so ill-served [Indigenous] … interests and needs' (Lincoln and Denzin 2008:569).

It is this light this, I aim to examine current ethical praxis used in Aboriginal health research and explore how this approach could be shifted to be inclusive of Indigenous worldviews, cultural protocols, ethics, and philosophy. This praxis shift is essential if the aim of health research is to improve Indigenous health.

## What constitutes ethics within a Western institution?

Ethics are codes of conduct that relate to social norms and they need to be articulated from the worldview of those who are to be researched. Generally, from a Western health research perspective in Australia, ethics means the upholding of ethical guidelines as documented by The National Health and Medical Research Council's (NHMRC) National Statement on *Ethical Conduct in Human Research (NHMRC 1999; NH&MRC, ARC et al. 2007)* evidenced in a research proposal submitted to a Human Research Ethics Committee. These guidelines are positioned to protect human beings involved in research, the researchers and their respective institutions (NH&MRC, ARC et al. 2007). Chapter 6 in particular highlighted how this approach has failed to protect Indigenous communities or Indigenous researchers from injury, as this

utilitarian approach fails to recognise or be respectful to non-Western worldviews (Denzin and Lincoln 2008).

Modern codes of ethical conduct in health research resulted from the Nuremberg Tribunal of 1947, which focused on Nazi medical crimes. Ten principles for appropriate medical experimentation known as the 'Nuremburg Code' were developed (Christians 2005; Ellis and Earley 2006; NHMRC et al. 2007:3). In 1964 the World Medical Assembly affirmed these principles in what became known as the Helsinki Declaration (Lincoln 2005; NH&MRC, ARC et al. 2007:3). These actions, evolving from World War II, have informed human rights doctrine in relation to the protection of humans with reference to the 1948 Universal Declaration of Human Rights and the development of 'modern research ethics' (Ellis and Earley 2006:2). The NHMRC of the UK and Australia, informed by the Helsinki Declaration, established in 1964 codes of conduct for researchers experimenting on humans, which were initially voluntary. They were enforced in Australia in 1992 after experiences of medical research trialing of untested drug therapies prescribed to patients by doctors for drug companies, which led to tragedies such as birth defects from the experimental drug Thalidomide and 'widespread abuses in clinical trials' (Dyer and Demeritt 2009:51).

In 1992 the Australian National Health and Medical Research Council became the statutory body regulating the ethical conduct of medical research on humans. This obligation required the establishment of Human Research Ethics Committees (HRECs) and the development of guidelines for ethical conduct in research on humans (NHMRC, ARC et al. 2007). Institutional ethical standards established the agenda for researchers in all areas of human inquiry. The principles have been derived from three ethical traditions: 'respect, from Kant; beneficence, from Mill and the utilitarians; and justice as a distributive ideal, from Aristotle' (Denzin and Lincoln 2005:37). These traditions, as a result of their origins, assumptions and ontologies are not attuned. Within the Indigenous research agenda these traditions of justice, beneficence and respect continue to be imposed by the majority upon the minority in relation to benefits for the greater good (Denzin and Lincoln 2005:37).

Codes of ethics have been prescribed for researchers under the convention of 'moral principles' (Christians 2005:144) that generally cover:

- Informed consent focused on individuals voluntarily agreeing to participate with a sound knowledge of consequences.

- Respect requiring that subjects participate voluntarily, without coercion.

- Design of the research being free of deception.

- Privacy and confidentiality being required to protect both identity and locale of those researched and maintenance of privacy. The aim is to protect the liberty of the individual.

- Accuracy to ensure data is valid and not fabricated, or fraudulent (Christians 2005:144).

Encompassing three principles articulated within the Belmont Report (NHMRC 1999:5).

> Respect for persons, that is, that individuals should be treated as autonomous agents and that persons with diminished autonomy are entitled to protection
> Beneficence, that is, the obligation to maximise possible benefits and minimise possible harms.
> Justice, addressing the resolution of the question of who ought to receive the benefits of research and bear its burdens (NHMRC 1999:4).

The actioning of these principles are assessed via a written proposal submitted to a Human Research Ethics Committee. This submission requires that researcher/researchers comply with the principles of ethical conduct as outlined by the National Statement (NHMRC, ARC et al. 2007). The current National Health and Medical Research Council's (NHMRC) National Statement on *Ethical Conduct in Human Research* has been developed jointly with the Australia Research Council (ARC) and the Australian Vice-Chancellors Committee (AVCC) (NHMRC, ARC et al. 2007:4). This aligns the academy and funding bodies by stipulating ethical praxis in human research.

The uptake of guidelines with the accompanying submission 'is frequently treated as a footnote to research practice' (Vallance 2005:1). Researchers and their institutions generally view this requirement as purely administrative, with the belief that what gets approved by an ethics committee is in every sense ethical research (Vallance 2005). This perspective contravenes the ethics of moral principles. However, research institutions requirements 'often engender an approach that focuses on avoidance and circumvention' (Vallance 2005:4) from which Indigenous health research has suffered (Shibasaki and Stewart 2005). Ethics committees in

academic institutions tend to be intramural, and their role is also to ensure the safety of their institution, and this is reflected in their assessment of research praxis.

## Aboriginal and Torres Strait Islander ethical guidelines

There have been numerous attempts to embody an ethical undertaking of Aboriginal health research. This approach has involved a number of players from the 1980s until today whose function and role require a brief outline. Importantly, the player's worldviews, roles and functions differ and it is critical to acknowledge this divergence in their undertakings of informing research conduct.

It is important to be mindful of the political environment in which the focus of ethical conduct in Aboriginal health research has most recently unravelled, with the latest government-endorsed guidelines produced during the Howard era[11] where Indigenous affairs were instrumentally restructured from a policy of self-determination towards a mainstream agenda. The NHMRC is a statutory body, whose brief of developing ethical guidelines that were meaningful to communities, had to be measured against the research community that had now an established Road map for research into Aboriginal health. Aboriginal health is a highly politicised area and the fact that the research pathway is poorly articulated and quite messy must not be presumed to be accidental.

The following table sets out the key stakeholder organisations involved in some way in the development of ethical guidelines for research with Aboriginal and Torres Strait Islander communities. I have explored their roles in this ethics environment to highlight the multiplicity of players.

---

[11] John Howard Prime Minister (1996–2007)

*Table 1*: **Ethics Stakeholders**

| Organisation | Role | Ethics Role |
|---|---|---|
| NHMRC<br>National Health and Medical Research Council (Government Organisation)<br>Peak body for health and medical research. | Provide advice on ethical behaviours in health care and health and medical research. Articulate research priorities. Fund health research activities. Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) of the NHMRC prepared, and consulted a Road Map for research completed 2002. *The NHMRC Road map – A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research (NHMRC 2002).* | Develop guidelines on ethical conduct in research on humans. Established HRECs Formalised HRESC structures Reviewed the 1991 *Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (NHMRC 1991).*<br> (NHMRC, ARC et al. 2007:69). Co-authored the National Statement on Ethical Conduct in Human Research 2007. |
| NAIHO (Non-Government Organisation)<br>National Aboriginal and Islander Health Organisation.<br>Established by Aboriginal community controlled health organisations in 1976. | Support and advocate for Aboriginal community controlled health organisations. | Developed in collaboration with the NHMRC the interim guidelines (Mundine, Edwards et al. 2001).<br>Did not have an ethics committee |

| | | |
|---|---|---|
| NACCHO (Non-Government Organisation) National Aboriginal Community Controlled Health Organisation changed its name from NAIHO to NACCHO in 1992. | National Peak Body for Aboriginal community controlled health organisations. 'Representing Aboriginal community control at a National level to ensure that Aboriginal people have greater access to effective health care across Australia (NACCHO 2008:1)' | Do not have an ethics committee. Promote the 1991 guidelines developed by NAIHO and the NHMRC (NACCHO 2008). |
| AH&MRC (Non-Government Organisation) Aboriginal Health and Medical Research Council. NSW Representative body for Aboriginal Community Controlled Health Organisations. ACCHS have been established to ensure Aboriginal people and communities have control over health services affecting them (Ethics Website:1). | In Partnership with NSW Department of Health. 1999 ethics committee produced a document *Guidelines for Research into Aboriginal Health (AH&MRC 2008).* | Ethics committee made up of Aboriginal health professionals, community based people, and medical and legal members who have expertise in Aboriginal health and research (Ethics website:1) Provide support to researchers regarding how to undertake safe research with Aboriginal communities. |
| AVCC The Australian Vice-Chancellors Committee | A council of Australia's Vice-Chancellors. Responsible for the advancement of higher education throughout the Nation. | Co-authored the National Statement on Ethical Conduct in Human Research 2007 |
| ARC The Australian Research Council | A statutory authority responsible to the Minister of Innovation, Industry, Science and Research. The body administer research funds and provide funds to research programs | Co-authored the National Statement on Ethical Conduct in Human Research 2007 |
| AIATSIS Australian Institute of Aboriginal and Torres Strait Islander Studies Government organisation | Research body, Publisher and clearing house on Australian Indigenous studies. | Authored the AIATSIS ethical Guidelines 2000. |

As previously established, Aboriginal and Torres Strait Islander peoples' ethics are based on their worldview that 'requires that protocols be set by the Aboriginal and Torres Strait Islander community' (Shibasaki and Stewart 2005:3) to be followed respectfully by researchers, be they Indigenous or non-Indigenous. Aboriginal communities' approaches are set within a self-determination and survival agenda which requires that they actively participate 'as stakeholders, research participants and researchers' (Shibasaki and Stewart 2005:3) in research that focuses on their communities. I believe that in the interests of social justice, ownership and control of the research and its findings must be in hands of the community along with a direct balancing of benefit to the community through capacity building and opportunities for employment. Research using methods and methodologies can ascertain this achieved in a meaningful way for communities.

Ethics within an Indigenous research agenda are not about administrative rhetoric. They are about complying with the rights and dignity of people who have been disenfranchised by past research experiences. The negotiation for change from disenfranchisement to self-determination has occurred over the last three decades and has led to the development of parallel and differentiated ethical guidelines for undertaking research with Indigenous peoples (Kaufert, Glass et al. 2004:38). The premise for this approach came from both Indigenous and non-Indigenous people regarding research being undertaken in Aboriginal communities. The agenda had to be shifted from the problematising conceptualisation of Indigenous practice. The utilisation of 'binding ethical guidelines' (Humphery 2001:199) was observed as a method that would assist in transforming 'Western intellectual approaches' (Humphery 2001:199).

In 1986 a national conference coordinated by the NHMRC and the Menzies Foundation focused upon 'Research priorities in Aboriginal Health'. Some two hundred attendants debated the agenda of Indigenous health research, its funding, practices and research priorities. The Aboriginal community representatives asserted the necessity for 'community control and involvement, information feedback, culturally appropriate research methods, and practical outcomes and benefits' (Humphery 2001:199). A key recommendation from this conference was the development of specifically focused Indigenous ethical guidelines produced by Indigenous peoples (Humphery 2001). The Camden workshop of 1987, convened by Shane Houston of the National Aboriginal and Islander Health Organisation (NAIHO), was given the task of

243

developing these guidelines. From this body of approximately thirty Aboriginal community representatives came a research agenda that focused upon a 'needs based approach, the concerted training of Indigenous researchers, and the ultimate ownership and control of research findings by Aboriginal communities' (Humphery 2001:1999). The outcomes of this workshop informed the *National Aboriginal & Islander Health Organisation (NAIHO) Report on the National Workshop on Ethics of Research in Aboriginal Health (1987) (Mundine, Edwards et al. 2001:1)*, and it was recommended they be adopted for all research in Aboriginal health by the Working Party of the National Aboriginal Health Strategy (NAHSWP 1989:212).These partly informed the Interim Indigenous health Guidelines of 1991, developed by the NHMRC, that maintained only three areas of focus: 'consultation, community involvement, and ownership of and publication of data' (Humphery 2000:17). Although they are fundamental to safe, relevant and useful research outcomes for Indigenous peoples, mainstream researchers ignored them and most Institutional ethics committees did not enforce their adoption (Paul and Atkinson 1999; Humphery 2001).

It has been argued that the 1991 guidelines adapted by the NHMRC provided a 'gateway' to access Aboriginal communities, because Human Research Ethics Committees (HRECs) gave permission to do research in Indigenous communities without observing the process (Humphery 2000:17; Cruse 2001). This gateway ensured the domination by Western institutions, via HREC, over what and how it would be done with Indigenous communities (Humphery 2000:19). This is disturbing as most committees lack reasonable Indigenous representation (Stewart, Shibasaki et al. 2006) with only 21% of HRECs nationally having 'formal mechanisms for Indigenous input in decision-making around ethics of health research involving Indigenous people' (Stewart, Shibasaki et al. 2006:292). For most HRECs this means a lack of insight into the politics and circumstance of particular communities that researchers are targeting (Kaufert, Glass et al. 2004). Kaufert et al. (2004:45) questions whether a non-Indigenous committee can assess the value or benefit to Aboriginal communities, the justice, and the impact of harm that may result from a research project (Kaufert, Glass et al. 2004:45). As argued by Mundine et al., even in the light of minimising Western paternalism and the belief in 'genuine intent, there can be gross ignorance of Aboriginal culture, protocol and experience' (Mundine, Edwards et al. 2001:8) that causes harm.

The latest ethical guidelines: Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC 2003), endorsed by the Australian Health Ethics Committee council at its 148th Session in June 2003, were the result of the revision of the Interim guidelines of 1991 (NHMRC 2003). The framework for the revised guidelines was developed at 'the Ballarat workshop' of 2002 that included participants from a 'Working Party of researchers, Aboriginal community controlled health sector representatives, Human Research Ethics Committee representative and policy makers' (NHMRC 2003:21-22).

The values that lie at the heart of the new guidelines are:

- Spirit and Integrity
- Reciprocity
- Respect
- Equality
- Survival and Protection
- Responsibility (NHMRC 2003:8).

They aim to guide researchers 'in the conception, design, and conduct of research' (NHMRC 2003:8). Each of the above values is explored with the emphasis on the key value of Spirit and Integrity that intersects all. The guidelines are 'intentionally broad and non-prescriptive' (Tozer 2006:19). This has prompted criticism on the grounds they are too 'unspecific to be of real value in ethics deliberations' (Tozer 2006:34). This is an important critique given the lack of Aboriginal participation on HRECs, suggesting that the guidelines do not provide the necessary guidance required for ethical conduct within diverse Aboriginal communities. At their very best, these guidelines attempt to explore the importance of respecting Indigenous values and enhancing relationships with the research academy. However, they also conform to a Western research agenda, as they 'have been created within the domain of medical epistemology, which is most closely aligned with positivist hypothetical deductive models of research' (Nicholls 2008:4). The new guidelines have also attempted to temper the interests of others by stating that they:

[a]re not intended to limit inappropriately the capacity of government departments, statutory bodies and health service organisation to collect and analyse data from routine collections (NHMRC 2003:13).

Another criticism of the criteria for ethical research is that the 'Monitoring, follow up and accountability of research projects after the ethics clearance' are not addressed (NHMRC 2003:21) by the guidelines. This lack of monitoring supports the notion that ethics submissions are simply an administrative hoop to be jumped through, and then forgotten about once the real work starts.

The new NHMRC guidelines have been strongly condemned by NACCHO on behalf of the ACCHO sector (NACCHO. 2004) on the basis that there has been a significant shift away from the principles of community control.

> The term 'control' essentially means that all stages of the research, Aboriginal people and communities participating in, or directly affected by the research will be fully informed about, and agree with, the purposes and conduct of the project. It goes beyond either involvement or consultation, and requires an acknowledgement that Aboriginal people have the right to make decisions about research affecting them (AH&MRC 2008:6-7).

Neither 'Values and Ethics' (NHMRC 2003) nor 'Keeping research on track' (NHMRC 2005) promote community ownership within the research process. Instead, the language promotes joint agreements and management on issues such as 'intellectual property rights' (NHMRC 2005:13-14) with researchers. In the light of past research and the inequity of power in Aboriginal communities, managing agreements with researchers is likely to be very 'tricky' (Smith 2005:85). The ideology behind Aboriginal control of the process is an attempt to balance the unequal power relations of the past and present. These relations have not been ameliorated by glossy texts, they require a profound strategy of rethinking and reflection on the way research continues ' "authorizing views" of us, "describing [us], teaching about [us], settling [us] and ruling[us]" ' (Smith 2005:88). The latest iteration of 'Values and Ethics' (NHMRC 2003) does not illuminate or transform this agenda. On the contrary, it has continued to disenfranchise the Aboriginal community.

NACCHO published an electronic statement on Ethical Research Guidelines (NACCHO 2008) alerting readers to its lack of endorsement of the current NHMRC guidelines along with 'Keeping research on track: a guide for Aboriginal and Torres Strait Islander people about health research ethics' (NHMRC 2006). The Board of Directors state that they were 'never approached for their endorsement of these guidelines' (NACCHO 2008:1). They view the current guidelines as:

- Deficient because they fail to provide guidance on the praxis of ethical research.
- Providing minimal information on the translation of data back to community and their organisations
- Not acknowledging of community representative bodies
- Breaching the recommendations of their own guidelines by failing to seek NACCHO endorsement (Peak National Aboriginal Community health body).

NACCHO is currently developing its own guidelines for ethical Indigenous health research and in the interim recommends that the 1991 NHMRC guidelines informed by NAIHO should be used by researchers (NACCHO 2008). I support this premise as currently indigenous communities are not protected by the current practice.

There is a direct link between the new Indigenous guidelines and the NHMRC's Roadmap for Indigenous research in health (NHMRC 2003). The new guidelines have circumvented vital concepts related to intellectual property, engagement, communication and supporting community development during the research process. These are all concepts that would limit the essential shift from disenfranchisement to self-determination, echoing concerns held by NACCHO, as well Rigney and Worby, that 'any pairing of Indigeneity and institutionalization should give the greatest pause for thought' (Rigney and Worby 2005:371).

Although these guidelines for research aim to shift the ethical conversation from rules and make the experience one of greater flexibility, 'incorporating alternative perspective, and exercise nuanced judgment' (NHMRC 2003:4), there continues to be:

> [a] lack of evidence to support the proposition that the formalisation of research guidelines and protocols has resulted in an increase in the flow of benefits from research to Indigenous peoples

or substantial changes to the way Indigenous peoples are positioned within the research process (Dunbar and Scrimgeour 2006:180).

A number of reasons for this have been highlighted by Meryan Tozer in his study, The Effectiveness and Suitability of Ethics Assessment Processes For Research About Indigenous Australians (Tozer 2006).

- Lack of education for researchers and their institutions related to the specific ethical needs of Indigenous peoples in relation to research
- Lack of Aboriginal participation in and on ethics committees
- Lack of access to the *AIATSIS Guidelines for Ethical research in Indigenous Studies (2000)* and the *NHMRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003)* through University Research Schools and Ethics Committees
- Ongoing resistance to follow existing Indigenous-Australian Guidelines (Tozer 2006:21)
- Lack of enforcement of guidelines (Taylor 2003).

Addressing these, especially the last point, requires ongoing commitment to change the way researchers in health and the academy think about Indigenous peoples. It highlights the maintenance of cognitive imperialism within the health sciences that continues to ignore the 'rights and interests of Indigenous peoples' who are considered only to be 'passive research subjects' (Kelly and O'Faircheallaigh 2001:2).

## Pathways are not clear for researchers

The problem is that when academic researchers and Indigenous peoples talk about research and ethics, they do not always mean the same thing (Dunbar and Scrimgeour 2006:183).

There are multiple players involved in enforcing ethical conduct in Aboriginal health research but their pathways are unclear. Because many see ethics as simply an administrative hoop that must be undertaken to keep institutions and funding bodies happy, few put in the effort to attempt to work through the maze.

The University of New South Wales ethics process is an example of this maze. In order to undertake Aboriginal health research in NSW, a researcher must make an ethics submission to their own university and the AH&MRC. The university in which I am currently studying advocates this point on its website. But finding information regarding exactly how to undertake health research with Aboriginal communities is a convoluted process. First, the researcher must go to 'policies and administration' to find the 'UNSW code of conduct' and then find the 'NHMRC 2007 National Statement of Ethical Conduct in Human Research'. The NHMRC 2007 document does recommend that you must consult with 'Values and Ethics' 2003 (NHMRC 2007:69–71,), however it does not provide the download address. Neither does the UNSW Frequently Asked Questions webpage for research provide any information on Indigenous research. There are, however, useful links and resources to the NHMRC 'Values and Ethics', 'Keeping research on track' and the *AIATSIS, Guidelines for Ethical Research in Indigenous Studies (2000).* As the NHMRC 2007 guidelines were co-authored with AVCC and ARC, there should be a more navigable pathway for researchers to follow. As UNSW is a university within NSW it should also be alerting researchers through a link to the AH&MRC ethics process.

The AH&MRC have guidelines on their website under the heading of ethics. This is a very transparent pathway. The key principles to be addressed by researchers are clearly defined within the AH&MRC guidelines in plain English. Importantly, they stress, as did the 1991 guidelines, 'As a first step, researchers should seek the active involvement and support of local Aboriginal community Controlled Health Services (ACCHSs), as the Aboriginal community-based body with expertise and experience in health' (AH&MRC 2008:7). The website suggests additional reading and recommends that researchers contact their organisation for support or assistance undertaking the submission process.

In 2006 the AH&MRC board requested a review of their ethics committee by the former Director General of NSW Health, Michael Reid. The review reconstituted the committee and established measures to enhance operations. The new committee first met in April 2007 and continues to meet bi-monthly. The committee follows the requirements of the *National Statement on Ethical Conduct in Research Involving Humans (2007)* and the NSW Department of Health for *ethics in lead agencies.* The committee has also established a 'specialist reference panel to

provide advice to the Committee, when required, on the scientific merit of research proposals' (Website:2).

Currently the AH&MRC recommends that their evaluation process requires the following criteria to be met.

a) Consistency with the *National Statement on Ethical Conduct in Research Involving Humans* (2007)

b) The Committee will only approve a project where:

(i)    The research will advance scientific knowledge and result in a demonstrated net benefit for the health of Aboriginal people and communities.

(ii)    There is Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings

(iii)    The research will be conducted in a manner sensitive to the cultural principles of Aboriginal society

(iv)    Aboriginal communities and organisations will be reimbursed for all costs arising from their participation in the research process

(v)    The project will utilise available opportunities to enhance the skills and knowledge of Aboriginal people, committees and organisations that are participating in the project (AH&MRC 2008:5).

It is important to note that the AH&MRC promotes the concept of community ownership over all aspects of research proposed.

## What informants have to say

> You can talk about ethics till you're blue in the face. The bottom line is that the way academics/researchers treat Aboriginal people sometimes in the research field breaches the fundamental notion of human rights: to be heard, to be respected, to be acknowledged, to be given a fair go, all of that stuff (Participant 4).

Throughout the thesis I have analysed research of the past and present and demonstrated how it has caused harm to Aboriginal people. Some of the reasons research has caused this harm has

been encapsulated by informants as being about unethical practice. The most commonly cited breach that I have witnessed is disrespectful behaviour, when people **feel** they have been put down and ignored. Dismissal of people's knowledge, experiences and not being heard causes injury. When Aboriginal people are asked to share their stories or experiences with researchers, they expect to be listened to. Not being listened to or heard is not respecting that person and hence their story or perspective is invalidated. While there are exceptions to this practice, this is one of the most common experiences that Aboriginal people have discussed when they relate their encounters with non-Indigenous peoples/researchers. The common statement made is that they just don't know how to listen (Atkinson 2002).

As the following participant elaborates,

> Well they don't get it because they don't feel that they have to learn something new because they know it because they're academics, they're researchers and there's a beautiful Pitjantjatjara word for that; 'pinaparti' which is you're not listening. There's you can't hear, but it's not because you can't hear because your ears are no good, you can't hear because you can't comprehend and you don't want to comprehend, you don't want to actually modify the way that you think about something and I think that's the tragedy because I think that's what ultimately research is (Participant 4).

This participant highlights a number of matters. Firstly those researchers do not feel they have something new to learn. Although they are in the field to collect data, the data, it seems must conform with the researcher's reality. If the data do not fit with the researcher's agenda and worldview, it is generally dismissed as irrelevant. This is a serious issue that underlies the problematic nature of western research on the 'Other'. Evidence is only validated when it fits within the framework of what the Western researcher views as relevant and meaningful to their solution or development. Although informants have entrusted researchers with important shared knowledge, it continues to be valueless to the researcher who is unable to grasp that this way of knowing is critical to solution development for the respective communities. In every sense it highlights the maintenance of Eurocentric thinking, and its assumptions of superiority and paternalism.

251

The term mentioned above, 'Pinaparti' the Pitjantjatjara word for 'you're not listening', indicates that listening is considered an important value, (Ungunmerr 1993a:35 cited in Atkinson 2002:18).The Gungari language group use 'Binan Goonj' meaning they hear but they don't listen (Eckermann et al. 1992:iii). Listening is important to all cultures and as Miriam Rose Ungunmerr from the Ngangikurunkurr Nation claims 'We could not live good and useful lives unless we listened'. In the Gamiliaroi language of NSW, Aunty Rose's country, the word is 'winanangargurri' which Judy Atkinson defines as 'listening deep', a methodology she uses, known as 'Dadirri', meaning 'deep listening' from the Ngangikurunkurr Nation (Atkinson 2002:15). The principle behind listening is that it 'invites responsibility to get the story – information – right' (Atkinson 2002:18). This is why researchers are not getting the story right, the story that has been shared with them, a breach of Aboriginal principles and values.

This lack of listening is considered disrespectful:

> I think too many non-Aboriginal researchers have taken the context out of what Aboriginal people are saying. Have disregarded it and treated it with contempt, and been minor in the whole research when really the essence of what people are saying is all there in the context of cultural meaning that they are talking about (Participant 4).

The undervaluing of Indigenous voices and knowledges in research on Indigenous health does injure people as it directly breaches Indigenous law. This way of doing research has been learnt through the teaching and practice of experts who lack cultural knowledge, it has been a cumulative process that has caused cumulative injury. This approach requires remediation.

As a result of this inability to be open to really hear or comprehend what is being shared with you from another worldview, many researchers respond by filling in their blanks of understanding with their own colonised dialogue. This leads to the documentation of problematising peoples, as the researcher has failed to grasp the context and culture in which these words and statements have meaning.

> Because of this, their results cease to be relevant or valid because they have failed to observe the cultural contexts for asking questions (Participant 4).

This is perhaps the most serious breach of ethics, as invalid research is unethical. It also leads to further misinformation and problematic constructions of Indigenous peoples that inform the maintenance of such practice. This experience of research is not unique to Aboriginal Australians as Ermine et al. (2005) note:

> The Elders said that academics "don't know what they don't know." They state that academia and in particular, the non-Indigenous researchers, are not fully aware of Indigenous 'ways of knowing' because they have no basis in western science and western knowledge. Very often information and knowledge in academia is made invalid by the 'not knowing' of the academic to appropriately process First Nation information (Ermine, Sinclair et al. 2005:20).

The Elders' argument is vital and lies at the core of my argument about the collation of valid data from research. Indigenous health will not improve while researchers continue to insert their own values and beliefs about Indigenous Australians, values and beliefs that remain on the whole misinformed. The paramount agenda of undertaking research irrespective of the values and concerns of those being researched is highly unethical and will produce more injurious outcomes because it is invalid.

Listening and hearing is an active process and method requiring a person to sit and observe the person speaking, allowing their story or narrative to unwind orally without interruption (Minichiello, Aroni et al. 2000; Atkinson 2002). This act demands respect of the speaker through a disciplined openness of the person 'listener' who is being provided with privileged information (Minichiello, Aroni et al. 2000). In the case of research, the very point of interviewing an informant is to 'gain access to, and an understanding of, activities and events which cannot be observed directly by the researcher' (Minichiello, Aroni et al. 2000:70). This basic process is about being able to listen and hear and requires an openness which Deborah Bird Rose affirms is a challenging process (Bird Rose 2004:22) for non-Aboriginal people. It is challenging because it is uncomfortable and disconcerting which makes the experience feel slightly unsafe. Being open is exposing yourself to a dialogue that may contradict your viewpoint, contest your very being and change the way you think (Bird Rose 2004). This shift in the way you think or view a situation is exactly what Aboriginal people are asking for when they ask to be listened to. This act of listening is actually an act of being open to another worldview perspective as Paulette Regan, PhD candidate, suggests:

As members of the dominant culture, we have to be willing to be uncomfortable, to be disquieted at a deep and disturbing level – and to understand our own history, if we are to transform our colonial relationship with Indigenous peoples (Regan 2005:7).

It is in this space of discomfort that Paulette asserts 'we are most open to deep, transformative learning' (Regan 2005:7). This is precisely the result from the process of listening that is required by Aboriginal people. Paulette asserts that this engagement involves 'our whole being—head, heart and spirit' (Regan 2005:7). With openness researchers will be able to appreciate the words of the following participant:

What I've learnt or felt people have tried to explain to me over time is that for those issues that occur on their [Aboriginal] land, for all those things that affect people, that they have their own authority to speak, and that to articulate that to someone else and in the academic manner to frame it within someone else's theoretical framework or whatever worldview, was not to present the evidence as it stood, so to speak. The evidence was that people's voice has its own authority, and it has its own source of authority even more so. To deny that was to deny the person, and to challenge their wellbeing, which is what is happening (Participant 2).

This requires the recognition and valuing of Indigenous knowledge systems, worldviews and the authority they hold in relation to Indigenous peoples. The subjugation of these knowledge systems and philosophies has caused inter-generational trauma, this continues today, through the maintenance of Western research hegemony. The challenge to a person's wellbeing should not be an outcome of research, however this thesis has shown clearly through each chapter that this is exactly what occurs.

This paradigm needs to shift and this means that Aboriginal people and their communities must be included in the entirety of research formulation: in defining the issue to be researched, laying down the ethical criteria for researchers to follow, involved in the development of the ethics submission; setting the direction of methods to be used; recommending community members to be a key component of the research team; assist in two-way training for all researchers; vetting all data and its interpretation; determining how the transfer of knowledge will occur; and having control of intellectual property. This process is about equitable balance that aims to ensure Aboriginal voices are respected and heard.

It's about seeing the people you are helping feel good, and they are doing something, and I had a part in helping them feel good themselves, and that is bigger than any bloody professor or doctor. It's actually doing something for these people's lives so there's going to be so much more drive and opportunities inside of them to go out there (Participant 1).

We are learning how to utilise our ways of knowing, being and doing to make research safe for our communities. It is this informed position that enables us to state:

I want to be in this, but I don't want to do it their way [Western research approaches]. Because the experiences I had with the liquor restrictions workshop it was so empowering, just hearing people get up and get involved in research and they had their own little messages, and they said just do this and that, common sense ways, just being polite (Participant 1).

## ISN: a response to unethical research

From 2002 to 2005 I was involved in the establishment of a group that we called the Indigenous Staff Network (ISN). It came about as a result of lone Aboriginal researchers and educators working in cultural isolation within a Western academic environment. The initial small number of Aboriginal participants of seven were employed within a number of University Departments of Rural Health (UDRH) throughout the country, whose key focus was and is health research and education in the areas of rural and remote health practice (Morrissey 2003). The aim of this group was to 'provide collegial support in a culturally secure environment where staff were not isolated physically, geographically, or culturally' (Creighton and Champion 2007:1) . The purpose was to support each other in the challenging environment of Western health research and education. I found, as did other Indigenous researchers, that our ways of knowing were being ignored by researchers who were undertaking research in our respective communities.

Indigenous researchers are employed to bring Indigenous knowledge to the research, but it often then gets lost in the workplace. That is, non-Indigenous staff or supervisors disregard this knowledge and don't listen to what Indigenous people have to say about the best ways of going about developing or implementing a project, particularly on communities. This is where a lot of tension comes from – Aboriginal researchers don't feel they are listened to (Dianne Walker, Capacity Development Officer, CRCAH cited in Laycock, Walker et al. 2009:15).

255

The tension that arises relates to Indigenous researchers' responsibilities to their communities and the aim of making research a safe and beneficial process for Aboriginal people. Ignoring the skills and knowledge Indigenous researchers bring to the research field puts the community at risk, and puts the research process at risk of producing invalid data.

Many researchers remain unreflective of how their uncritical training impacts upon their ways of doing research, breaching Indigenous ethics. Universalised in a notion of one truth and Western reasoning leaves little room for openness to another way of viewing the world and their values and protocols. Historically, non-Indigenous researchers considered themselves 'experts' in the field of Aboriginal research and this belief system has been maintained through acts of ignoring the advice provided by Indigenous researchers. This interpretation is supported by an ISN member:

> There are a few researchers who have been around for some time and have a track record in Aboriginal health research. They think why should they have to read the ethical research guidelines? They think they know it all. There is a lot of arrogance out there about the research process, and people believe that they are doing the right thing. They are very western in their thinking, so to them they believe they are doing the right thing, but they don't consider the Indigenous thinking (Participant 5).

Although there are guidelines for researchers to follow, they remain no more than an administrative instrument to complete. As they do not enforce notions of respect, they continue to place Aboriginal researchers on 'tricky ground' (Smith 2005:85). While our academic institutions are responsible for ensuring our workplace is safe, there is often inadequate support:

> They bring you in and as soon as you're in the workplace they assume that you're the same as them now … you know, you're here now, you either survive or you don't, they feed you to the sharks sometimes (Indigenous researcher cited in Laycock, Walker et al. 2009:38).

ISN was set up to ensure we survived. We were only too aware of what our token role within our institutions meant, but our role was not token within our communities. As we knew:

> Doing health research in ways that are culturally acceptable involves putting Indigenous values at the centre of the research process and honouring traditional and Indigenous knowledge, views and values. It involves more Indigenous people and communities controlling what, why, how, and

256

when research is done, as well as how it is used. To achieve these things, Indigenous participation and decision making is required through all parts of a research project (CRCAH cited in Laycock, Walker et al. 2009:5).

As a group ISN had a united voice and approach that attempted to guide a safe and beneficial research process within Aboriginal communities. ISN's aim was 'to enhance respect, credibility, and transfer of knowledge' in the areas of Indigenous research and education (Creighton and Champion 2007:1). However, this approach was often undermined by researchers and other employees who did not appreciate the importance of our community values and protocols, or our roles as community members.

ISN members made their organisations aware that they were 'governed by local [Aboriginal] cultural protocols and principles' as well as those of the organisation (Creighton and Champion 2007:1). This point was critical to our advocacy role and at times this position put us in direct conflict with non-Indigenous academics, however this stance ensured that communities could rely on our support (Creighton and Champion 2007). Our role as cultural brokers was essential within the rural/remote health setting in relation to research, because of the imbalance of power that many researchers held and used over communities. Our attempts to address these imbalances led to taking every opportunity to promote the importance of respectful and collaborative approaches to research with communities at health conferences, and in papers.

In many ways the cultural brokerage position was our most exacting role and at the centre of the difficulties we had working within a Western institution. We all worked 'within the system to understand how it works and to change it' (Creighton and Champion 2007:4). This role is hard and the ISN 'tries to challenge that academic worldview, and its entrenched stereotypes, and make Indigenous culture visible' (Creighton and Champion 2007:4). ISN became a highly visible Indigenous community that supported Aboriginal ways of knowing, being and doing for ourselves and the communities we worked within. This focus gave us strength to address the difficulties as articulated by an ISN member:

> Without the ISN I would have been working in an environment that was isolated and non-inclusive. I would not have had support. ISN has made me confident in my voice and direction (ISN Member cited in Creighton and Champion 2007:4).

We worked towards Aboriginal communities needs being prioritised over the researcher-driven approach of the university faculties we worked within, ensuring benefit for communities rather than injury. This process required the community to drive the research agenda with the support of Indigenous researchers following the cultural protocols of each community.

## Elders affirm the ethical principles and values for us

> Elders are scholars in their own right within the First Nations knowledge system (Ermine, Sinclair et al. 2005:14).

Aboriginal knowledges developed through a unique connection with and cognition of the spiritual, physical, spatial, relational, ecological, social and emotional Indigenous world (Battiste 2002). These knowledges have been cultivated through approaches to survival, which enmeshed research activities and praxis for sustainable and hence reciprocal processes. Research activities focused on 'our common humanity and our survival was ultimately the purpose for knowledge held by different people' (Ermine, Sinclair et al. 2005:22). They informed belief and values systems linked to a holistic way of viewing the world where balance equates to survival. As Indigenous knowledges for populations are 'grounded in the land and people' (Cruse 2001; Sefa Dei 2002:.5) they are known to be localised and not universal. The Western dominance of universality is alien to Indigenous peoples, reflects an ignorance of the balance equation (Ermine, Sinclair et al. 2005) and causes harm. This section will explore Indigenous ethical protocols and values and their historical and ontological derivation.

Knowledge development through an ancient tenure to country is considered by Fals Borda (1980) and Roberts (1998) to distinguish what is traditional Indigenous knowledge (Sefa Dei 2002). It is recognised for its oral and aural nature rather than a Western textual format and is transferred through the teachings of Elders trans-generationally via many mediums. Importantly this transfer and acceptance of knowledge is different to the western model.

Elders are respected, and trusted because of their level of knowledge (Sefa Dei 2002) because the 'truth' relates more to the integrity of the person sharing knowledge rather than the knowledge being shared (Sefa Dei 2002). By witnessing Elders' mentorship and life experiences, we trust their 'truths'. Elders' transfer of knowledges requires them to assess the readiness of the

individual rather than the collective learner. This is imperative as with the giving and acquisition of knowledge comes responsibility (Sefa Dei 2002).

> Knowledge is not a commodity that can be purchased and exploited at will. Because knowledge carries with it power to do good or ill to the knower and the community, many Elders decline to have their knowledge recorded in writing or electronic media. They want to be assured that the seeker is properly instructed and compliant with the ethical obligations that will be assumed (Castellano 2004:12).

This is the reality of knowledge transfer that is different to the dominant Western model.

> Aboriginal knowledge was invalidated by Western ways of knowing. This unconscious, subconscious and conscious means of invalidating Aboriginal knowledge served to perpetrate a superior/inferior relationship around knowledge and how this knowledge is passed on. Systemic racism was clearly perpetrated in this way ( Stiffarm, 1998 : xi Absolon and Willett 2004:9).

It is recognised that our Elders hold Indigenous epistemologies and provide teaching through the utilisation of Indigenous ontology (Ermine, Sinclair et al. 2005). Their role is essential to the development of Indigenous paradigms as they practise Indigenous ontologies of knowing, being and doing. The mentoring of this ontology enables paradigms to be developed that meet the needs of Aboriginal peoples. In this way, Elders are pivotal to and part of Indigenous research methodologies and ethics (Ermine, Sinclair et al. 2005).

> Philosophically speaking, the Elders' dialogues, as a methodology, does not need validation from any other knowledge institution nor is it presumed that the western conventions of knowledge production apply in the First Nations' cultural context (Ermine, Sinclair et al. 2005:13-14).

Our Elders have authority in relation to moral and ethical matters relating to law, society and culture (Castellano 2004; Ermine, Sinclair et al. 2005). They have been in the past the law makers, law keepers and the judges of the law. Their standing in our community is not gender specific and therefore both men and women are considered to be equal in importance in the holding of law. They hold responsibility in the jurisdiction of all key components of the law which is a holistic model encompassing and deliberating upon all facets of physical, spiritual, mental, emotional, land, animal and spirit. As our teachers, they have expectations that we will

travel their journey and be the bridge between our culture and the culture we work within (The Kupa Piti  Kungka Tjilpi Tjuta 2003).

> The Elders said that knowledge and values had significance in traditional life … These values in turn maintained the integrity of the people … Children were taught that sicknesses arise from not listening to what Elders said (Ermine, Sinclair et al. 2005:15).

Learners have a responsibility to listen and pay respect to Elders. They have sacrificed much for us to survive; however they will never sacrifice the concept of respect, as it is imperative to our survival. I am respectful to those who have 'looked after me' through the giving of knowledge; this is my obligation to their duty of care of growing up me (Myers 1986). The authority of their Eldership is not one of domination; it is authority through knowledge, developed through their actions, mentorship of integrity and hence they are held in esteem.

## Respect

As explored within my methodology chapter, I have been supported, grown and held through this thesis process by a group of female Elders. Their voices, knowledge and lived experiences have informed my journey. Over the years we have talked back and forth about what Aboriginal ethics look like, what they mean and how can they be actioned.
Aunty Beryl stated that ethics:

> Is all about respect, respect and the Law. Law governs our lives, the land, our environment, and our relationships with everything. You have to respect this (Aunty Beryl).

Interestingly, Ermine, et al. (2005) asked the same question of their Elders and their response was,

> [e]thics is about respect, respect for the whole circle of life (Ermine, Sinclair et al. 2005:17).

Ermine et al.'s (2005) dialogue with Elders establishes that we as learners learn through internalising knowledge that we take in through observation and listening, and we have learnt it when we can put it into action (2005:22). Through this process I have grown trust around my ability to understand Aboriginal ethics and protocols which the Elders and I hold as core cultural values.

260

Respect is an overarching value and protocol that is at the core of developing a meaningful and sustainable relationship. This relationship is orchestrated by law, because 'Law belongs to people and to country' (Bird Rose 1996:32). The law and knowledge through respect embody our ethical conduct. What we mean by the term respect differs from the use of the word within the NHMRC National Statement on Ethical Conduct in Human Research (NHMRC 1999; NHMRC, ARC et al. 2007). Respect, in the Indigenous sense means to listen and hear and value what we have to say about ourselves and our experiences, even if what we have to say challenges your ways of knowing. Respect means you're open enough to acknowledge that there are many ways of being in this world, and that they all have their own authority.

Ermine et al. (2005) explore this openness as an ethical space, where dialogue between two worldviews needs to take place, so that there can be an opportunity for ethical research. They believe the:

> order of research, established from western hegemonic modes of thought requires the urgent
> advancement of a new research order for the expression of ethical principles in studies that cross
> cultural borders and specifically involve Indigenous Peoples' (Ermine, Sinclair et al. 2005:11).

This praxis has not been achieved by Western thinking, and requires a 'new knowledge and pedagogy from different worldviews' (Ermine, Sinclair et al. 2005:11). Through this collaborative process there is an opportunity to honour all worldviews. This is timely as there continues to be as supported by the Elders dialogue a 'rift between knowledge systems and the lack of understanding on the part of the "west" with respect to Indigenous lifeways' (Ermine, Sinclair et al. 2005:11). This ethical space could achieve a new way forward and is a transformative option 'for respectful and collaborative research relationships to unfold and exist in the future' (Ermine, Sinclair et al. 2005:11).

The ethics of Indigenous research lie within a charter of social justice with collective self-determination, empowerment and emancipation with cultural survival at its core. Decolonising research challenges the power that Western Institutions enforce through agendas of ethical conduct relating to Indigenous peoples because Western perceptions of justice and beneficence for over two hundred years have worked against us. The Indigenous research methodology is to ensure benefit is derived and articulated by an Aboriginal community perspective. 'Ethics are

pedagogies of practice' (Denzin 2003:1). This agenda is both political and moral and requires the decolonisation of the Western research epistemology (Smith 1999; Denzin 2005) and practice.

## A reflective model for decolonisation

I present this model as a way forward merging the wisdom of Indigenous peers from Australia, Canada, the Americas and New Zealand and our Elders. It has developed through the analysis of the literature, interviews with participants and deep critical reflection of my own research journey. It is one step towards doing no harm and reducing the risk of injury to Indigenous Australians that now accompanies Indigenous health research praxis. It also offers up an opportunity for openness where we can co-generate knowledge together, and this has been the essence of this thesis.

The model establishes a sequence of steps to be taken by researchers that are non-negotiable values the Elders believe will make a difference to the ways of knowing, being and doing of non-Indigenous researchers. It has been developed to prepare researchers, Indigenous and non-Indigenous to be respectful. It is in preparation for being able to approach an ethical dialogue with another worldview. These steps need to be taken before approaching the reading and completion of an ethics submission.

*Table 2*: **Decolonisation framework**

| 1.Respect |
|---|
| This requires a deep acknowledgement that you do not know it all, comprehending this point is about respecting yourself, allowing you to not fear what you don't know. Once that fear has left you, you can be respectful of others. |
| 2. Being respectful gives you an openness that enables you to listen; you have to listen deeply so you can hear. |
| Not knowing can be a fearful space, and many want to cover that not knowing by pretending to know, and they can appear aloof in maintaining this pretense. This stance is immediately recognised by community people, who question the value of providing answers to the researcher's questions, as already they recognise that the researcher will not listen deeply and hear what is being explained to them. On the other hand if the |

researcher is respectful and acknowledges that they don't know, this act is observed as openness. There can be recognition by community people that this person is open to know and knowledge will be shared. It is up to the person/researcher to sit quietly and listen, not interrupt the flow of knowledge being shared. If your mind is busy thinking of the next question to ask, you are not listening deeply. You have to listen deeply to really hear what is being shared with you, the gift that you are being given.

3. Once you comprehend what you are being told, you are connected to the person speaking to you; this creates a space for mutuality and inclusion.

Comprehending what you are told does not occur immediately. It requires thoughtful reflection and later discussion with the person who shared this information with you to clarify that you got the story right. This means that research is not a process that occurs over an hour and is then finished. It means establishing a communicative connection with your informant.

> Research that seeks objectivity by maintaining distance between the investigator and informants violates Aboriginal ethics of reciprocal relationship and collective validation (Castellano 2004 :105).

Connecting to the person who is sharing with you is an ethical practice; you are establishing a space in which people's truths can be shared without fear of being put down.

4. Once in this space you can collaborate effectively, work together.

This is a mutual space that honours the spirit of both persons' integrity, or as Ermine et al. explain 'through this collaborative process there is an opportunity to honor all worldviews' (Ermine, Sinclair et al. 2005:11). In every sense this is what we are all working towards, honoring everyone's worldview.

5. Working together can facilitate a relationship.

Working together can only occur when the circumstances ensure there is a level playing ground. In relation to research this requires that community has control of the process otherwise their circumstances remain subservient to the powerful researcher. The building of relationships requires a shift from the coloniser and the colonised, to a more balanced equation of knowledge seeker and knowledge holder/expert. This relationship is

achievable and has been documented by researchers such as Deborah Bird Rose (Bird Rose 2000) and Fred Myers (Myers 1986).

6. Relationships come with responsibilities that are complex and multi-faceted. Law within country has established the framework for these protocols. A key doctrine of the Law is to do no harm to any person, being or place. These responsibilities are what are known as reciprocity, the obligation that comes with relatedness.

Relationships and responsibilities fit within the research language of transparency and accountability. This notion attempts to ensure that relationships developed through the process are not extinguished once data collection is completed. Accountability and responsibility to communities remains a priority in the transfer of this data and its publication and benefits (Ermine, Sinclair et al. 2005:36).

Fulfilling these obligations, builds trust, trust must be earned, it is not a given, especially considering the negative experiences of the past two hundred years. If all these steps can be achieved, then there can be balance or equity.

This model needs to be understood as a process, since guidelines in the past have failed to prevent injury. This is a process for the decolonisation of Indigenous health research, on a local level, for both researchers and the researched that will hopefully inform the Indigenous health reform agenda, using a bottom-up approach.

## Conclusion

Analysis of experiences of participants, ISN members, health researchers, Elders and the literature suggest that ethics are critical within and to the Aboriginal health research agenda.

> Ethics, the rules of right behavior, are intimately related to who you are, the deep values you subscribe to, and your understanding of your place in the spiritual order of reality. Ethics are integral to the way of life of a people. The fullest expression of a people's ethics is represented in the lives of the most knowledgeable and honorable members of the community [Elders]. Imposition of rules derived from other ways of life in other communities will inevitably cause problems, … (Castellano 2004:103).

The rejection or dismissal of this depth of value is excruciatingly felt, as these values are integral to every person's identity and hence well-being. The breaching of these values must be challenged, and spoken up too. For at least thirty years Aboriginal Community Controlled Health Organisations have advocated for change within the research process. This process entailed in part the development of ethical guidelines for Aboriginal health research in Australia. However, what was initially achieved in the 1991 guidelines in an attempt to balance power has been carefully dismantled over the decade known as the Howard era, an era in which Indigenous affairs in every sphere have been derailed by the domination of Western power and its knowledge systems; where our calls for 'self-determination, autonomy and control' (Rigney, 1999:10) have been silenced by acts of intervention that were rationalised and constructed as being in our best interest.

A major challenge in research is the chasm that divides Aboriginal and Western ethics. It is also the challenge we face within the mainstream environment. Although existing guidelines for ethical conduct in Aboriginal health that have attempted to embody values important to Aboriginal communities, they have not prevented the breaching of Indigenous ethics or prevented the injury that ensues.

This suggests that guidelines and laws are not the answer to ensuring research is undertaken in a safe and beneficial manner with Aboriginal communities. From an Indigenous standpoint, the universalism of Western codes of ethics continues to promote a colonial authority of supervisory power over Indigenous research. Although ethics guidelines fit within the recognised institutional process of research, they obviously don't prepare researchers for ethical praxis within another worldview setting. The episteme of western biomedical practice appears to be unable to shift from its own cultural position, making it unviable to be open to another.

The legacy of research and policy, past and present has ensured that the premise of Western institutional moral behaviours require interrogation when applied to Indigenous peoples. Rigney and Worby elaborate upon the catastrophes suffered by Indigenous Australians resulting from institutionalisation of our affairs. They provide a warning, based upon recent history, that academic institutions will have to respond to a Royal Commission on their acts of injustice within the Indigenous research agenda (Rigney and Worby 2005:371). The previous chapters of

this thesis have demonstrated that what has constituted ethical and moral behaviour from the perspective of Western Institutions has in fact breached the rights of Aboriginal peoples and their communities. Rigney and Worby's warning is not farfetched.

> Most existing research on Indigenous peoples is contaminated by Eurocentric biases. Ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality. … At the core of this quest is the issue of how to create ethical behavior in a knowledge system contaminated by colonialism and racism. Nowhere is this work more needed than in the universities that pride themselves in their discipline-specific research. These academic disciplines have been drawn from a Eurocentric canon, an ultra theory that supports production driven research while exploiting Indigenous peoples, their languages and their heritage (Battiste 2008:303).

One major form of ethics are codes of conduct that inform social norms and need to be articulated from the worldview of those being researched (Castellano 2004).This articulation from an Indigenous worldview is essential to our self-determining process of recovering our ways of knowing, being and doing. Using methods that privilege our perspectives, cultural protocols, ethics, voices and knowledges of Indigenous peoples through a safe and beneficial of Aboriginal praxis is what ethical research is about. Internationally, Indigenous peoples are cognisant of and experienced in knowing that Western philosophical paradigms are unable to adequately or safely provide Indigenous truths and or meaningful solutions. This led one Indigenous leader to conclude:

> Well the way I see research and the way it benefits Aboriginal people is firstly it is evidence based information in the sense of the appropriate processes, appropriate questions asked in the appropriate way by having language speakers talk to Aboriginal people and its through that avenue that we can get evidence based information that really should be influencing government and state policies and how services are delivered. And if the services are not being delivered and people are saying so then that in itself is evidence based (Participant 3).

The only way Indigenous health and affairs will improve is when we are acknowledged as experts of our own lives. Our input into research about ourselves must be paramount to the Indigenous health research agenda. We have developed approaches that meet our needs to respectfully capture valid data that can inform government and state policies. These approaches

266

are critical to shifting our representations and constructions from problematic to resilient. These approaches should inform the Indigenous health research agenda and will achieve improved research outcomes. However, accepting this approach as shown in this thesis requires a shift in consciousness of those who hold the power and control what knowledge will be produced about us. Shifting this consciousness requires the utilisation of a decolonisation framework. Once we have achieved this shift together we have the opportunity to build more meaningful and respectful relationships with each other.

# Chapter 9

# Discussion and conclusion

## Decolonising Indigenous health research

> Third world intellectuals write out of and within a political situation whose pressures are constant, not momentary annoyances or minor empirical concerns to be brushed aside in the interests of a higher goal. The unresolved political situation is very near the surface, … because the authors write from a position …of people whose message of resistance and contestation is the historical result of subjugation (Said 1994:311).

## Introduction

This thesis has explored, from an Indigenous perspective why research has not improved Aboriginal health. It is based on the concerns of Indigenous Australians about their appalling health status and their distrust of Western research. The exploration became a journey for me, as the researcher. I have had to walk the path of the methodologies and apply the methods to myself as they emerged from the two-way research process with Elders, Indigenous community members and non-Indigenous people. The use of a decolonising framework and process has been essential in transforming my own internalised oppressive belief system, created through colonisation, that we are problematic and cannot change things, to a belief that our ways of knowing being and doing together with respectful non-Indigenous ways of knowing, being and doing can benefit our health and well-being. This thesis argues that decolonisation is a critical process for shifting a problematic and disabling colonial mindset that has been internalised by both Indigenous and non-Indigenous Australians. This process can effectively shift the way Indigenous health research is approached, enabling research to become a site of collaborative participatory action focused upon mutual beneficial outcomes. It is in this light that research will no longer be considered a dirty word, and Indigenous people's ways of knowing health have the opportunity to improve.

The thesis was undertaken because health research has failed to improve Aboriginal health. Such a failure as a result of the colonial ideology embedded in its Western positivistic research

practice premised upon 'Objectivity' and 'Validity'. This research approach has ensured the systematic exclusion of critical information such as:

- Historical context
- Political and social settings
- Research/researched relationships and the disparities of power
- Indigenous knowledges and voices
- Indigenous worldviews
- Indigenous diversity related to country, law, language and cultural protocols.

This has meant that:

- A Western expert gaze has become a dominant and self-sustaining regimen in health research
- Constructions are drawn from the experts' perceptions, observations and worldview
- Descriptive and problematic constructions become part of the Western truth system of knowing Indigenous Australians
- Terra nullius informs the essentialist approach of 'victim blaming'.

These ways of doing Aboriginal health research have compounded the existing trauma and plethora of dis-ease through injury. These approaches to Aboriginal health research have been supported through colonial institutions such as governments, funding bodies and the academy. This continues despite mounting evidence that these approaches are ineffective in alleviating the poor health status of Indigenous Australians (Atkinson 2002; Sherwood and Edwards 2006; ABSAIHW 2008; Shahid, Bessarab et al. 2009).

This chapter brings together and discusses the findings of the previous chapters to arrive at a new understanding of Indigenous health research in Australia and provide an Indigenous health research model. The model for Indigenous health research praxis has been developed as a result of evidence I have built, analysed and reflected upon. By entering into this explanation of the model I have had to exemplify myself and my own journey as to what is critical for this shift to occur. This has occurred through the reanalysis of the evidence and the utilisation of an Indigenous critical approach to underpin the method that I have walked.

## The Context

Examination of the historical and contemporary context revealed the deep and ongoing impact of colonisation and colonial ideology within the Western paradigm imposed in Australian Indigenous health research. In relation to the question asked by this thesis I have found that the term 'research' encompasses multiple features that are not obvious to the uncritical or unreflective eye.

## Colonisation and its impact

The invasion and subsequent colonisation of Australia by the British imperial regime offers a central focus for the problematic relationships that have developed between Indigenous Australians and their colonisers. This relationship has been part of the construction of Aboriginal ill-health as an Aboriginal problem.

Chapter 1 established that colonisation was not peaceful; rather it resulted in much suffering and injury for those colonised (Connor 2003). The cumulative effect of a dominant colonial power using military forces to usurp, and policies to control and manage resistance in defending their newly settled lands has caused ongoing injury and suffering (Connor 2003). These practices have contributed to the hostile relationships between Indigenous and non-Indigenous Australians.

British imperialistic power has been acknowledged internationally for its entrepreneurial dominance from the 16th century onwards. 'At home', in Britain this prevailing way of knowing and being was reflected in the country's 'art, literature, and cultural discourse' (Said 1994:127). This cultural discourse emanated from Britain's dominance in the areas of industry, military force, technology and "morality", establishing, as its ideological binarism, that those countries that did not share this level of power and might were inferior (Said 1994:127). This discourse has been employed in Australia, Canada and America from the 18th century into the present (Said 1994:127). Indigenous Australia became the ontological Orient dominated by Britain from 1788 and was made subservient, as was the custom, by the British/Western cultural discourse (Said 1994).

This ideology was also used to legitimise Britain's endeavours, particularly in Australia, in dismissing Aboriginal tenure through claims of a continent that was 'uninhabited', 'unoccupied'

and 'unpeopled' (Reynolds 1987:3). These representations were the 'contrasting images' (Said 1995:2) to Britain, a densely populated country. The discourse informed both the British colonial authorities who chose to colonise Australia and the Australian jurisprudence (Reynolds 1987:4), that would not be overturned until 1992 by the High Court of Australia's ruling in the Mabo case (Attwood 2005:29). The Mabo ruling recognised that the discourse of terra nullius was a lie, and finally an Indigenous truth was acknowledged, by both the Australian legal system and the Federal Government under the stewardship of Prime Minister Keating (Attwood 2005:29), that is, that Australia is, was and always had been Aboriginal land.

Britain's claiming possession of the Australian continent under the premise of terra nullius established a uniquely different colonial practice than that observed in New Zealand, Canada and the United States (Ivison, Patton et al. 2000). The terra nullius premise immediately and legally stripped Indigenous Australians of their sovereignty and rights to negotiate any form of treaty or compensation for their loss of tenure and status. These points of departure of British imperial practice I believe underlie the reality that Indigenous Australians health status when compared to other Indigenous peoples around the world, is considered to be far worse (Ring and Brown 2003).

The doctrine of terra nullius was proven by the Australian jurisprudence to be a fictional claim in the 1992 Mabo Case ruling. It was a myth that lasted some 200 hundred years and one that Indigenous people believe is the critical and unspoken central theme of political injustice for both Indigenous and non-Indigenous Australians. From an Indigenous perspective Australia was stolen under an illegitimate claim of a 'land belonging to no one' (Butler, Cameron et al. 1995:5). Once the colonisers arrived they realised that the land was occupied, and the original inhabitants were resisting every aggressive action taken by the colonisers to usurp their tenure. The colony had a problem, it was an 'Aboriginal problem' and it had to be solved.

The legitimacy of British tenure of their new continent was at stake and it is here that Orientalism became an important feature of narrating a nation (Ivison, Patton et al. 2000). It is clear that this notion of legitimacy remains unspoken, yet has framed all responses related to Indigenous Australians since invasion. Colonial academics were supported through funding to substantiate Aboriginal Australians' primitiveness and problematic nature to legitimise British

271

tenure and derive solutions, as demonstrated in Chapter 1. There was another legitimising strategy that Stanner remarked on as 'the great Australian silence' which has effectively reinforced the unspoken nature of what was done to ensure legitimate occupation of the continent by the colonisers (Attwood 2005:17). It is this silence or amnesic practice that continues even today, impacting daily upon Indigenous and non-Indigenous Australians' relationships. Colonial indoctrination has informed how we relate to each other; it has become enmeshed within our worldviews, as discussed in Chapter 2. This relationship has been developed using a 200-year-old lie.

This amnesic colonial practice underpins the maintenance of unease in this country. I believe it is maintained in research that does not provide the historical, political and social circumstances of Indigenous Australians' health stories. Failing to contextualise Indigenous people's health in research enables avoidance of dealing with the causal agents, and sustains an Indigenous-problem-based approach. This avoidance and unease further resonates through to the broader community who remain unreflective and defensive of this unspoken past. The implications of such unease and defensiveness are meted out through institutional racism, that in turn affects everyone's health, be they Indigenous or non-Indigenous people. This way of doing research causes harm to Australia as a whole.

## The Aboriginal health research agenda

Indigenous Australians' health research context has been created by the dominant ethnocentric colonial discourse that imposed its superior and dominating worldview upon subservient others. Equally, colonisation enabled this discourse to demonstrate the superiority of Western culture. Chapter 3 illustrated that the field of Aboriginalism was the discourse used in Australia to 'know' the Aboriginal 'Other' and from this scientific pursuit, problematic constructions of Indigenous Australians were developed. Notably, these constructs were embedded in the thinking of the medical profession and mainstream Australia.

Positivism as a dominant method of human sciences has been informed by the 'bio-medical' gaze of medicine (Foucault 1994:199). (Bio-medical practice focused upon an organism or germ that caused disease within the vacuum of a physical body for its clinical treatment. The gaze suggests the power of medicine to observe and control this condition). It is an approach used in

Aboriginal health research that is highly valued from a traditional Western perspective and supported by funding and research institutions, as demonstrated in Chapter 5. This approach has maintained the plethora of descriptive accounts of health deficits suffered by Indigenous Australians (Sanson-Fisher, Cambell et al. 2006). It generally excludes the historical, political and social circumstances that contextualise the current health status of Indigenous Australians (Sherwood 2009). However, this decontextualisation is, as I have argued, an essential feature of the colonial Australian strategy of forgetting and silencing and is largely responsible for placing blame on Aboriginal Australians for their poor health status.

This Orientalism approach using a positivistic method reinforces the power of the Western researcher in a number of ways:

- Health funding and peer review selection is dependent upon these expert researchers having extensive track records. This effectively blocks 'other narratives from forming and emerging' (Said 1994:xiii).
- The traditional practice of peer review remains intact, informing the Aboriginal health research agenda, and who is to benefit from the research undertaken (Street, Baum et al. 2009).
- The status of the expert speaking on behalf of the object being studied is maintained.
- Experts' constructions, whether valid or not, are reiterated in further positivistic research via literature reviews and establishing a point of reference to support findings that maintain the 'Aboriginal problem', as it validates 'belief models of first world societies' (Street, Baum et al. 2009:2).
- The model of researcher-driven research, contrary to the ideology of Indigenous control of the agenda is supported (Street, Baum et al. 2009).

Consequently, this approach to Aboriginal health research reinforces the notion that research is a tool of colonisation and remains so because it is critical that the power remain in the hands of the superior Western researcher by 'making statements about it [the Other], authorizing views about it, describing it, by teaching it, settling it, ruling over it' (Said 1995:3). The model developed within this thesis is about balancing power, and this requires a two-way approach, inclusive of Indigenous people's philosophy and ethics. This effectively shifts the approach of dominance

that is unhealthy to a collaborative participatory approach where new relationships can be built, a shift that is critical to improving the health outcomes of Indigenous Australians.

## Contrasting images of difference

Indigenous Australians' health research context has been informed by this dominant ethnocentric discourse that needed colonisation as a means for establishing its superior and dominating worldview upon its subservient Others. The inverse is also true in that colonisation enabled this discourse to further demonstrate the superiority of Western culture. Chapter 3 illustrated that the field of Aboriginalism was the discourse used in Australia to know the Aboriginal 'Other' and from this scientific pursuit of many disciplines, problematic constructions of Indigenous Australians were developed. Notably, these constructs informed both the medical profession and mainstream Australia.

Dr Peter Moodie, considered by his peers to be an expert in Aboriginal health, demonstrated that although he was able to critique some of the structural features that impacted on Aboriginal health representation, he was still heavily influenced by the Orientalist discourse. He highlighted 'contrasting images' (Said 1995:2) of Aboriginal people handicapped by their lack of Western 'traditional' domestic skills' (Moodie 1973:267). As a local general practitioner in Bourke, Western NSW, Moodie had access to prevailing evidence that challenged the constructs formed by previous Aboriginal health experts, namely Cilento. However, his conclusion regarding the causes of poor Aboriginal health status, as examined in Chapter 3, maintained and renewed Cilento's constructs of some fifty years earlier (Guba and Lincoln 1989:145).

Why would Moodie do this? Western culture is observed in this instance to be highly desirable for the Aboriginal population. If they chose to be healthy, they would be complying with both the medical and political agenda of assimilation of that time. Aboriginal resistance to the dominant colonial authority was described as non-compliance which, it was agued, directly resulted in their poor health status. The problem with this discourse is that it held and continues to inform what is assumed to be 'scientific truths' (Said 1995:46). This discourse operates 'by persuading people to internalise its logic and speak its language; to perpetuate the values and assumptions of the colonisers' (McLeod 2000:18). The internalisation strategy is simple in that it plays upon the notion of difference. I believe that using this notion of difference has absolved the

health professional and governments of blame. Such a discourse justified and legitimates the blaming of the 'Other' for their very otherness.

For Indigenous Australians in order to survive in this country, they too had to 'internalise its logic and speak its language' (Said 1995:46), that is they too were and are colonised. Chapter 1 explored the policies that directly enforced, with threat of punishment or worse, the colonising internalisation process. This process ensured Indigenous Australians were bombarded with images and descriptions of their inferior status especially through the media, and national educational literature. Colonial indoctrination also imposed regimens that took away any sense of control over individual and collective Indigenous lifestyles. These enforced ways of knowing oneself as marginalised and different were reinforced by the dominant culture's internalisation of this notion of difference and the manner in which they treated Indigenous Australians. Indigenous well-being was attacked through this indoctrination process that sought to subvert all notions of sovereignty, identity, strength and resilience. Survival came at a great cost, undermining every aspect of physical, spiritual, emotional, cultural and relational well-being. Being forced to speak the language of the coloniser meant the loss of languages, internalising the logic of western dominance breached law, causing injury and suffering.

Yet this ideological standing on difference is still being used as the causal agent of poor health status, and is exemplified in Chapter 6 in the Ewald et al. study (Ewald, Hall et al. 2003). I have argued that Ewald et al.'s evaluation of a trachoma treatment in an Aboriginal community uses the exemplification of difference to blame the Aboriginal community for the lack of success of this program. The discourse used in the MJA article questioned the effectiveness of environmental health practice in the management of a 'medical' problem as well as medical compliance of the Aboriginal community.

Environmental health practice is a preventative regimen and does not fall directly under the authority of the health sector and consequently is schematised as irrelevant in the management of a medical disease (Bailie and Myfawny 2001; Murray, Bell et al. 2003). Medical compliance, on the other hand, is about the power of the doctor and 'the failure of the patient' (Humphery, Weeramanthri et al. 2001:ix). Medical compliance has more recently been considered to be an inappropriate term, especially when used within 'a cross-cultural context' (Humphery,

Weeramanthri et al. 2001:ix). Ewald et al. used this discourse to promote the legitimacy and centrality of Western medical practice and directly challenge alternative approaches (Humphery, Weeramanthri et al. 2001:x). Compliance of the 'Other' is colonisation at its finest, entrenching constructions of Aboriginal people as the causal agents of their health status.

Othering and problematising is further manifested through the notions of difference that are used throughout the article as the following discourse suggests: 'Population mobility (both within and between communities)'; Trachoma is 'almost exclusively a disease of Aboriginal people'; high rates are due to 'inadequate hygiene, crowding, low socioeconomic status and an arid environment'; 'reservoirs of infection' are children and their carers (Ewald, Hall et al. 2003:65). This is a discourse focused on making statements about the 'Other' by authorising a view of the Other's failure to comply. It has described this failure in terms of contrasting images related to cultural and environmental differences resulting from a lack of traditional Western lifestyles (Said 1995:3). Contravening evidence suggests that blame in relation to medical compliance in this project rests with the health professional who failed to effectively communicate with their Aboriginal clients (Devitt, Hall et al. 2001; Cass, Lowell et al. 2002). Added to this was a failure to acknowledge the barriers, which can be structural and/or socioeconomic, to following such medical advice (Humphery, Weeramanthri et al. 2001).

Ewald et al.'s study simply failed to ask its clients why and instead produced an article for the readership of other health professionals based on a Western worldview's assumption of the problematic Aboriginal Other. White Anglo-Europeans were and are brought up holding a worldview of hierarchical superiority and they benefited from this way of perceiving the world. For those colonised, the imposition of their inferiority through physical and psychological means disempowers and becomes internalised as trauma (McLeod 2000:19).

## The expert gaze continues

Research has and continues to support the building of 'experts' through the recognition and support of their peers and research funding processes (Street, Baum et al. 2008). Expert status in the area of Aboriginal research is similarly enjoyed and develops in the same vein. The expert has a dual role in Aboriginal health research. They establish descriptive truth statements about the Indigenous Other that then are elevated to authorative positions, and they are complicit with

the more important task of displacing 'the natives' point of view' (Said 1994:203). Scientific research has 'the power to narrate, or to block other narratives from forming and emerging' (Said 1994:xiii). This lies at the heart of Indigenous anxiety about the colonial manifestations of research.

The story of injury research in Chapter 6 exemplifies the expert's role. The experts were supported as the leading knowledge producers because of their established track record and they received funding for the project via the 'traditional order' grants process. This selection process through the traditionalist peer review framework reinforces the Western model of knowledge production through established Western research practice and the beneficial outcomes for the researchers from such research. The institutional funding guidelines underpin the project and not the Aboriginal community involved. It is this power base that enables peers to view a research project's process and practice as successful or not, unrelated to outcomes promised to those being researched.

This inequitable power structure became obvious in the injury project described in Chapter 7 when the participants and researchers in the field attempted to have a say in the process. These researchers' (who are participants in this thesis) and their respective participants' inside knowledge regarding respectful and safe research praxis was rejected. Informants' media of presenting their stories that were meaningful to Aboriginal people in this region were also rejected, as were the Indigenous conceptualisations of what injury meant to them and the solutions required to remediate them. There is a critical gap in this area of Indigenous health which will remain so until the traditional order shifts its position of controlling what knowledge will be produced about the 'Other'. Consequently, the injury project did 'block other narratives from forming and emerging' (Said 1994:xiii). This blocking has an injurious and unethical impact as it silences the voices of those who hold the knowledge for solving the issues of injury within their communities (Atkinson 2002:14).

Chapter 7 provides evidence of another type of expert, the self-proclaimed expert whose role is just as dangerous in limiting Indigenous narratives. Dr Crundall identified himself as an expert in the field of drug and alcohol, and was employed as the Director of the NT Office of Alcohol Policy and Coordination. In that position he was appointed as the chair of the NT Licensing

Commission's Evaluation Reference Group (ERG) of the Alice Springs grog trial, and he co-authored the evaluation report. His employment and multiple roles during the trial establish that he was in no way independent of 'government and industry interests' (Wakerman 2003:6).

Importantly, Crundall as chair of the ERG, attempted to limit Indigenous participation methodologically in the household phone survey through a number of exclusionary premises specifically targeting Aboriginal people. The Tangentyere Town Camp survey, was established when the reality of this action became evident to Tangentyere Council, the NT Health Department's Central Australian Ethics Committee and the ERG. However the results of the Town Camp survey were effectively silenced by Crundall and Moon's report (Bell 2003). Although the findings and recommendations of Crundall's report had been seriously questioned in relation to their scientific validity, they were enacted by the NT's Department of Licensing, despite the contravening evidence provided by the Tangentyere Council's Report.

Constructions of Indigenous peoples and the solutions to address these constructions were drawn purely from the experts' perceptions, observations and worldview that continue to be privileged over those views of Aboriginal people themselves.

## What impact has research colonisation had?

The science of positivism used in Aboriginal health research has been an effective colonial strategy of forgetting and silencing the unspoken past. It is a field of knowledge production used in health science that holds power in its 'correlative constitution' (Foucault 1991:27). This power has been used to objectify the 'Other' through an empirical Western gaze, artificially isolated from any contextual features, especially history, in an attempt to observe the 'signs and symptoms' (Foucault 1994:91) of their objects' dis-ease. Chapter 1 challenges this field of science by offering up a number of historical, social and political circumstance that have contributed to Indigenous Australians' poor health status.

The ideology of Orientalism that set about representing Aboriginal people as the inferior and primitive 'Other' has been part and parcel of British colonisation of Indigenous Australians and, in particular, of the subsequent field of Aboriginal health research. This ideology maintains a deafening silence regarding an unpalatable past and contributes to and reinforces the notion of the 'problematic Aboriginal', enabling governments and health services to blame Indigenous

Australians for their health status. This has encouraged and maintained racism, discrimination and marginalisation of Indigenous Australians in the field of health research and sustained the expert whose knowledge of the 'Other' holds greater value than that of Aboriginal people themselves, disregarding their experiences both intergenerationally and currently. The policies and practices developed out of this ideology fail to acknowledge or address the underlying causal agents that have and continue to contribute to the health disparities of Indigenous Australians.

The ideology and its destructive effects as summarised above have colonised Indigenous and non-Indigenous peoples alike.

## Injury: The pernicious and perverse outcome of research

A fundamental message I received from this exploration is that injury is a recurring theme that has resulted from the Western colonial practice of research on Aboriginal people. It is not only an outcome of Aboriginal health research; it is a product of a dominant way of knowing and constructing Aboriginal Australians within the paradigm of Western science. It is here that the old saying, 'the pen is mightier than the sword' holds up truths in relation to the impact research has had on Indigenous Australians. As I have shown, Orientalist and racist constructions of a different and problematic 'Other' are maintained and renewed through unreflective positivistic research. These damaging contrasting images have informed and led to violence, trauma, marginalisation, and devastating policy and practice as examined in Chapter 1.

Chapter 3 established that problematic constructions were developed in the field of Aboriginalism/Orientalism and these representations informed Australian society and the health profession. Aboriginal health research from the 1870s onwards developed disparaging accounts of primitive Aboriginal Australians as the cause of their impending dying out, and it is here that blaming the victim for this health status became an established and common practice. The problematic construction developed through Aboriginal health research and the blaming tendency has resulted in poor health service provision to Aboriginal people; an outcome of research that ensures Aboriginal health will not improve. This was re-emphasised by Cox's article highlighting that the impact of persistent bad press describing Aboriginal people as the problem, informed the way health services responded to their Indigenous clients. Critically, she found that the negative treatment Aboriginal clients received by health services was not a thing

of the past, it is a current practice (Cox 2007). The bias and stereotypical beliefs held by health service providers about Aboriginal people cause injury: physically through the lack of adequate care; and psychologically through 'race-based traumatic stress' (Bryant-Davis 2007:135) created by and through institutional racism. The information gathered and analysed in this thesis regarding Aboriginal health and research has shown that these dominant ways of knowing us in health are powerful and dangerous and do cause injury.

Reflecting on the literature, stories provided by participants, Elders and my own experiences in research have helped me grasp how this injury occurs and its consequences. As established by Cox, deficit Aboriginal health data and problematic constructions 'inform the attitudes and actions of many mainstream health staff' (Cox 2007:8) and are supported by their 'dominant value systems' (Cox 2007:8) in the way they approach Indigenous Australians in their daily work practices. The same can be said for non-Indigenous researchers, who similarly have been informed about Indigenous Australia through the writings of experts. Chapter 6 provides three stories that exemplify this. Story three offers an account of injury that resulted directly from the non-Indigenous researcher's own attitudes, based on 'dominant value systems' (Cox 2007:8). The non-Indigenous researcher's Western informed assumptions about health service provision were challenged by the way services were provided within an Aboriginal medical service. As a result of this obvious difference, the non-Indigenous researcher chose to attack the service providers (who were also key informants for the project evaluation). The abuse was exacerbated when I (the other researcher) attempted to intervene. This reaction to Indigenous approaches to Indigenous health care highlights the level of arrogance many non-Indigenous researchers practice in the field. Rather than examining their own lack of knowledge, they dismiss what they do not know as irrelevant or useless.

Emotional injury was, of course, a direct result of this improper and perhaps racialised behaviour towards the informants and me. The long-term impact of this appalling and unreflective action could be injurious to the health service and the broader Indigenous community it serviced. I was left to absorb the unwelcome fact that we Aboriginal Australians, are still objects of study, whose realities and circumstance are irrelevant to the all-important research product.

The injury story in Chapter 6 highlights other levels of injury that occur during the research practice that were clearly articulated by the participants:

- Ignoring what Indigenous people believe are the causes and solutions to their injury
- Breaking promises and breaching ethical conduct
- Not listening to communities: this devastated the participants and reaffirmed the disparity of power in this project of the researcher over the researched.

Participants also felt that:

- The authority of the expert in the project was aligned only to the expert's best interest and not in the provision of good outcomes for Aboriginal communities. Comprehending this level of insincerity is hurtful and injured the Indigenous researcher
- Decisions and solution development dominated by the experts were ill-informed and unsafe, resulting in the shaming of the Indigenous researcher
- Community members were hurt as a result of not being heard, and did not want to talk any more
- The project was never completed and hence the voices of all involved were silenced, and a body of meaningful literature in this area is not available for solution development.

The crux of injury for Indigenous people within the Aboriginal health research agenda is when their views, voices and ways of knowing are disregarded. This act of rejection hurts us and denies our communities any sense of control in their lives and health agendas. This results in psychological injury that is internalised and challenges individual and collective well-being.

The far-reaching injuries demonstrated in my analysis the ERG evaluation report of the 2003 Alice Springs Liquor restrictions outlined in Chapter 7 are still unfolding. The failure yet again of experts and governments to listen to the views of Aboriginal people and their organisations can be understood as a continuation of the colonial silencing of Indigenous voices. Kurtz et al. have characterised such acts as structural violence (Kurtz, Nyberg et al. 2008), and this is the case in this particular story.

# Do no harm: ethics and cultural protocols

Chapter 8 highlighted the concerns of Indigenous and non-Indigenous participants about the lack of ethical conduct by many researchers undertaking Aboriginal health research. As established here and in Chapter 2, different ways of knowing, being and doing inform how ethical conduct is perceived and undertaken. Both Indigenous and non-Indigenous worldviews have at the core of their research ethical mandates of doing no harm (NHMRC 2003; NHMRC, ARC et al. 2007). However, as already argued, injury resulting from research clearly indicates that the Western ethical guidelines do not prevent harm to Indigenous people in health research.

It is evident from the stories recounted in this thesis and reports in the literature that ethics submissions are generally acknowledged as administrative hoops to be jumped through prior to the research, and before the research is becomes a reality (Vallance 2005). Promises are made on paper but often not followed through in the field, as highlighted in the injury story in Chapter 6. From evidence gathered for this thesis it appears that Indigenous communities are not given the opportunity to view the submission or to attest to the fulfillment of these written promises. If, as has been the case in the account and experiences given in this thesis, most ethics submissions are developed without Aboriginal community collaboration, then they fail to be inclusive of Aboriginal cultural protocols.

This collaborative planning and the development of research methods should be at the heart of ethical conduct. If ethical planning is undertaken in partnership with Aboriginal communities, there are opportunities for the building of relationships, acknowledging what respect means and ensuring benefit meets the needs of communities along with benefit for the researchers; this is reciprocity. Herein lie Indigenous ethical conduct principles. These are breached when research is done **on** communities rather than working **with** them; voices and views are silenced; cultural protocols are ignored; community people are disrespected; Indigenous knowledge systems and praxis are rejected; injury is caused; and problematic ill-informed constructions are maintained. The stories in Chapters 6 and 7 showed that the non-Indigenous researchers were unable to comply with this Indigenous perspective of ethical conduct despite every project having jumped through the ethics submission administrative hoop. It is evident that this approach is ineffective in preventing injury or harm to Aboriginal communities. It also clearly demonstrates that researchers and the systems that support research have not listened to what Aboriginal people

and their organisations have asked for in relation to ethical praxis in Aboriginal health research, as detailed in Chapter 5.

## Indigenous researchers

Indigenous researchers are explored under this heading of injury and cultural protocols because they are injured in research when non-Indigenous researchers fail to be guided by Indigenous researchers' insider knowledge and status. Indigenous researchers take on risks being part of any research project. This relates to differences in worldview, insider status, ethical values, and Aboriginal law. Once you enter into a research relationship with an Aboriginal community, you immediately take on a responsibility to maintain that relationship in a manner that is respectful and obligatory. Once respect is breached, the Indigenous researcher is considered responsible for this breach, as they are seen to be the person who established the relationship.

This level or responsibility is ignored often by non-Indigenous researchers and creates injury for both the Indigenous researcher and the community being researched, as was evident in the stories in Chapter 6.

## What are specific injurious outcomes?

Past research has injured Aboriginal Australians through the problematic constructions in discourse that misrepresent their lives and their ways of knowing. This resulted in multiple outcomes that did not bode well for the health and well-being of Indigenous Australians. These events contributed to collective and inter-generational trauma that has been compounded through equally problematic political and social interventions.

Analysis in this thesis supports arguments that the ongoing nature of marginalisation through research has further contributed to the injury experienced by Aboriginal people as stress has an 'additional negative impact for those traumatised by the past and current disadvantageous social circumstances' (Raphael, Delaney et al. 2007:338).

The stories of Indigenous health research and the analysis by the Elders and other participants lead to the same conclusion in health research that Trudgen made in regard to general Aboriginal well-being. Indigenous people's self-esteem and well-being suffer from the persistent constructions of themselves as problematic (Trudgen 2000:64).

Self-depreciation is another characteristic of the oppressed, which derives from the internalization of the opinion the oppressors hold of them. So often do they hear that they are good for nothing, know nothing and are incapable of learning anything – that they are sick, lazy and unproductive – that in the end they become convinced of their own unfitness (Freire 1972:38-39).

The psychological oppression Freire describes of the oppressed is created by the powerful dominant culture through subjugation and research (Freire 1972:34). It is a process that is kept alive from 'generation to generation of oppressors, who become its heirs shaped in its climate' (Freire 1972:34). The climate supports this notion, through consciousness of the necessity of duality of difference and the importance of material ownership. This ideology of ownership dominates the oppressors' need to objectify and then possess the planet and people, enabling the de-humanisation of those objects to be possessed (Freire 1972:34). These constructions have colonised both the minds of the oppressed and the oppressors (Freire 1972). This colonisation has been demonstrated in this deconstruction of Aboriginal health research.

The impact of these misrepresentations of problematic Indigenous people resonates with health professionals, policy writers and researchers who have accepted these names or constructions (Trudgen 2000). The acceptance of these constructions prevents meaningful and effective strategies, instead programs are developed that fit with the dominant cultures' view of the Aboriginal problem (Trudgen 2000:65); this is evidently the case with many strategies in the field of Aboriginal health.

Raphael et al. write that it is only recently that these issues have 'been documented in ways that have meaning to Aboriginal people' (Raphael, Delaney et al. 2007:339). This point is significant as the narration of these issues, worries and stressors are critical to their exploration and healing.

## How can this be understood?

Injury, that is, 'trauma , psychological injury' (Raphael, Delaney et al. 2007:338) permeates the lives of Indigenous Australians in the way described by Silburn (Silburn cited in Creswell 2007:2) as stress cycles. Health research, as I have evaluated it, is deeply implicated in this process.

Injury related to past and present research has featured as a key finding from the stories shared with me and those of my own research experiences. It is generally a result of many non-Indigenous researchers and health professionals' lack of unawareness of their own colonial indoctrination that has taken place within the country's education systems (Said 1994:270), in the media and in community imagining. It is invisible because it has been occurring over the last two hundred years. It is this indoctrination of silence and the entrenching of Western superiority or the privileging of whiteness that has ensured that what little information mainstream Australians received through the media and research articles would be not contested (Langton 1993; Thomas 2001). Subsequently, problematic constructions developed in research about Aboriginal Australians have informed mainstream Australia and its health professions. This legacy flows into how non-Indigenous researchers and health professionals relate to Indigenous people while undertaking research (Shahid, Bessarab et al. 2009).

So research is not only failing to improve the health outcomes of Indigenous Australians, it is actually making their health worse; it has been and is doing harm.

## What is good Aboriginal health research praxis

An Indigenous perspective of what is good research is aligned to having a sense of control in its development, process and outcomes. It is research undertaken to improve the lives and well-being of Indigenous people and their communities and it is done in a respectful and safe way. Story four in Chapter 6 and the Tangentyere Town Camp survey in Chapter 7 offer important points of reference for good research praxis in Indigenous communities.

In both examples the research was undertaken as a means for action and creating change. Respect was the overarching principle that informed every step of the process that was a collaborative approach working with and not on the community. The process was informed by and followed community cultural protocols, and information sharing was a high priority, enabling the transfer of knowledge between the community and researchers. Every person, whether informants or other researchers, was listened to and acknowledged as critical to the success of each project in providing valid and robust data. Story four in Chapter 6 is an example of research creating positive change. It was set within an urban community and the research only occurred once the community and Aboriginal organisations agreed that it was necessary. The

dissemination of the data collected through the research became the critical tool influencing change and this occurred as a result of two-way knowledge brokerage. The project was successful in producing change.

The Tangentyere Town Camp survey in Chapter 7 provides a different but equally compelling example of good health research. It came about quickly as a response to the lack of Aboriginal participation in the householder survey run by NTDHCS. Once the decision was made by Tangentyere Council to ensure Aboriginal voices would be heard in relation to how the trials had impacted on them, Town Campers were involved from the beginning, throughout and after the survey had been completed. Time was spent ensuring that the researchers felt safe and that the process would be run respectfully and safely. As many of Town Campers are multi-lingual speakers, it was critical that researchers were chosen for their language skills. This often does not occur in Aboriginal health research projects but is vital to ensure that the data collected is valid. Town Campers were asked how they wanted the final story reported back to them and this was undertaken as requested. As reported in the chapter, the final story of the survey was ignored by the NT Licensing Commission. However, the process of undertaking the research did create changes, information was shared throughout the community about the trials, people gained a lot of knowledge about their rights, Tangentyere Council established a research hub, Town Campers were listened to and heard, and people believed that made a difference.

## Growing the theory

The journey I have taken has been a two-way process inclusive of Indigenous and non-Indigenous ways of knowing, being and doing. Learning how to balance these two approaches has essentially created my thesis. This is because a thesis remains a Western academic project that continues to hold authority over how knowledge will be produced. I had to learn and use these Western orthodoxies so that this thesis would be recognised within the Western power base, but I was not going to do this in a manner that was not true to my participants, Elders or worldview. I had to develop an approach that would be considered 'scholarly' within the academy as well as being 'scholarly' within the Indigenous community and respectful and safe for Aboriginal and Torres Strait Islander peoples. My theoretical approach is the story about finding this balance through methodologies that can improve Indigenous health outcomes.

It must be stressed that finding the balance of two worldviews within the Western Academy has been a very difficult and frustrating undertaking. I have been schooled through two divergent educational processes while generating this thesis: one an Aboriginal Elders' group that recognises that it must be a two-way process, the other a Western group that continues to observe that their teachings are superior and should dominate. The Aboriginal Elders' group is cognisant of this approach, however they believe this is my journey to ensure that I find the balance of presenting our truths. Most of our work together on this journey is not well represented because of the overwhelming requirements of Western knowledge production which unfortunately have impacted upon my ability to reflect the balance.

What drove me to this journey has been living in a country that continues to be hostile to Indigenous Australians. In my professional and personal life I am reminded daily of this unpleasant and antagonistic relationship between Indigenous and non-Indigenous Australians. Because of my fairer complexion, many non-Indigenous health and educational professionals have shared with me unwittingly their ill-informed perceptions of our people. When I bring up my Aboriginal status, I am told 'Oh you are not like them though'. When I question how many Aboriginal people they actually know, I find they generally have never known an Aboriginal person, and yet they are prepared to make racist and destructive statements about us. I realised through these experiences that these ill-informed constructions were causing injury; they hurt me and I observed how they hurt us, through Indigenous health data, educational statistics, incarceration rates, and the list goes on. These experiences also made me question how we can improve Aboriginal health or education when these mainstream professionals generally are so hostile to Indigenous Australians. How do we change these ways of knowing us? I asked the Elders how we change this, and they said:

> We've got to educate them; we've got to work side by side with them if they are fair dinkum about helping our people, then black and whites have to work together (Elders group).

and

> You've got to find good strong people, people who have knowledge and skill, you've got to find them and use them! Ask them to work with you (Elders group)

and

> You know there's a lot of wisdom (Indigenous knowledge) there, and that wisdom is not being harnessed. It's just being let go like a wild horse you know? You get him in and ride him, you tame him, you let him go and it's no good, you got to keep there, stay there in the saddle (Elders group).

and

> You can't bypass the Elders. They are the people with the knowledge (Elders group)

The Elders' advice of educating us all required the generation of this thesis. Through this process of working with the Elders I came to appreciate how colonised my own mind and body was. This colonised status impacted on my ability to really listen and be open to other ways of knowing. This inability to be open and listen impacted on how I viewed the world. It prevented me from appreciating the importance of many truths in telling our health story. I had been indoctrinated. I had internalised the colonial logic and spoke its language. I participated in the antagonistic relationships that were created through this logic. I was stressed by it, and it hurt me physically, emotionally and spiritually, as expressed below:

## My Sisters

I rage with pain, unspoken
My heart heavy and constricted
My sister's death unwanted
I am fed up with this ridiculous loss
Numbed by its persistence
My other sisters are consumed by grief
That they are unable to articulate
Their pain is heavy and wearing, draining their life force and optimism
How can we go on?
Heavy hearted, strangled by this oppression
The negativity of our context, is extended by our environment
We are the people who cared and nourished the land our sisters and brothers
Today we witness their demise, as a result of ongoing violence that affects our very psyche
Our will to survive is strong, however our will to remain reminded of our loss in every way is unnerving
When will we hear the words that need to be said to heal our hearts, souls and peoples?
When will we see our land being healed and our knowledge and philosophy respected?
Stop killing my sisters with your hate
Stop this ongoing litany of lies and dread for my people!
I worry intensely regarding the impact this death will have upon my sisters

The ripple of pain, unleashes an erosive action upon a symbolic – esoteric heart, a heart that has been described for so long as non-human
This heart wears scars of generations of dehumanisation, torture, trauma and denial
Its ability as an esoteric organ to soak in and absorb the pain – in the end breaks, crumbles and the wash of pain is continued.
It never ends (Sherwood cited in Broken Hill and Menindee Rural Crisis Intervention Project 2001:6)

The Elders and the Indigenous academies helped me acknowledge that I was colonised and that this required healing. The Indigenous decolonising literature provided a critical informative step to shifting this mindset and the Western academy gave me the skills to critique the colonial logic, using its own language. It was through this critique process that a number of realisations arose. This thesis required a multi-method approach to articulate a way of improving health outcomes for Indigenous Australians.

The theoretical approaches of Postcolonialism and Orientalism both informed the impact of colonisation on the colonised 'Other' and the coloniser. These impacts inform, in part, the unhealthy relationships that still exist in Australia between Indigenous and non-Indigenous Australians as a result of contrasting images, unpalatable and unspoken pasts, and the historical, political and social circumstances that shaped the lives and relationships of colonial and colonised Nations. From these two theoretical approaches I grew to appreciate how the colonial act of research had been so detrimental to Indigenous Australians and other Indigenous peoples throughout the world. I also gained an insight into how the colonisers have similarly been indoctrinated, and they, like me, had internalised these ways of knowing into a colonial mindset. This Western colonial mindset was nurtured in another way for those descendents of the colonisers, based upon a belief of Western superiority along with the doctrine of an unbalanced history.

Orientalism and Postcolonialism provided critical tools for the deconstruction of colonisation; however they did not unpack the whole colonial story that informs the current Indigenous Australians' health status, which continues to be worse than other colonised Indigenous populations in the world (NACCHO and Oxfam 2007). Indigenous Australians' positioning through colonisation has differed from most Indigenous Nations worldwide, in that the doctrine of terra nullius claiming Australia was a land belonging to no one had to be legitimated by the colonists. It is here that the 'Aboriginal Problem' first arose and despite the debunking of the

200-year-old myth through the Mabo case, political Australia maintains Aboriginal people are the problem that they are still trying to solve. The maintenance of the ideological and colonial mindset of the 'Aboriginal problem' has been evidenced throughout this thesis both in the literature and the stories of participants. It is used often to supplant undemocratic practices such as the removal of the Anti-discrimination Act targeting Aboriginal Australians to control and manage these unruly and resistant populations. Our very presence in this country is the problem and this has been clearly played out by actions taken by the country against Indigenous Australians historically, politically and socially.

Terra Nullius has also informed how research is undertaken on us.

> Yes it's a big power game that's all it is. To keep the Aboriginal people down and oppressed and not let them speak out for what their values are in regard to health (Elders group).

Indigenous health research has, through the silencing of Indigenous voices and views, de-humanised and problematised Aboriginal Australians, a strategy informed through the doctrine of terra nullius, a land belonging to no people. This ideological stand, coupled with positivistic methods that decontextualise the historical, political and social circumstances of Indigenous peoples, ensures Indigenous Australians are further problematised; they have resisted efforts to be assimilated, and hence they are cast as the problem. The descriptive data of Indigenous health deficits, supported through funding bodies and government agencies, simply reinforces these conceptualisations. It is this plethora of information that indoctrinates health professionals and future Indigenous health researchers. This unhealthy relationship is maintained through the ideological constructs of a 200-year-old myth. Recognising this positioning is the first step towards shifting this agenda. The promotion and utilisation of a decolonisation framework is the way forward.

The methods I used to decolonise and become open helped me to see the depth and complexity of issues and to observe the unique experiences of Indigenous Australians in relation to their health status. I gained an insight into the importance of balancing stories and histories about Australia and ourselves. Furthermore, I came to appreciate the importance of Indigenous critical theory in relation to unpacking stories of the past and present. This process highlighted the

recurring themes of colonial power that have been articulated throughout the thesis and this chapter.

The critical evidence shared by participants and Elders reinforced the recurring themes that are problematic in Indigenous health research. Their stories also provide clear examples of how research, done unreflectively, can re-traumatise and cause injury to Indigenous researchers and communities (Atkinson 2002). Importantly, they also offered opportunities to learn, examine success, and exemplify resilience, a story so often left untold. It was through my work with participants and Elders that I developed the decolonising framework for respectful, ethical and safe Indigenous health research. This process was co-generative and informed through Indigenous ways of knowing, being and doing and community cultural protocols.

As previously stated, this thesis is a multi-method approach that grew from many ways of knowing, being and doing. What I have learnt along the way is that these many ways of knowing can come together effectively if a framework for, and experience of decolonisation is embedded within the research process. New ways of knowing can be produced through this coming together respectfully. I have arrived at my findings using an Indigenous research methodology. It is a methodology that requires balance and respectful praxis. From this praxis I have found that injury is a major consequence of the ongoing nature of colonisation through Indigenous health research. Indigenous injury requires further investigation, balanced through an IRM approach to illuminate a way forward.

*Figure 2*: **The continuum of co-generating knowledges — a decolonisation journey**
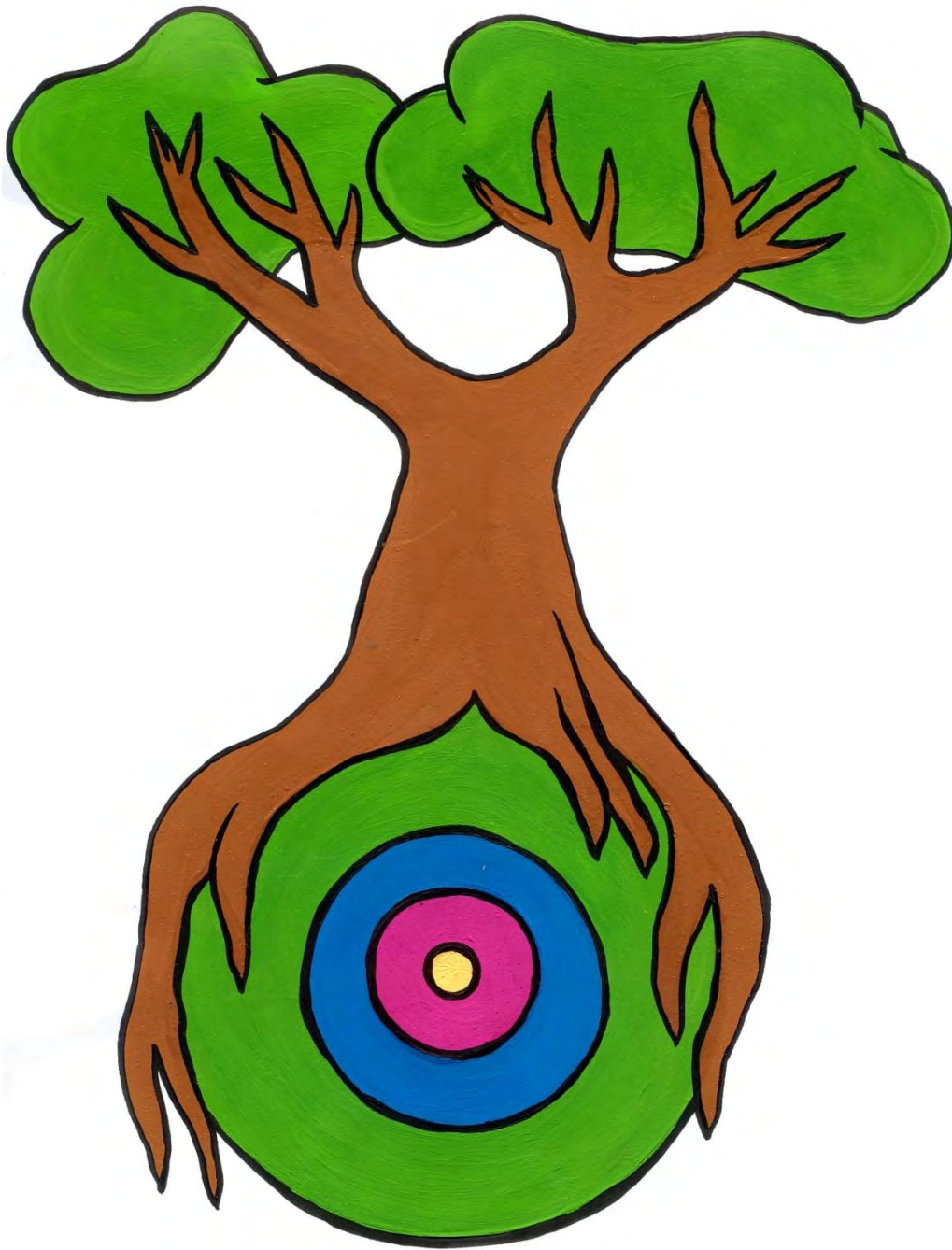


**Illustrated by Willurei Kirkbright-Burney 2010**

This model is informed by the continuum of learning developed within the living method in Chapter 4. As learning is a life-long journey that never stops, it is a growing process that requires support and nurturing from the many layers surrounding the learner. The roots of the tree are the supports that hold the learner through their lifelong journey; these roots are the Elders and the Mother. It has been developed to symbolise that decolonisation is an ongoing journey that can grow wonderful outcomes. It is has been this journey that has informed the following ways forward.

## Ways forward – the Critical Indigenous Health Research Approach

The Way forward to improving the health outcomes of Indigenous Australians through health research, I have argued, requires the decolonisation of the Indigenous health research agenda. This is because every Australian, Indigenous or non-Indigenous, working in the field of Aboriginal health or research has been indoctrinated through a dominant colonial Western system. This indoctrination has informed how we relate to and know or not know each other. Appreciating that our relationships and ways of knowing have been informed by this dominant way of knowing Indigenous Australians is a critical step towards a personal decolonising journey.

Decolonisation is an ongoing journey and requires safe spaces for ongoing dialogue between first Australians and the rest of the country. This dialogue is necessary to restore rights, recognise injuries and ameliorate injustices in health research and its outcomes. It is about developing a contextualised discourse of Indigenous health informed through a balance of histories and truths of every Australian. This requires the utilisation of a decolonising framework to ensure our colonial ideology relating to Indigenous health knowledge production and research practice is transformed.

It is anticipated that health researchers informed though a decolonisation framework will be encouraged to develop openness that enables respect of Indigenous knowledges, cultural protocols, collaborative praxis and ensuring benefit is articulated through the views and voices of Aboriginal communities and their organisations. This openness can inspire the co-generation of new knowledges to develop improved health outcomes of Indigenous Australians through health research. Researchers need to be supported by their institutions and funding bodies who similarly

293

need to reflect a decolonised Indigenous health research agenda. As such health research funding bodies must build and fund decolonised Aboriginal health research that is responsive to research focused on health improvement and collaborative community participation, allowing Indigenous voices to emerge and construct their own realities.

As Indigenous ethics is at the heart of good health research for Aboriginal Australians. Aboriginal health research ethics bodies should be established and funded appropriately in every State and Territory throughout the Nation with the capacity to oversee ethical conduct of research projects and cease projects that are causing injury. All Institutions must refer Indigenous health research projects to these funded Aboriginal health research ethics bodies, to ensure that their practice and ongoing process is considered ethical praxis and that benefit for Aboriginal communities is considered a priority of the research.

This new way of knowing and ways forward can transform Indigenous health research to ensure the outcomes needed to improve health outcomes are achieved.

## Conclusion

My thesis has shown that colonisation continues in Australia and is maintained and sustained through a number of approaches within the Aboriginal health research agenda such as funding; peer review; the Aboriginal health 'expert'; excluding the contextual circumstances of Indigenous Australians lives and health; culturally insensitive and unreflective research practice; descriptive deficit data production; replication of problematic constructions that inform the wider health professional workforce; and the negating of an emerging Indigenous voice in relation to their resilience and survival. It has also found that these approaches cause stress resulting in injury. These approaches and the resulting injury have not improved Aboriginal health and well-being

Using my own methodological journey and a critical Indigenous theoretical approach, the thesis worked towards developing decolonised Aboriginal health research focused on health improvement. These approaches are inclusive of Aboriginal ways of knowing, being and doing and have been spelt out in my methodology chapter and Chapter 8, (It's just good manners). These approaches are divergent to the practice essentialised in the Goldilocks scenario, as they are focused on 'doing no harm'.

294

Elders and participants argued that research is a site of struggle and our challenge is to inform this process, rather than reject it, as good research can and does provide the outcomes we need to create the action we need for change when we are at its helm. The culmination of the analysis of the findings of this project is the necessity of a decolonising framework. This methodology provides the space for Indigenous and Western knowledge systems to co-generate new ways of knowing in respectful co-existence and in which to improve the health and well-being of Indigenous Australians and the country.

# References

ATSIC, Indigenous Cultural and Intellectual Property Taskforce (1999) The 1989 UNESCO Recommendation and Aboriginal and Torres Strait Islander Peoples' Intellectual Property Rights. <u>A Global Assessment of the 1989 Recommendation on the Safeguarding of Traditional Culture and Folklore: Local Empowerment and International Cooperation, 27–30 June 1999, Washington DC, USA.</u> ATSIC. Canberra., ATSIC**:** 12.

ATSISJC (2006) Aboriginal & Torres Strait Islander Social Justice Report 2005. Sydney, Human Rights & Equal Opportunity Commission.

ATSISJC (2009) Social Justice Report 2008. <u>Social Justice Report</u>. Sydney, Australia Human Rights Commission.

ABS (2003) Australian Demographic Statistics Quarterly: 2001. Canberra, Australian Bureau of Statistics.

ABSAIHW (2001) Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2001. Canberra ABSAIHW.

ABSAIHW (2008) The Health and Welfare of Aboriginal and Torres Strait Islander Peoples. Canberra, ABSAIHW.

Absolon, K. and C. Willett (2004) "Aboriginal research: Berry Picking and Hunting in the 21<sup>st</sup> Century." <u>First Peoples Child & Family Review: A Journal on Innovation and Best Practices in Aboriginal Child Welfare Administration, Research, Policy and Practices.</u> **1**(1): 5–17.

Adelson, N. (2005) "The Embodiment of Inequity." <u>Canadian Journal of Public Health</u> **96**(Supplement 2): s45–s61.

Aerts, D., L. Apostel, et al. (2007) World Views from fragmentation to intergration. <u>Internet Edition 2007</u>. C. Vidal and A. Riegler. Brussels.

AH&MRC (2008) AH&MRC Guidelines for Research into Aboriginal Health: Key Principles. Sydney, AH&MRC**:** 10.

AIDA (2009) Submission to the National Primary Health Care Strategy. Canberra, The Australian Indigenous Doctors' Association Ltd**:** 21.

AIHW. (2002, 4/09/2002) "Indigenous Health: Overview." Retrieved 2/03/04, 2004.

Alford, K. (2005) Discussion Paper No. 13: Comparing Australian with Canadian and New Zealand Primary Health Care Systems in Relation to Indigenous Populations: Literature Review and Analysis. <u>Discussion Paper</u>. O. V. K. H. Unit. Melbourne, Onemeda VicHealth Koori Health Unit**:** 1–52.

Altman, C. J. (2007) The Howard Government's Northern Territory Intervention: Are Neo-Paternalism and Indigenous Development Compatible? Canberra, Centre for Aboriginal Economic Policy Research**:** 1–19.

AMSANT (2008) Options for Alcohol Control in the Northern Territory. AMSANT. Alice Springs, AMSANT**:** 1–5.

Anderson, I. (2007) "Health Policy for a Crisis or a Crisis in Policy?" in <u>Coercive reconciliation</u>. J. Altman and M. Hinkson. North Carlton, Australia., Arena Publications Association**:** 133–140.

Anderson, I. (2007) "Policy Processes" in <u>Social determinants of Indigneous Health</u>. B. Carson, T. Dunbar, D. Chenhall, R and R. Baillie. Crows Nest, NSW, Allen& Unwin**:** 231–52.

Anderson, I. et al. (2006) Measuring the Health of Aboriginal and Torres Strait Islander Peoples: A Background Paper for the Project "Action Orientated Indicators of Health and Health Systems Development for Indigenous Peoples in Australia, Canada, and New Zealand". Melbourne**:** 1–51.

Anderson, I. and K. Humphrey (2007) "Editorial: Aboriginal Health & History." <u>Health and History</u> **9**, 1–4.

Anderson, W. (2002) <u>The Cultivation of Whiteness: Science, Health and Racial Destiny in Australia.</u> Melbourne, Melbourne University Press.

Anderson, W. (2007) "The Colonial Medicine of Settler States: Comparing Histories of Indigenous Health." <u>Health and History</u> **9**, 1–7.

Anderson, W. (2008) "Re: Northern Territory Emergency Response Review Board." <u>NT Intervention Submission</u>, 2.

ANTaR (2009) "Indigenous rights organisation welcomes UN report on Northern Territory." http://www.antar.org.au/media/ANTaR-welcomes-UN-report.

Archibald, J. (2008) <u>Indigenous Storywork Educating the Heart, Mind, Body and Spirit</u>. Vancouver, UBC Press.

Atkinson, J. (2002) <u>Trauma Trails Recreating Song Lines: The Transgenerational Effects of Trauma in Indigenous Australia.</u> North Melbourne., Spinifex Press Pty Ltd.

Atkinson, J. (2007) Indigenous Approaches to Child Abuse. <u>Cooercive reconcilliation</u>. J. Altman and M. Hinkson. North Carlton, Australia, Arena Publishing Association**:** 151–62.

Atkinson, J. et al. (2002) "Broadening the focus of research into the health of Indigenous Australians: We know the problems – we need to seek solutions rather then more statistics." <u>MJA.</u> **177**(6): 286–87.

ATSIWTFV (1999) The Aboriginal and Torres Strait Islander Women's Task Force on Violence Report. Brisbane, Department of Aboriginal and Torres Strait Islander Policy and Development (DATSIPD) 401.

Attwood, B. (1992) 'Introduction'. <u>Power, Knowledge and Aborigines.</u> B. Attwood and J. Arnold. Bundoora., La Trobe University Press. **35:** pp. i–xvi.

Attwood, B. (2003) <u>Rights for Aborigines.</u> Crows Nest, Allen & Unwin.

Attwood, B. (2005) <u>Telling The truth About Aboriginal History.</u> Sydney, Allen & Unwin.

Austin, T. (1997) <u>Never Trust a Government Man: Northern Territory Aboriginal Policy 1911–1939.</u> Darwin, Northern Territory University.

Bailie, R. and R. Myfawny (2001) "Household infrastructure in Aboriginal communities." <u>MJA</u> **175**: 363–66.

Bamblett, M. (2006) Stop the abuse of our children's culture. <u>SNAICC News</u>. North Fitzroy, Victoria, SNAICC NEWS**:** 1.

Banuri, T. M., F.A. (1993) <u>Who will save the Forests?: Knowledge, power and environmental destruction.</u> London, Zed Books.

Bartlett, B. (1998) "Aboriginal Health." <u>New Doctor.</u> Summer 1998: 23–6.

Bartlett, B. (1998) Origins of Persisting Poor Aboriginal Health. <u>Public Health & Community Medicine.</u> Sydney, University of Sydney.

Bartunek, J. and M. Louis (1996) <u>Insider/Outsider Team Research.</u> London, Sage Publications.

Battiste, M. (2002) Indigenous Knowledge and Pedagogy in First Nations Education: A Literature Review with Recommendations: Prepared for the National Working Group on Education and the Minister of Indian Affairs Indian and Northern Affairs Canada (INAC) Ottawa, Apamuwek Institute.

Battiste, M. (2008) Research Ethics for Protecting Indigenous Knowledge and Heritage: Institutional and Researcher Responsibilities. <u>Handbook of Critical And Indigenous Methodologies</u>. K. Denzin, Norman., S. Lincoln, Yvonna and T. Smith, Linda. Los Angeles, SAGE**:** 497–510.

Battiste, M. and Y. Henderson (2000) <u>Protecting Indigenous Knowledge and Heritage; A Global Challenge.</u> Saskatoon, Canada., Purich Publishing Ltd.

Beaver, C. and Y. Zhao (2004) Aboriginal and Torres Strait Islander Primary Health Care Review: Investment Analysis of the Aboriginal and Torres Strait Ilsander Primary Health Care Program in the Northern Territory. <u>Consultant Report 2</u>. Canberra, OATSIH.

Behrendt, L. (2003) <u>Achieving Social Justice: Indigenous Rights and Australia's Future.</u> Sydney, The Federation Press.

Bell, S. (2003) Letter: Alice was let down by poor grog trial report: Congress. <u>Alice Springs News</u>. Alice Springs, Alice Springs News.

Berkes, F. (1998) Indigenous Knowledge as Challenge to the Positivist-Reductionist Paradigm. <u>Sacred Ecology: Traditional Ecological Knowledge and Resource Management.</u> London, Taylor and Francis.

Berndt, C. H. and R. M. Berndt (1996) <u>The World of the First Australians: Aboriginal Traditional Life: Past and Present.</u> Canberra, Australian Institute of Aboriginal Studies.

Bhabha, H., K. (1989) "Remebering Fanon: self, Psyche, and the Colonial Condition" in <u>Remaking History</u>. B. Kruger and P. Mariani. Seattle, Bay Press.

Bhabha, H., K. (1999) "Cultural Diversity and Cultural Differences" in <u>The post-colonial studies reader</u> B. Ashcroft et al. London, Rouledge.

Bhabha, H., K. (1999) "Signs Taken for Wonders" in <u>The post-colonial studies reader</u> B. Ashcroft et al.. London, Routledge.

Bhatia, K. A., P. (1995) An Overview of Aboriginal and Torres Strait Islander  Health: Present Status and Future Trends. Canberra, Aboriginal and Torres Strait Islander Health Unit, Australian Institute of Health and Welfare.

Bird Rose, D. (1991) <u>Hidden Histories</u>. Canberra, Aboriginal Studies Press.

Bird Rose, D. (1996) <u>Nourishing Terrains: Australian Aboriginal Views of Landscape and Wilderness.</u> Canberra, Australian Heritage Commission.

Bird Rose, D. (2000) <u>Dingo makes us human</u>. Cambridge, Cambridge University Press.

Bird Rose, D. (2004) <u>Reports from a Wild Country.</u> Sydney, UNSW Press.

Bishop, R. (1997) "Maori people's concern about research into their lives." <u>History of Education Review.</u> **26**: 25–41.

Bishop, R. (1998) "Freeing ourselves from neo-colonial domination in research: A Maori approach to creating knowledge." <u>Qualitative Studies in Education</u> **11**(2): 199–219.

Bishop, R. (1999) Collaborative Storytelling: Meeting Indigenous Peoples' Desires for Self-Determination in Research. <u>The World Indigenous People's Conference: Education</u>. Albuquerque, New Mexico**:** 1–30.

Bissett, D. (2004) Appalling: That's the state of our health. <u>The Koori Mail</u>. Lismore**:** 37.

Blair, N. (2003) "Searching for an Indigenous research methodology." Retrieved 11/06/2003, from http://www.newcastle.edu.au/news/uninews/oldnews/april%2.

Brady, M. and D. Martin (1999) Dealing with alcohol in Alice Springs: an assessment of policy options and recommendations for action. <u>CAEPR Working Paper</u>. Canberra, CAEPR**:** 1–35.

Brady, W. (1992) <u>Beam me up Scotty, communicating across world views on knowledge, principles and procedures for the conduct of Aboriginal and Torres Strait Islander research</u>. National Aboriginal and Torres Strait Islander Higher Education Conference Proceeding., University of Southern Queensland, Toowoomba., National Aboriginal and Torres Strait Islander Higher Education.

Brady, W. (1999) "Observing the Other." <u>Eureka Street</u> **9**(1): 28–30.

Brands, J. and M. Gooda (2006) "Putting the users of research in the driver's seat: the Cooperative Research centre for Aboriginal Health's new approach to research development." <u>Australian Aboriginal Studies.</u> **2**: 27–35.

Brantlinger, P. (2003) <u>Dark Vanishings: Discourse on the Extinction of Primitive races, 1800–1930</u>. London, Cornell University Press.

Breen, S. (2003) Re-inventing Social Evolution. <u>Whitewash; On Keith Windschuttle's Fabrication of Aboriginal History</u> Manne R. ed. Melbourne, Black Inc. Agenda.

Briscoe, G. (2003) <u>Counting, Health and Identity: A History of Aboriginal health and demography in Western Australia and Queensland 1900–1940.</u> Canberra, Aboriginal Studies Press for the Australian Institute of Aboriginal and Torres Strait Islander Studies.

Broken Hill and Menindee Rural Crisis Intervention Projects (2002) <u>Final report and model of best practice 1999–2000</u>. Sydney, Partnerships Against Domestic Violence Coordinated by the Commonwealth Office of the Status of Women.

Brooks, D. (2003) <u>A town like Mparntwe: a guide to the Dreaming tracks and sites of Alice Springs</u>. Alice Springs, Jukurrpa Books.

Broome, R. (2002) <u>Aboriginal Australians: Black responses to White dominance 1788–2001</u> Crows Nest, NSW, Allen & Unwin.

Brown, A. and N. Brown (2007) "The Northern Territory Intervention: voices from the centre of the fringe." <u>MJA</u> **187**(11/12): 621–23.

Brown, A., M. Morrissey & J. Sherwood (2006) "Uncovering the Determinants of Cardiovascular Disease among Indigenous People." <u>Ethnicity & Health.</u> **11**(2): 191–210.

Bryant-Davis, T. (2007) "Healing Requires Recongition: The Case for Race-Based Traumatic Stress." <u>The Counselling Psychologist</u> **35**(1): 135–43.

Burgess, P. et al. (2005) "Healthy Country: Healthy People?" <u>Australian and New Zealand Journal of Public Health.</u> **29**(2): 117–22.

Butler, K., K. Cameron, et al. (1995) <u>The myth of terra nullius: Invasion and resistance – the early years.</u> Sydney, Board of Studies NSW.

Cadet-James, Y. (2001) "Thoughts About Research from an Indigenous Perspective." <u>Aboriginal and Islander Health Worker Journal.</u> **25**(1): 17–8.

Cass, A., A. Lowell, et al. (2002) "Sharing the true stories: improving communication between Aboriginal patients and healthcare workers." <u>MJA</u> **176**: 466–70.

Castellano, B., Marlene. (2004) "Ethics of Aboriginal Research." <u>Journal of Aboriginal Health.</u>: 98–114.

Caute, D. (1970) <u>Fanon</u>. Great Britain, Fontana/Collins.

Chalmers, A. (1990) <u>Science and its Fabrication</u>. Buckingham, UK., Open University Press.

Christians, G., Clifford (2005) "Ethics and Politics in Qualitative Research" in <u>The Sage Handbook of Qualitative Research</u>. N. Denzin and Y. Lincoln. Thousand Oaks, CA, Sage Publications, Inc**:** 139–64.

Clapham, K., S. Mark, et al. (2006) "Injury profiles of Indigenous and non-Indigenous people in New South Wales." <u>MJA</u> **184**(5): 217–20.

Close, G. R. et al. (1994) "Guidelines on the prevention and control of otitis media and its sequelae in Aboriginal children." Medical Journal of Australia.(suplementary)

Comte, A. (1972) A General View of Positivism. London, Trubner.

Connor, J. (2003) The Australian Frontier Wars 1788–1838. Sydney, UNSW Press.

Couzos, S. and H. Taylor (2003) "Trachoma" in Aboriginal Primary Health Care. S. Couzous and R. Murray. South Melbourne, Oxford University Press: 572–93.

Cowlishaw, G. (1992) Studying Aborigines: Changing Canons in Anthropology and History. Power, Knowledge and Aborigines. B. Attwood and J. Arnold. Bundoora, Victoria., La Trobe University Press. 35: 20–31.

Cox, L. (2007) "Fear, Trust and Aborigines: The Historical Experience of State Institutions and Current Encounters in the Health System." Health and History 9, 1–13.

CRCAH (2006) "Approach to research." Cooperative Research Centre for Aboriginal Health, 1–5.

CRCAH (2008) CRC for Aboriginal Health Annual Report 2007–2008. Annual Report CRCAH. Darwin, CRCAH: 100.

Creighton, A. and S. Champion (2007) Indigenous researchers for Indigenous health research: the history, nature and achievements of the Indigenous Staff Network. 9th National Rural Health Conference. Albury, NSW., National Rural Health Conference: 1–5.

Cresswell, A. (2007) 'Breaking the cycle'. The Australian. Sydney, retrieved 12/02/2010http://www.theaustralian.com.au/news/health-science/breaking-the-cycle/story-e6frg8y6-1111113612144.

Cruickshank, J. (2000) "Ethnocentrism, Social Contract Liberalism And Positivistiv-Conservatism: Rorty's Three Theses on Politics." Res Publica 6(1): 1–23.

Crundall, I. (2003) "Response to Review of the Summary Evaluation of the Alice Springs Liquor Trial." CARPA Newsletter(35): 30–9.

Crundall, I. (2004) A Trial of the Alice Springs Alcohol Trial. Third Australasian Drug Strategy Conference, Australasian Drug Strategy Conference

Crundall, I. (2006) Northern Territory Alcohol Consumption and Related Attitudes:2006 Household Survey. Darwin, Northern Territory Department of Justice.

Crundall, I. and C. Moon (2003) "Extract:: Report to the Licensing Commission: Summary Evaluation of the Alice Springs Liquor Trial." CARPA Newsletter (35): 8–13.

Crundall, I. and C. Moon (2003) Report to the Licensing Commission: Summary Evaluation of the Alice Springs Liquor Trial. Darwin, Northern Territory Government.

Cruse, S. (2001) "Encouraging Research Guidelines to be put into Practice: An Aboriginal Health Research Ethics Committee in Action." Kaurna Higher Education Journal.(7): 62 (23–7)

Cunneen, C. (2001) Conflict, Politics and Crime: Aboriginal Communities and the Police. Sydney, Allen & Unwin.

Cunningham, C., J. Reading, et al. (2003) "Health research and indigenous health." BMJ. 327: 445–47.

Cunningham, J., A. Cass, et al. (2005) "Bridging the treatment gap for Indigenous Australians." MJA 182(10): 505–6.

D'abbs, P., E. Hunter, et al. (1994) Alcohol-related violence in Aboriginal and Torres Strait Islander Communities: a Literature Review. National Symposium on Alcohol Misuse and Violence. Canberra, Commonwealth of Australia.

Daes, E. (1995) Principles and Guidelines for the Protection of the Heritage of Indigenous Peoples. <u>United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities, Commission on Human Rights, United Nations Economic and Social Council.</u> New York, United Nations Economic and Social Council.

Deloria, V. (1997) <u>Red Earth White Lies: Native Americans and the Myth of Scientific Fact.</u> Colorado, Fulcrum Publishing Golden.

Denzin, K., Norman and S. Lincoln, Yvonna (2005) "Locating the Field".in <u>The Sage Handbook of Qualitative Research</u> K. Denzin, Norman and S. Lincoln, Yvonna. Thousand Oaks, Sage**:** 33–41.

Denzin, K., Norman. (2005) "Emancipatory Discourse And The Ethics And Politics of Interpretation".in <u>The Sage Handbook of Qualitative Research</u> . Thousand Oaks, CA., Sage**:** 933–58.

Denzin, K., Norman. and S. Lincoln, Yvonna (2005) "Introduction: The Discipline and Practice of Qualitative Research". In Third Edition. <u>The Sage Handbook of Qualitative Research</u>. K. Denzin, Norman. and S. Lincoln, Yvonna. Thousand Oaks, Sage Publications**:** 1–32.

Denzin, K., Norman. and S. Lincoln, Yvonna (2008) "Introduction: Critical Methodologies and Indigenous Inquiry". in <u>Handbook of Critical  And Indigenous Methodologies</u>. K. Denzin, Norman., S. Lincoln, Yvonna and T. Smith, Linda. Los Angeles, Sage**:** 1–20.

Denzin, N. (2003) 'IRBS and the Turn to Indigenous Research Ethics', University of Illinois College of Law, Retrieved 3 April 2005, from http://www.law.uiuc.edu/conferences/humansubject/papers/CHPT_14-1401-CAS_1.pdf

Denzin, N. and Y. Lincoln, Eds. (2000) "The Discipline and Practice of Qualitative Research" in <u>A Handbook of Qualitative Research</u>. London, Sage Publications, Inc.

Denzin, N. and Y. Lincoln, Eds. (2000) "Paradigms and Perspectives in Transition" in <u>A Handbook of Qualitative Research</u>. Thousand Oaks, Sage Publications.

Devitt, J., G. Hall, et al. (2001) Underlying Causes. <u>The Health and Welfare of Territorians</u>. T. H. S. Epidemiology Branch. Darwin, Territory Health Services**:** 11–16.

Dion, S. (2004) "(Re)telling to Disrupt: Aboriginal People and Stories of Canadian History." <u>Jourrnal of the Canadian Association for Curriculum Studies</u> **2**(1): 55–76.

Dodson, M. (1997) "Over-coming discrimination against Indigenous people – Australia's experience." Retrieved 17/05/2000, from http://www.hreoc.gov.au/social_justice/speeches/j8_7_8.html.

Dodson, M. (2003) "The end in the beginning" in <u>Blacklines</u>. M. Grossman. Melbourne, Melbourne University Press.

Dodson, M., Ed. (2003) "Unfinished Business: A Shadow Across Our relationships" in <u>Treaty: let's get it right!</u> M. Nakata Canberra, Aboriginal Studies Press.

Dunbar, R. (1995) <u>The Trouble with Science.</u> London., Faber and Faber.

Dunbar, T., A. Arnott, et al. (2004) working towards change in Indigenous health research. CRCATH. Darwin.

Dunbar, T. and M. Scrimgeour (2006) "Ethics in Indigenous Research – Connecting with Community" <u>Bioethical Inquiry</u> **3**: 179–85.

Durie, M. (2004) "Understanding health and illness: research at the interface between science and indigenous knowledge" <u>Intrenational Journal of Epidemiology.</u> **33**(5): 1138–43.

Dwyer, J. and K. Silburn (2009) Final Consultation Report: Review of the NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health Through Research. Canberra, NHMRC: 37.

Dwyer, J., K. Silburn, et al. (2004) Aboriginal and Torres Strait Islander Primary Health Care Review: National Strategies for Improving Indigenous Health and Health Care. Consultant Report 1. Canberra, OATSIH.

Dyer, S. and D. Demeritt (2009) "Un-ethical review? Why it is wrong to apply the medical model of research governance to human geography." Progress in Human Geography 33(1): 46–64.

Eckermann, A. et al. (1992) Binan Goonj Armidale UNE Press.

Elder, B. (1988) Blood on the Wattle. Brookvale, NSW, National Book Distributors.

Ella, R., P. Smith, et al. (1998) Securing the Truth: NSW Government Submission to the Human Rights and Equal Opportunity Commission Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families. Sydney, Department of Aboriginal Affairs.

Ellis, C. and P. Bochner, Arthur. (2000) "Autoethnography, Personal Narrative, Reflexivity" in Handbook of Qualitative Research. N. Denzin and Y. Lincoln Thousand Oaks, Sage Publications. Inc.: 733–68.

Ellis, J. and M. Earley (2006) "Reciprocity and Constructions of Informed Consent: Researching with Indigneous Populations" International Journal of Qualitative Methods 5(4): 1–9.

Ermine, W. (2000) A Critical Examination of the Ethics in Research Involving Indigenous Peoples, The Indian and Northern Education Program. Saskatoon, Saskatchewan. Master of Education: 149.

Ermine, W., R. Sinclair, et al. (2005) Kwayask itotamowin: Indigenous Research Ethics: Report of the Indigenous Peoples' Health Research Centre to the Institute of Aboriginal Peoples' Health and the Canadian Institutes of Health Research. Saskatoon, SK, Indigenous Peoples' Health Research Centre: 57.

Ermine, W., R. Sinclair, et al. (2004) The Ethics of research Involving Indigenous Peoples. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics. Saskatoon, SK., Indigenous Peoples' Health Research Centre Saskatoon, SK.: 1–272.

Ewald, D. et al. (2003) "An evaluation of a SAFE-style trachoma control program in Central Australia." MJA 178: 65–8.

Fannon, F. (1999) "National Culture" The post-colonial studies reader B. Ashcroft et al. London, Routledge.

Feather, J. (2004) The information society a study of continuity and change. London, Facet publishing.

Ferguson, W. and J. Patten (1938) "Cries From the Heart: Aborigines Claim Citizens Rights!" in Voices of Aboriginal Australia Past Present Future. I. Moores. Sringwood, NSW, Butterfly Books: 54–61.

Finnane, K. (2003) Grog Trial: give our families a fair go. Alice Springs News. Alice Springs: 2.

Flyvbjerg, B. (2001) Making Social Science Matter: Why Social Inquiry Fails and How It Can Succeed Again. Cambridge, Cambridge University Press.

Foltz, G., Tanice. and W. Griffin (1996) "'She changes everything she touches' Ethnographic Journeys of Self-Discovery" in Composing Ethnography. C. Ellis and P. Bochner, Arthur. Walnut Creek, Altamira Press.

Foster, D. et al. (2005) <u>Population and Mobility in the Town Camps of Alice Springs</u>: A report prepared by Tangentyere Council Research Unit. Desert Knowledge CRC Report 9, December 2005. Alice Springs, Desert Knowledge CRC**:** 60.

Foster, D. et al. (2006) "'Researching ourselves back to life': new ways of doing Aboriginal alcohol research." <u>Drug and Alcohol Review</u>(25): 213–17.

Foucault, M. (1961) <u>Madness and Civilization: A History of Insanity in the Age of Reason</u>. London, Penguin.

Foucault, M. (1980) <u>Power/ Knowledge: Selected Interviews & Other Writings 1972–1977.</u> New York, Random House.

Foucault, M., Ed. (1980) <u>Two Lectures</u>. Power/Knowledge: Selected Interviews & Other Writings 1972–1977. New York, Pantheon books.

Foucault, M. (1989) <u>The Archaeology of Knowledge</u>. London, Routledge Classics.

Foucault, M. (1991) <u>Discipline and Punish: The birth of the Prison.</u> Ringwood, Penguin Books.

Foucault, M. (1994) <u>The Birth of The Clinic: An Archaeology of Medical Perception.</u> New York, Vintage Books A Division of Random House, Inc.

Foucault, M. (2002) <u>The Order of Things</u>. New York, Routledge Classics

Foundation., N. R. (2002) "Indigenous Knowledge Systems." Retrieved 15/10/02, from http://www.nrf.ac.za/focuseareas/iks/

Franklin, M. and I. White (1991) The History and Politics of Aboriginal Health. <u>The health of Aboriginal Australia</u>. P. Trompf and J. Reid. Sydney, Harcourt Brace Jovanovich.

Fredericks, B. (2003) <u>Us Speaking about Women's Health: Aboriginal women's perceptions and experiences of health, well-being, identity, body and health services.</u> School of Health and Human Performance Faculty of Arts, Health and Sciences. Rockhampton, Central Queensland University**:** 460.

Freemantle, J. et al. (2006) "Patterns, trends, and increasing disparities in mortality for Aboriginal and non-Aboriginal infants born in Western Australia, 1980–2001: population database study." <u>The Lancet</u> **367**(9524): 1758–1766.

Freire, P. (1972) <u>Pedagogy of the Oppressed.</u> Ringwood Victoria., Penguin Education.

Freire, P. (1989) <u>Learning to question: A pedagogy of liberation.</u> New York., Continuum.

Fuery, P. and N. Mansfield (2000) <u>Cultural Studies and Critical Theory.</u> South Melbourne, Oxford University Press.

Gandhi, L. (1998) <u>Postcolonial Theory</u>. St.Leonards, Allen &Unwin.

Giddens, A. (1985) "Jurgen Habermas" in <u>The Return of Grand Theory in the Human Sciences</u>. Q. Skinner. Cambridge, Canbridg University Press**:** 121–40.

Giroux, H. and S. Giroux (2008) Challenging Neoliberalism's New World Order: The Promise of Critical Pedagogy. <u>Handbook of Critical And Indigenous Methodologies</u>. Denzin, N., S. Licoln, Y and Smith, Linda. Los Angeles, SAGE**:** 181–90.

Godfrey-Smith, P. (2003) <u>An introduction to the philosophy of science Theory and Reality</u>. Chicago, The University of Chicago Press.

Goodall, H. (1996) <u>Invasion to Embassy: Land in Aboriginal Politics in New South Wales, 1770–1972.</u> St. Leonards., Allen & Unwin in association with Black Books.

Grant, M., I. Wronski, et al. (2008) "Aboriginal Health and History" in <u>Aboriginal Primary Health Care An Evidence-based approach</u>. S. Couzous and R. Murray. Sydney, Oxford University Press**:** 1–28.

Gray, A., P. Trompf, et al. (1991) The decline and rise of Aboriginal families. <u>The Health of Aboriginal Australia</u>. J. Reid and P. Trompf. Sydney, Harcourt: 80–122.

Gray, D. (2003) "Response to Review of the Summary of the Alice Springs Liqour Trial by Ian Crundall." CARPA Newsletter(53): 30–9.

Gray, D. (2003) "Review of the Summary Evaluation of the Alice Springs Liquor Trial A Report to Tangentyere Council and Central Australian Aboriginal Congress, June 2003." CARPA Newsletter(53): 14–29.

Gray, D. (2006) Building Indigenous research capacity: an example from Central Australia. Perth, National drug Research Institute, Curtain University of Technology.

Greenwood, D., J and M. Levin (2000) "Reconstructing the relationships between universities and society through action research" in Handbook of Qualitative Research. N. Denzin & Y. Lincoln. Thousand Oaks, Sage Publications Inc.

Grey, G. (2007) A Cautious Silence: The politics of Australian anthroplogy. Canberra, Aboriginal Studies Press.

Grieves, V. (2009) Aboriginal Spirituality: Aboriginal Philosophy The Basis of Aboriginal Social and Emotional Wellbeing. **Discussion Paper Series: No.9, Cooperative Research** Centre for Aboriginal Health, Darwin: 68.

Guba, G. and Y. Lincoln (1989) Fourth generation evaluation. Newbury Park, CA., Sage.

Guba, G. and Y. Lincoln, (2005) "Paradigmatic Controversies Contradictions, And Emerging Confluences" in The Sage Handbook of Qualitative Research. N. Denzin & Y. Lincoln. Thosand Oaks, Sage Publications: 191–215.

Haebich, A. (1988) For Their Own Good. Nedlands., University of Western Australia.

Haebich, A. (2000) Broken Circles. Perth, Fremantle Arts Centre Press.

Harper, D. (2000) "Reimagining Visual Methods" in Handbook of Qualitative Research. N. Denzin & Y. Lincoln. Thousand Oaks, CA., Sage Publications Inc: 717–32.

Harris, L. D. and J. Wasilewski (2004) "Indigeneity, an Alternative Worldview: Four R's (Relationship, Responsibility, Reciprocity, Redistribution) vs. Two P's (Power and Profit) Sharing the Journey Towards Concious Evolution." Systems Research and Behavioral Science **21**, 1–15.

Hasluck, P. (1961) The policy of Assimilation. Decisions of Commonwealth and State Ministers at the Native Welfare Conference, Canberra, January 26th and 27th, 1961, Commonwealth.

Hassel, C. (2004) "Can Diversity Extend to Ways of Knowing? Engaging Cross-Cultural Paradigms." Journal of Extension. **42**(2): 7.

HealthInfoNet. (2001) "Aboriginal and Torres Strait Islander Health Bulletin." Journal articles Retrieved 03/03/01 from www.healthinfonet.ecu.edu.au

Henry, J., T. Dunbar, et al. (2002) Indigenous Research Reform Agenda: Changing institutions. Darwin, CRCATH.

Henry, J., T. Dunbar, et al. (2002) Indigenous Research reform Agenda: Rethinking research methodologies. Links Monograph Series: 2. Darwin, CRCATH: 1–20.

Henry, J., T. Dunbar, et al. (2004) Indigenous Research Reform Agenda: A review of the literature. Links Monograph Series :5. Darwin, CRCATH: 68.

Hinkson, J. (2007) "The 'Innocence' of the Settler Imagination" in coercive reconcilitation. J. Altman and M. Hinkson eds. North Carlton, Australia, Arena Publishing Association: 287–94.

Hogan, E., J. Boffa, et al. (2006) "What price do we pay to prevent alcohol-related harms in Aboriginal communities? Alice Springs trial of liquor licensing restrictions." Drug and Alchol Review **25**: 207–12.

House of Representatives Standing Committee on Family and Community Affairs (HRSCFCA). (2000) Health Is Life Report on the Inquiry into Indigenous Health. Canberra, The Parliament of the Commonwealth of Australia: 170.

Howard, D. (2009) When hearing the message is critical. National Indigenous Times. Canberra, NIT. **Issue, 177,8**: 31.

Howells, K. (2008) The Treatment of Anger in Offenders. Anger and Indignous Men. A. Day, M. Nakata and K. Howelles. Sydney, The Federation Press: 20–30.

Hulcombe, J. (2006) Injury Project: Discussion Document. Allice Springs, Tangentyere Council: 4.

Hulcombe, J. (2006) NHMRC Injury Prevention Research Report. Alice Springs, Tangentyere: 46.

Hume, L. (2002) Ancestral Power: The Dreaming, Consciousness and Aboriginal Australians. Melbourne, Melbourne University Press.

Humphery, K. (2000) Indigenous Health & 'Western Research'. Discussion Paper No.2. Melbourne, VicHealth Koori Health Research & Community Development Unit: 1–34.

Humphery, K. (2001) "Dirty questions: Indigenous health and 'Western research'." Australian and New Zealand Journal of Public Health. **25**(3): 197–202.

Humphery, K., T. Weeramanthri, et al. (2001) Forgetting Compliance: Aboriginal Health and Medical Culture. Darwin., Northern Territory University Press in association with The Cooperative Research Centre for Aboriginal and Tropical Health.

Hunter, A. (2004) "Introduction to the Circumpolar World University of the Arctic – BCS 100: Traditional and Western Systems of Knowledge." Retrieved 07/02/05., 2005, from http://www.artic.org/bcs/BCS/100/bcs100_m10.pdf.

Hunter, E. (2001) "Aboriginal and Torres Strait Islander Suicide." The Australian Network for Promotion, Prevention and Early Intervention (Auseinet) Retrieved 14/9/05, from http://ausienet.com/suiprev/occpapers/.

Hurst, S. and P. Nader (2006) "Building community involvement in cross-cultural Indigenous health programs." International Journal for Quality in Health Care **18**(4): 294–8.

Ivison, D., P. Patton, et al. (2000) "Introduction" in Political Theory and the Rights of Indigenous Peoples. D. Ivison, P. Partton and W. Sanders. Cambridge, Cambridge University Press.

Janke, T. (1998) Our Culture, Our Future Report on Australian Indignous Cultural and Intellectual Property Rights. Canberra, Australian Institute of Aboriginal and Torres Strait Islander Studies and The Aboriginal and Torres Strait Islander Commission

Johnson, G. et al. (2003) "Letter to the Editor" MJA **179**: 116–17.

Kahakalau, K. (2004) "Indigenous Heurisitic Action Research: Bridging Western and Indigenous Research Methodologies" Hulili: Multidisplianry Research on Hawaiian Well-being. **1**(1): 19–33.

Kaplan-Myrth, N. (2004) Political Visions: Blindness Prevention Policy As A Case Study Of Community-Government Relations In Aboriginal Health. Discussion Paper No. 10. Melbourne, VicHealth Koori Health Research & Community Development Unit.: 1–38.

Kaufert, J. et al. (2004) Background Paper on Issues of Group, Community or First Nation Consent in Health Research. Winnipeg, MB Canada, Aboriginal Ethics Policy Development Project,Canadian Institutes of Health Research – Ethics Office, Institute for Aboriginal Peoples Health.

Kelly, R. and C. O'Faircheallaigh (2001) Indigenous Participation in Managing University Research. <u>Aboriginal Politics and Public Sector Management, Research Paper No. 10</u>. Brisbane, Centre for Australian Public Sector Management Griffith University.: 1–9.

Kelm, M. (1998) <u>Colonizing Bodies</u>. Vancouver, UBC Press.

Kelm, M. (2005) "Diagnosing the Discursive Indian: Medicine, Gender, and the "Dying Race"" <u>Ethnohistory</u> **52**(2): 371–406.

Kemmis, S. (2006) Critical Theory and Participatory Action Research. <u>Sage Handbook of Action Research</u>. P. Reason and H. Bradbury. Thousand Oaks, CA, SAGE: 121–38.

Kemmis, S. and R. McTaggart (1990) <u>The Action Research Planner</u>. Geelong, Deakin University Press.

Kemmis, S. and R. McTaggart (2000) "Participatory Action Research" in <u>A Handbook of Qualitative Research</u> N. Denzin & Y. Lincoln. Thousand Oaks, Sage Publications.

Kenny, C. (2004) <u>A Holistic Framework for Aboriginal Policy Research</u>. Canada. Ottawa, Status of Women Canada: 66.

Kenny, S. (1994) <u>Theoretical Foundations.</u> Melbourne, Nelson.

Kidd, R. (1997) <u>The Way We Civilise</u>. St.Lucia., University of Queensland Press.

Kidd, R. (2000) <u>Black Lives, Government Lies.</u> Sydney, UNSW Press book.

Kim, K. (2005) <u>Discourse on Liberation: An Anatomy of critical theory</u>. Boulder, Paradigm Publishers.

Kincheloe, J., L and McLaren, Peter. (2000) "Rethinking Critical Theory and Qualitative Research" in <u>Handbook of Qualitative Research.</u> N. Denzin and Y. Lincoln. Thousand Oaks., Sage: 279–314.

Kincheloe, J. and S. Steinberg (2008) "Indigenous Knowledges in Education: Complexities, Dangers and Profound Benefits" in <u>Handbook of Critical And Indigenous Methodologies</u>. N. Denzin, Y. Lincoln and Smith, L. Los Angeles, SAGE: 135–56.

Kincheloe, L., Joe and K. Tobin (2009) "The much exaggerated death of positivism." <u>Cultural Studies of Science Education</u> **4**: 513–28.

Kovach, M. (2005) <u>Indigenous Knowledge(s) and Research: Creating Space for Different Ways of Knowing within the Academy</u>. First Nations, First Thoughts., Centre of Canadian Studies., Canadian Studies centre Events – Conferences.

Kuhn, T. (1962) <u>The Structure of Scientific Revolutions.</u> Chicago, University of Chicago Press.

Kunitz, S. (1996) <u>Disease and Social Diversity: The European Impact on the Health of non-Europeans</u>. New York, Oxford University Press.

Kurtz, D., J. Nyberg, et al. (2008) "Silencing of Voice: An Act of Structural Violence" <u>Journal of Aboriginal Health</u>: 53–63.

Ladson-Billings, G., (2000) "Racialized Discourses and Ethnic Epistemologies" in <u>A Handbook of Qualitative Research</u> N.Denzin & Y. Lincoln. Thousand Oaks, California., Sage Publications, Inc.

Lafrance, J. and B. Bastien (2007) "Here be dragons! Reconciling Indigenous and Western knowledge to improve Aboriginal child welfare" <u>First Peoples Child & Family Review: A Journal on Innovation and Best Practices in Aboriginal Child Welfare Administration, Research, Policy and Practices.</u> **3**(1): 105–26.

Laming, C. et al. (2000) "A Targeted, single-dose azithromycin strategy for trachoma" <u>MJA</u> **172**: 163–6.

Langford, R. F. (1983) "Our Heritage – Your Playground" <u>Australian Archaeology</u> (16): 1–6.

Langton, M. (1982) "'Urbanising Aborigines: The Social Scientists' great Decepetion'" <u>Social Alternatives</u>: 16–22.

Langton, M. (1993) <u>Well I heard it on the radio and saw it on the television.</u> Sydney, Australian Film Corporation.

Langton, M. (1998) <u>Burning Questions.</u> Darwin., Northern Territory University.

Langton, M. (2002) <u>Ancient Jurisdictions, Aboriginal Polities and Sovereignty</u>. Indigenous Governance Conference, Canberra.

Larkin, S. (2006) "Evidence-based policy making in Aboriginal and Torres Strait Islander health" <u>Australian Aboriignal Studies</u> (2): 17–26.

Larson, A., M. Gillies, et al. (2007) "It's enough to make you sick: the impact of racism on the health of Aboriginal Australians" <u>Australian and New Zealand Journal of Public Health.</u> **31**(4): 322–28.

Lavallee, B. and L. Clearsky (2006) "'From Woundedness to Resilience': A Critical Review from an Aboriginal Perspective" <u>Journal of Aboriginal Health.</u> **September**: 4–6.

Laycock, A., D. Walker, et al. (2009) <u>Supporting Indigenous researchers: a practical guide for supervisors</u>. Darwin, Cooperative Research Centre for Aboriginal Health.

Lee, S., Tiffany (2008) Transforming Research Through Indigenous Cultural Protocols: Issues of Access, Privacy, and Resepect. <u>Access, A Zone of Comprehension, and Intrusion Advances in Program Evaluation</u>, Emerald group Publishing Limited. **12**.

Lekoko, N., Rebecca (2007) "Storytelling as a Potent Research Paradigm for Indigenous Communities." <u>Alternative</u> **Special Supplement**: 83–95.

Lemert, C. (2005) "Foreward Liberating Critical Talk" in <u>Discourses on Liberation : An Anatomy of Critical Theory</u>. K. Kim. Boulder, Paradigm Publishers.

Leon de la Barra, S. et al. (2009) "Health research policy: a case study of policy change in Aboriginal and Torres Strait Islander health research" <u>Australia and New Zealand Health Policy</u> **6**, 1–32.

Liddle, J. and B. Shaw (1983) <u>Some research Guidelines</u>. Alice Springs, Central Australian Aboriginal Congress.

Lincoln, Y. (2005) "Institutional Review Boards And Methodological Conservatism: The Challenge to and from Phenomenological Paradigms" in <u>The Sage Handbook of Qualitative Research</u>. N. Denzin & Y. Lincoln. Thousand Oaks, Sage: 165–81.

Lincoln, Y. and N. Denzin (2008) "Epliogue: The Lion Speaks" in <u>Handbook of Critical and Indigenous Methodologies</u>. N. Denzin, Y. Lincoln, and L. Smith. London, SAGE: 563–71.

Lincoln, Y. and E. Guba (2000) "Paradigmatic Controversies, Contradictions, and Emerging Confluences" <u>A Handbook of Qualitative Research</u> N. Denzin & Y. Lincoln. Thousand Oaks, CA., Sage.

Link, G., Bruce and J. Phelan (1995) "Social Condition as Fundamental Causes of Disease." <u>Journal of Health and Social Behavior</u> **35** (Extra Issue): 80–94.

Lui-Chivizhe, L. and J. Sherwood (2000) <u>Creating an Optimistic Future for Indigenous Research in Education: Re-visioning both Outcome and Process: Emergence of and Indigenous research methodology.</u> Australian Association for Research in Education (AARE), The University of Sydney.

Lyon, P. (1991) "The Continuing Dilemma: Liquor Licensing, Aborigines & Take-Away Alcohol in Central Australia." **39**.

Mackean, T. and M. Watson (2004) "Indigenous Sovereignty and Indigenous Health."
    Indigenous Law Bulletin., 1–4.

Maddison, S. (2009) Black Politics. Crows Nest, NSW, Allen & Unwin.

Mak, D (2006) "Better late than never: a national approach to trachoma control." MJA **184**(10):
    487–8.

Malezer, L. (2003) "Aspiring to a Treaty or Constructive Arrangement – The Experience of
    Aboriginal Peoples and Torres Strait Islander Peoples of Australia" Expert Seminar on
    Treaties, Agreements and Other Constructive Arrangements Between States and
    Indigenous Peoples, Geneva. (FAIRA) Geneva., Office of the United Nations High
    Commissioner for Human Rights.: 7.

Manne, R. (2003) Introduction: . Whitewash: On Keith Windschuttle's Fabrication of Aboriginal
    History. R. Manne. Melbourne, Black Inc. Agenda: 1–16.

Marglin, S. A. (1990) "Colonising Minds" in Dominating Knowledge: Development, Culture &
    Resistance. F. Marglin and S. A. Marglin. Oxford., Clarendon Press.

Martin-Booran Miraboopa, K. (2001) "Ways of Knowing, Ways of Being and Ways of Doing:
    Developing a theoretical framework and methods for Indigenous re-search and Indigenist
    research" The Power of Knowledge, the Resonance of Tradition – Indigenous Studies:
    Conference 2001., Australian Institute of Aboriginal and Torres Strait Islander Studies,
    Canberra.

Martin, K. (2007) Ways of Knowing, Being and Doing: A Theoretical Framework and Methods
    for Indigenous and Indigenist Re-search. Australian Public Intellectual
    (TheKupaPitaKungkaTjilpiTjuta) Network. Australia, API.

Masters, J. (1995) "The History of Action Research." Action Research Electronic Reader
    Retrieved 12/08/07, from http://www.scu.edu.au/schools/gc/ar/arr/arow/rmaster.html.

May, D. (1994) Aboriginal Labour and the Cattle Industry. Melbourne, Cambridge University
    Press.

McConaghy, C. (2000) Rethinking Indigenous Education. Canberra, Post Press.

McCoy, B. (2008) Holding Men: Kanyirninpa and the health of Aboriginal men. Canberra,
    Aboriginal Studies Press.

McGregor, R. (1997) Imagined Destinies: Aboriginal Australians and the Doomed Race Theory,
    1880–1939. Melbourne, Melbourne University Press.

McLeod, J. (2000) Beginning postcolonialism. Manchester., Manchester University Press.

Memmi, A. (1965) The Colonizer and the Colonized. Boston, Beacon Press.

Memmott, P., R. Stacy, et al. (2001) Violence in Indigenous communities. Canberra, Crime
    Prevention Branch, Comonwealth Attorney-General's Department.

mhfa (2008) "Aboriginal Mental Health First Aid Training and Research Program:Trauma and
    Loss: Guidelines for providing Mental Health First Aid to an Aboriginal and Torres Strait
    Islander Person." 1–5. Retrieved 22/07/09, from http://www.mhfa.com.au/

Minichiello, V., R. Aroni, et al. (2000) In-Depth Interviewing Principles, Techniques, Analysis.
    Sydney, Longman.

Mitchell, J. (2007) "History" in Social determinants of Indigenous Health. B. Carson, T.
    Dunbar,et al. Crows Nest, NSW, Allen & Unwin: 41–64.

Mobbs, R. (1991) "In sickness and health: the sociocultural context of Aboriginal well-being,
    illness and healing" in The Health of Aboriginal Australia. J. Reid and P. Trompf.
    Sydney, Harcourt Brace Jovanovich Group (Australia) Pty Ltd: 292–325.

Moodie, M., Peter (1973) Aboriginal Health. Canberra, Australian National University Press.

Moreton-Robinson, A. (2000) <u>Talkin' Up To The White Woman: Indigenous Women and Feminism.</u> St.Lucia., University of Queensland Press.

Moreton-Robinson, A. (2004) Whiteness, epistemology and Indigenous representation. <u>Whitening Race: Essays in social and cultural critics</u>, AMR.

Morris, B. (1992) "Frontier Colonialism as a Culture of Terror" in <u>Power, Knoweldge and Aborigines</u>. B. Attwood and J. Arnold. Bundoor, Victoria, La Trobe University Press. **35**: 72–87.

Morrissey, M. (2003) "Developing an appropriate research methodology" in <u>AHREN News</u>. Canberra, AHREN. **2**: 1–15.

Morrissey, M. (2003) "Poverty and Indigenous health." <u>Health Sociology Review</u> **12**(1): 17–30.

Mundine, K., L. Edwards, et al. (2001) "Why an Aboriginal Ethical Perpsective is Necessary for Research into Aboriginal Health." 1–9.

Murray, R. (2003) "Aboriginal Health And The Policy Process" in <u>Aboriginal Primary Health Care</u> S. Cozous & R. Murray, South Melbourne, Oxford University Press.

Murray, C. (2007) "The 'Colouring of the Psychosis': Interpreting Insanity in the Primitive Mind." <u>Health and History</u> **9**, 1–11.

Myers, F.  (1986) <u>Pintupi Country, Pintupi Self: Sentiment, Place, and Politics among Western Desert Aborigines.</u> Washington, Smithsonian Institution Press.

NACCHO (2003) "Substance Misuse" in <u>Aboriginal Primary Health Care</u> S. Couzos and R. Murray. South Melbourne, Oxford University Press: 594–607.

NACCHO. (2008) "Ethical Research Guidelines." Retrieved 15/09/2009 from http://www.naccho.org.au/activities/ethicalp1.html.

NACCHO. (2008) "What is NACCHO" Retrieved 6/10/2009 from http://www.naccho.org.au/aboutus/aboutus.html

NACCHO and Oxfam. (2007) Close The Gap: Solutions to the Indigenous Health crisis facing Australia. Canberra, NACCHO and Oxfam Australia.: 1–28.

NACCHO. (2004) "Ethical health guidelines – protest to continue." <u>NACCHO NEWS</u> **15**: 28.

NAHO. (2003) <u>Ways of Knowing: A Framework for Health Research</u>. Ottawa., NAHO: 1–29.

NAHSWP (1989) <u>National Aboriginal Health Strategy Working Group: National Aboriginal Health Strategy</u>. Canberra, Commonwealth.

Nakata, M. (1998) "Anthropological texts and Indigenous standpoints." <u>Australian Aboriginal Studies. Australian Institute of Aboriginal and Torres Strait Islander Studies.</u>: 3–12.

Nakata, M. (2001) <u>Kaurna Higher Education Journal</u>. (7): 62.

NATSIHC (2004) National Strategic Framework for Aboriginal and Torres Strait Islander Health; Framework for Action by Governments. Canberra., NATSIHC.

Newfong, J. (1995) "100 years of welfare" in <u>Voices of Aboriginal Australia Past, Present, Future.</u> I. Moores. Springwood, NSW., Butterfly Books: 64–8.

NHMRC (1989) Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research. Canberra, NHMRC: 10.

NHMRC, ARC, et al. (2007) <u>National Statement on Ethical Conduct in Human Research</u>. Canberra, NHMRC.

NHMRC (1991) <u>Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research</u>. Australia. Canberra, NHMRC.

NHMRC (1999) <u>National Statement on Ethical Conduct in Research Involving Humans</u>. Canberra, NHMRC: 68.

NHMRC (2002) <u>The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health Through Research</u>. NHMRC. Canberra, NHMRC: 25.

NHMRC. (2003) "Indigenous Health Research Program." Retrieved 24/03/03 from http://www.health.gov.au/nhmrc/research/srdc/indigen.htm.

NHMRC (2003) <u>Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.</u> Canberra, NHMRC.

NHMRC (2006) <u>Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics</u>. Canberra, NHMRC.

NHMRC. (2008) "Indigenous health." Retrieved 21/10/2009 from htp://www.nhmrc.gov.au/your_health/indigenous/index.htm.

Nicholls, R. (2008) <u>Discursive Ethics: Regulatory Guidelines for Researching Indigenous Australia</u>, University of Western Sydney: 1–9.

Nienhuys, T., Sherwood, J. ,Bush, J. (1991) "Hearing loss in a sample of central Sydney Aboriginal school children." <u>Australian Journal of Audiology</u> **13**(1): 13–22.

O'Brien, R. (1998) "An Overview of the Methodological Approach of Action Research." Retrieved 9/5/07 from http://www.web.net/~robrien/papers/arfinal.html.

O'Shane, P. (1992) "Aborigines And The Criminal Justice System" in <u>Aboriginal Perspective on Criminal Justice</u>. C. Cunneen. Sydney: 1–18.

Okere, T., et al. (2005) "All Knowledge is first of all Local Knowledge: An Introduction." <u>Africa Development</u> **xxx**(3): 1–19.

Ollapallil, J., R. Benny, et al. (2008) "The growing burden of injuries and trauma in Alice Springs." <u>Injury, International Journal of the Injured</u> (3955): 3–9.

*Onemda* VicHealth Koori Health Unit. (2008) We can Like Research....in Koori Hands: A Community Report on *Onemda* VicHealth Koori Health Unit's Research Workshop in 2007. Melbourne, *Onemda* VicHealth Koori Health Unit, The University of Melbourne.

Paradies, Y., R. Harris, et al. (2007) The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda. <u>Discussion Paper Series No.4</u>. CRCAH. Darwin, CRCAH: 27.

Parekh, B. (1997) The West and its others. <u>Cultural Readings of Imprialism: Edward Said and the Gravity of History</u> K. Ansell-Pearson, B. Parry and J. Squires. London, Lawrence and Wishart: 173–93.

Paul, D. and D. Atkinson (1999) "Learning From the Past or Ignoring the Lessons?" <u>New Doctor.</u>(Summer 1999): 31–3.

Pawu-kurlpurlurnu, J., Wanta, M. Holmes, et al. (2008) Ngurra-kurlu: A way of working with Warlpiri people. Alice Springs, Desert Knowledge CRC: 40.

Pearce, N. (1996) "Traditional Epidemiology, Modern Epidemiology, and Public Health." <u>American Journal of Public Health</u> **86**(5): 678–83.

Phillips, G. (2003) <u>Addictions and Healing in Aboriginal Country.</u> Canberra, Aboriginal Studies Press.

Phillips, G. and W. Brown (1991) <u>Making Sense of Your World</u>. Chicago, Moody Press.

Pholeros, P., S. Rainow, et al. (1994) <u>Housing for health – towards a healthier living environment for Aborigines.</u> Sydney, Healthhabitat.

Popper, K. (1972) <u>The Logic of Scientific Discovery</u>. London, Hutchinson.

Porsanger, J. (2004) "An Essay About Indigenous Methodology." Retrieved 17/02.2006 from uit.no/getfile.php?PageId=977&FileId=188.

Pryor, M. (1998) <u>Maybe Tomorrow.</u> Victoria, Penguin Books.

Rains, F. (1999) "Indigenous Knowledge, Historical Amnesia and Intellectual Authority: Deconstructing Hegemony and the Social and Political Implications of the Curricular "Other"" in <u>What is Indigenous Knowledge?</u> M. Semali, Ladislaus and L. Kincheloe, Joe. New York, Falmer Press: 305–16.

Ranzijn, R., K. McConnochie, et al. (2009) <u>Psychology and Indigenous Australians Foundations of Cultural Competance</u>. South Yarra, Victoria, Palgrave MacMillan.

Raphael, B., P. Delaney, et al. (2007) "Assessment of Trauma for Aboriginal People" in <u>Cross-Cultural Assessment of Psychological Trauma and PTSD</u>. J. Wilson and C. So-kum Tang, Springer: 337–58.

RAWG (2003) Final Report of Community Consultations on the NHMRC Road Map. Canberra, NHMRC: 9.

RAWG (2003) The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health Through Research. Canberra, NHMRC.

Royal Commission into Aboriginal Deaths in Custody (RCIADIC) (1990) <u>National Report: Overview and Recommendations.</u> Canberra, Commonwealth of Australia.

Reconciliation and Social Justice Library, R. (1998) "Timeline ( Of Little – and not so little – Known Facts)." Retrieved 26/05/2005. From http://www.reconciliation.org.au/home/

Regan, P. (2005) "A Transformative Framework for Decolonizing Canada: A Non-Indigenous Approach." <u>IGOV Doctral Student Symposium.</u> Retrieved 8.2.06, 2006, from http://web.uvic.ca/igov/pdf/A%20Transformative%20Framework%20Decolonizing%20Canada.pdf.

Reid, J. and D. Lupton (1991) "Introduction" in <u>The Health of Aboriginal Australia</u>. J. Reid and P. Trompf. Sydney, Harcourt Brace Jovanovich, Publishers.: xi–xxi.

Reynolds, H. (1987) <u>Frontier – Aborigines, settlers and land.</u> Allen & Unwin.

Reynolds, H. (1987) <u>The Law of The Land</u>. Ringwood, Victoria. Penguin Books Australia Ltd.

Reynolds, H., Ed. (1999) <u>New Frontiers: Australia.</u> Indigenous Peoples Rights. Melbourne, Oxford University Press.

Reynolds, H. (1999) <u>Why Weren't We Told?</u> Ringwood, Viking Penguin Books Ltd.

Reynolds, H. (2001) <u>An Indelible Stain? The question of genocide in Australia's history.</u> Ringwood, Penguin Books Australia Ltd.

Rigney, D. and G. Worby (2005) "Towards an Indigenous research charter" in <u>Indigenous Archaeologies Decolonizing Theory and Practice</u>. C. Smith and H. Wobst, Martin. New York, Routledge: 369–91.

Rigney, L. (1999) <u>The First Perspective: Culturally Safe Research Practices on or With Indigenous peoples.</u> Chacmool Conference, University of Calgary, Calgary, Alberta, Canada., Yunggorendi First Nations Centre For Higher Education and Research, Flinders University.

Rigney, L. (1999) "Internalisation of an Indigenous Anticolonialist Cultural Critique of Research Methodologies: A guide to Indigenist Research Methodology and its principles." <u>the Journal for Native American Studies, Wicazo Sa Review Fall.</u> **14**(2): 109–21.

Rigney, L. (2001) "A First Perspective of Indigenous Australians Participation in Science: Framing Indigenous Research Towards Indigenous Intellectual Sovereignty." <u>Kaurna Higher Education Journal.</u>(7): 1–11.

Rigney, L. (2006) Indigenist Research and Aboriginal Australia. <u>Indigenous Peoples' Wisdom and Power</u>. E. Kunnie, Julian and I. Goduka, Nomalungelo. Hampshire, England, Ashgate Publishing Limited: 32–48.

Rigney, L. (1997) "Internationalisation of An Indigenous Anti-Colonial cultural critique of research methodologies" HERDSA Annual International conference proceeding.

Ring, I. and N. Brown (2003) "The health status of indigenous peoples and others." BMJ **327**(7412): 404–5.

Ring, I., T. and N. Brown (2002) "Indigenous Health: chronically inadequate responses to damning statistics." Medical Journal of Australia. **177**(2): 629–31.

Roden, D. (2000) "Trachoma on the decline." Rural Practice: 30–32.

Roper, K et al. (2008) "Prevalence of trachoma in Aboriginal communities in the Katherine Region of the Northern Territory in 2007." MJA **189**(7): 409.

Rosewarne, C. and J. Boffa (2003) "Alcohol & Alice Springs: Meeting the Needs and Wishes of the Community." 1–9. Retrieved 20/07/08 from http://www.austlii.edu.au/au/journals/ILB/2003/38.html

Rowse, T. (1995) "expert testimony." Arena Magazine: 32–5.

Rowse, T. (2002) White Flour, White Power. Cambridge., Cambridge University Press.

Royal, T. A. C. (2002) Indigenous Worldviews A Comparative Study. Te Puni Kokiri-Ministry for Maori Development Fullbright New Zealand Winston Churchill Memorial Trust. New Zealand, Te Wananga-o-Raukawa: 84.

Saggers, S. and D. Gray (1991) Aboriginal Health & Society: The Traditional and Contemporary Aboriginal Struggle for Better Health. Sydney, Allen& Unwin Pty, Ltd.

Saggers, S. and D. Gray (1991) Policy and practice in Aboriginal health. The Health of Aboriginal Australia. J. Reid and P. Trompf. Sydney, Harcourt Brace Jovanovich Group (Australia) Pty Ltd.: 381–417.

Saggers, S. and D. Gray (2001) "Theorising Indigenous health: a polictical economy of health and subtsance misuse." Health Sociology Review **10**(2): 21–32.

Saggers, S. and D. Gray (2007) "Defining what we mean" in social determinants of Indigenous Health. B. Carson, T. Dunbar, R. Chenall and R. Bailie. Crows Nest, Allen & Unwin.: 1–20.

Said, E. (1994) Culture and Imperialism. Scoresby, Victoria., Random House Australia (Pty) Limited.

Said, E. (1995) Orientalism: Western Conceptions of the Orient. London, Penguin Books.

Sanson-Fisher, W., Robert, M. Cambell, Elizabeth, et al. (2006) "Indigenous health research: a critical review of outputs over time." MJA **184**(10): 502–5.

Sarantakos, S. (2005) Social Research. New York, Palgrave Macmillian.

Sartre, J.-P. (1957) Introduction. The colonizer and the colonized. Boston, Beacon Press.

Sarup, M. (1996) Idenity, Culture and the Postmodern World. Edinburgh, Edinburgh University Press.

Schlick, M. (1974) General Theory of Knowledge. New York, Springer-Verlag.

Schlunke, M., Katrina. (2005) Bluff Rock Autobiography of a massacre. Curtin University Books.

Schon, D. (1991) The Reflective Practitioner: How Professionals Think in Action. Avebury, Ashgate Publishing Ltd.

Schultz, A. L., T, (1974) The Structures of the Life-world. London, Heinemann.

Scott, J. (2002) "Cultural Heritage and Sacred Sites: World Heritage from an Indigenous Perspective." Retrieved02/06/2005, from http://www.dialoguebetweennations.com/N2N/PFII/English/JohnScott.htm

Sefa Dei, G., J. (2002) "Rethinking The Role Of Indigenous Knowledges In The Academy." NALL(Working Paper #58): 1–24.

Semali, L. and J. Kincheloe (1999) "What is Indigenous Knowledge and Why Should We Study It?" in What is Indigenous Knowledge? Voices from the Academy. M. Semali, Ladislaus, and L. Kincheloe, Joe. New York., Falmer Press: 3–57.

Shahid, S., D. Bessarab, et al. (2009) "Exploration of the beliefs and experiences of Aboriignal people with cancer in Western Australia: a methodology to acknowledge cultural difference and build uunderstanding." BMC Medical Research Methodology 9, 1–11.

Sherwood, J. (1992) A Report on the Strategies to Addess the Impact of Otitis Media on the Educational of Aboriginal and Torres Strait Islander Children in New South Wales. Sydney, The Office of Education and Youth Affairs Otitis Media Steering Committee NSW AEGC inc: 20.

Sherwood, J. (1993) " The Management of Aboriginal Children with Otitis Media" Aboriginal & Islander Health Worker Journal. 17(4).

Sherwood, J. (1997) "Guidelines for the prevention and control of Otitis Media in Aboriginal Children." Aboriginal and Islander Health Worker Journal. 21(1): 17–21.

Sherwood, J. (1999) "What is Community Development?" Aboriginal and Islander Health Worker Journal. 23(2): 7–8.

Sherwood, J. (2001) "My Research Journey." Kaurna Higher Education Journal.(7): 62.

Sherwood, J. (2009) "Who is not coping with colonisation? Laying out the map for decolonisation." Australiasian Psychiatry 17 Supplement(1): S24–S27.

Sherwood, J. and T. Edwards (2006) "Decolonisation: A critical step for improving Aboriginal health." Contemporary Nurse 22(2): 178–202.

Sherwood, J., I. Gentle, et al. (2003) Workshop: Methodological, ethical, logistical and systems issues in Indigenous health research. 2003 General Practice and Primary Health Care Research Conference. Canberra.

Sherwood, J. and K. McConville (1994) Otitis Media and Aboriginal Children: A Handbook for Teachers and Communities. Sydney, Board of Studies.

Shibasaki, S. and P. Stewart (2005) Cooperative Research Centre for Aboriginal Health Workshop Report:: Aboriginal and Torres Strait Islander people involved in Ethics Cooperative Research Centre for Aboriginal Health Workshop Report: Aboriginal and Torres Strait Islander people involved in Ethics Yunggorendi Mande, Flinders University, Adelaide, South Australia.

Sinclair, R. (2004) "Aboriginal Social Work Education in Canada: Decolonizing Pedagogy for the Seventh Generation." First Peoples Child & Family Review: A Journal on Innovation and Best Practices in Aboriginal Child Welfare Administration, Research, Policy and Practices. 1(1): 49–61.

Sire, J. (1988) The Universe Next Door. Downers Grove, InterVarsity.

Sissons, J. (2005) First Peoples. Indigenous cultures and their futures. London, Reaktion Books.

Smallacombe, S. (1999) "What is Ethical Indigenous Research?" in A Question of Ethics: personal perspectives. M. Langfield. Victoria., The History Institute Victoria, Inc.: 13–24.

Smallacombe, S., M. Davis, et al. (2007) Desert Knowledge CRC: Final report of the Scoping Project on Aboriginal Traditional Knowledge. D. K. CRC. Alice Springs, Desert Knowledge CRC: 89.

Smith, L. (1999) Decolonizing Methodologies. Dunedin, University of Otago Press.

Smith, L. (2005) "On Tricky Ground: Researching the Native in the Age of Uncertainty" The Sage Handbook of Qualitative Research. N. Denzin and Y. Lincoln. Thousand Oaks, SAGE Publications: 85–107.

Smylie, J. M., Carmel Mary; Kaplan-Myrth; Steele, Leah; Tait, Caroline; Hogg, William. (2003) "Knowledge translation and indigenous knowledge." Circumpolar Health 2003. Nuuk. **2003**: 139–43.

Solomon, J. (1994) "Worldviews." Retrieved 22/03/05 from http://www.probe.org/docs/w-views.html

Spencer, B. and F. Gillen (1927) The Arunta. London, MacMillan and Company Limited.

Stanner, W. E. H. (1972) Some Aspects of Aboriginal Health. Better Health For Aborigines? Report of a National Seminar at Monash University, St. Lucia, Queensland, University of Queensland Press.

Stanner, W. E. H. (1979) White Man Got No Dreaming Essays 1938–1973. Canberra, Australia National University Press.

Stewart, P., S. Shibasaki, et al. (2006) "Aboriginal and Torres Strait Islander participation in ethical review of health research." Australian and New Zealand Journal of Public Health **30**(3): 291–92.

Street, J., F. Baum, et al. (2007) "Developing a collaborative research system for Aboriginal health." Australian and New Zealand Journal of Public Health **31**(4): 372–78.

Street, J., F. Baum, et al. (2008) Making Research Relevant: Grant Assessment Processes in Indigenous Research. Discussion Paper Series No.3. Darwin, CRCAH and Flinders University: 49.

Street, J., F. Baum, et al. (2009) "Is peer review useful in assessing research proposals in Indigenous health? A caese study." Health Research Policy and Systems **7**(2): 1–8.

Stringer, E., T. (1999) Action Research. Thousand Oaks, CA., Sage Publications.

Struthers, R. (2001) "Conducting Sacred Research: An Indigenous Experience." WICAZO SA Review Spring 2001: 125–33.

Studdert, D., T. Vu et al. (2010) "Ethics review of multisite studeis: the difficult case of comunity-based Indigenous health research." MJA **192**(5): 275–80.

Studley, J. (1998) "Dominant Knowledge Systems and Local Knowledge." Retrieved 15/10/2002, from http://www.mtnforum.org/resources/library/studj98a.htm.

Sullivan, P. (2006) Indigenous Governance: The Harvard Project on Native American Economic Development and appropriate principles of governance for Aboriginal Australia. An AIATSIS Research Discussion Paper; Number 17. AIATSIS. Canberra, AIATSIS: 35.

Tangentyere Council (2000) The Tangentyere Protocols. Alice Springs, Tangentyere Council: 30.

Tangentyere Council, Centre for Remote Health, National Drug Research Institute, et al. (2003) A Survey of the attitudes of Aboriginal Town Camp residents to the Alice Springs liquor licensing restrictions: A submission to the Northern Territory Licensing Commission. Alice Springs, Tangentyere Council: 21.

Tatz, C. (1999) Genocide in Australia. Canberra, Aboriginal Studies Press.

Tatz, C. (2001) Aboriginal Suicide is Different: A Portrait of Life and Self-Destruction. Canberra, Aboriginal Studies Press.

Taylor, H. (2001) "Trachoma in Australia." MJA **175**(7): 371–72.

Taylor, R. (2003) "An Indigenous perspective on evaluations in the inter-cultural context: how far can one throw a Moree boomerang?" Evaluation Journal of Australasia **3**(2): 44–52.

The Fred Hollows Foundation, F. (2005) "A brief history of health policy." Indigenous Health in Australia **9**, 1–4.

The Kupa Piti  Kungka Tjilpi Tjuta (2003) "The Land" in Elders Wisdom from Australia's Indigneous Leaders. P. McConchie. Port Melbourne, Vic., Cambridge University Press: 11–26.

Thomas, D. (2001) The Beginnings of Aboriginal Health Research in Australia. Melbourne, VicHealth Koori Health Research & Community Development Unit. Discussion Paper no.3: 1–24.

Thomas, D., P. (2004) "The upsurge in interest in Indigenous health in the 1950's and 1960's." MJA **180**(10): 521–3.

Thomas, D., Piers. (2004) Reading Doctors' Writing: Race, politics and power in Indigenous health research 1870–1969. Canberra., Aboriginal Studies Press for the Australian Institute of Aboriginal and Torres Strait Islander Studies.

Thomson, N. (1991) "A review of Aboriginal health status" in The Health of Aboriginal Australia. J. Reid and P. Trompf. Sydney, Harcourt Brace Jovanovich Group (Australia) Pty Ltd: 37–79.

Thomson, N., R. Murray, et al. (2003) "Aboriginal Health Status" in  Aboriginal Primary Health Care S. Couzous and R. Murray. South Melbourne, Oxford University Press: 38–60.

Thomson, N. and I. Ring (2008) "Health Status" in Aboriginal Primary Health Care. S. Couzos and R. Murray. Sydney, Oxford University Press: 74–113.

Thomson, N. (1998) "Eye health of Aboriginal and Torres Strait Islander People" Aboriginal and Torres Strait Islander Health Reviews, Number 1. Perth, National Aboriginal and Torres Strait Islander Health Clearinghouse.

Torzillo, P. and C. Kerr (1991) "Contemporary issues in Aboriginal public health" in The Health of Aboriginal Australia. J. Reid and P. Trompf. Sydney, Harcourt Brace Jovanovich, Publishers: 326–80.

Tozer, M. (2006) Indigenous-Australian Institutional Research Ethics A Study of The Effectiveness and Suitability of Ethics Assessment Processes For Research About Indigenous-Australians. Canberra, National Indigenous Postgraudate Association Aboriginal Corporation (NIPAAC): 172.

Trudgen, R. (2000) Why Warriors lie down and die. Darwin., Aboriginal Resource and Development Services Inc.

Turnbull, P. (1997) "Ancestors, not Specimens: Reflections on the Contraversy over the Remains of Aboriginal People in European Scientific Collections." Retrieved 9/6/2004 from http://www.jcu.edu.au/aff/history/articles/turnbull.htm.

Tynan, M., P. Atkinson, et al. (2007) "If You Don't Have Health, What's the Use of Living?" in Beyond Bandaids: Exploring the Underlying Social Determinants of Aboriginal Health. I. Anderson, F. Baum and M. Bentley. Casuarina, NT, CRCAH: 1–19.

Ulrik, J., D. Foster, et al. (2005) "New ways, old ways" in National Rural Health Conference: Central to Health: sustaining well-being in remote and rural Australia. Alice Springs, National Rural Health Conference: 1–5.

Vallance, J., Roger (2005) "Research ethics: Reforming postgraduate formation." Issues in Educational Research **15**: 1–11.

Van der Woerd, K. and N. Cox, David (2005) "From Theory to Practice: Methodological and Ethical Issues for Research with First Nations Communities." Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health **4**(1): 40–6.

Vickery, J., S. Faulkhead, et al. (2007) "Indigenous Insignts into Oral History, Social
 Determinants and Decolonisation" in Beyond Bandaids: Exploring the Underlying Social
 Dtermients of Aboriginal Health, Papers from the Social Determinants of Aboriginal
 Health Workshop. I. Anderson, F. Baum and M. Bentley. Adelaide, Coopertaive
 Research Centre for Aboriginal Health: 19–36.

Vos, T., B. Barker, et al. (2007) The burden of diesease and injury in Aborignal and Torres Strait
 Islander peoples: Summary Report. Brisbane, Centre for Burden of Diseases and Cost-
 Effectiveness, School of Population Health, The University of Queensland.

Wakerman, J. et al. (2003) "Editorial:Focus on Alice Springs Alcohol Restrictions Trial.."
 CARPA Newsletter (35): 6–7.

Wall, S. (2006) "An Autoethnography on Learning about Autoethnography." International
 Journal of Qualitative Methods **5**(2): 1–12.

Walsh, F. and P. Mitchell (2002) "Aboriginal People in Central Australia" in Planning for
 Country. F. Walsh and P. Mitchell. Alice Springs, jukurrpa books: 200.

Walter, M. and S. Saggers (2007) "Poverty and Social Class" in social determinants of
 Indigenous Health. B. Carson, T. Dunbar, D. Chenhall, Richard and R. Bailie. Crows
 Nest, Allen & Unwin: 87–104.

Wand, P., F, Anne and J. Eades, Sandra (2008) "Navigating the process of developing a research
 project in Aboriginal health." MJA **188**(10): 584–7.

Webb, J. et al. (1998) Fictions, Politics and Prejudice in Australia: Aliens & Savages. Sydney,
 Harper Collins Publishers.

Weber-Pillwax, C. (2004) "Indigenous Researchers and Indigenous research Methods: Cultural
 Influences or Cultural Determinants of Research Methods." Pimatisiwin: A Journal of
 Aboriginal and Indigenous Community Health **2**(1): 77–90.

Weir, M. (2001) Indigenous Australians And Universities: A Study Of Postgraduate Students'
 Experience In Learning Research. Armidale, University of New England: 435.

Wenitong, M. (2008) "Injury and trauma issues from a primary health care perspective." Injury
 International Journal of the Injured **3955**: s37–s41.

West, E. (2000) The Japanangka Teaching and Research Paradigm: An Aboriginal Pedagogical
 Framework. Indigenous Research and Postgraduate Forum., Aboriginal Research
 Institute :University of South Australia., Aboriginal Research Institute.

Williams, G. C., W; Schulter, P. (2002) "Assault-related admissions to hospital in Central
 Australia." MJA **177**: 300–4.

Wilson, S. (2008) Research is Ceremony Indigenous Research Methods. Winnipeg, Manitoba,
 Fernwood Publishing.

Wolfe, P. (1999) Settler Colonialism and the Transformation of Anthropology. London, Cassell.

Woods, D., G (2002) A history of criminal law in New South Wales: the colonial period,1788–
 1900. Annandale, NSW, Federation Press.

Wright, A. (1997) Grog Wars. Broome, Magabala Books.

Yunupingu, G. (1997) "From the Bark Petition to Native Title" Our Land is Our Life
 G.Yunupingu. St.Lucia., University of Queensland Press.

Yunupingu, G. (1997) "Introduction" Our Land is Our Life G.Yunupingu, St.Lucia., University
of Queensland Press.

# Appendix A

*Table 3*: **Contrasting methodologies of the Alice Springs Grog Trial**

The following table provides a comparative approach to the surveys undertaken by Tangentyere Council and that commissioned by the Liquor Commission. This approach has been taken to explore the critical differences in methods and results, although both were based upon the same line of questions formulated by the ERG.

| | **Tangentyere Council Town Camp Survey** | **Liquor Commission Evaluation: Telephone survey** |
|---|---|---|
| Ethics | Approved | Approved once agreement on an approach to include Indigenous participation. |
| Objectives | 1. Document attitudes of Alice Springs Town Camp residents to the liquor licensing restrictions that were introduced in April 2002.<br>2. Record views of town camp residents on the impact of the restrictions and related issues. | To conduct a telephone survey of Alice Springs town households to assess the direct impact of the restrictions on individuals and their attitudes to the trial (Crundall and Moon 2003:8). |
| Methodology | 277 respondents interviewed in cross-sectional household survey, sample selected from town camp households, with numbers being proportionate to the number of households in each camp. Twelve people declined and were replaced by another person from the same household or by a person from the next adjacent household.<br><br>If after three visits to a particular household there was no eligible person available, a replacement was made from the next adjacent household.<br><br>Within households, for a variety of reasons – including individual and family mobility, culturally-based deference to the household head, and problem associated with alcohol dependence – it was | 402 respondents were surveyed. Target group: Alice Springs residents of voting age. 'The design excluded sections of the community, including residents with limited English comprehension, those requiring an interpreter, those less than 18 years and people without a household telephone.<br><br>Random sample was drawn from electronic database of telephone listings. This achieved sample was 402, with refusals by 235' (Crundall and Moon 2003:8).<br><br>'Percent female: 52.5<br>Percent Indigenous: 6.0' (Crundall and Moon 2003:8). |

|  |  |  |
| --- | --- | --- |
|  | difficult to select individuals at random.<br><br>During the survey, one of the camps was inaccessible to interviews because of 'sorry business'. Those numbers were selected from other camps<br><br>Despite this, the final sample was broadly representative of the town camp population, if not random in a strictly statistical sense'. (TangentyereCouncil, National Drug Research Institute et al. 2003:4) |  |
| Process | Survey conducted by a team of ten Aboriginal people. Questions based on those agreed by the ERG and asked in the telephone survey of town households.<br><br>Additional open-ended questions were asked to elicit detailed suggestions to address alcohol related problems in Alice Springs.<br><br>Age and Aboriginal language usually spoken in households, gender and camp of residence were recorded (TangentyereCouncil, National Drug Research Institute et al. 2003:6). | The Department of Community Services and Health contracted Market Equity to conduct a telephone survey of Alice Springs town residents to assess the direct impact of the restrictions on individuals and their attitudes to the trial (Crundall and Moon 2003:8). |
| Community | 'The study population is comprised of all residents of, and visitors to, the 19 town Aboriginal Town Camps in Alice Springs, aged 18 years or more'.<br><br>There were a total of 206 dwellings within the 19 camps based on the Australian Bureau of Statistics 2000 Census of population and Housing data. Occupied by approximately 1435 | 'Direct Comment: Individuals made 52 contacts directly to the Evaluation Team: 60% via the website, 23% by letter and 17% by telephone.<br><br>Responses categorised as follows: (15%) expressed explicit support,(4%) non-support, (58%) provided observations about the impact of the trial, (21%) offered further actions to address alcohol |

| | | |
|---|---|---|
| | people, of whom 989 are aged 18 years or over' (TangentyereCouncil, National Drug Research Institute et al. 2003:3). | problems. Several used it as a "soapbox" for expressing broad opinions and attitudes about race, regulation etc (7.5%). There were also a number who sought information about alcohol issues unrelated to the trial (19%) (Crundall and Moon 2003:8). |
| Data Analysis | Quantitative data from the completed interview schedules were entered into a Microsoft Excel spreadsheet. Summary table and descriptive statistics were produced using the program SPPS 11.0 for Windows. Qualitative data from open ended questions were entered into a Microsoft Word table. Qualitative data reviewed by various research team members, both explicit and implicit themes were identified, and classified into broad thematic categories. Results and the analyses made by the research team were reviewed by Tangentyere Council's Executive Health Sub-Committee and by the full Executive Committee. On the basis of both results and reviews, recommendations were developed for future restrictions and complimentary measures (TangentyereCouncil, National Drug Research Institute et al. 2003:8) | Not explained. However it was discussed earlier in this chapter by the authors Crundall and Moon that they did not analyse all their data (Crundall 2003). The means of analysis for any of their data are not explored. Gray found that the there were many anomalies with the data stated to be analysed which confounded the evaluation outcome fed to the Liquor Commission (Gray 2003; Hogan, Boffa et al. 2006). |
| Results / Findings | Results showed a high level of awareness of restrictions and a lower level of knowledge of the | Most respondents felt restrictions only allowing light beer to be sold in hotels prior to 11.30 am had not |

| | key complementary measures introduced to support the restrictions.

Half the residents were in favour of the most important restrictions – the restriction on takeaway trading hours and the ban on sale of beverages in containers of more than two litres.

Over the course of trial period support for the restrictions on takeaway hours increased, but for the ban on containers of more than two litres remained static – largely due to the adverse effect of the substitution to the two litre casks of port.

Views on effectiveness of restrictions were mixed. Those aware of key compulsory measures were more likely to view them as having a positive impact; and over half the residents thought the restrictions had no effect in reducing drinking and related problems.

Majority believed the existing restrictions should be retained or strengthened. While there was some opposition to the existing restrictions, in part, this was due to recognition of the fact that the substitution of fortified wine for table wine has had an adverse effect.

Findings reflected majority in the Town Camps were concerned about the misuse of alcohol and believed that something should be done to address it. | affected them directly.

Proportion of respondents in favour of this restriction did not vary much (43.8% at start and 46.5% at end). Proportion not in favour increased marginally from 33.1% to 38.6%.

Majority of respondents indicated later opening of takeaway outlets had not affected them directly.

The proportion of people in favour of this restriction did not vary much over the course of the trial (moving from 44.3% to 43.4%), but there was a small increase in the proportion not in favour (42% versus 48.8%).

More than three-quarters felt the restriction on containers had no effect on them personally. Most of the remainder felt that it had a negative effect. Over the course of the trial, the proportion in favour of this restriction declined from 48.5% to 43.3% and the proportion not in favour increased from 37.6% to 48.0%.

Almost half of the respondents felt that the trial of restrictions and complementary measures had no effect on Alice Springs as a whole.

More than a quarter felt the trial had a positive effect and around one in six indicated it had a negative effect. Proportion in favour of trial dropped from 61% to 56%, while the proportion not in favour increased from 27% to 37%.

Respondents living in Alice Springs for more than five years were more likely to regard the overall trial as |

| | A number of suggestions were made to address the problem. Focused on further restrictions on availability (particularly the banning of 2-litre casks of port), discouraging public drinking, and taking measures to curb problems caused by visitors to the camps (TangentyereCouncil, National Drug Research Institute et al. 2003:15-16) | having a negative impact, while residents of a shorter term were more likely not to have an opinion. There were no significant differences based on gender, indigenous status or age.<br><br>More than half felt that the Licensing Commission should either keep restrictions as they are (24%) or strengthen them (30%). A third felt that the restrictions should be removed(Crundall and Moon 2003:9). |
|---|---|---|
| Translation and transference of findings | Three reports were produced: A scientific report for Tangentyere council and the Licensing Commission and a plain English version for Town Camp residents and their respective housing associations. | Crundall states there were three evaluation reports conveyed to the Licensing Commission in May 2003, (Crundall 2004). |
| Recommendations | 1. The current restrictions should be strengthened. | 1. All three restrictions be continued. A further restriction on two litre Port casks should be trialed for three months in conjunction with a focused campaign designed to reduce further substitution. This extension should be reviewed in three months and if there is not clear gain then all container limits should be removed. |
| | 2. No takeaway alcohol should be sold on Sunday. | 2. That local Aboriginal leadership devise strategies in conjunction with Licensing commission and Police members of the local liquor industry. A partnership approach should underlie this recommendation. |
| | 3. That the licensing Commission support any further applications by Town Camp Housing Assoiciations to be declared as a restricted area under section 74 of the N.T. Liquor Act. | 3. Relevant agencies collaborate and devise demand reduction strategies that reinforce and extend the supply measures. |

| | | |
|---|---|---|
| | 4. Where possible, there should be a reduction in liquor outlets in Alice Springs. No new licences should be granted unless it can be demonstrated to the Licensing Commission that such licences are part of a strategy to reduce alcohol related harm. | 4. Non-Indigenous problem drinkers need attention and strategies need to be devised to address the issues surrounding them. |
| | 5. Restrict the supply of fortified wine and spirits. | 5. With the exception of the Sobering up Shelter (SUS) and Central Australian Division of Primary Health Care (CADPHC) initiatives, the complementary measures will be assessed again in 12 months in terms of viability and utility. |
| | 6. Strengthen laws and consequences for traders selling alcohol to intoxicated persons and minors. | 6. The ERG should continue as a local body to monitor alcohol issues in Alice Springs. |
| | 7. In the case of future restrictions, provision should be made for an interim review to address measures that may adversely affect the outcome of the restriction and the community as a whole. | 7. A data base of harm indicators be maintained and readily interrogated. Licensing Commission take responsibility for maintaining a liquor database and the production of regular reports. |
| Recommendations regarding Complementary Measures | 8. Decrease drinking in public spaces by increasing the range of safe and responsible drinking environments. | 8. The Sobering up Shelter continues to remain open for its current hours on a Monday. |
| | 9. Maintain the Day Patrol and the extension to the opening hours of the Drug and Alcohol Services Association's (DASA) Sobering up Shelter. | 9. Operations of Day Patrol should be continually reviewed so it attends the area's most likely to exhibit problems. This should be negotiated in conjunction with Police. |
| | 10. Develop a comprehensive strategy to address the problems of visitors on Town Camps. | 10. Not clear |
| | 11. Increased advertising of Night Patrol, Day Patrol and Wardens programs. | 11. DASA should follow up clients to determine if referrals are acted on. |
| | 12. Increased advertising of DASA's Sobering up Shelter and CAAAPU (TangentyereCouncil, National Drug Research Institute | 12. By the end of 2003 CADPHC should follow up its brief intervention training course. |
| | | 13. Any further measures to address |

| | | |
|---|---|---|
| | et al. 2003:16-19). | alcohol-related harm should clearly state what they are meant to achieve so it is understood what priority is being addressed.<br>14. Services should review their protocols and communication channels to ensure that access to health and safety interventions by those not drinking in the CBD is not compromised (Crundall and Moon 2003:13) |

There are a number of issues that this diagram highlights regarding the rigour of the parallel projects.

1. The NTDHCS phone survey of 402 people from a population of 28,500 people provides a statistical coverage of 1.4%. The Town camp survey interviewed 277 people from an approximate population of just under 2000 providing a more comprehensive coverage of 13.8% (Brown, Morrissey et al. 2006:204).

2. The NTDHCS phone survey effectively discriminated against Aboriginal participation through its methodological sampling process as well as its exclusionary rationale.

3. The NTDHCS limited survey time was a direct result of their methodological approach.

4. The NTDHCS survey was undertaken from within its own Department, this action was not independent as stated, it was the NT government working for the NT government (Wakerman 2003).

5. The NTDHCS failed to provide an explanation of their analysis of data. Much of the findings raised within the Report to the Liquor Commission have been questioned regarding their validity by both the ERG and Dennis Gray (Hogan, Boffa et al. 2006).

6. Although Dr Crundall explained that the Evaluation Report presented to the ERG was meant to be community friendly and hence did not provide data, it was not circulated to the community.

7. The Town Camp survey results were fed back to the Town Camp residents in a plain English report that did explore the data and was explained through community meetings.

8. The Town Camp survey ensured 'Aboriginal direction, ownership, participation and accountability back to the people' (Foster 2005:1). A method proving to be effective, educational and culturally safe providing, reliable and valid data (Foster 2005).

323

9. The process and outcomes of each project reflect the divergent philosophies and agendas of the researchers. The Indigenous research project aimed to inform change, the non-Indigenous project simply glanced at the problem and ignored it.

# Appendix B

**Interview Schedule**

The following questions were provided to participants as a guide for discussion and were not used to limit open and in-depth discussion.


**Interview topics to be discussed with participants:**

1. Why has research not improved Aboriginal health?
2. How have we been going about researching Indigenous health?
3. What has driven this approach, both historically and contextually?
4. What are the deficits of this approach and have they contributed to why it has not worked?
5. What is different about Indigenous ways of knowing?
6. What are we missing in Indigenous health research?
7. What do Indigenous people want from health research and health researchers?
8. What does an Indigenous methodology look like in this context and how can it be applied?

# Appendix C

THE UNIVERSITY OF NEW SOUTH WALES

**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM**

**Why has health research not improved Aboriginal health?**

We would like to invite you to be involved in a study of the reasons why Aboriginal health has not been improved through health research. The investigator, Juanita Sherwood, and her supervisors from the Universities of New South Wales and South Australia, hope to learn how Aboriginal health research can better provide the positive health outcomes that Aboriginal people want.   You were selected as a possible participant in this study because you have knowledge about Aboriginal health research and its impact on Aboriginal communities.

If you decide to participate, Juanita would like talk to you for about an hour to discuss a number of things related to research, health and Aboriginal communities. Your story is vital to understanding how these things impact on individuals and communities, and will be treated with respectfulness and confidentiality. Please do not feel pressured to answer any questions you are uncomfortable with, or in a way you think we would like to hear. Your story is what is important to us.

*Juanita will record your interview on audiotape using a small hand held tape recorder .The interview will then be typed up and given to you to read to make sure she has accurately taken down what you have stated. This also gives you the opportunity to make any changes to the recorded interview as you see fit. After you have confirmed that your transcribed interview is correct Juanita will provide you with a copy for your records. Approximately two months later Juanita will provide you with the chapters she has written with your interviews positioned within the text. This will be done to make sure you are happy with where it is placed in relation to context, tone and analysis. It is important that you feel that your story is rightfully recorded, and situated so that that the meaning of your discussion remains true to the messages you conveyed to Juanita. The interviews will be kept on Juanita Sherwood's computer which has password access only known by her. This is a measure taken to keep your information private and safe.*

*If at any time during the interview you would like to stop, please let us know. We can re\start at a later time, or not at all if you feel uncomfortable.*

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. If you give us your permission by signing this document, we plan to publish the findings in Juanita's PhD thesis, plus some journal articles at a later date. In any publication, information will be provided in such a way that you cannot be identified, and will be passed onto you for permission before publication.

Complaints may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone 9385 4234, fax 9385 6648, email ethics.sec@unsw.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions, please feel free to ask us. If you have any additional questions later, MS Juanita Sherwood, 08 8951 4700 will be happy to answer them.

You will be given a copy of this form to keep.


THE UNIVERSITY OF NEW SOUTH WALES


**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)**

*Why has health research not improved Aboriginal health?*



**You are making a decision whether or not to participate. Your signature indicates that, having read the Participant Information Statement, you have decided to take part in the study.**



...........................................................   ..............................................................
Signature of Research Participant              Signature of Witness

..............................................
 (Please PRINT name)

..............................................
(Please PRINT name)

..............................................
Date

..............................................
Nature of Witness

..............................................
Signature(s) of Investigator(s)

..............................................
Please PRINT Name

## REVOCATION OF CONSENT

### *Why has health research not improved Aboriginal health?*

I hereby wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with The University of New South Wales, *(other participating organisation[s] or other professional[s]).*

..............................................
Signature

..............................................
Date

..............................................
Please PRINT Name

The section for Revocation of Consent should be forwarded to Juanita Sherwood, Centre for Remote Health, Alice Springs, PO Box 4066, NT, 0871.

Attwood, B. (1992). 'Introduction'. Power, Knowledge and Aborigines. B. Attwood and J. Arnold. Bundoora., La Trobe University Press. **35:** ppi-xvi.

Bird Rose, D. (1996). Nourishing Terrains: Australian Aboriginal Views of Landscape and Wilderness. Canberra, Australian Heritage Commission.

Brown, A., M. Morrissey, et al. (2006). "Uncovering the Determinants of Cardiovascular Disease among Indigenous People." Ethnicity & Health. **11**(2): 191-210.

Crundall, I. (2003). "Response to Review of the Summary Evaluation of the Alice Springs Liquor Trial." CARPA Newsletter(35): 30-39.

Crundall, I. (2004). A Trial of the Alice Springs Alcohol Trial. Third Australasian Drug Strategy Conference, Australasian Drug Strategy Conference

Crundall, I. and C. Moon (2003). "Extract:: Report to the Licensing Commission: Summary Evaluation of the Alice Springs Liquor Trial." CARPA Newsletter(35): 8-13.

Denzin, N. and Y. Lincoln, Eds. (2000). The Discipline and Practice of Qualitative Research. Handbook of Qualitative Research. London, Sage Publications, Inc.

Dodson, M., Ed. (2003). Unfinished Business: A Shadow Across Our relationships. Treaty : lets get it right! Canberra, Aboriginal Studies Press.

Dunbar, T. and M. Scrimgeour (2006). "Ethics in Indigenous Research - Connecting with Community." Bioethical Inquiry **3**: 179-185.

Foster, D., Mitchell, Julia, Ulrik, Jane, Williams, Raelene. (2005). Population and Mobility in the Town Camps of Alice Springs: A report prepared by Tangentyere Council Research Unit. Desert Knowledge CRC Report 9, December 2005. Alice Springs, Desert Knowledge CRC**:** 60.

Foucault, M. (1961). Madness and Civilization: A History of Insanity in the Age of Reason. London, Penguin.

Foucault, M. (1980). The Politics of Health in the Eighteenth Century. Power/Knowledge: selected Interviews & Other Writings 1972-1977. C. Gordan. Great Britain., The Harvester Press.**:** 166-182.

Foucault, M. (1980). Power and Knowledge: Selected Interviews and Other Writings 1972-77. Brighton.

Foucault, M. (1989). The Archaeology of Knowledge. London, Routledge Classics.

Foucault, M. (1994). The Birth of The Clinic: An Archaeology of Medical Perception. New York, Vintage Books A Division of Random House, Inc.

Gray, D. (2003). "Response to Review of the Summary of the Alice Springs Liqour Trial by Ian Crundall." CARPA Newsletter(53): 30-39.

Hogan, E., J. Boffa, et al. (2006). "What price do we pay to prevent alcohol-related harms in Aboriginal communities? Alice Springs trial of liquor licensing restrictions." Drug and Alchol Review **25**: 207-212.

HREOC (1993). Social Justice Report. Sydney, HREOC.

Said, E. (1995). Orientalism: Western Conceptions of the Orient. London, Penguin Books.

Sherwood, J. (2009). "Who is not coping with colonisation? Laying out the map for decolonisation." Australiasian Psychiatry **17 Supplement**(1): S24-S27.

Smith, L., T. (1999). Decolonizing Methodologies. Dunedin, University of Otago Press.

Stanner, W. E. H. (1979). White Man Got No Dreaming: Essays 1938-1973. Canberra, Australian National University Press.

TangentyereCouncil, C. U. o. T. National Drug Research Institute, et al. (2003). A Survey of the attitudes of Aboriginal Town camp residents to the Alice Springs liquor licensing restrictions: A submission to the Northern Territory Licensing Commission. Alice Springs, Tangentyere Council**:** 21.

TheKupaPitaKungkaTjilpiTjuta (2003). The Land. Elders. P. McConchie. Cambridge, Cambridge University Press**:** 11-26.

Wakerman, J. D., C; Wilson, C; Knight, S; Tahini, J. (2003). "Editorial:Focus on Alice Springs Alcohol Restrictions Trial.." CARPA Newsletter(35): 6-7.