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# Decolonising ethics? A critical analysis of researchers' intended ethical research practices

Alister Thorpe

ORCID ID: 0000-0002-8593-0965

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Faculty of Medicine, Dentistry, and Health Sciences

Melbourne School of Population & Global Health

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# Preface

The following sections positon Indigenous knowledge from my tribes and family clans within my thesis. Gunai Brabiralung Mukdhang is my mother tongue. Gunai, Yorta Yorta, Gunditjmara, Wurundjeri, and Kulin creation stories firmly ground my thesis within these knowledge systems.

Permission was sought and given from respected Elders Narweet Carolyn Briggs, Getja Zeta Thomson, Uncle 'Watbalimba' Wayne Thorpe, and Wyrker Milloo Gary Murray to share these stories.

## *Bunjil[1] the Eaglehawk – Kulin Creator Spirit*

*One day – many, many years ago – there came a time of chaos and crisis. The Boonwurrung and the other Kulin nations were in conflict. They argued and fought. They neglected their bilk. The native murnong was neglected. The animals were over-killed and not always eaten. The gurnbak were caught during their spawning season. The iilk were not harvested.*

*As this chaos grew the warreeny became angry and began to rise. The wurneet became flooded and eventually the whole flat plain was covered in baany. It threatened to flood their whole birrarang-ga. The people became frightened and went to Bundjil, their creator and spiritual leader. They asked Bundjil to stop the warreeeny from rising.*

*Bundjil was angry with his people, and he told them that they would have to change their ways if they wanted to save their biik. The people thought about what they had been doing and made a promise to follow Bundjil. Bundjil walked out to the warreeny, raised his tjeera and directed the warreeny to stop rising. Bundjil then made the Boonwurrung promise they would respect the laws.*

*N'arweet Carolyn Briggs (2014, pp.21-22)*

[1] Bunjil and Waa are moieties for the Kulin Nation

## *Waang the Crow – Creator spirit, Kulin Nation*

*There were five young women called the Karatgurk, who lived on the Yarra Flats. They dug up yams with their kurniangs, or digging sticks, at the ends of which they carried live coals from their last camp-fire. This fire they would share with no one…*

*One day, however, Waang found a cooked one lying about. He tasted it and liked it better that way, so he resolved to get some fire from the Karatgurk to cook his yams. However, they would not give it to him.*

*Waang flew off and caught a number of snakes which he carefully hid in an ant-hill. Then he sat on a log close to it, and called out in a friendly way to the Karatgurk…*

*The girls ran at once and began digging hard with their sticks to get to the larvae. They had not dug far when the snakes came hissing out, and chased them as they ran away screaming. Then the girls turned and began hitting at the snakes with their sticks; and they hit so hard that some of the coals were knocked off and fell on the ground.*

*Waang was waiting for this. He pounced on the coals and hid them in the kangaroo-skin bag he was carrying…*

*Bunjil, the Eaglehawk, had seen what had happened, and he called out to Waang 'Give me some fire. I want to cook a possum'…*

*…Waang cooked the possum and threw it down to Bunjil who saw that it was still smoking, and he tried in vain to blow it into a fire. Being unable to do so he ate the possum while all the Kulin gathered around to see how they would get fire. And as the Kulin gathered they all began to shout to Waang for the fire, until he became scared, and flung the fire amongst the crowd…*

*Bunjil's young men, Djurt-djurt, the Nakeen Kestrel, and Thara the Quail Hawk seized the rest of the fire as it fell, and threw some at Waang, the Crow, and burnt him. Since then all crows have been black.*

*Aldo Massola (1968, pp.52-53)*

## *Boorun the Pelican – Gunai Creator Spirit*

*There was a time when the first Gunai, who was Boorun the Pelican, came down from the mountains of the northwest and reached the level country. He crossed the Latrobe River near Sale and continued his journey to Port Albert; he was alone carrying a bark canoe on his head. As he was walking he heard a constant tapping sound but, look as he may, he could not find the source of it. At last he reached the deep waters of the inlet and put his canoe down. Much to his surprise, he saw a woman sitting in it. She was Tuk the Musk Duck. He was very pleased to see her and she became his wife and the mother of all the Gunai."*

*Gunai Traditional Custodians (Gunaikurnai Land and Waters Aboriginal Corporation, 2022)*

# *Baime the Snake – Yorta Yorta Creator Spirit*

*Ina yillian nbanga gungaia tu-tu-la tun-gudya ganggawa woka. Womeriga Biami nha-wal Gumukan Winyan mulamuk coolaman. Biami ngarri Gumuka birra birra ngana nyan-uk mayila. Paabia wurwich winyarrin nunyir birra broongama ngana woka paabia baka-narrak.*

*Gumuka winyaril yawal burraya yorta naan mayila. Djinagaga paabia marralatjum yawal thurramdjuba galka winyarrin nunyir woka. Conamurra thulla Gumuka yawal burroya yoorunguk yurratha, bayeet yeeta imigo mayila dora gaka. Biami garaba Gumuka Winya yorta naan. Biami yarganidia dora Gane. Gane ngani wy-yeen nukul woka. Gane woda-amoo Biami yargandia bookoot woka. Nhawal dhamnal ganatj gangawa woka. Womeriga Biami lotjpatj dora birayarwool Gumuka-narrak Winya-narrak yanagai Gane broongama nyanuk.*

*Gumuka bawu turneja punrira nurruga moogoo winyarrin nunyir bait-tun woka. Kalimna boorja choondonga kyema deekula woota yedabila. Biamil yargandia wooata munura mugingula gorkarra, gangangoor gangangoor wurumaty uta gorkarra gangawa uta Dangala, Yorta Yorta woongle moolaawa malawa uniar.*

*In the time of creation there was a calm over the vast, mist-covered land. Biami the Creator Spirit saw the old woman, Gumuk Winga, with her empty coolaman. She looked very hungry. Biami then told the old woman to go and search for some yams. So she then picked up her digging stick and set out across the land with her dog.*

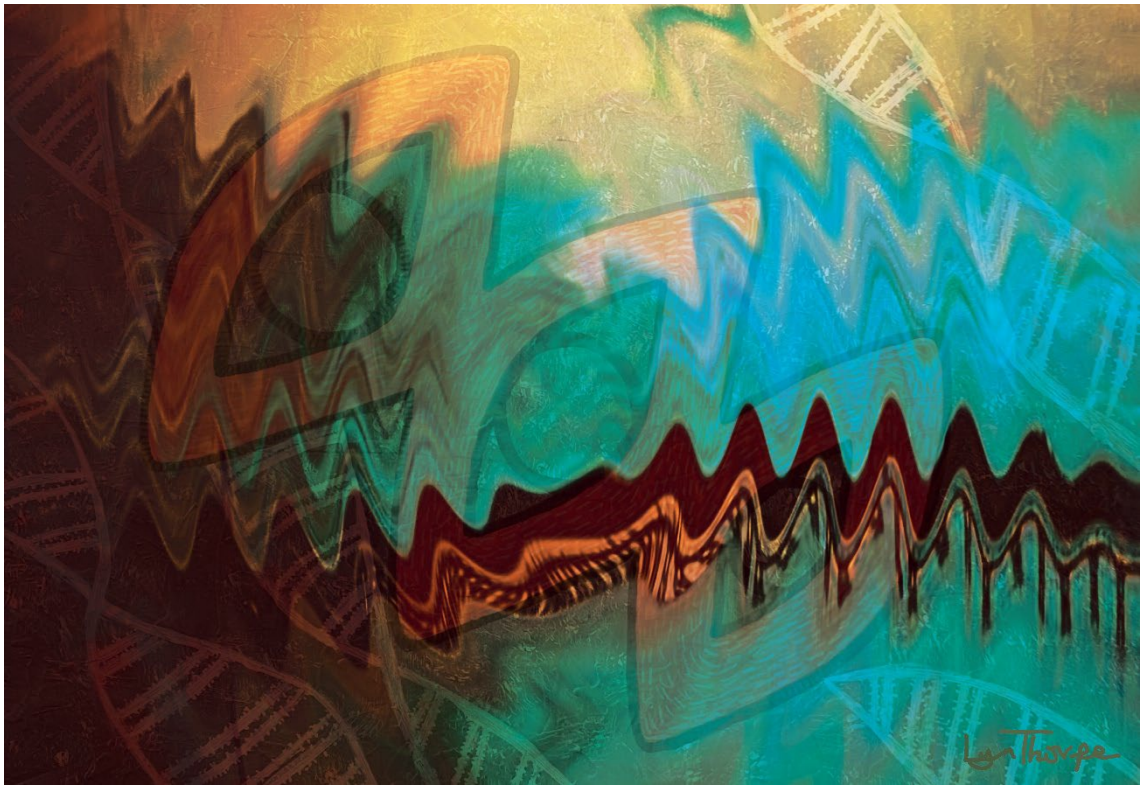
*The old woman walked and walked a long way away and could not see any yams. As time went on she became very weary, walking slowly with her digging stick dragging along the earth. Day turned to night, she walked far under the moonlit sky, singing softly and hoping for some yams to appear.Biami waited for the old woman but could not see her anywhere. Biami called out to Gane, the great rainbow Snake, who was laying asleep beneath the earth. When Gane heard Biami calling out to him, he lifted his head and made his way to the surface of the earth. He lay there looking out over the dry land when Biami asked him to go and find the old woman and bring her back safely.*

*Gane then set off following the marks in the earth left by the old woman's digging stick. His great body moved across the land pushing the earth into hills and valleys, leaving deep crevices in the earth. Beautiful colours from his body spread throughout, covering trees, plants, birds, butterflies and all other creatures.*

*Then Biami called out in a loud voice, and thunder cracked as lightning flashed across the sky and rain fell. It rained for days, filling up the deep crevices in the earth that were made from the rainbow snake's body. Then the rain stopped and the mist cleared and the river Dungala was formed. This is the name used by the Yorta Yorta people. Others know it as the Murray River.*

*Djetcha (Aunty) Zeta Thomson (Victorian Aboriginal Corporation for Languages, 2014, pp.52-53)*

*Figure 1 BAIAME Murrangurrang: Baiame Always Forever (past; present; future) Ancestral Continuum.*



*Note 1 The 3 shield shapes & bloodlines (dna) represent Ancestral Continuum to People & Country, The Dhungala (river & Country) Creation, sky stories all intertwined… ByLyn Thorpe 2024*

## *Myndie the Snake – a Yung Balug Creation Story*

*"Bunj-il the wedge-tail Eagle in our dreaming stories created the land and people. Myndie[2] the Giant serpent enforced the lore and morality, carved our waterways that embedded our lives. Myndie, a mythological giant creature a punisher of evil People exceedingly feared by all the Kulin Tribes of northwestern and central Victoria, said to be in the form of a great lion-maned Serpent with a rainbow forked tongue. Myndie travelled over the tree-tops and could stretch itself over about twenty to thirty miles and so reach any bad Tribe called out by Bunj-il the Creator Spirit.*

*Myndie's Country was at Mt Buckrabanyule in Dja Dja Wurrung Country, a significant granite hill south-west of Boort, which* ***Myndie only left when Bunjil ordered it to go and punish a Tribe for disobedience****.*

*Myndie, and his hissing voice, heard in the night, filled every Aborigine with dread. He was not less than ten miles in length, with an enormous maned head that spat poisonous toxins on evil Tribes and individuals.*

*Myndie large head, and hissing protruded a three-pointed tongue; rainbow-like, stretching across forest treetops, clinging to the tops of trees by its' tail. All sorts of epidemics were caused by* ***Myndie, whose scales appeared as smallpox scars****. This snake had a deadly toxic odour, which warned all People of its approach; this was fortunate, for to see the Myndie was certain death.*

***This giant Serpent met its death at the hands of two great warriors, Pilla and Inda****, who attacked it while it was sleeping, but their spear points immediately became blunt. Quarrelling between themselves because of this, Pilla stabbed Inda in many places, and Inda in return struck Pilla with his boondie a severe blow on the nose.*

*Finally reconciled, the two Warriors completed the work of killing Myndie. Then they made a great feast. Greasing themselves with the fat, they returned home to a rejoicing People.*

***These two heroes were later changed by Bunj-il into the Opossum (Pilla) and the Native Cat (Inda).*** *They still retain the scars of their dreadful battle — the furrow down the nose of the Djaroon opossum and the white spots of the Yung Balug native cat.* ***Today, Myndie is still a protector of our spiritual and moral values, the legend lives on ready to punish evil and breakers of lore…****"*

*Neyerneyemeet Wyrker Milloo Gary Murray Yung Balug Clan at Boort, Charlton, and Mt Buckrabanyule Dja Dja Wurrung Country (2024)*

[2] Myndie is unique to Yung Balug as against all other domestic and global narratives, the intangible and intangible. First Peoples oral histories now many written into the evidential legal processes in Treaties, native title, land justice and cultural heritage, reinforces and embeds our local Sovereignty, lore and inheritance as First Peoples just as Catholicism, Judaism and Christianity does globally interconnects global churches and State. Myndie makes us Yung Balug as distinct from surrounding Clans. Our story, our Country.

| | | | |
|---|---|---|---|
| **gommera / bunjil / bolda in** | tribal elder | **muktung** | Excellent speech |
| **dyirrumba** | make | **layun** | good |
| **kutbun** | carry | **dyinban** | breathe |
| **darnoo-ngunnin** | hold | **Kut bun** | wear, carry |
| **kinaway** | exchange | **doorahbun** | journey |
| **limba** | preserve | **lewin** | news |
| **dilba** | catch | **wanik** | path / track |
| **wudhur** | fast | **dardee** | strong |
| **yardaman** | slow | **yaakun** | mother |
| **dyillay / yoo-dyillay** | healthy / unhealthy | **moongun** | father |

## Abstract

From an Indigenous[3] standpoint, how do researchers demonstrate the values of reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity? The purpose of this research was to explore how researchers implemented the National Health and Medical Research Council's ethical guidelines for research with Indigenous communities according to the experiences of three distinct groups: Indigenous participants, Indigenous community coordinators, and researchers.

A decolonising approach was adopted applying a critical race-grounded methodology to privilege Indigenous voices and to allow broader examination of dominant social structures in the Australian context. Using Indigenous standpoint theory this research described the complex structural conditions related to Indigenous ethical processes that exist at the cultural interface between Indigenous and academic systems.

This study revealed Indigenous community-controlled research governance models for reviewing, approving, and monitoring researchers, were being established independently of the research sector. This study also identified the challenges of complying with ethics in two worlds, revealed the undervalued contribution of Indigenous communities to ethical research, and revealed systemic barriers and enablers for ethical Indigenous health research.


[3] From hereby onwards I use the term 'Indigenous' as it is frequently used in the health context both globally and in Australia Terminology is fluent, inconsistent, contested, and largely not determined by us. It is part of broader problems with the concept of pan-Aboriginality, in attempts to construct collective identities. I respectfully acknowledge the distinct 'first peoples', 'language groups', or 'nations' as self-determined.

# Declaration

This is to certify that

*(i) the thesis comprises only my original work towards the Doctor of Philosophy at the University of Melbourne except where indicated in the preface.*

*(ii) due acknowledgement has been made in the text to all other material used;*

*(iii) the thesis is fewer than 100,000 in length, exclusive of tables, maps, bibliographies and appendices*

Alister Thorpe

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## Glossary of terms

| NHMRC Values and Ethics[4] | |
|---|---|
| **reciprocity** | In the research context, reciprocity implies inclusion and means **recognising partners' contributions** and ensuring that research outcomes include **equitable benefits** of value to Aboriginal and Torres Strait Islander communities or individuals. 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. |
| **respect** | Within Aboriginal and Torres Strait Islander cultures respect is reinforced by and in turn strengthens dignity. A respectful relationship induces **trust and co-operation**. Strong culture is a personal and collective framework built on respect and trust that promotes **dignity and recognition**. Respectful research relationships acknowledge and affirm the **right of people to have different values, norms and aspirations**. |
| **equality** | One of the values expressed by Aboriginal and Torres Strait Islander Peoples and cultures is the **equal value of people**. One of the ways this is reflected is a commitment to **distributive fairness and justice**. Equality affirms Aboriginal and Torres Strait Islander Peoples' **right to be different**. |
| **responsibility** | Central to Aboriginal and Torres Strait Islander societies and cultures is the recognition of core responsibilities. These responsibilities include those to **[C]ountry, kinship bonds, caring for others** and the maintenance of harmony and balance within and between the physical and spiritual realms. A key responsibility within this framework is to **do no harm**, including avoiding having an adverse impact on others' abilities to comply with their responsibilities.<br>When engaging Aboriginal and Torres Strait Islander Peoples in the research enterprise, **researchers carry responsibilities in addition to the science of their inquiry**. The nexus between their research and community life brings responsibilities for which they or those of the community with whom they work may be held accountable. Ethical research occurs when harmony between the sets of responsibilities is established, **participants are protected**, **trust is maintained** and **accountability is clear**. |
| **survival and protection** | Aboriginal and Torres Strait Islander Peoples continue to act to **protect their cultures and identity** from erosion by colonisation and marginalisation. A particular feature of Aboriginal and Torres Strait Islander cultures and these efforts has been the **importance of a collective identity**. This collective bond reflects and draw strengths from the values base of Aboriginal and Torres Strait Islander Peoples and cultures.<br>Researchers will need to make particular effort to deal with the perception of research held by many Aboriginal and Torres Strait Islander communities as an exploitative exercise. They will need to demonstrate through **ethical negotiation, conduct and dissemination of research** that they are trustworthy and will not repeat the mistakes of the past. |
| **spirit and integrity** | This is an overarching value that binds all other values into a coherent whole. It has two components. The first is about the **continuity between past, current and future generations**. The second is about behavior, which maintains the coherence of Aboriginal and Torres Strait Islander values and cultures. Any behaviour that diminishes any of the values could not be described as having integrity.<br>Researchers are perceived as owing an obligation to the **spirit and integrity of communities** not just to individuals. It is clear that Aboriginal and Torres Strait Islander communities will look to see if what is proposed is **consistent with their values**. |

[4]These definitions have been adapted [with emphasis added] from the 2003 National Health and Medical Research Council's Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

| | |
|---|---|
| | However, the responsibility to demonstrate consistency falls to those proposing research.<br>**Community decision making based on shared values** is an implicit part of spirit and integrity. |

| Institutional terms | Definition[5] |
|---|---|
| **ethical relationships** | Considering the principles and values of Aboriginal and Torres Strait Islander cultures. Eliminating 'difference blindness'. |
| **equality of partners** | Ethical research processes treat all partners as equal notwithstanding that they may be different. |
| **Doing no harm** | There is a clear responsibility for researchers to do no harm to Aboriginal and Torres Strait Islander individuals or communities and also to those things that they value. |
| **ethical** | Right or morally acceptable |
| **unethical** | wrong or morally unacceptable |
| **ethical review** | Review of research by an HREC or other body. |
| **ethical review body** | Body set up to carry out ethical review of human research. |
| **ethics** | The concepts of right and wrong, justice and injustice, virtue and vice, good and bad, and activities to which these concepts apply. |
| **accountability** | The measures by which researchers, review bodies and institutions can demonstrate that their responsibilities have been, or are being, fulfilled. Typical accountability measures involve reporting from one level of the hierarchy to a higher (or more general) level |
| **beneficence** | Doing good to others: here also includes 'non-maleficence', avoiding doing harm |
| **benefit** | That which positively affects the interests or welfare of an individual or group |
| **community** | A collection of individuals, which may extend from the whole population to a smaller grouping associated by cultural, ethnic, geographical, social or political factors or some other commonality |
| **consent** | A person's or group's agreement, based on adequate knowledge and understanding of relevant material, to participate in research |
| **monitoring (of research)** | The process of verifying that the conduct of research conforms to the approved proposal |
| **participant (in research)** | Anyone who is the subject of research in any of the ways set out in Purpose, scope and limits of this document |
| **risk** | The function of the magnitude of a harm and the probability that it will occur |

[5]These terms have been adapted from the 2003 National Health and Medical Research Council's Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

## Abbreviations

| | |
|---|---|
| ACCO | Aboriginal Community Controlled Organisation |
| AHEC | Australian Health Ethics Committee |
| AHMRC | Aboriginal Health and Medical Research Council |
| AIATSIS | Australian Institute for Aboriginal and Torres Strait Islander Studies |
| AIDA | Australian Indigenous Doctors Association |
| ARC | Australian Research Council |
| FPAV | First Peoples' Assembly of Victoria |
| HREC | Human Research Ethics Committee |
| IREC | Indigenous Research Excellence Criteria |
| NIRAKN | National Indigenous Research Knowledges Network |
| NACCHO | National Aboriginal Community Controlled Health Organisation |
| NHMRC | National Health and Medical Research Centre |
| NHLF | National Health Leadership Forum |
| OATSIH | Office of Aboriginal and Torres Strait Islander Health |
| ORIC | Office of the Registrar of Indigenous Corporations |
| PCIC | Principle Committee Indigenous Caucus |
| UN | United Nations |
| VACCHO | Victorian Aboriginal Community Controlled Health Organisation |
| VAHS | Victorian Aboriginal Health Service |

# Chapter one: Introduction

Ethical frameworks for Indigenous health research in Australia are well established through the National Health and Medical Research Council (1991, 2003, 2018) and through the Australian Institute for Aboriginal and Torres Strait Islander Studies (2012, 2020).

In addition, ethical principles have been developed by Indigenous organisations (Aboriginal Health & Medical Research Council Ethics Committee, 2013; Aboriginal Health & Medical Research Council, 2023) and medical research institutes with Indigenous research programs (Morey, 2017). Practical principles for applying ethics when conducting Indigenous health research have also been identified (Jamieson, 2012, Laycock, 2011, National Health and Medical Research Council, 2005; 2018a; 2018b, O'Donahoo & Ross, 2015).

There have been multiple iterations of ethics and research principles, guidelines, and companion documents in each jurisdiction for the last 25 years. Common themes that are reinforced in Indigenous health research globally include engagement; control; ownership; respect; leadership; partnership; reciprocity; obligations; and benefits/outcomes. Yet it is difficult to measure how, if, and to what extent ethical principles for Indigenous health research are complied with in research practice.

In an ethical research context researchers will often talk about how they respect Indigenous cultural protocols. But what does this really mean in practice? For example, what does the broad principle of 'reciprocity' mean in an Indigenous cultural context for the Indigenous people of south-eastern Australia[6]? And how can this be translated into practice in a 'Western' research context?

In 2013, the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS) and the Lowitja Institute conducted an evaluation of the National Health and Medical Research Council's (NHMRC) two ethical guidelines for Indigenous health research in Australia (National Health and Medical Research Council 2003, 2005) and found a general lack of awareness of these documents among those who participated in the evaluation, and a lack of consistency with other key Indigenous ethics guidelines. The evaluation raised concerns about the process

[6] I am from various Indigenous nations in the South-east of Australia so most of my cultural, and community knowledge, and experiences are relevant to these communities. My positionality, including my cultural connections are further described in chapter four

and integrity of Human Research Ethics Committees' assessment of Indigenous ethics applications and recommended stronger monitoring and review processes.

Additionally, a recent survey (Burchill, 2023), and evaluation (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute) noted that accountability, monitoring, and 'policing' of the implementation of ethics in Indigenous health research was insufficient and substandard. There are limited mechanisms for Indigenous communities to ensure that ethics principles are complied with, and there is minimal Indigenous participation in ethical assessment and review procedures.

## Research Questions

This qualitative study embedded a decolonising and Indigenous standpoint approach. The purpose of this study was to explore how researchers operationalised the NHMRC's Values and Ethics Guidelines (National Health and Medical Research Council, 2003), and to better understand how Indigenous communities participated in the development, assessment, and monitoring of ethics. This study includes two research questions:

- From an Indigenous worldview, to what extent are the NHMRC Values and Ethics guidelines implemented by researchers[7] when conducting Indigenous health research projects?
- What role do Indigenous people and communities have in ensuring researchers comply with the NHMRC Values and Ethics guidelines in their research activities?

## Aims

The study planned to critically examine how ethical principles were defined, translated, and demonstrated by researchers using qualitative research methods. This study was designed to better understand the ethical practices of researchers through the lived experiences of Indigenous communities. This study also aimed to gain a better understanding of how Indigenous communities supported researchers to conduct ethical research in their communities. Finally, this study set out to explore Indigenous participation in the ethical review of Indigenous health research. In summary, the broad aims were to:

[7] Unless specifically referred to as Indigenous or non-Indigenous any reference to the terms *researcher, academic, or scholar* are generalised. In the context of my research question I am referring to any researcher undertaking Indigenous health research involving Indigenous people

- Explore Indigenous experiences of researchers' application of NHMRC ethical practices
- Explore how researchers demonstrate compliance with Indigenous health research ethics guidelines
- Understand the role of Indigenous communities in ensuring ethical research
- Explore Indigenous experiences of participation in formal ethical review of Indigenous health research proposals

## Ethical clearance

The research conducted as part of this thesis was given ethical approval from the University of Melbourne Human Research Ethics Committee (project ID number: 1851751.1). The Melbourne School of Population and Global Health's Human Ethics Advisory Group (HEAG) reviewed the application and suggested amendments before it was approved with amendments by the Medicine and Dentistry Human Ethics Sub-Committee (HESC).

## Conflict of interest

The Lowitja Institute funded and contributed to this project through the Indigenous Research Reference Group (IRRG). To manage any potential or perceived conflicts the Lowitja Institute's role was fully disclosed to potential research participants.

# Chapter two: Literature review

A review of the relevant literature was done prior to the study being conducted. Extensive searches of University peer review databases were carried out and additional sources of grey literature were collected from Government, and institutional databases and websites. In addition both published and unpublished literature from Australian and internationally was reviewed. After the data collection and analysis phases of this study the literature review was updated to include relevant peer reviewed journal articles relating to emerging themes. Unpublished literature was identified through key informants, appropriate organisations and governments for relevant documents, and sourced from internet searches for relevant documents. A table of relevant research and ethics principles and guidelines from research institutions, universities, and Indigenous organisations in Australia, New Zealand, and Canada is in appendix A. The following chapter provides a critical review of the literature relevant to the *institutional review* and *researcher practice* of Indigenous health research ethics in Australia.

## The history of ethics

The etymology of the modern use of the word 'ethics' comes from the Greek language 'ethos' which is a derivative of the word 'ethike', meaning 'moral' (Aristotle 2009). The ancient Greek philosopher Aristotle (2009, pp20) also relates the word 'ethike' to (moral) virtue and his influential writing offers further enlightenment on virtuous habits;

> *"Virtue, then, being of two kinds, intellectual and moral, intellectual virtue in the main owes both its birth and its growth to teaching (for which reason it requires experience and time), while moral virtue comes about as a result of habit, whence also its name (ethike) is one that is formed by a slight variation from the word ethos (habit). From this it is also plain that none of the moral virtues arises in us by nature; for nothing that exists by nature can form a habit contrary to its nature"*

In essence, Aristotle believed that ethical codes could be refined and developed through experience. This revelation clearly suggests that people, and perhaps society, continue to develop and evolve ethical values as we learn from our experiences.

It was centuries later, as a result of human rights atrocities committed in the name of science, before 'moral' codes were even contemplated in research practices. The Nuremburg code (a set of research ethics principles for human experimentation) was developed in response to

the infamous case of human medical experimentation on prisoners of war by Nazi doctors in Germany (Annas and Grodin 1992).

Following the establishment of the Nuremburg code, the Helsinki declaration which was adopted by the World Medical Association in 1964 (World Health Organization 2001), further informed the ethical conduct of medical professionals around the world. Since these two pivotal statements there has been considerable development of national, state, and local responses to ethics issues in health research. Through these examples it is clear to see the important role that human rights have had on the development of ethical standards and the administration of more robust regulatory systems in research practice.

## Indigenous affairs in Australia and the Indigenous research reform agenda

Historically, in Australia Indigenous health research has been conducted by non-Indigenous researchers and institutions, with Indigenous participants having little to no control over how research is collected, used, stored, and disseminated. Since colonisation Indigenous people in Australia have been researched and studied extensively (Bainbridge et al., Humphrey, 2001, National Health and Medical Research Council, 2005, Thomas et al, 2014, Watson et al, 2010).

Recent research practices involving Indigenous communities have somewhat improved with the development of Indigenous research protocols that aim to empower Indigenous peoples and communities in Indigenous research (Aboriginal Health & Medical Research Council 2023, Aboriginal Health & Medical Research Council Ethics Committee 2013, Australian Institute for Aboriginal and Torres Strait Islander Studies 2012, 2020, Henderson et al. 2002, Jamieson et al. 2012, Laycock et al. 2011, Maar et al. 2011, National Health and Medical Research Council 2003, 2005, 2018a, 2018b, Morey, 2017, O'Donahoo & Ross 2015; South Australian Health and Medical Research Institute (SAHMRI) 2014, Victorian Aboriginal Community Controlled Health Organisation, 2023, Walker).

Yet, despite a comprehensive multi-jurisdictional ethical framework advocating for Indigenous-led research, Burchill et al., (2023) (reporting on the result of their survey) concluded that “Indigenous health research in Australia is largely informed by non-Indigenous views, led by non-Indigenous people, and undertaken in non-Indigenous organisations” (p. 93).

So the challenges, issues, and concerns about how research is conducted in Indigenous communities by researchers remain. Similarly, the implementation and uptake of Indigenous research principles by national research institutes and universities is still unclear. Accountability, monitoring, and 'policing' of the implementation of ethics in Indigenous health research is still inadequate (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute), and Indigenous representation in the review of ethics is insufficient (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, Stewart et al., 2006).

To better understand the progress of Australian ethical health research it is important to reflect on the Indigenous historical political context and the struggle for health, and human rights in Australia. The foundation for change for Indigenous peoples in Australia has consistently been exemplified by activism and struggle, which was met with considerable opposition.

The 1960's human rights movements in Australia were a precursor to the emergence of community control and self-determination approaches. The self-determination policy era in the 1970's was an Indigenous political phase that aimed to provide Indigenous communities with autonomy over decision making. It was during this time that Indigenous community controlled organisations such as the Redfern Aboriginal Legal Service (in Sydney), and the Victorian Aboriginal Health Service were established (Schaap et al., 2013). Some critics have variously described the policy as a failed 'top down' approach (Sherwood 2013, citing Maddison, 2009, p.28, p35), or as a "false attempt at helping Indigenous people marred by the ongoing racism and colonizing processes of both White people and the state" (Kowal 2008, p346).

Although self –determination as a Government policy was not fully enacted, the ideology underpinned the development of Indigenous community control principles (Schaap et al., 2013). In the subsequent decades these movements provided the context for greater scrutiny about "the ways in which research and knowledge about Indigenous people was gathered" (Watson et al., 2010, pp 4).

At the 2017, the National Indigenous Research Conference convened by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) in Canberra, Alyawarre

woman, Pat Anderson and Professor Mick Dodson of the Yawuru people, both spoke at length about the history of Indigenous affairs in this country and its impact on the health of Indigenous communities. Both renowned Indigenous health and human rights advocates, they underlined historically significant moments that have shaped policy, including the 1967 referendum, the rise of self-determination (1972), the Mabo decision (92), the Bringing them home report (97), the Royal Commission for Aboriginal Deaths in Custody (88), the Northern Territory Emergency Response of 2007, the history of the United Nations Declaration for the Rights of Indigenous Peoples in Australia, and the Gurindji walk off (Dodson 2017; Anderson 2017). Yet, they also bemoaned the failure of successive Governments to act on much of the evidence. Anderson (2017) outlined the cyclical nature of policy development, the lack of policy evaluation, and poorly applied and documented policy renovations. Anderson (2017) also stated that Government policies concerning Indigenous peoples were subject to 'constant frenetic change' that have arguably hampered efforts to 'close the gap' between the health of Indigenous people and non-Indigenous people. It is within this historical background that ethical frameworks for Indigenous health research have been developed.

Understandably, the stimulation of Indigenous human rights activism in Indigenous affairs influenced emerging Indigenous academics, along with Indigenous communities to call for reform of research practices. Numerous reviews, evaluations, commentary pieces, and critiques have contributed to the discourse about health research with Indigenous peoples in Australia (Anderson et al., 2003, Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, Burchill, 2023, Dudgeon et al., 2010, Dunbar & Scrimgeour 2005, Grenz, 2023, Hawkes et al., 2017, Henry et al., 2004, Huria et al., 2019, Johnstone M 2007, O'Donahoo & Ross 2015, Thomas et al., 2014).

## Indigenous ethical research guidelines in Australia

There have been several iterations of Indigenous ethical research guidelines since they were first developed in Australia in 1991 (National Health and Medical Research Council). Subsequently other institutes have developed their own principles for research with Indigenous peoples. There have been Indigenous specific ethics guidelines and general principles developed by national research bodies (National Health and Medical Research Council 2003, 2005), national institutes (Australian Institute for Aboriginal and Torres Strait Islander Studies 2012; 2020), Indigenous health focused research institutes (Laycock et al.

2011; South Australian Health and Medical Research Institute (SAHMRI) 2014), Aboriginal Community Controlled Health Organisations (ACCOs) (Aboriginal Health & Medical Research Council Ethics Committee 2013, Aboriginal Health & Medical Research Council 2023, Victorian Aboriginal Community Controlled Health Organisation, 2023), and academics (Jamieson et al. 2012; O'Donahoo & Ross 2015). However do these guidelines truly embody ethical values from an Indigenous standpoint? And how do non-Indigenous institutions and researchers interpret and apply them?

The NHMRC documents (2003, 2005) are particularly ambiguous with values-based frameworks lacking clear examples and are open to individual interpretation. The guidelines were purposefully left open to interpretation to allow researchers to have autonomy over their ethical approach and to adapt their research according to the Indigenous community they were working with. Indigenous community input into the guidelines also advised against a 'one size fits all' or 'tick box' template that could not reflect the diversity of Indigenous Australian communities.

The lack of uniform approach has arguably created challenges with interpretation and consistency of ethical practices. For researchers, this can be problematic as it prevents systematic application in the field. While a formulaic approach is not necessarily required, nor appropriate, the lack of consistency and coordination of various ethical protocols accentuate challenges between philosophy and practice. There seems to be a disconnection between the practical implementation advised in '*Keeping Research on Track*' (herewith referred to as KROT) (National Health and Medical Research Council 2005), targeted at Indigenous communities, and the interpretation based 'Values and Ethics' (National Health and Medical Research Council 2003), targeted at researchers.

The difference in approach of these two documents demonstrated inherent problems with how Indigenous ethics were operationalised within the academy and within Indigenous communities. Researchers were responsible for ensuring they complied with the values and ethics guidelines (National Health and Medical Research Council 2003). Ethical review is theoretically an independent process that researchers are expected and supported to comply with. It is part of the research 'fabric' within universities. As part of the review process researchers interpret the values and develop an ethics application in response for their proposed health research in Indigenous communities. Researchers and the institutions they

were employed by ultimately had control over determining the ethical approach and once they have been approved they are trusted to do the right thing. Conversely, Indigenous communities are expected to keep researchers 'on track' by monitoring them. The KROT (National Health and Medical Research Council 2005) advises Indigenous communities, or participants, involved in research to 'monitor', 'supervise' and 'assess' researchers ethical approach without clearly identifying how communities would be resourced to undertake these tasks. Indigenous communities are also often expected to participate in research for the 'greater good' of their community. However expectations for Indigenous communities to monitor and measure ethical accountability are rarely supported by research funding. As a result many Indigenous communities are unable to sufficiently review potential research projects for ethical compliance because they don't have the required capacity and resources to contribute to the process. The unequal distribution of power within Indigenous health research between researchers and Indigenous communities can be problematic for establishing ethical Indigenous health research. Researchers are highly empowered to carry out Indigenous health research according to their experience and worldviews and yet Indigenous communities are rarely empowered to monitor and control Indigenous health research according to theirs.

A benefit of the NHMRC employing highly flexible policy documents is that it has promulgated the formation of specific jurisdictional or topic focused protocols that encourage autonomy over how research is done (Aboriginal Health & Medical Research Council Ethics Committee 2013; Bainbridge et al. 2013; Couzos et al. 2005; Henderson et al. 2002; Mundine, Edwards, and Williams 2001; O'Donahoo & Ross 2015; South Australian Health and Medical Research Institute (SAHMRI) 2014). In community settings research procedures are still bound by NHMRC regulations. However, adherence to additional community protocols serve to strengthen research relationships with communities and empower them in the process.

In recent years, Aboriginal Community Controlled Health Organisations (ACCHO's) have more actively participated in research and are setting the agenda for research priorities (Aboriginal Health & Medical Research Council Ethics Committee 2013; Couzos et al. 2005; Watson et al. 2010,). The number of Indigenous researchers is also increasing (Thomas, Bainbridge, and Tsey 2014). Specific Indigenous research protocols have been developed by Indigenous-led organisations located within the Indigenous community (Watson et al 2010, Laycock et al

2011, Aboriginal Health & Medical Research Council Ethics Committee 2013, Aboriginal Health & Medical Research Council, 2023, Victorian Aboriginal Community Controlled Health Organisation, 2023) and from Indigenous-led units within academic institutions (Morey et al., 2017, South Australian Health and Medical Research Institute (SAHMRI) 2014). These non-compulsory protocols provide an additional layer of ethical oversight for Indigenous communities.

However, Indigenous researchers and organisations are not exempt from complying with ethical principles. Gower's (2014) doctoral thesis explored the practical implementation of ethics in Indigenous contexts through a case study analysis. Gower advocated for researchers to undertake cultural competence training to strengthen ethical conduct in Indigenous contexts, and also exposed the lack of ethical oversight for third parties involved in research. The case study method provided a spotlight on certain specific circumstances. However, given the research was restricted to one case study, it has limited applicability, and the findings do not provide sufficient depth of information on the range of issues that may exist in different settings. It also does not address systemic issues concerning the implementation and review of Indigenous ethics through dominant 'white' academic institutes. This study attempts to expand Gower's contribution by examining the conduct of researchers through the experiences of Indigenous people involved in health research.

In 2018, the NHMRC's 2003 values and ethics guidelines (along with the KROT) were rescinded and replaced with updated guidelines, following an evaluation and national review (National Health and Medical Research Council, 2024a). Further discussion on the evaluation and review is in the discussion chapter in the sub-section *Evaluation and revision of the 2003 NHMRC Guidelines*.

To summarise, Government and institutional ethical Indigenous research reform has occurred alongside Indigenous organisations development of guidelines to inform how research with Indigenous communities should be initiated, conducted and reviewed. As an Indigenous researcher, there are also a number of other complex layers for practicing ethical Indigenous research including, but not limited to: local, regional, and community contexts; individual versus collective agreement; consent; decision-making processes; community representation; conflicts of interest; competing priorities between universities and Indigenous communities; the challenges of working in daunting academic institutes with

academic pressures. Indigenous researchers carrying out research with Indigenous people (regularly with their own communities) often must deal with community and academic tensions. Adding to the density of the ethical landscape most universities and research institutes have introduced additional ethics procedures for research with Indigenous communities.

## Engagement with Indigenous health research participants

Defining engagement is important when considered in the context of Indigenous health research guidelines. Engagement is a principle that has been identified in all the Indigenous ethical guidelines, but further examination reveals the complexity and breadth of this term in Indigenous contexts.

Thorpe et al stated that engagement can be conceptualised as ranging from "violent conflict, as in military engagement, to respectful co-existence of self-determining communities" (2016, pp 5). Citing Arnstein (1969), Thorpe et al (2016) described how engagement in a decision-making context can be ranked through a 'ladder of citizen participation' that either empowers (citizen control, partnership), controls (therapy, manipulation), or provides tokenistic engagement (consultation, informing). Thorpe et al also called into question the idea of collective informed consent, noting "minority populations remain at risk of discrimination through the process – who is authorized to speak for First Peoples" (2016, p. 6).

Kowal, Anderson, and Bailie (2005, p. 468) referencing Baum, defined different types of Indigenous participation in the research process "from consultation with Indigenous people, to research conducted by Indigenous researchers and/or an Indigenous community-controlled organization". Rationales or motivations for Indigenous participation in research is designated into four distinct themes by Kowal, Anderson, and Bailie (2005): pragmatic rationale which indicates that Indigenous participation is required for practical reasons to complete research, such as providing accessing to a community or for recruitment ;moral rationale suggests that owing to historical injustices in research, and the impact of colonisation, Indigenous research and resources should be controlled by the people; interventionist rationale concludes that participating in health research will benefit the health of Indigenous participants; epistemological rationale represents the idea that "knowledge possessed by Indigenous people (their beliefs, perceptions and attitudes) is the best quality

knowledge about Indigenous health, and Indigenous participation is the best way to access that knowledge" (Kowal et al., 2005, p. 469).

The literature states that Indigenous health research should include Indigenous people in the entire research process to improve opportunities for communities to benefit from research. Guidelines developed by the National Health and Medical Research Council (2003, 2005, 2018), the Australian Institute of Aboriginal and Torres Strait Islander Studies (2012, 2020), and the Lowitja Institute (Laycock et al., 2011) clearly indicate that for Indigenous research to be effective it must involve Indigenous people in the planning, development and dissemination of research.

The development of relationships is particularly important in settings where there are power imbalances between groups because of existing societal structures – or where one group has been oppressed, or colonised by another (Tuhiwai-Smith 2012).

Engagement principles have also been established between Governments, Universities and Indigenous communities, but implementation of engagement mechanisms and the subsequent impact on research outcomes in Indigenous research projects are rarely measured (Burchill, 2023, Mayo and Tsey 2009, Thorpe et al. 2016).

An Indigenous research group from the University of Melbourne identified a range of facilitators to Indigenous participation in health research including production and promotion of existing community controlled research, promotion of ethics, opportunities to discuss research, the meaning of research, evaluation, increased support and capacity development, community endorsement, ideas coming from community, culturally appropriate forms of research, and Indigenous people working alongside researchers to promote mutual capacity building (Onemda VicHealth Koori Health Unit, 2008).

Appropriate engagement is critical for developing trust, respect, and principally is about empowerment and self-determination for Indigenous peoples (Hunt, 2013, Penman, 2006, Thorpe et al., 2016). Indigenous communities prefer researchers to adopt a 'partnership' approach to allow for stronger community control and ownership, to align with community priorities and needs (Laycock et al. 2011, Onemda VicHealth Koori Health Unit 2008,), and support community collaboration in the development of research ideas (Henry et al. 2004).

Other engagement principles for research may include respecting cultural protocols and the development of appropriate relationships, both formally and informally (Laycock et al. 2011).

However, the implementation of engagement mechanisms and the subsequent impact on research outcomes in Indigenous health research projects are rarely measured. What is also unclear is the ways in which researchers interpret what constitutes 'appropriate' engagement. Who decides on the research engagement strategy? How are local cultural protocols incorporated? Who are the relevant Indigenous community members, organisations, traditional owners that can authorise research partnerships (and under what terms)? These are just a few of the questions that are raised when considering appropriate research engagement with Indigenous communities.

## Knowledge translation, exchange or dissemination?

Knowledge translation and exchange has long been recognised as a critical part of the research process (Brands and Gooda 2006). However, a significant volume of Indigenous health research fails to inform public health policy, programs, and practice. Knowledge translation guidelines refer to community identified feedback mechanisms, transparent discussion and agreement about research outputs, and typically include discussion about issues relating to authorship, data governance, and intellectual property (Onemda VicHealth Koori Health Unit 2008; South Australian Health and Medical Research Institute (SAHMRI) 2014).

Gaps in knowledge translation practices in health sectors are challenges for policy and decision-makers in Canada (Straus, 2009). Morton Ninomiya et al., (2022) in their Canadian study about "promising and wise" Indigenous knowledge translation practices, identified seven categories of effective knowledge trasnslation methods including meaningful involvement of potential Indigenous end users of research; identified materials, tools, and mechanisms for translation; sharing "culturally relevant knowledges"; use of relevant Inidgenous research principles and practices; "organizational change and sustainability"; "developmental evaluation during the project"; and finally early preparation and identifiaction of knowledge translation goals (p.12).

In the Australian context, Brinckley et al., (2022, p.2) argue that "the application of KT in Indigenous research in Australia is still an emergent field, with limited evidence available on

how to appropriately conduct KT with Aboriginal and Torres Strait Islander peoples in the research context in Australia". Yet, Laycock et al (2011) highlighted the Lowitja Institute's (formerly the Cooperative Research Centre for Aboriginal Health) 'facilitated development approach' to Indigenous research that focuses on the translation or exchange of research knowledge. The Lowitja Institute have developed several resources and strategies highlighting the relevance, appropriateness, and effectiveness of this approach to research where Indigenous communities are partners and are involved in identifying research priorities (Laycock et al. 2011). More recently the Lowitja Institute have profiled a series of Indigenous research projects for their excellence in knowledge translation activities (Williams et al., 2021).

Both the Wardliparinnga Aboriginal research unit in South Australia and the former Onemda unit in Victoria advocated for Aboriginal research to be in "Aboriginal hands" to empower communities and to deliver improved community outcomes related to research (Onemda VicHealth Koori Health Unit 2008; South Australian Health and Medical Research Institute (SAHMRI) 2014). However, for Indigenous communities to be empowered in a health context they need access to knowledge about their health. Indigenous research and knowledge produced as part of Indigenous research therefore becomes an incredibly important community asset. Yet, the translation of findings into practice could be further improved to strengthen the link between Indigenous knowledges and data and the development of effective Indigenous policies and programs.

### Impact, outcomes, and benefits for Indigenous participants in research

Research impact measures the outcomes of research and is an emerging field, particularly in Indigenous research. Kok et al's (2016) empirical analysis emphasised the importance of locally led research meeting locally identified needs to maximise opportunities to utilise research results.

Identifying measurable outputs from research related to expected community benefits has rarely been carried out in Indigenous research and more emphasis on measuring research outcomes is being encouraged by funders and communities alike.

Research institutes, funders, and Governments are increasingly looking for better evidence about the outcomes and benefits arising from research and thus it is becoming a greater

priority for researchers to determine and report such outcome measures (Commonwealth of Australia, 2013, The University of Melbourne 2012).

Despite these initiatives, a continuing criticism of Indigenous health research is the inadequate evaluation of the impact of research outcomes and benefits that improve the health and wellbeing of Indigenous populations. Furthermore, several papers published in Australia have proclaimed that health research has contributed little to improving Indigenous health (Bainbridge et al., 2015, Thomas et al., 2014; Kinchin et al., 2017). A critical analysis of Indigenous health research publications in Australia, Canada, New Zealand and the United States of America showed that for each country over 75 per cent of research was descriptive (Sanson-Fisher et al. 2006).

To compound the issue, many research projects and programs that appear to have had beneficial outcomes are rarely evaluated, or are poorly measured and despite demonstrating effectiveness many programs cease to be funded (Schokman and Russell 2017). Since Humphrey (2001) raised the prickly question about the value of 'Western' research in Indigenous communities more than twenty years ago not enough has been done to demonstrate its impact.

In my experience 'quality' Indigenous health research obviously does have an impact. Especially research carried out by Indigenous researchers and communities because they know what works best. The challenge has always been how we improve measurement of research impact in Indigenous health research, and how we design Indigenous research projects that prioritise the generation of tangible outcomes and benefits. How, then, can we increase opportunities for researchers (and communities engaged in research) to influence funders and decision-makers to utilise sound quality research to inform health policy and practice?

## Building capacity (for researchers, Indigenous researchers or communities?)

Ethical principles for Indigenous research outline the obligation of research to support local community capacity development. The *guidelines* task those involved to consider how research will "enhance the capacity of communities to draw benefit beyond the project, eg through the development of skills and knowledge or through broader social, economic or political strategies…" (2003, p. 11).

In 2012, an article (Jamieson et al., 2012) authored by a number of prominent academics in the Indigenous health field, reiterated that capacity building was an 'essential principle' for research with Indigenous peoples and advocated for research budgets to incorporate the hiring of Indigenous staff.

Elston et al (2013) stated that several factors influenced Indigenous researchers' academic outputs (conferences, book chapters, journal articles). Through their intervention aiming to build Indigenous research capacity, Elston et al (2013) identified 'space', Indigenous knowledge systems, Indigenous ownership, Indigenous leadership, and respect, identity, and the cultural interface as key themes impacting on Indigenous researcher capacity development.

However, I would argue the definition for capacity development in this context seems to be aligned to 'Western' academic notions and fails to fully explore expectations of Indigenous community capacity building objectives. Cultural capacity to undertake Indigenous health research could be an area for further research.

There is also a broader agenda to strengthen the Indigenous research workforce and further develop the capacity of Indigenous researchers. Recently, in Australia there has been an emphasis on several schemes promoted by national research funding agencies. In 2012, the Australian Research Council called for tenders for a Special Research Initiative to develop an Indigenous research network. The tender was awarded to ten collaborating universities, led by the Queensland University of Technology, with the National Indigenous Research and Knowledges Network (NIRAKN) launching in July 2013 (, National Indigenous Research and Knowledge Network, 2017). Professor Aileen Moreton-Robinson, (2016) inaugural NIRAKN director identified several structural barriers that impeded the objectives of NIRAKN and affected Indigenous postgraduate students which included; burden of academic, family, and cultural obligations; lack of Indigenous role models;inapparopriate supervisors; and cultural isolation in academic environments.

The OCHRe network is a national Indigenous researcher network recently funded by the NHMRC focused on four areas; Indigenous leadership and governance; careers, expertise; and methodological training (Menzies School of Health Research, 2021). This network is being led

by prominent Indigenous academics Dr Pat Anderson, Professor Sandra Eades, Professor Gail Garvey, and Professor Alex Brown.

## Indigenous participation in Human Research Ethics Committees

Health research ethics administrative processes include Human Research Ethics Committees (HRECs), and sometimes additional review committees such as Human Ethics Advisory Groups (HEAGs) that can be difficult, complex, and time-consuming to navigate.

In a 2006 study, (Stewart et al.) the authors reported that an overwhelming 44 per cent of NHMRC registered ethics committees admitted to only having 'informal and ad hoc mechanisms', and 45 per cent reported 'no mechanisms' at all, for Indigenous involvement in research review. In time things have not really progressed, according to the NHMRC latest HREC activity report (2022) over two thirds of HRECs (n=127) did not have an Indigenous committee member.

Scholars have criticised HRECs for various reasons including; gatekeeping research (Grenz, 2023) and for increasing administrative burden and 'ethics creep' (Gorman, 2011, Guta et al, 2013). This is a factor arguably impacting on Indigenous participation in HRECs within universities.

Of concern, a recent evaluation reported that ethics committee members accepted that "ethics committees were not routinely using *Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander Research* when assessing Aboriginal and Torres Strait Islander health research" (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, p. 24).

Overall, there is a significant dearth of Indigenous involvement in the review and assessment of ethics, with a number of states and territories in Australia not having specific Indigenous HRECs. This deficit in ethical processes could be due to several factors including community capacity, funding, resources, research fatigue, and apathy.

## Indigenous health research ethical guidelines in New Zealand, Canada, and the United States

Comparable ethical guidelines for research with Indigenous peoples have been developed in Canada (Assembly of First Nations 2009; Canadian Institutes of Health Research 2012, 2022, Castellano, 2004, Macaulay et al., 1998, Scott & Receveur, 1995), the United States of America

(American Indian Law Center 1999, Casteel, 1998, Mihesuah 1993, Parker et al., 2019) and New Zealand (Hudson et al., 2009, Hudson and Russell, 2009, Walker et al., 2006).

The implementation of ethical principles for Indigenous health research has proven to be complex, challenging, and hard to measure across jurisdictions locally, regionally, nationally, and internationally. Additional standards in the conduct of research aim to prevent exploitative, unequal, and questionable research practices that were apparent historically in Australia. This sounds great in theory, but how well are these principles applied in real world settings when under significant time constraints and in the presence of academic structural forces? Can ethical guidelines for health research with Indigenous people go beyond tokenistic pursuits?

It is encouraging to see the various emerging and developing methods, policies, structures, and programs to support excellence in research practices with Indigenous peoples. However, significant and important questions regarding Indigenous health research ethics, translation, and impact principles remain, including how ethical guidelines are applied and measured. Will improved implementation of research principles lead to improved outcomes and impact? Is Indigenous representation in ethical review mechanisms adequate, resourced, and sustainable? If not, how can these vital elements be remedied? This research aims to better understand the ways Indigenous communities contribute to ethical research and review, and provide further knowledge about how Indigenous ethics are translated and applied in practice by researchers in the Australian context.

## Chapter three: Theoretical framework

Indigenous knowledge systems are underpinned by 'connection' and the 'relationships' between the land, the people, the animals, the observable world and the spiritual world whereas 'Western' knowledge systems fundamentally aim to 'categorise' and 'collect'. Academic systems are notoriously patriarchal, where philosophers are the grandfathers of 'Western' knowledge and time honoured traditions and ceremonies dictate the transfer of knowledge to the privileged. Most Indigenous knowledge systems are based on kinship systems that are underpinned by strict cultural protocols. Knowledge transfer is intergenerational and shared by knowledge holders, law men and women through ceremony, song, dance, art, language, and storytelling, to the people. Indigenous knowledge systems have been used in Australia for over 3000 generations. Within academic institutional settings there is a clear discrepancy between how these two distinct knowledge systems are valued.

This is a simplistic comparison between two diametrically opposed worldviews, but it serves to illustrate the differences between Indigenous and non-Indigenous societies. Indigenous and non-Indigenous forms of knowledge production are equally important for contributing to our understanding of the world. However, it is imperative that Indigenous knowledges and perspectives that encompass ancient knowledge relevant to the identity and traditional practices of Indigenous peoples are incorporated into academic settings to further broaden the minds of future thought leaders in Australia. They both encompass simple and complex concepts that might appear foreign and difficult to translate without the appropriate context. As an Indigenous man living in a colonised society, the aim of my thesis is to navigate what Nakata (2002, 2007a) calls the 'cultural interface'. With a shared understanding of knowledge embracing two world views. Nakata (2007a, p.9) describes the cultural interface as "this contested space between the two knowledge systems, the cultural interface, things are not clearly black or white, Indigenous or Western."

The emergence of Indigenous methodologies, epistemologies and decolonising approaches in health research has created opportunities to scrutinise aspects of academic research through an Indigenous lens. Indigenous scholars in Australia and around the world have developed Indigenous ontologies, epistemologies, knowledge systems and methodologies (Foley 2003, Kovach 2009, Martin and Mirraboopa 2003, Moreton-Robinson 2013, Nakata

2007ab, Rigney 1999, Tuhiwai-Smith 2012, West et al., 2012). By applying Indigenous ways of being, knowing and doing we compel the academy to respect, contemplate, and value Indigenous knowledges. Introducing Indigenous concepts and perspectives aligns with a more holistic version of academic excellence and challenges and strengthens notions of academic integrity and freedom of expression.

Embedding Indigenous ways of knowing, being, and doing into research practices have created a pathway for Indigenous researchers to analyse and interpret the world through an Indigenous lens as well as challenge traditional academic systems for obtaining knowledge. Indigenous methodologies are designed to examine, contest, liberate, and decolonise dominant and oppressive discourses. It is for these reasons that I applied Indigenous knowledge systems and methodologies in my research. However, I also incorporated 'Western' theories and methods that complemented this conceptual approach and supported the amplification of Indigenous voices. Specifically, this thesis was informed by an Indigenous ontology that positions me through my connection to Country. My knowledge and interpretation of cultural values and protocols are derived from my experiences on Country with my elders and other knowledge holders.

My articulations of an Indigenous standpoint connects with the philosophy of Indigenist research methodology (Rigney 1999) influenced by critical social theory and methods. Critical theory is described by Rigney as being an overtly political approach that fundamentally aims to;

> *"…free individual groups and society from conditions of domination, powerlessness and oppression which reduce the control over their own lives. In rejecting positivistic scientific methods critical theory is committed to human emancipation through reforming society." (1999, p. 637).*

Indigenist research principles also necessitate contextualising subjectivity through Indigenous ancestry. Martin and Mirraboopa (2003) suggest that I, as an Indigenous researcher need to "present the assumptions upon which my research is formulated and conducted" and to allow "others to locate me and determine the types of relations that might exist" (2003, p.204).

Indigenous standpoint theory developed by Nakata (2007b) espouses three important principles. First, is complex social positioning, second, is the push-pull experience between

the Indigenous and non-Indigenous world, and lastly, the constant tensions that arise between these positions (Nakata, 2007b).

Indigenous standpoint theory empowered me to draw upon my own experiences in the framing and conduct of this research and analysis of the findings as an Indigenous person, community member and academic. The standpoint provided a platform to acknowledge cultural obligations to my people and Country. It also allowed me to position myself academically, and politically.

Utilising these theories and positioning myself in the research in this way acknowledges the discourse of the colonialist society's impact on Indigenous knowledge formation with the intention to disrupt and challenge dominant worldviews. Tuhiwai-Smith outlines the importance of this approach explaining that;

> *"(I)t is surely difficult to discuss research methodology and indigenous peoples together, in the same breath, without having an analysis of imperialism, without understanding the complex ways in which the pursuit of knowledge is deeply embedded in the multiple layers of imperial and colonial practices" (2012, Chapter Introduction, para. 2).*

Indigenous standpoint theory values subjectivity as a strength rather than a deficit and contests the notion of objectivity (Foley 2006; Moreton-Robinson 2013). No research is inherently objective as all people have established worldviews and values that influence their decision making and thinking (Foley 2006; Moreton-Robinson 2013). Recognition of inherent biases is also consistent with principles of constructive grounded theory that argue all knowledge is interpreted and constructed (Charmaz, 2014).

Unsurprisingly the philosophies of Indigenous research methodologies are closely aligned with Indigenous ethical principles. Linda Tuhiwai-Smith (2012, Chapter 8 Twenty-five Indigenous Projects, para. 2) describes twenty-five Indigenous projects that integrate Indigenous research methods or social science approaches "which in turn have arisen out of methodological issues raised by research with various oppressed groups". Arguably some Indigenous methodologies have been developed in response to perceived unethical research practices.

The emergence of Indigenous conceptual frameworks is an important step for Indigenous empowerment and decolonisation of research practices in Australia. I purposefully used an

Indigenous methodological framework to unpack the Australian ethical health research system that has been developed and designed through Western knowledge constructs and analyse the way it works, operates, and is applied by key actors.

Consistent with this theoretical framework my research incorporated an Indigenous epistemology (Foley 2003) and I purposefully adopted a decolonising approach (Tuhiwai-Smith 2012; Chinn 2007) from an Indigenous standpoint (Foley 2006; Moreton-Robinson 2013) throughout the conduct of this research.

# Chapter four: Positionality

I am a multi-clanned Indigenous man with connection to many nations throughout Victoria. I position myself in this study as a Gunai (Eastern Victoria) man – through my Father and his forefathers, as a Gunditjmara (Western Victoria) man – through my Grandparents, and as a Yorta Yorta (Northern Victoria) and Wurrundjeri Woi-wurrung (Naarm, Melbourne) man – through my Mother and my Grandparents.

> *"Men known as bunjils were experts in their own fields. The wind controller was called Bunjil Willancy, Bunjil Krower controlled the rain. Other bunjils were in charge of the animals they were named after and were skilful in catching them." (Pepper & De Araugo, 1985, p. 5)*

My worldview has been shaped by my lived experiences. My people. My country. My ancestors. This is my story, my lens that I view the world. I have applied Indigenous ways of knowing that validate my cultural knowledge to deconstruct and decolonise heath research ethics. Indigenous cultural protocols govern the morals and practices of our peoples. This is underpinned by Indigenous law(s) upheld by complex kinship and social structures that are still currently practiced in many places across Australia.

Technical expertise and relevant subject matter experience is obviously beneficial to inform community decision making protocols in relation to Indigenous health research. However, it is equally important to consider kinship obligations, and cultural responsibilities, to ensure cultural accountability to Indigenous communities. This research has been conducted honestly, and transparently from this cultural standpoint and the following data collected has been examined through this lens. My own worldview, my identity, and my own experiences have contributed to the critical analysis within this thesis.

## Multi-clanned positioning

I am a Gunai man. Gunai country is located in the Southeastern corner of this land now known as Australia. The Gunai nation is made up of five clans, the Brabralung, the Krowatungalung, the Brayakoolung, the Tatungalung, and the Bratwulung. I belong to this country through my Father and his Father before him. The Gunai tribe is based on a patrilineal kinship system. I am the direct descendant of multiple generations of Gunai men. Fathers, and lore men. Gunai knowledge holders. Our creator spirit is Boorun the pelican. He is the protector of all Gunai people.

Through my mother I am a Yorta Yorta, Wamba Wamba, Dja Dja Wurrung and Wurrundjeri Woi-wurrung man. My Nan Doris Atkinson (nee Cooper, Briggs) and my Pop Neville Atkinson grew up on Cummeragunja mission in New South Wales. Yorta Yorta country is located in North of Victoria and borders New South Wales. Wamba Wamba country is located in the Northwest of Victoria on both sides of the Murray. Dja Dja Wurrung country is in Central Victoria. Wurrundjeri Woi-wurrung country is mostly Melbourne (Naarm) and Central Victoria.

I am a Gunditjmara man. My Great Nan Edna Brown (nee Clarke) and my Nan Alma Thorpe (nee Brown) are strong Gunditjamara women. The Gunditjmara nation has over 100 clans and is situated in the Western districts of Victoria. In Port Fairy the Convincing Ground Massacres killed 120 of our people.

I have an unbroken connection to all of my Country. A connection that persists despite the impact of colonisation and the genocidal practices that came with it. My ancestors, and by extension me and my family, are survivors of attempted genocide and assimilation. As a descendant belonging to the first peoples of this country I have been subjected to ongoing oppressive policies and regimes established by the colonizing power. This nation was built on the lie of Terra Nullius' (land of no people). In the colonial settlement period, the battle for land set the stage for conflict between settlers and Indigenous people. Our people were massacred and displaced. We were removed from our own homelands and forced onto others.

Due to the impact of colonisation much of our lore and kinship, language and culture has been broken. However, Indigenous values, culture, and practices should not be considered static. Indigenous people and nations are resilient and have resisted socially, politically, and ideologically to invasion in the struggle to maintain culture and identity. Cultural protocols have evolved and adapted. I have ongoing cultural obligations to my clans, my Nations, my community, and my Country. Throughout my life I have been continually reminded of these responsibilities by my family and my community. Many Aunties, Uncles, and Elders in my family have strong cultural knowledge and have lived experiences but a lot of knowledge about language, kinship systems, ceremonial practices, and sacred sites on my Country, still need to be regenerated due to the impacts of colonisation and the harsh reality of invasion that we've faced in this part of the Country. However, our kinship and identity, and shared

cultural obligations to Country continue to be of the utmost importance to our First Peoples Nations. These areas are essential to demonstrate the strength and resilience of our peoples and highlight the enduring importance of Indigenous knowledges, cultural heritage, languages, country, ceremonies, and lore.

I positioned myself within this research as a man from these nations, respectful of the cultural protocols of these nations. The perspective of these distinct groups influenced the way I conducted this research with Indigenous communities and embedded cultural accountability, and cultural integrity.

## Academic positioning

When I was sixteen, I had my first experience in Indigenous health research as a peer researcher for the Young Peoples Project (YPP) for the Victorian Aboriginal Health Service (VAHS), and in 1998 I was employed as an Indigenous project officer for the Injecting Drug Use project (IDU). From 2007-2021, I worked in various research roles at Onemda VicHealth Koori Health Unit, and the Indigenous Health Equity Unit at the University of Melbourne. My research is underpinned by Indigenous standpoint theory and decolonising approaches to examine structural and societal disparities. Through my academic work I have established relationships with Indigenous communities, organisations and researchers across Australia. In 2013, I completed my Master of Public Health at Deakin University through the Institute of Koorie Education. In 2021, I was appointed as the Alma Thorpe research fellow at Moondani Balluk at Victoria University.

As an Indigenous researcher my conceptual approach has been influenced by concepts borne out of the Indigenous community-controlled health sector. My ethical values were moulded by my experience with VAHS and then Onemda. VAHS schooled me about community control and taught me how to engage our communities, support and identify community research agendas, negotiate data ownership and interpretation, and develop knowledge translation and exchange strategies. The academic contribution of Indigenous people and our Indigenous knowledges must be recognised, respected, and valued.

Throughout my candidature I have held significant academic responsibilities in the areas of teaching, research, and ethical review. When I started my PhD I had already been working at the University of Melbourne for almost a decade. At the time I was working at Onemda as

the coordinator of the Indigenous health specialisation for the MPH. This required extensive teaching, and coordinating responsibilities. As part of my role I was required to lead an extensive transformation of the MPH course through the integration of Indigenous health subjects. Additionally, I was asked to take responsibility for completing a significant evaluation project because colleagues had moved on. Finally, due to various reasons the Onemda program was dissolved leaving me without an academic support base. The burden of carrying some of the academic Indigenous health responsibilities were squarely placed on my shoulders. As a result I went to Victoria University seeking an academic environment that could support me culturally and intellectually.

These positions are not unusual for Indigenous people. We are often pulled from one responsibility to another. Cultural and academic obligations don't always align and this can be a mitigating factor for Indigenous people involved in academic research. The demand for Indigenous knowledge and expertise within universities is stronger than ever but sometimes Indigenous people are pulled into these positions before they are ready.

## Political positioning

From a broader Indigenous political perspective, I have a vested interest in how research potentially creates systemic reform to address the underlying social determinants of health for Indigenous communities.

I believe Indigenous people must lead, or control, the conceptualisation, design, and monitoring of research done in our communities. I am committed to research that supports Indigenous leadership, governance, kinship, relational networking, and respects Indigenous decision-making. I am accountable to Indigenous community representative structures that demonstrate self-determination and respect Indigenous human rights. I strive to only contribute to research that benefits our peoples.

In December 2019, I became a member of the inaugural First Peoples Assembly of Victoria (FPAV), a democratically elected Indigenous representative body in Victoria. The FPAV was tasked with developing a comprehensive treaty negotiation framework with the State Government of Victoria. The promise of a treaty with the State Government, was a huge opportunity for Indigenous communities in Victoria. As a member of multiple sovereign Traditional Owner groups I had a cultural obligation to participate in this important once in a

lifetime opportunity. My family gave me the responsibility to uphold our family rights through this process. This has been an empowering moment for me, but also a heavy cultural burden to carry. Under these circumstances my personal goals became secondary. After being elected for a second term in 2023 I have committed to a leadership role to contribute to a collective negotiation for treaty with the state, underpinned by our Indigenous sovereignty and inherent rights.

## Chapter five: Critical Race-Grounded Methodology (CRGM)

In chapters three and four I outlined the theoretical framework and reflected on my positionality in this research. This chapter briefly describes critical race theory (CRT), grounded theory (GT), and finally the hybrid of the two, critical race-grounded methodology (CRGM) that is the foundation of my methodological approach. In this research I have undertaken a critical race-grounded methodological approach that privileged Indigenous experiences and allowed broader examination of Australian ethical research systems within a colonial context.

The development and emergence of CRT occurred in the mid-1970s in the United States and is largely attributed to prominent critical legal scholars such as Kimberlé Crenshaw, Patricia Williams, Richard Delgado, and Derrick Bell among others (Dunbar Jnr, 2008). The CRT emerged in part as a response to institutional racism within the American legal system (Guinier, 1991, Guinier & Carter 1994, cited in Parker and Lynn, 2002). Essentially, CRT aims to examine power dynamics that occur within socio political settings due to race (Su, 2007 and Writer, 2008, as cited in Benveniste et al., 2018).

Therefore, to understand critical race theory we also need to understand and define race as a concept. In its original form in the United States CRT argues that 'race' is a social construct that is used to oppress and exploit people of colour (Delgado & Stefancic, 2017, Dunbar Jnr, 2008, Lopez, 1994, Smedley & Smedley, 2005). Racism is implicit in the legal institutions and the law as they function to create and maintain social, political, and economic inequalities. The construction of 'race' inherently highlights power dynamics between different groups (Smedley & Smedley, 2005). 'Western' society has arguably been built on complex social systems based on class, capitalism, and the development of bureaucracy that enshrines structural inequities. Dunbar Jnr (2008), and Parker and Lynn (2002) noted the role of CRT in scrutinising notions of 'objectivity' and 'neutrality' within dominant social structures.

The use of 'narratives' and 'storytelling' was recognised as a fundamental tenet of CRT (Denzin & Lincoln, 2008, Dunbar Jnr, 2008, Moodie, 2018, Parker and Lynn, 2007). Dunbar Jnr (2008) contends that the 'lived experiences' central to CRT could provide insights into the shared experiences of Indigenous peoples that have been oppressed and/or colonised. Further, Dunbar Jnr argues that stories from an Indigenous perspective were a useful method of inquiry because "[s]tories provide data that have a focus on ways in which cultural and social

constraints act upon individuals. They are a powerful tool for reflection. The language used is an act of epistemology" (2008, p.90-91). Counter-story telling has been acknowledged as a 'cornerstone' that could empower Indigenous perspectives (Moodie 2018), and be an instrument for marginalised peoples to challenge "the majoritarian stories that make White privilege appear natural" (Solorzano and Yosso, 2002, p.93 as cited in Dunbar Jnr, 2008). Matsudo (1987, p.10 cited in Parker and Lynn, 2002) argued that perspectives and experiences of victims were critical in CRT to understand "hierarchical relationships of power". Critical race theory draws upon 'lived experiences' to examine the root causes of structural disadvantage (Dunbar Jnr, 2008, Ford et al., 2010, Moodie 2018). The emphasis on investigating deep rooted systemically driven inequity employed by CRT allows researchers to critically examine how dominant societies (the colonial settlers in the context of Australian society) promote 'structural forces' that reinforce socioeconomic and racial disparities (Ford et al., 2010).

The utility of CRT in colonial settler contexts has been debated by various scholars, both Indigenous and non-Indigenous (Bargallie & Lentin, 2021, Denzin & Lincoln, 2008, Moodie 2018). Moodie (2018) argued that CRT focused too much on 'race' and not enough on 'place'. According to Denzin and Lincoln, (2008), and Smith (2000), in order for it to work in Indigenous contexts CRT required modification to address the "histories of resistance and struggle, emancipation and success, meanings and traditions that are specific to Indigenous communities" (cited in Moodie 2018, p.36).

Whilst there has been debate about its relevance, Indigenous theorists recognised the potential value of CRT in Australia. Prominent scholars discussed the potential synergy between CRT and Indigenous methodologies (Denzin & Lincoln, 2008, Dunbar Jnr, 2008), espoused its connections with qualitative research (Parker and Lynn, 2002, Denzin & Lincoln, 2008), and explored how CRT could be used in Indigenous contexts (Bargallie & Lentin, 2021, Russell, 2020). Denzin and Lincoln (2008) outlined the developing connection between decolonising approaches with critical race theory, and urged Indigenous researchers to "show critical theorists how to ground their methodologies at the local level" (p.x, 2008).

Moodie (20018), Bargallie and Lentin (2021) sought to expand upon CRT by introducing concepts such as 'decolonising' and 'Indigenous sovereignty', and adapting existing concepts in an effort to develop localised race theories that were applicable to the Australian context

(Bargallie & Lentin, 2021, Moodie 2018). Bargallie and Lentin (2021) critiqued the limitations of 'interest convergence' within CRT and recommended introducing the concept of 'sovereign divergence' originally proposed by Singh (2020, cited in Bargallie and Lentin, 2021) as it emphasised the importance of Indigenous sovereignty and self-determination as non-negotiable aspects of Indigenous struggles against racism.

Internationally, scrutiny of CRT through Indigenous perspectives has led to emerging localised theories, that include additional principles for their specific contexts, such as Tribal Critical Race Theory (TribalCrit) (Moodie, 2018, Russell, 2020), and Latin Critical Race Theory (LatCrit) (Denzin & Lincoln, 2008). Decolonising methodologies in concert with CRT have been successfully applied by researchers in the Australian context (Bargallie, 2020 cited in Bargallie & Lentin, 2021). Bargallie and Lentin (2021, p.676) contend that the tenets of CRT "do not replace or erase locally produced knowledges, theoretical frameworks, or methodologies, but rather sit alongside them and permit deeper engagement with both critical race theory and Indigenous and/or decolonial approaches".

In Australia, Indigenous academics have also used CRT to study the efforts of Australian universities to embed Indigenous perspectives into their curricula (McLaughlin and Whatman, 2011) and to examine the hierarchical structures within Australian universities that oversee the development and delivery of Indigenous studies (Fredericks, 2009). Benveniste et al. (2019) also used CRT in their study to examine staff practices in Indigenous boarding schools in Australia.

Grounded theory (GT) is a qualitative research methodology developed by Glaser and Strauss in 1965 involving the construction of theories through the gathering and analysis of data (Charmaz 2014). Glaser and Strauss outlined strategies for grounded theory in their seminal work *The Discovery of Grounded Theory* (1967) which "provided a powerful argument that legitimized qualitative research as a credible methodological approach in its own right rather than simply as a precursor for developing quantitative instruments" (Charmaz, 2014, p.6). After their initial collaboration Glaser and Strauss went on to expand on the theory from opposing positions, subsequently different branches of GT have been established according to each of their philosophies (Charmaz, 2006, Chun Tie et al., 2019). Strauss and Corbin's (1990) symbolic interactionism and Charmaz's (2006) constructivist perspective have made notable contributions to the expansion of GT (Chun Tie et al., 2019).

Charmaz (2017, p.36) constructivist grounded theory, recognises the importance of researchers' "developing methodological self-consciousness". This requires reflexivity (Harding, 1991 cited in Charmaz, 2017) and positionality (Clarke, 2005, cited in Charmaz, 2017). Charmaz (2017, p.36) describes how Indigenous scholars have used this approach as a strength to "juxtapose their experience against conventional methodological assumptions". Importantly, scholars have rationalised ways to advance grounded theory using theoretical frameworks (Mitchell Jnr, 2014). Mitchell Jnr (2014, p.1) argues for the introduction of a "theoretical framework" in GT, as a transparent way of positioning the research and "shape the research questions, data collection and analysis, and findings." I agree with this approach because it recognises the role of the researcher in the construction of theoretical concepts. Mitchell Jnr (2014, p.2) asserted that "a focused analytical lens allowed me to co-construct a focused theory grounded in the participants' experiences".

The CRGM is an emerging methodology that combines elements of critical race theory (CRT) and grounded theory (GT) (Malagon et al, 2009). Malagon et al advocate for a critical approach that looks at systems of oppression but from a grounded theory method that draws from experiential knowledge (Malagon et al., 2009). The CRGM was a liberating methodology with a focus on social justice (Malagon et al., 2009). Malagon et al (2009, p. 254) propose that "to situate grounded theory within a critical race framework, we strengthen the interdisciplinary, methodological toolbox for qualitative critical race research, which seeks to build theory from the lived experiences of the researchers' informants and research collaborators" and claim that a "critical race-grounded methodology has potential to be a tool for social change". Stokes (2023) used CRGM in a study to analyse the 'racialized' experiences of latinx students during Trump's presidency in the United States.

The proponents of CRGM also recommend an 'abductive' approach to data analysis (Malagon et al., 2009). Charmaz (2006) describes the process of 'abduction' as "a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanations for the observed data, and then forms hypotheses to confirm or disconfirm" (p.186). To be precise, the inductive method of grounded theory (to generate concepts from the data) has been reframed as an abductive approach through a CRT theoretical position that allows broader examination of social structures (Malagon et al., 2009). However, Malagon et al (2009) thought the use of grounded theory alone was inadequate for examining dominant

structural forces and recommended using a 'CRT lens' to move toward a theory that encompassed both social and structural forces in research.

Three methods, theoretical sampling, a conditional matrix and collaboration are identified as strategies to support the application of critical race-grounded methodology in research (Malagon et al., 2009). How I have applied these methods in this research are further described in the following methods chapter.

## *Doorahbun[8]: A conceptual and methodological journey*

*The stories at the beginning and end of my thesis are a direct connection to my cultural obligations. They describe the cultural protocols of our peoples. Each story told by respected Elders that I am connected to through family and lore. They hold me culturally accountable.*

*This was the cultural foundation for my conceptual journey.*

*Early in my study I was lucky enough to attend a workshop with the one and only Professor Aileen Moreton-Robinson. What a privilege… I got to discuss my PhD topic with one of our most distinguished Indigenous academic leaders. Her feedback was generous thoughtful and inspiring.*

*That moment helped shape my research questions. The workshop reinforced to me the importance of validating Indigenous ways of being, doing, and knowing through our research. I had to (re)position myself in the research.*

*It made me rethink the purpose of my study and to identify a methodology that would allow me to critically examine the structural power of universities. This started my methodological journey.*

*I was drawn to Indigenous standpoint theory, Indigenist research, and decolonising methodologies because they privileged Indigenous thinking and perspectives, and they had the power to disrupt. We don't think like Western knowledge producers. Critical race theory has a similar social justice lens and is also a tool to examine institutions. This led me to critical-race grounded methodology.*

*The challenge was to put it all together*

*To do this I located myself within an Indigenous conceptual framework. This positioned my research culturally, politically, and academically.*

*Applying the methodology was no doubt a challenge. I had an inner struggle, culturally and intellectually. Repositioning. What helped me was critical feedback from Indigenous academics and family, unwavering support from my supervisors, and one comment from my Indigenous supervisor.*

*I feel the tension between my methodology and conceptual framework ultimately benefitted the research. In the end I realised that **I was** embedding an Indigenous perspective. The experiences of Indigenous people in this study were privileged. And all of the findings have been conceptualised through Nakata's (2002, 2007a) cultural interface.*

[8] First of four vignettes drawn from my aide-mémoire

# Chapter six: Methods

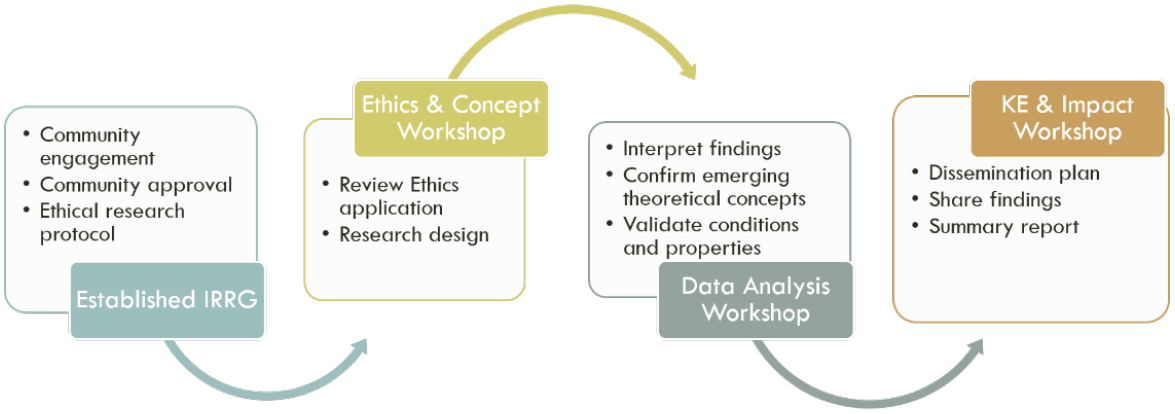
The research methods used in this study determined data collection, data analysis, ethics, and recruitment. My theoretical framework provided a conceptual foundation for my methodological approach, which also informed my methods.

Three core grounded theory methods were used; collaboration (Malagon, et al., 2009); theoretical sampling (Charmaz, 2006); and the conditional matrix (Strauss & Corbin, 1998), in line with critical race-grounded methodology (Malagon, et al., 2009). A methods audit trail outlines how these methods have been applied throughout the study (see Appendix B).

## Collaboration

Collaboration is a method required by CRGM (Malagon et al., 2009) for engagement with community participants and involved inclusive processes for data analysis to ensure "co-construction of knowledge" with my participating community research sites. An Indigenous Research Reference Group (IRRG) was established to ensure collaboration was embedded within the study. The IRRG participated in several workshops (see Figure 2). This approach provided the IRRG, and Indigenous research participants, with the opportunity to contribute to the data analysis to ensure accuracy and provide contextual input. The development of an IRRG and an Indigenous ethical research protocol embedded the method of collaboration.

*Figure 2 IRRG Collaboration through workshops and data analysis*




## Theoretical sampling

Theoretical sampling (Bryman 2004) enables the use of 'cultural intuition to expand on properties emerging from the data. Data collection continues with targeted sampling until

no new properties emerge leading to theoretical saturation (Charmaz, 2006). Theoretical sampling was used to "illuminate and make clear the variations, properties, dimensions and relationships between codes and categories" (Ligita et al., 2020, p.118). Journaling allowed me to keep theoretical memos for use in reflective data analysis consistent with theoretical sampling (Charmaz, 2006). A sample of these memos are in appendix C.

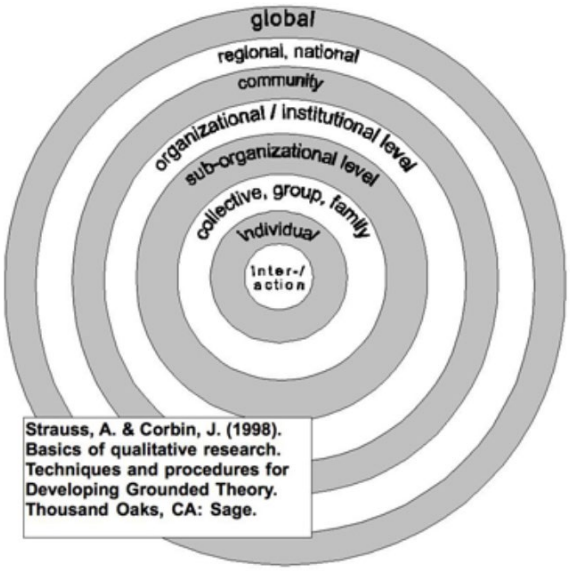
## Conditional matrix

The conditional matrix (see Figure 3) is an analytical coding tool used to visualise intersections between micro and macro conditions (Strauss & Corbin, 1998). Charmaz (2006, p.182) argues the matrix is relevant for "building a systematic, logical, and integrated account, which includes specifying the nature of relationships between significant events and phenomena."

For this study, I adapted the matrix to an Indigenous worldview. In the construction of conditional matrices the concept of the cultural interface (Nakata, 2007a) was used as a cultural method for analysis to conceptualise the space between academic structures and cultural structures where the idea of ethics is contested. This is also an adaptation of Malagon et al (2009) suggested use of 'cultural intuition'.

Strauss (1993, cited in Hildenbrand, 2007) identify 'eight qualities' of a conditional matrix. The outer international level focused on politics and philosophies; national policies and regulations; community; organisations and institutional structures; collective groups; level focusing on interactions; and at the centre actions.

*Figure 3 A conditional matrix*



## Ethical research protocol from an Indigenous standpoint

In this study I interpreted ethical conduct from an Indigenous standpoint, from my perspective as a Gunai man. Ethics from an Indigenous cultural point of view were explored and incorporated as a protocol. As an Indigenous ethicist, I sought to develop an ethical framework that transparently demonstrated how I aimed to address the Indigenous values and ethics guidelines throughout my research. This included an Indigenous advisory group structure with collaborative workshops, and Indigenous knowledge construction and translation methods.

The NHMRC's six values of reciprocity, respect, equality responsibility, survival and protection, spirit and integrity (2003) were proactively considered from an Indigenous ethical standpoint. Along with my own interpretation of the values I drew upon resources developed by Indigenous and academic institutions (NHMRC, 2005, Laycock et al, 2011, AIATSIS, 2012) to assist Indigenous communities to monitor research and ensure it aligns with ethical guidelines. Practical elements were combined from these three documents to create an ethical research protocol comprised of three areas; pre-research; during research; and post-research. This resulted in an ethical protocol related to the *guidelines* (see Appendix D) that I endeavoured to address throughout my research.

### Indigenous Research Reference Group (IRRG)

The Indigenous research reference group (IRRG) was formed to provide advice on community protocols and research activities, review ethical conduct, and support knowledge translation. In total, eight different people were part of the advisory group over the course of the study.

To establish the IRRG I approached three Indigenous people with relevant research experience and expertise in research ethics and asked if they were interested in being on the Indigenous Research Reference Group. Three Indigenous community members agreed to these roles. Through a series of initial meetings guiding principles were developed and agreed on. These members endorsed the ethical research protocol, recommended appropriate community engagement, and advised on cultural protocols before the research commenced.

Three community study sites were also approached (these sites have been de-identified) and agreed to participate in the research. The three identified Indigenous community sites nominated Indigenous representatives for the IRRG. The IRRG were brought together to

monitor progress of the research for the duration of the project. Community research approval processes were carried out and community support letters were provided.

The IRRG provided advice about recruitment, contributed to data analysis, mitigated risks, and supported knowledge translation activities. IRRG members from the relevant sites advised on specific strategies for recruitment and assisted with targeting initial key informants. Importantly, the IRRG provided critique on the research proposal and advised on how to navigate cultural protocols. The IRRG allowed Indigenous community partners to monitor the progress of the research. Any relevant ethical compliance issues were also discussed with the IRRG as required.

The IRRG was also asked to participate in several workshops (see Figure 2) over the course of the research as part of the collaboration method required by CRGM (Malagon et al., 2009). Firstly, I ran a pre-ethics workshop with objectives to develop and review the ethics application for the University of Melbourne, resulting in a comprehensive ethical research protocol (attachment). Several meetings and rigorous discussion were held with the IRRG to provide feedback before ethics was formally submitted to the University of Melbourne. Secondly, a data analysis workshop was held for IRRG members to interpret the results and thematic concepts emerging from the data. Finally, a knowledge translation workshop was undertaken to outline a research dissemination plan to share the findings with Indigenous institutions and communities, participants, and other stakeholders. In total three workshops were held focusing on engagement and conceptualisation, interpretation of results, and knowledge exchange.

### Indigenous community approval

Indigenous community control is understood as a form of independent decision-making within the Indigenous health sector (National Aboriginal Community Controlled Health Organisation, 2024). This term harkens back to the political 'self-determination' era in the 1970's that saw Indigenous people fight for their rights to govern their own communities (Schaap et al., 2013). Community controlled health, legal, and other services have been embraced by Indigenous communities as a tool to empower Indigenous voices and enact self-determination. In recent years the community controlled sector has been utilised by mainstream services as a mechanism for community engagement, authorisation, and

approval. 'Aboriginal community-controlled health organisations' (ACCHOs) are normally governed by Indigenous boards that have been elected by Indigenous community members.

Permission to conduct this research was sought from all participating Indigenous communities through relevant approval processes endorsed by the IRRG. There were multiple research approval protocols undertaken to gain community consent from each study site. These were carried out with each participating Indigenous community partner to gain their approval before the formal University of Melbourne ethics procedures were started.

One partner required a formal written research application be submitted to their internal research sub-committee. They submitted recommendations to their board who considered the proposal for approval. After they agreed to participate in the research a support letter was provided. The two remaining study sites provided letters of approval and support after the research proposal was presented to senior staff of the organisations. Although consent processes were done through a 'western' bureaucratic construct, participating organisations embedded their own collective approval protocols and were recognised Indigenous community controlled and governed organisations.

### Knowledge exchange, translation and impact

A knowledge exchange and dissemination strategy was co-constructed in partnership with the IRRG through the ethics application process (Brands & Gooda, 2006). As mentioned previously a small workshop was held with the IRRG to determine the most appropriate way to share the findings of this research with the Indigenous communities that participated in the research. Unfortunately, the outbreak of Covid-19 had a significant impact on engagement and knowledge translation activities.

Another workshop will be held with the IRRG once the thesis has been submitted, and examined. A summary report with recommendations, and a copy of the final examined thesis will be provided to each site through the IRRG.

### Two data collection methods

Two methods, semi-structured interviews, and an aide-mémoire, were used to explore the research questions established in this study. Semi-structured interviews are an accepted method of data collection associated with grounded theory and thus aligned with the CRGM (Malagon et al., 2009). The aide-mémoire was a useful tool that supported me to draw upon

my “cultural intuition to explore the themes that derive from our data” (Malagon et al 2009, p.266). These methods were incorporated to ensure data collection addressed the methodological aims of my research.

### Semi-structured interviews

Semi-structured interviews were carried out with three participant groups at three Indigenous community sites and one university site. In-depth interviews (Serry and Liamputtong 2010) were done with both Indigenous and non-Indigenous participants to get an understanding of how researchers operationalise ethics principles in health research with Indigenous communities. Approximately twenty four hours of interviews were recorded and transcribed for this research.

Indigenous past participants of research, Indigenous community coordinators, and researchers (Indigenous and non-Indigenous) were asked about how researchers practice ethics principles in health research with Indigenous communities. Study participants were asked about; their past experiences with Indigenous health research, how researchers conducted ethical procedures, opinions of researchers’ ethical conduct, and the role of Indigenous communities’ in ethical review of research.

A plain language statement (PLS) and consent form were provided at each interview (Appendix E). Participants at each site signed consent to participate in the research and record the interviews for transcription. The consent forms gave participants the option to withdraw from the study at any time without prejudice. Interviews were transcribed verbatim through an external transcription service. In addition to digital recording interview notes were taken to link conceptual ideas and support future analysis. Participants were given the opportunity to review their transcript and, if necessary, provide amendment prior to analysis to ensure accuracy.

The Interview questions were predominately informed by the NHMRCs Values and Ethics guidelines (2003) and KROT (2005), and the Lowitja Institute’s researcher guide (Laycock et al. 2011). A preliminary literature review of Indigenous health research ethical guidelines in Australia also informed the development, structure, and themes of the interview schedule. The interview schedule was then pilot tested for relevance with the Indigenous Research Reference Group and selected researchers from the University of Melbourne (the pilot

interviews were not included in the final analysis). The final interview schedule was thematically arranged according to the values and tailored to each participant group because each group related to ethical practices within different contexts (see Appendix F). For instance researchers were generally asked about how they applied the guidelines whereas past participants were asked about their experiences of applied ethical practices. The interview guide was revised to expand upon and refine theoretical concepts emerging from the data (see Appendix G).

Study participants were asked about: their experience with Indigenous health research; the role they had in ethical procedures; if feedback from researchers was provided at the conclusion of the research, and how researchers were held accountable in complying with their undertakings for the conduct of their research in accord with the six NHMRC principles for ethical conduct in Indigenous research.

Previous studies have shown the difficulties that can arise when researchers are engaged as participants (Wiles et al. 2004). A method to counter anticipated problems with researchers as participants was described by Wiles et al as 'informed deference' (2004). This involved the researcher exploring the previous work of research participants and to ask relevant questions but also to "defer to their expertise and knowledge" when querying challenging topics. The perceived intent of this study to reveal 'unscrupulous' research practice was potentially problematic. Tension in interviews with non-Indigenous researchers was alleviated through recognition of their expertise and experience in Indigenous health research.

## Aide-mémoire

An aide-mémoire or researcher journal was kept reflecting on my own perspectives and experiences as an Indigenous researcher and to document my own ethical practices. This was useful method to incorporate my 'cultural intuition' (Malagon et al., 2009). Detailed notes were kept of reflections and conceptual ideas. This was a useful mechanism to ensure I reflected on my role as an Indigenous researcher at different stages of the research (Bryman 2004). This fits well with an Indigenous standpoint philosophy (Foley, 2006, Nakata, 2007b) as I positioned myself in the research as an Indigenous person, with a reflexive approach and contemplated the influence of my "cultural, political, and social context" (Bryman 2004, p. 500) in the generation of new knowledge. Using a journal, I was able to interrogate my own privileges and decision making power as the 'researcher' within a traditional academic

institution. I also attempted to capture critical ethical moments in the research and interrogate the different conditions that influenced my decision making. Four vignettes summarising key reflections are included focusing on methodological approach, ethical practice as an Indigenous researcher, experiences as an ethical reviewer, and cultural obligations.

## Recruitment

Purposive sampling was used to identify Indigenous communities and organisations and to recruit Indigenous community participants to the study. In addition theoretical sampling was used to reach data saturation. Theoretical sampling is suggested as a method by Malagon et al (2009) that allows researchers to use their 'cultural intuition' to expand on properties emerging from the data by further targeted sampling. The aim of this strategy is to reach 'theoretical saturation' by gathering data on theoretical categories through targeted sampling until no new properties are revealed and/or when no further inquiry into theory is necessary (Charmaz, 2006).

Three distinct groups, Indigenous participants, Indigenous community coordinators, and researchers, that have participated in or conducted Indigenous health research (since 2003) were recruited to participate in semi-structured interviews. Non-Indigenous researchers who had previously been involved in Indigenous research were eligible to participate in this study, however they were not specifically targeted as part of the sampling strategy because the study aimed to privilege Indigenous experiences. The interviews explored personal experiences of ethical conduct in Indigenous health research.

## Three Indigenous communities and one university

The Indigenous Reference Group gave advice about how to engage with potential Indigenous community research partners. Discussions were held with a range of relevant Indigenous community stakeholders. Indigenous organisations were invited based on their involvement in Indigenous health research projects since the enactment of the current NHMRC Values and Ethics guidelines (2003). Criteria also included development of specific engagement, ethics, translation strategies, relevant principles regarding NHMRC Values and Ethics guidelines (2003) and KROT (2005), or relevant principles from the Lowitja Institute's (Laycock et al 2011) publication.

Three Indigenous organisations were approached and agreed to take part in the study. In addition further participants were recruited from a university in order to achieve theoretical saturation (see Table 1 for a brief description of each research site). Each organisation monitored the research through the IRRG and assisted with recruitment of eligible Indigenous participants in their communities.

*Table 1 Description of research sites*

| Site | Description | Jurisdiction |
|---|---|---|
| Regional Indigenous organisation | Community research focus | Victoria |
| Metro Indigenous organisation | Health service | Victoria |
| National Indigenous research institution | National research focus | National |
| **University** | **Research focus** | **Victoria** |

## Study participants

The community sites supported recruitment of Indigenous people from their community to participate in semi-structured interviews. Researchers, Indigenous staff, and Indigenous community members, that had experiences with Indigenous health research, were targeted to participate in interviews through each Indigenous study site. Participant selection criteria was based on participants having relevant experience with health research projects. The IRRG members from the relevant sites advised on specific recruitment strategies and assisted with targeting key informants.

Inclusion eligibility criteria specified involvement as an Indigenous 'past participant', an Indigenous 'community coordinator' or a researcher (Indigenous and non-Indigenous) having participated in, facilitated or conducted, any type of Indigenous health research project since 2003. Table 2 shows participants by site, role, and Indigenous status. Three non-Indigenous respondents participated in the study, with two recruited through the university and one from the National Indigenous research institution.

*Table 2 Participants by site, role, and Indigenous status*

| Site | Researcher (r) | Community coordinator (cc) | Past participant (pp) | Total |
|---|---|---|---|---|
| Regional Indigenous organisation | 2 | 1 | 4 | **7** |
| Metro Indigenous organisation | 4 | 5 | - | **9** |

| | | | | |
|---|---|---|---|---|
| National Indigenous research institution | 7 | 1 | - | **8** |
| University | 3 | - | 1 | **4** |
| *Indigenous* | *13* | *7* | *5* | ***25*** |
| **Total** | **16** | **7** | **5** | **28** |

As part of the strategy to recruit Indigenous 'past participants' community notices were posted on community noticeboards, shared through organisational email networks with permission from relevant study sites (see community notice in Appendix H) . Some face to face meetings were also held with selected groups to promote the research.

To recruit Indigenous community coordinators a targeted email was sent out from Indigenous community study sites on behalf of the research project. Community study sites identified opportunities to share the targeted email at face to face meetings, and at relevant organisational meetings. The IRRG representatives for each site also shared the research with community members that previously assisted with research coordination at their location.

Researchers that were part of the National research institution's network were invited to participate in the study in several ways. A targeted email was sent out to their researcher database on behalf of the research project.

Indigenous participants were offered gift vouchers to compensate for their time and to reimburse travel expenses. More details about the approach to data analysis and theoretical conceptualisation are provided in the next section

## *Djillay Kinaway: How to be an ethical Indigenous researcher?*[9]

*Positionality*

*From my perspective it was more important for me to uphold my cultural relationships in relation to this research. The cultural community approval was most important to me.*

*Community priority*

*Firstly, I identified key Indigenous community organisations with an interest in ethical research. I used my community and professional networks. I then organised to meet with a small group who informally agreed to support this research. This group became my advisory group.*

*Multiple meetings*

*We had many meetings to discuss the project. Input and feedback was given along the way. It was a challenge to meet. I felt guilty for imposing time sensitive burdens on the group.*

*Community approval*

*To get formal support I had to apply for three separate community approval processes. The community approval process took time to navigate because they have better things to do!*

*Knowledge exchange and benefit?*

*A knowledge exchange workshop was held with the group to work out the best way to share the findings with community. PhD requirements create an interesting obstacle for recognition and acknowledgement.*

*Reflecting on my ethical 'performance'*

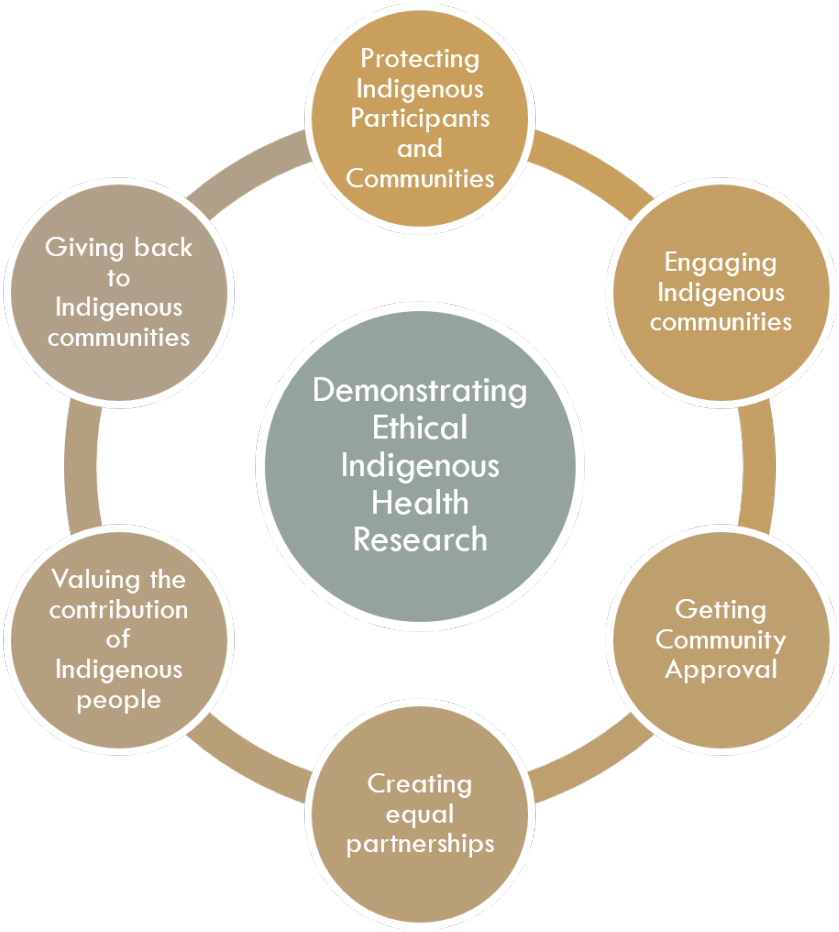
*On reflection I know there are things I can strengthen and other things that were less important. But what holds me accountable are my relationships with my Indigenous community partners and with my community.*

[9] An explanation of my ethical approach is presented in my methods chapter. Here I reflect on pivotal moments and unique ethical challenges.

## Chapter seven: The findings

The following chapters present the findings within six broad areas; Engaging Indigenous communities; Getting community approval for research; Creating equal research partnerships; Valuing the contribution of Indigenous people; Giving back to Indigenous communities; and Protecting Indigenous participants and communities (see Figure 4).

*Figure 4 Focused codes diagram*




This study examined how researchers[10] addressed the NHMRC Values and Ethics *guidelines*[11] (2003) in practice and findings are expressed from an Indigenous world view. Interviews were held with three different participant groups, Indigenous past participants, Indigenous community coordinators, and Indigenous/non-Indigenous researchers, to explore their

[10] Respondents did not always differentiate between *Indigenous* and *non-Indigenous* researchers. On other occasions respondents referred to the specific conduct of *non-Indigenous researchers*. In these circumstances specific descriptors have been used for clarity. The concept of the '*Indigenous researcher'* was contested in this study. Respondents sometimes generalised their experiences with researchers.

[11] For brevity hereafter referred to as the *guidelines*

experiences of researchers' ethical practices whilst participating in, coordinating, and/or conducting Indigenous health research.

The interview questions focused on 'past' ethical practices. However, many participants also made suggestions about how to strengthen future ethical practices and identified additional protocols they felt were necessary for research conducted in their communities. Each participant was provided with a copy of the guidelines. The findings reveal how participants thought researchers had demonstrated the NHMRC ethical values in previous research they had been involved in. All respondents were asked general questions about good experiences of research and about what could be done better. Researchers participating in this study were specifically asked to provide details about their experience in Indigenous health research.

All codes were cross checked, interpreted, and substantiated by the Indigenous Research Reference Group. Following their feedback additional codes were also considered. These focused codes and corresponding 'in vivo'[12] codes encompass the broad range of participants' experiences in Indigenous health research. These findings contribute to further knowledge about how researchers demonstrated reciprocity, respect, equality, responsibility, survival and protection, spirit and integrity. Finally, where relevant, ethical values were referenced to highlight how they relate to the NHMRC guidelines and emphasise where findings overlap, repeat, and intersect with each other.

The following sections demonstrate how researchers upheld the values of reciprocity, respect, equality, responsibility, survival and protection, and finally spirit and integrity, from the experience of participants' in this study.

[12] 'in vivo' codes are specific terms emerging from the data often used by grounded theorists to retain participant meanings within the coding (Charmaz, 2014)

# Chapter eight: Engaging Indigenous communities

The *guidelines* advocate for the development of 'ethical relationships' with Indigenous communities (National Health and Medical Research Council, 2003). Indigenous participants in this study had clear views about appropriate ways to build relationships with Indigenous communities. They were able to articulate 'right and wrong' ways to engage Indigenous communities. To engage appropriately Indigenous researchers had to build trust with Indigenous communities.

In the interviews past participants and community coordinators were asked if they trusted researchers and how they found out about research projects they participated in. Researchers, on the other hand were asked how they gained the trust of Indigenous communities, and how they supported involvement in their research.

## Earning trust with Indigenous communities

In order to establish authentic relationships researchers had to build trust with Indigenous communities. A respondent described this as process of 'becoming known' to Indigenous communities. They described how a researcher had to work in a community organisation to demonstrate their commitment before their research would be approved:

> *"She come to us before the ethics application, and it delayed her whole project ... It delayed her whole project 12 months because* ***she had to go and do work at the [Indigenous organisation] for 12 months and become known*** *before she could put her ethics application in."* ***Community coordinator turned researcher***

In this example the researcher was asked to provide a tangible benefit to the community before the research commenced instead of after it had been completed. Indigenous communities expected researchers to build authentic relationships with them. Indigenous researchers and community coordinators thought it was important to spend time talking and listening to the community. An Indigenous researcher described how they sat down with an Indigenous community before they determined their research as a sign of 'cultural respect':

> *"Before any formalised research questions had been formalised by an ethics application* ***I sat down with the community and spoke about the project [before] it had even been formed.*** *I think that that's cultural respect for the community is that, is I didn't just go in there [with a preconceived research project].* ***…So that, for me that's what cultural respect was. It was a process of gradually coming to the right research questions." Indigenous researcher***

Engaging before the development of research proposals and ethics application demonstrated respect for the experience, knowledge, and credibility that Indigenous communities could contribute. Another Indigenous researcher described the importance of consulting with communities to determine research priorities:

> *"**It starts with the design and the consultation even before we get to ethics**… It's part of the process. And you've got to demonstrate that side of it. You can't go in and say we will consult. With a fully-fledged application. **You've got to say this was developed with Aboriginal people who identified their priority**, this research priority and they're now research partners. Equal. You know, like (laughs). Not just token you know we've got a, well, we've got a little AI [associate investigator] over there supporting it."* ***Indigenous researcher***

Some respondents described how they were scrutinised by Indigenous communities in the process of building relationships. The process of building a rapport and gaining trust could be time consuming and extensive if you were not known to the community. And in many cases, this required a sustained level of commitment and contribution:

> *"And that's what I was saying before, like, it's not really a ticked box here, or especially with [Indigenous community leader]. It's more **like a testing period where you'll have conversations and then, you know, see how you're contributing before there'll be …[commitment]" Indigenous researcher***

'Becoming known' enhanced researcher credibility in the community. A non-Indigenous researcher acknowledged how crucial it was to build genuine community relationships stating:

> *"I think really **importantly it's about building relationships**. It's about having those **face-to-face connections**, you know, so that when you see someone in your community, you know, you might be down at the shop buying a coffee and you'll run into someone, you know, you've seen it at the [Indigenous organisation] talk how, how's it going? What you know, what's going on? And you actually **build that personal relationship**. I think that's really important. And I think perhaps that's **something that the universities don't do well**… Or have you considered doing this with your research **because you've actually bothered to build a relationship**. So, I think that's something that's really important to, to remember that **relationships in this space are important**. **Non-Indigenous researcher***

They also described how sustained engagement transformed their relationships with Indigenous communities and colleagues into genuine friendships that she felt an obligation to protect.

> *"If you legitimately wanted to create positive change or effect positive change particularly for our people in this environment,* ***you have to take the time to understand, engage and you know work with the community****. …I think it's the values and your relationships. And I'm very aware that I've taken a long time to build collegial and friendships with my colleagues and friends in the Aboriginal community. And I am not going to jeopardise that for anybody or anything you know.* ***So, if you sell out once your reputation it's gone."*** ***Non-Indigenous researcher***

Indigenous researchers also had to build trust and maintain relationships with Indigenous communities.

> ***"…it takes, you know, it take, it'd take half the time before people started to trust me, and then at the end I was like overwhelmed with people coming and asking for support and stuff, so it's like once they feel ready, yeah."*** *Indigenous researcher*

Building capacity and investment in community relationships was identified as authentic demonstration of ethical values by one Indigenous participant:

> *"If they were true to those values they would build the relationships first with community, work alongside them, build capacity around research with community and make that investment."* ***Community coordinator***

Indigenous communities tested the compatibility of prospective researchers before they committed to their proposed projects. An Indigenous researcher explained this as the 'testing' and 'tuning' phase of the relationship:

> *"Yeah,* ***testing****, seeing if they're compatible…Before you commit, you're* ***tuning****…And you're doing that with every stakeholder. …testing the waters."* ***Indigenous researcher***

Researchers were expected to prove they were obligated to the Indigenous community they were planning to do research with. How researchers interacted with community determined if they would be permitted to go ahead with research:

> *"Even then, it's even just like minor things like* ***testing their body language*** *in an interaction. And you know* ***how much of their white guilt do they project that holds my voice back?*** *, and that can even be as simple as like their first initial like interaction in* ***judging how you look as an Aboriginal person****."* ***Indigenous researcher***

Indigenous participants expected researchers to display accountability to the community, especially when research was being established. An Indigenous researcher explained how they would build a rapport with the community by regularly attending different events and

meetings she was invited to. Usually these were informal gatherings, but they were important for showing the community that she was willing to invest time in the relationship:

> *"So each community has different events, so I just go along to their events or their meetings or whatever it is they have, that they invite me to. And yeah, it just kinda evolves from there. There's no formality to it."* ***Indigenous researcher***

Once obligations were established researchers were expected to maintain these through the research project, and sometimes beyond. Indigenous researchers were also expected to 'front up' and be accountable to Indigenous communities. Trust was earned through being present. Researchers that fulfilled their promises and obligations to the Indigenous community were more likely to be trusted. High standards of engagement and accountability transformed into reliability, respect, and integrity:

> *"[S]o we've got to prove it ourselves and* ***make sure that we deliver****. And that* ***we're trustworthy****. …Totally a key element and kind of* ***delivering what you say you're gonna do****. And if you can't you're gonna say why."* ***Indigenous researcher***

Some researchers expressed their difficulties dealing with conflicting responsibilities and the impact this had on engagement. Systemic academic pressures were highlighted as a particular area that caused anxiety in Indigenous researchers. This pressure seemingly encouraged researchers to adopt a 'fly in fly out' approach with one respondent claiming:

> *"But I think the other thing too is from, you know, from my point of view as a researcher, yes,* ***I've got a lot of other pressures****, I've got teaching coming up,* ***I've got other research projects coming up****, et cetera. But at the end of the day when you're working with a community of participants, are you, you know, again,* ***do you just want to be a fly in fly out researcher?*** *Where you go in once, do the job, and that's it, bang, you move on to another community, you do something else, you go somewhere else.* ***Or do you actually want to form a long-term relationship with a participant group?" Indigenous researcher***

Lack of effort to build relationships with Indigenous stakeholders was considered disrespectful. Indigenous communities did not trust research institutions that failed to build authentic relationships:

> *"...In this community there's a real distrust with [institution department]* ***they have not done the groundwork to be able to build good relationships in the Aboriginal community here.*** *And I don't think a lot of work has to be done to fix that."* ***Indigenous researcher***

An Indigenous researcher felt people were more willing to participate in research if they had relationships with the researcher. The relationship created an obligation between the researcher and the participant that went beyond the ethics:

> *"I think the participants were more willing to engage in the evaluation part of the project because they knew that [known Indigenous researcher] and I had fashioned that. You know, she designed a project. I'd design the evaluation and* ***they were just much more willing to engage."*** ***Indigenous researcher***

From an Indigenous community perspective this provides another protective layer within the research that extends beyond academic regulations. A past participant would only participate in research when they knew and trusted the researchers:

> *"****I've got to trust the actual researcher now*** *…most people that I talk to I actually know. And I've had a relationship with them before. And I trust them as people and researchers."* ***Past participant turned Indigenous researcher***

However, the issue of trust was predominately raised by Indigenous respondents in this study suggesting that non-Indigenous researchers were less aware or perhaps less concerned with establishing trusted relationships. Some non-Indigenous researchers in this study expected people to trust them because they were professionals from respected institutions.

Some non-Indigenous respondents also felt institutional ethical review systems were overly burdensome and believed additional community driven procedures just added to this burden. In fact, some researchers felt that community 'gatekeeping' of research was an overreaction:

> *"****Some people are better, and some people are worse****, you know, of course. And you can say yes or no, but then the gatekeeping within communities and the filtering me- mechanisms are just getting more and more complex, and I don't think people on the ground have the, especially in a lot of these organisations, the capacity. As in, they don't have enough staff, but also* ***they don't have the research background themselves, or they probably could be doing the research themselves****."* ***Researcher***

However, this position fails to grasp why many Indigenous communities want to determine their own processes for reviewing and monitoring research. Community models of approval and review are arguably grassroots strategies designed to foster trusted relationships with researchers. Trust is placed in the researcher to do the right thing by participants. A network of trust is established and grows over time when researchers commit to long-term

partnerships. Without research focused bodies communities lack cohesive, coordinated strategies for dealing with and managing researchers and research institutions.

By the same token trusted Indigenous community members were essential for facilitating research within communities. The more trusted people involved in a research project the more trust is reinforced:

> ***"So then that gives an extra layer of trust because they're like, "Oh, we know this person." So yeah, it's all relationships." Indigenous researcher***

Similarly, non-Indigenous researchers that make the effort to foster long-term community relationships, without an agenda, develop a rapport that can expedite research processes if trust has been maintained. An Indigenous community coordinator felt more comfortable doing additional research with someone that had demonstrated a good approach in the past and was committed to supporting the organisation involved:

> *"And she had the same approach, talk to [Indigenous organisation] I'll pay for you to employ someone you own the data you can pull out any time you like. There's no onus on you for extra work. She also came with references. …Oh I knew her. She worked at the [health institution], she's a doctor in [health service], she's a professor so she's got, she's well known, sort of. But being well known doesn't mean that you're okay. Could be well known for doing the wrong things but she she's had good approach to working for Aboriginal people, the right approach."* ***Community coordinator***

Researchers that committed to consistently working with the same community were more likely to establish trusted relationships with Indigenous community partners.

### Engaging communities through Indigenous organisations, Indigenous community leaders, and Indigenous community groups

Respondents in this study described how some researchers utilised the networks of Indigenous organisations to engage with communities. Researchers effectively recruited Indigenous organisations, community leaders, advisory groups, and community coordinators to support their engagement with Indigenous communities. A respondent based at an Indigenous organisation agreed to engage with communities on behalf of researchers when they were part of the conceptualisation of research:

> *"We've had people come to us and sit down and say that we've got an idea what do you think? And that's great. 'Cause then we go, oh, wow, that's great you've come to us now. We'll go and talk to our members or we'll work with you on what*

*we think, you know. , and so, yeah, we've just recently had some groups do that which is great."* ***Community coordinator turned Indigenous researcher***

Given their expertise and experience in Indigenous health, Indigenous peak health representative bodies have traditionally played a role in facilitating and/or screening research for their members. Indigenous health organisations that were predominately community controlled were often collaborators with university researchers and would engage Indigenous community members as part of their role in the research. These organisations had established community networks. Indigenous organisations were community hubs that had the ability to bring the community together:

*"Do you want us to work with you on developing a research design to help you? And drive that yourself and we'll just bring everyone together."* ***Community coordinator turned Indigenous researcher***

Within some universities Indigenous staff were recruited specifically to broker relationships with Indigenous organisations. This included coaching and mentoring non-Indigenous researchers on how to engage appropriately:

***"[We] always try to recruit some local community people to work with us and help us. And guide us."*** ***Researcher***

The influential role of Indigenous community leaders was highlighted by many respondents. Some Indigenous participants advised researchers to meet and discuss their research proposals with respected Indigenous community leaders. An Indigenous researcher in a regional area explained how researchers were expected to meet with a recognised community leader before they were given 'permission' to engage with the community:

*"Here the permission isn't actually a tick a box. The permission is that you're sitting here you're contributing you're talking constantly to [Indigenous community leader] about what you're doing and he'll say yes or no and then next week he might say, "Do it this way." So it's not actually, like, yes, or no. It's about an evolving conversation and, and it's about how you contribute and how he can see you're going to [make an impact]"* ***Indigenous researcher***

Although community leaders were sought out for advice an Indigenous researcher thought it was also too easy for researchers to dismiss that advice:

***"I think it's really easy to dismiss community and that leadership and just go on your own kind of way." Indigenous researcher***

Another Indigenous researcher thought engagement was complex and challenging in Indigenous communities with conflicting views about proposed research:

> *"But it is fraught with difficulties because as we know, right, community is not one unified homogenous mob, you know. There's different views about research."* ***Indigenous researcher***

## Facilitated engagement

Community coordinators were often the liaison between community organisations and research institutions. They were also usually expert facilitators of community engagement. They guided researchers through community protocols and provided advice on how to appropriately conduct the research within their community. An Indigenous organisation involved in research funded an experienced community member to monitor research:

> *"My role was to make sure the cultural content and all the other things about the research were done right that if it strayed from an ethical point of view or methodology then I had to sort of comment on that."* ***Community coordinator***

Indigenous academic leaders within universities also influenced the way engagement with Indigenous communities was carried out. One respondent respected Indigenous researchers that 'guided' their colleagues through appropriate engagement with Indigenous communities:

> *"There are also great examples where they have, you know, actually sat down and not always but mostly* ***there is a strong Aboriginal researcher in that unit or in that organisation that's guiding that process****. In my opinion, yeah. You know, look at [Indigenous researcher]… and look at [Indigenous researcher]. And so, where they're positioned,* ***we generally get the researchers coming very early and want to talk to us very early*** *on and so* ***I think having a strong Aboriginal researcher in a leadership position in academic organisations will definitely help change that landscape and, In a positive way."*** ***Community coordinator turned researcher***

Some researchers used Indigenous community organisations to fulfil their obligations to engage with Indigenous communities. This placed an additional cultural load on organisations that researchers may not understand:

> *"[B]ecause a lot of onus gets put on [Indigenous] organisations to be that, to hold that trust and research comes in and sort of takes advantage of that."* ***Past participant***

When Indigenous organisations take responsibility for engaging the community on behalf of researchers they carry reputational risk. Ultimately, if researchers failed to deliver it is the organisation that would be held accountable by the community for endorsing the research:

> ***"And we've been burnt by that. We've committed to research projects where we thought they were good and we tried to do too much. And in the end we lost our way with that." Community coordinator***

## Summary: Chapter eight

The importance of authentic, ethical research relationships cannot be understated. It is a fundamental pillar of ethical research with Indigenous communities. Moreover, once relationships are created, and if they are developed with genuine respect, there is an expectation from Indigenous communities that they continue. And if the roots of the relationship are deep enough researchers may find they become obligated to the community and its priorities. The seed for obligating researchers happens early in the relationship and is an underlying premise of ethical research partnerships. Commonly, connections developed with communities created additional obligations that are outside the scope of the research – but are seen as essential for maintaining reciprocal relationships. The outcome is a realignment of accountability to Indigenous community partners and stakeholders.

Most Indigenous organisations have long-standing existing community relationships that have developed over time. These organisations often broker engagement with local communities for outside researchers. Researchers can utilise organisational community networks to target engagement with communities. Yet, many Indigenous organisations have specific focuses (health, legal, education, drug and alcohol, childcare etc) and are not resourced to deal with research requests. The responsibility to ensure research groups are ethical and culturally safe is an additional burden. Furthermore, without relevant research knowledge, expertise, and experience they can be vulnerable to exploitation and manipulation.

Similarly, Indigenous people that belong to specific Indigenous communities normally have existing networks and family relationships (often based on kinship ties) that bind them to community obligations. Indigenous people involved in research can use these trusted networks to engage communities and establish strong research projects. If anything goes wrong, accountability already exists through their relationships. They can be held accountable, culturally, socially, and ethically. There are obligations and responsibilities attached to each relationship that extend beyond the research. The existing relationships that some Indigenous researchers have are consistent with this community cultural accountability framework.

Many Indigenous people who facilitate community engagement for health research projects are caught between multiple roles with conflicting obligations. They carry a community

cultural load that can put them in challenging positions when research is incompatible with community protocols.

Academics who became known and trusted by Indigenous communities effectively became part of these same community accountability frameworks due to their relationships. To do quality Indigenous research personal connections are required to 'become known' to Indigenous communities. There was an inherent understanding that community protocols would be upheld due to these community obligations. This creates a bond that arguably elevates the researcher-community relationship.

Unfortunately, some researchers transferred their relationship obligations to their Indigenous community partners rather than develop their own. They exploited the cultural framework that existed within communities to justify their research but failed to uphold their own obligations. Similarly, fly in fly out researchers are not conducive for sustainable research partnerships with Indigenous communities.

To summarise academic researchers developed trusted relationships by 'becoming known' to Indigenous communities themselves, they also collaborated with trusted researchers or community members, and partnered with trusted organisations.

Some researchers overemphasised the benefits of their research proposals as an incentive for Indigenous organisations to participate. This was potentially reinforced by an intrinsic sense of obligation to community that Indigenous organisations held.

## Chapter nine: Getting community research approval

This chapter explores how researchers obtained community approval to do research involving Indigenous communities. Respondents were asked how research was approved by Indigenous communities from their experience. Indigenous past participants and community coordinators were also asked how decisions were made in their specific community. The differences and intersections between institutional ethical approval and Indigenous community approval are further explored in this chapter which addresses the specific process of research approval from both an Indigenous and institutional context.

Formal ethical approval is straightforward and mostly controlled through academic institutions. Indigenous community approval is usually a prerequisite for getting academic ethical approval. However, the process for collective Indigenous approval relies on an understanding of relevant Indigenous community settings and is supported by various Indigenous community structures and decision making protocols.

How researchers, academics, and Indigenous community leaders achieve collective consent varied greatly depending on their relationships, and their individual approaches:

> ***"…wading through and navigating through the political environment, a lot of those things actually took a lot of the time." Community coordinator***

Respondents discussed the importance of appropriate collective consent processes. University HRECs normally required some form of community endorsement for research with Indigenous communities. When it came to Indigenous health research, the following participants thought getting community approval was of higher importance than getting institutional approval:

> *"I didn't care what [the academic institution] said.* ***If the community didn't want me to do it then there's no way in hell I'd do it.*** *But, you know, that's ... at the end of the day that's, that's what true research integrity is from a cultural perspective in my opinion."* ***Indigenous researcher***

Researchers needed to have an in-depth understanding of accepted community decision-making processes to get community research approval. Many described the challenges of dealing with community politics, meeting community expectations and addressing both formal and informal processes to achieve approvals:

> *"And to be honest, an extra layer that I do worry about is* ***if there's a particular family or person in control and if you get along well with them or not.*** *So then it's like our or an internal politics, so I've always just tried to be really, not take any sides or anything, and anything that goes on here because* ***I want to keep a good relationship with that****. So I think on one hand, while you have your official processes,* ***there's also non-official kind of things that go on behind the scenes****…"* ***Indigenous researcher***

Support from an Indigenous community controlled organisations was a common method for getting approval for research. This usually came in the form of a formal support letter from the governing board.

> ***"When it comes time to actually do the research and you put in ... Especially around Aboriginal research, like, all you need is a letter from a community." Indigenous researcher***

In many circumstances defining or identifying Indigenous communities was challenging because who/what is 'community' was not straightforward. Some communities had diverse kinship and identity structures that potentially complicated the approval process:

> ***"There might be eight languages spoken in a community, right?" Indigenous researcher***

Further, representation of communities could be fluid, contested, and diverse:

> ***"Aside from the fact that even in a particular community have, however big it is, there's extraordinarily different voices…" Researcher***

Indigenous communities held diverse opinions and consensus was not easy to achieve. Decision-making could be ad hoc and uncoordinated between different community stakeholders creating a dilemma for researchers striving to get approval for their research:

> *"…there was diverging views. I don't wanna go in too much detail, but at the end of the day there wasn't consensus. And so, , I, I was fair to that dilemma about, , there wasn't consensus and, and how do you deal with that dilemma when there's within community non-consensus."* ***Indigenous researcher***

> *"…the key stakeholders are our, you know, our key Aboriginal organisations, it could be an Aboriginal service within a health setting. And then you've got a local- you've got some Aboriginal people involved in that. But there's no one- there's no communication from each group."* ***Community coordinator***

Indigenous participants in this study identified examples of community governance structures that were purpose built for research. In pursuing these partnerships

> *"...because that connection was with her, with her grandmother, or her gran- on grandfather… So it goes back to there.* ***So, she had that right to speak on that country****, except for [Indigenous nation]. And they don't understand that, 'cause they're all talking,* ***they'd come up there and talk big on their country. And that's a ... that's something that you don't do****. Which is why when I go to meetings, you're very quiet, you don't ... unless you're asked, then you speak. Not overtake a meeting, or whatever, or when it's not required, because you don't go and do that.* ***It's called respect. Respect goes a long way****." **Community coordinator***

### Getting collective consent from Indigenous communities

Sometimes formal agreements or MoUs were developed. An Indigenous researcher used Memorandums of Understanding (MOUs) based on the *guidelines* for two of their projects with an Indigenous organisation and a University to establish clear rules for the research.

> *"**But it's an agreement between, you know, the researchers and [the Indigenous organisation] and [the academic institution]** …so I just drew up the agreement based on the values and ethics guidelines for the NHMRC which states that each Aboriginal society, i.e. [the Indigenous organisation], and **the Aboriginal community have their own established values and protocols** and that six important ones are responsibility, respect, reciprocity, survival and protection, equality, and spirit and integrity. So that's the first part of the MOU." **Indigenous researcher***

An MOU was used by one Indigenous researcher to strengthen and clarify their Indigenous organisation's partnership with an institution.

> ***"So the research sub-committee which should have a board member, looks at it and goes through stuff that whether it's ethical, whether it's useful, whether it's worthwhile and then we would we would say, yes we agree or no forget about it. So that's the process." Community coordinator***

Managing multiple community approval processes was difficult for some researchers. Some respondents queried the amount of time it took to get approval within Inidgenous organisations:

> *"It went to the research subcommittee, then it went up to the CEO, then it went up to the board. And then the board looked at it and then said,* ***"Go back and double check with the [Indigenous organisation] research subcommittee." Indigenous researcher***

During the interviews researchers were asked how they respected authority of Indigenous groups. One group of researchers would not go ahead with research without specific approval from an Indigenous led regional ethics committee:

> ***"Actually, the executive won't sign any site-specific authorisation unless we have a letter of endorsement from the [Indigenous organisation ethics committee]. So that is a rule, he will not allow any research to happen without that letter. So that's a commitment he's made to the [Indigenous organisation]." Non-Indigenous researcher***

A participant recommended that Indigenous organisations incorporate thorough approval processes through their governing structures to ensure appropriate decision-making practices are undertaken to build a collective consensus:

> ***"[Y]ou need more than advisory group; you need your board.*** *Someone, you know, someone needs to lead it on the board. You also need to have a group of, a reference group; not an advisory group, a reference group that needs to be,* ***"Okay, I'm speaking on behalf of the organisation. We're saying this."*** *...It just needs to be more than one person's view."* ***Community coordinator turned researcher***

Getting research approval in places where community decision-making processes were fractured was challenging. This left some Indigenous communities polarised in their acceptance of the research.

> ***"Well there might be two opposing factions and one of them really wants you there and the other one doesn't, or you know a whole range of things that you've gotta kind of judge and guide for yourself." Researcher***

Lack of consensus often resulted in community tension. Some researchers were accused of 'shopping for approval' with different groups. This contentious approach to approval could lead to some communities vulnerable to being coerced into research. Participants also criticised instances where accepted collective decision-making processes were avoided or sidestepped, and executive approval was given to presumably expedite large research projects:

> ***"So, she, one person, approved something on a national scale and didn't do the right process. The person, the people who should have made that decision should have got back into the members meeting, and the members should have said "yes" or "no," not a, a single worker." Community coordinator turned researcher***

One Indigenous participant suggested impromptu engagement with relevant Indigenous community leaders can also be used to start a conversation about research. However, this approach requires an existing relationship a high level of understanding of community protocols and practices, and patience and perseverance. This would likely happen long before

any research projects had been discussed or organized and would be part of building a rapport and trust with a community:

> *"[Y]ou know, I'm not from there but I feel like they've adopted me and because I have embedded myself, my family and we are, we do have very close relationships so I feel like that's already there. Whereas possibly non-Indigenous researcher coming in, I mean I feel that they need to do that work to some degree. Like they shouldn't just expect that information so freely. And they do have to build the trust of the community."* *Past participant turned Indigenous researcher*

## Who speaks for Country?

Indigenous communities have multiple decision-making bodies, Indigenous organisations, and other collective groups to represent their interests – but who has the authority to approve research on behalf of the Indigenous community? Respondents also raised concerns about non-Indigenous institutions that created internal Indigenous review processes without appropriate Indigenous community authorisation.

An Indigenous researcher suggested formal traditional owner groups provided an appropriate structure for engagement. Furthermore, participants talked about the certainty of engaging with cultural leadership structures that have been defined by Indigenous communities themselves:

> *"And there's all ... one spokesperson.* ***One or two spokespersons, and that's the way it should be. Yeah, very, very structured.*** *And they discuss that before that big meeting, they just don't go in there like we do, invited and nobody talks. Those fellas already had their big meeting, and* ***they're very clear on what they want, they have selected people to speak and that's the way****, and that sorta structure is what we should be doing, because that is our traditional structures."* ***Indigenous researcher***

In relation to the First Nations in Australia, 'the right to speak on country' is a fundamental cultural protocol. Similarly, informed consent is a core concept of research approval processes – although this usually relates to an individual's personal consent rather than consent representing a community. Collective consent by Indigenous communities is usually done by an authorised traditional owner body or mandated through organisational approval. Complicating things further the concept of an Indigenous 'community' is multi-layered and depends on local interpretation.

Participant responses, reflected different interpretations of Indigenous community depending on the context within which the term was used. Definitions of Indigenous

communities were found to be contested by many participants and included different views on who had the "right to speak for country". This was true for both Indigenous and non-Indigenous participants in this study. The legitimacy of Indigenous community engagement was also disputed. Indigenous informants believed some researchers were not equipped to identify the appropriate Indigenous community members to engage with and questioned how this was determined:

> ***"So, it's interesting let's define community 'cause that's the first thing, well, who's community?" Community coordinator turned Indigenous researcher***

Researchers need to ensure they recruit the appropriate Indigenous community representatives. Identifying the 'right' Indigenous representatives can be a conundrum for researchers without any prior relationship with communities and/or without an understanding of the particular cultural protocols of specific communities.

This research highlighted the challenge of gaining collective approval in places with multiple Indigenous community authorities. It exemplifies how important it is to understand and identify appropriate approval processes recognised by the local Indigenous community

> ***"[A]s part of the ethical guidelines, they need to say, what organisations were supportive and what were, which ones weren't." Indigenous researcher***

Research proposals with Indigenous communities required thorough review, through Indigenous community decision-making processes. A few researchers described the development of Indigenous research advisory groups embedded within academic and government institutions to receive guidance on cultural appropriate research.

> *"[B]ut because we're a state-wide service here, there's no one AMS or peak body that represents all of the work that we do.* ***So we kind of didn't fit the standard model in terms of getting community advice, important guidance, helping us to navigate the process in a culturally appropriate, sensitive and responsive way."*** ***Researcher***

Some respondents disagreed with the institutionalisation of Indigenous advisory and approval groups. They reported that in some instances collective approval accepted by university ethics committees did not comply with their Indigenous community approval processes. Some participants believed it was just as important to record community disapproval of research in the ethical process. This was because they (within their own

communities) had experienced some research projects going ahead despite lack of consensus within their community.

Indigenous representation is a complex matter and Indigenous organisations, and communities have numerous ways of defining, authenticating, and mandating Indigenous representatives. A critical mass of researchers is widely seen as fundamental for Indigenous control of Indigenous research. But some respondents claimed that some Indigenous researchers were disconnected from Indigenous communities:

> ***"[T]here are a number of Aboriginal researchers out there, I believe within my heart, some of those are so disconnected from reality, because they got caught up in a system. …But they become so disconnected from their own communities or they haven't really grown up in their communities, but they're seen as the experts on Aboriginal issues, and people and that's just not right." Community coordinator***

### Unsanctioned community approval

Without proper guidance institutions might impose systems that potentially contravene Indigenous community protocols and create divisive research practices that impact community cohesiveness. A mistake or getting approval from the 'wrong' Indigenous community representative, or being cited in an approval without your knowledge, had the potential to cause conflict and disharmony within the community. Historically, this has been a challenging process for researchers to navigate.

> ***"[A]nd proper protocols and permissions not being followed, you know. That's a big no no in our community." Community coordinator***

Many of the Indigenous interviewees, particularly those in community coordinator type roles within Indigenous organisations, felt it was inappropriate for Indigenous people based in Governments or universities to green light research on behalf of Indigenous communities. Although they were sometimes also part of the Indigenous community they were seen as agents working on behalf of institutions, and participants believed they did not have executive authority to approve health research in Indigenous communities. It was assumed that their institutional responsibilities hindered their ability to act in the interests of Indigenous communities:

> ***"And them blackfellas from government ... You know, that's ... I don't care if you work for government, but don't speak on our behalf. You don't ... You can't go***

> ***into government and then speak. You work for government." Community coordinator turned researcher***

The 'institutionalisation' of research approval processes emerged as a significant area of concern. An Indigenous researcher inferred institutions in her region were engaging Indigenous researchers to inappropriately approve research:

> ***"Yeah, but then they'd just be able to say all right so I'll just go to that doctor at [research institution] who says she's Yorta Yorta and she can sign off of that." Indigenous researcher***

Some institutions have been accused of strategically appointing individuals to their Indigenous research advisory groups to fast-track approval processes. Ethical review and approval processes have been accelerated due to the pressure of external funding timelines, unfortunately this approach also effectively circumvents community approval protocols. It is important to note that studies that have Indigenous researchers are still required to engage with communities through the research process:

> ***"Or they might have one Aboriginal academic in a team working with them. But the discussion and the consultation with the members haven't, or sorry with the community hasn't yet happened." Indigenous researcher***

Despite the existence of strong ethical guidelines there are systemic problems with how Indigenous people are empowered through the research process. Some institutions embedded Indigenous representation in their systems without appropriate community accountability mechanisms. Internal Indigenous review panels and committees provide a platform for Indigenous people within the organisation. However, it is not always clear who these Indigenous review panels represent, and some Indigenous researchers have questioned whether these models have been appropriately mandated for community approval of research. One Indigenous researcher felt these types of advisory groups, assembled by institutions, were not adequate:

> *"They can put in the, yeah the thing to go to the reference panel and get feedback on the application and* ***then they say that's Aboriginal community consultation****. Now, the take on it and it's a bit of a confusing thing. So I kind of I'm a bit sensitive about how this has been recorded and what I'm being quoted as saying because I've upset some people at [academic institution] by saying* ***that it is absolutely not if it's all spaced out of a university, and it's not the same as community consultation and that they absolutely cannot use that as saying it is Aboriginal governance…" Indigenous researcher***

Respondents in this research also scrutinised the role of Indigenous researchers that worked within institutions. Some participants asserted that some Indigenous researchers did not have the right to speak for Indigenous communities. Despite, their research expertise and knowledge they did not have the authority to speak on their behalf through their academic roles:

> ***"He might be a good researcher. …But he does not speak on behalf of Aboriginal people." Community coordinator turned Indigenous researcher***

Some respondents felt there was a lack of cultural accountability without clear cultural connections and obligations within a community. Some participants with experience as researchers understood they did not have cultural authority to in certain contexts and self-regulated:

> *"I was just really conscious that I didn't wanna speak for anybody."* ***Indigenous researcher based at an institution***

The issue of researcher independence within these agreements is rarely accounted for and raises complexities around data ownership and sovereignty. It can also create internal conflict between community obligations and academic aspirations for Indigenous researchers with existing community relationships.

> *"…trying to sort through this stuff that I'm trying to do with, with this research project was around, it was called an* ***agreement making space****. I think that came from the NHMRC material that I was looking at, where there was a, there was a specifically articulated um, information about the requirement to actually* ***formulate an agreement making process between researchers and participants and community****.*

## Community objection to research

Examples of communities objecting to research were provided by some respondents. In the following case an Indigenous researcher advised their Indigenous research partner to stop a project because due to ethical concerns they had:

> *"I tried saying to her, well look,* ***I'm not actually happy continuing to work on this project****, I'm not happy for it to go to print, so I'm gonna hold off on working on this document until we sort these issues out.* ***So I said I'm gonna put a hold on it until such time that we can sort through some of these issues that are really bothering me. They [Indigenous organisation] backed me every step of the way. They ended up investigating the project and calling it to a halt." Indigenous researcher***

Alternatively, some researchers continued to forge ahead with research proposals even though they were rejected by community leaders. This was a concern frequently expressed by many Indigenous community members interviewed for this study:

> ***"And the other thing is, like [Indigenous researcher] said, if they're told not to do it, then they don't do it. Yeah, and not see it pop up in 12 months' time as a completed project." Indigenous researcher***

Respondents also expressed that Indigenous approval processes did not have the same level of authority as university ethics committees:

> ***"[I]f you're doing mainstream to get your ethics approval and they have status as a legal Body to give approval. But what do we have as Aboriginal community that has status to say Yes or no at the same level?" Indigenous researcher***

Institutions regularly shopped research proposals to Indigenous communities after they had already determined the research design and completed the ethics application:

> ***"…And that's the other red flag for me is when someone will come through, come to you with the research project after the ethics application. …If you come up [with] the ethics application, you're already tied into what you need to do." Community coordinator turned Indigenous researcher***
>
> *"…but rather than go away and say: "Yup, no, the community won't support our project",* ***they'll just go find somebody else in the community that will say yes.*** *Rather than ethically taking on the concerns of the community which is what you would think the research ethics should be about."* ***Indigenous researcher***

## Summary: Chapter nine

The Indigenous community control sector were the main stakeholders providing research approval in this study. Researchers sometimes established MoUs and formal agreements with communities but often they were just provided with a letter of support to gain approval. Indigenous community controlled approval processes compelled researchers to develop stronger relationships with Indigenous communities to support their research to proceed. Indigenous communities and regional peak bodies established protocols for engaging with and getting approval from their communities. However, Indigenous community-led processes were deemed 'unnecessary' or irrelevant to some researchers. It was clear from responses that participants believed that Indigenous mechanisms for approval sometimes challenged the authority of formal institutional structures.

Researchers sometimes struggled to navigate through numerous community protocols with different community stakeholders. Lack of coordination was seen by some as an issue with community decision-making processes that slowed down the research process. However research was often not the priority of Indigenous communities. Also some communities had multiple decision making processes which meant gaining consensus often needed time to incorporate different viewpoints.

Respondents reflected on scenarios where they felt inappropriate authorisation for research had occurred. They suggest that these had occurred either through ignorance of the ethical process or through efforts to fast track engagement and approval. The discussions and questions about legitimate representation were a constant theme throughout the research enquiry. Varying opinions were given about Indigenous representative mechanisms formed by non-Indigenous institutions.

Organisational approval through Indigenous community structures could also be contentious. Respondents noted that it was difficult to achieve universal permission to commence research in regions where there were complex community governance arrangements. There were also inconsistent processes applied through different levels of Indigenous representative authorities. Processes that included multiple complex levels of approval made it difficult to develop standard practices to facilitate organisational approval for Indigenous health research. Some respondents questioned whether written community clearance prior was adequate and suggested more formal agreements were required.

The presence of Indigenous people in research teams does not mean automatic community collective consent for a project. The researchers, white and black, still had to go through the necessary community protocols. Although some researchers and institutions used Indigenous researchers specifically to expediate community research processes they sometimes failed to understand the complexities around Indigenous representation and authorisation processes. How Indigenous people represent Indigenous communities', and their level of authority is nuanced and depends a lot on context.

Institutionally based Indigenous review and approval mechanisms were considered an alternative to community-based ethical review models. Some respondents challenged the impartiality of an *internal* Indigenous review model and questioned how they were established. The implication suggested these models for *internal institutional approval* would only be appropriate if Indigenous communities were involved in the inception of the model and process. However the respondents indicated that there was lack of transparency or information as to how these models were instigated or convened. Some respondents believed that the introduction of such models to enable institutional approval by some universities aimed to monopolise Indigenous health research in their regions. However, it's also clear that Indigenous participation, empowerment, and leadership is critical for strengthening university ethical procedures in relation to Indigenous health research. Trusted relationships would be essential in order to establish strong research partnerships and clear protocols in the conduct of these models.

Participants questioned whether Indigenous advisory groups specifically established within universities could truly be impartial in their ethical review of research in Indigenous communities. It wasn't clear how Indigenous committees were independent from their institutions. Despite this model of increasing Indigenous involvement in the ethical review and approval process through internal committees, also it was perceived by some respondents that such involvement enabled institutions to evade important community-controlled approval mechanisms. Without proper rules for establishment these internal committees further entrenched institutional control over Indigenous health research. The process does not always necessarily foster open and honest critique. Internal processes could potentially isolate Indigenous people and unduly pressure them into making inappropriate research decisions on behalf of Indigenous communities.

# Chapter ten: Creating equal research partnerships

Respondents were asked about Indigenous community involvement in determining research design, including being involved in making decisions about the development of research priorities, conceptualisation, and objectives. Questions in relation to recruitment, collective decision-making, and project modification were also used to prompt further discussion. As a follow up revised questions about modification of research were used in later interviews with researchers and community coordinators to further explore the concept of equal leadership. Indigenous participants in this study shared their understanding of research partnerships between Indigenous communities and researchers.

## Empowering and privileging Indigenous communities and participants

A common theme emerging from the interviews was the concept of community empowerment through research. Many believed Indigenous-led research had the potential to empower the community. It was argued the community benefitted more from inclusive research that Indigenous people felt ownership of. When research was grounded in the community it created a ripple effect that created other tangible benefits, such as employment:

> *"If you empower the communities to be the lead, there's such a ripple effect that comes from that and that is the empowerment of Aboriginal people feeling included." Indigenous researcher*

Researchers wrestled with the pressure to benefit Indigenous communities in their research. For some researchers the ethical requirements prompted further consideration and forced them to reflect on how their research design, methods, procedures, and methodologies truly privileged the Indigenous communities they engaged with:

> *"…[F]or me that stuff [Indigenous methodologies] was really good 'cause it spoke to the current concerns and the yarns we were already having, you know. Was it gonna be* ***privileging Aboriginal voices, Aboriginal world views****. Were we taking into consideration the community's needs.* ***Was it going to benefit the community****, what I was proposing?"* ***Indigenous researcher***

Indigenous people and communities are no longer satisfied with being an equal research partner. They want to take control of Indigenous health research and determine their own community grounded priorities. These findings overwhelmingly reinforced the aspirations of Indigenous communities to lead Indigenous health research conducted with their people:

> ***"We should have complete control of any research that happens in our communities. …Complete control and authority over any research." Past participant***

Indigenous researchers interpreted equal partnerships as Indigenous-led research. This included being involved in research output activities:

> ***"…when it comes to authorship, when it comes to presentation, when it comes to ethics governance, when it comes to actually doing research, formulating, designing research, it's gotta be Indigenous led." Indigenous researcher***

Indigenous respondents largely believed research practices and outcomes were strengthened when led by home grown Indigenous researchers. Empowering Indigenous communities to lead research logically amplified the voice of Indigenous people, created more inclusive research, and mobilised community support:

> *"[T]**here's always gotta be Aboriginal champions**, you know, who are central actually, action ... I call 'em **action men or action women, who actually make things happen.** Um, you know, key people ... I've had a couple of ... I don't, don't know if I should mention names 'cause we're recording, but **key champions who, you know, were well known to community for driving research, and deadly Aboriginal researchers."** **Indigenous researcher***

Community researchers with linkages to Indigenous communities had a greater understanding of their community protocols and practices. Indigenous participants, researchers, and coordinators felt more ownership and control over research that was controlled by Indigenous community partners. Perhaps, because these Indigenous partners were part of an existing cultural accountability framework. Community researchers had existing community relationships and were keenly aware of their community obligations:

> *"…so the good thing about involving staff is like culturally wise is there's a [pause] what worked was there was a sense of ownership by the whole, organisation. Um, and all the projects I've been involved in"* ***Indigenous researcher***

> *"And I think that, because there was such, these were big changes the fact that the community had ownership over it and they ran and drove it, they accepted that change a lot easier than it being forced upon them."* ***Community coordinator***

Some respondents stated that they had more confidence in health research projects when they were led by Indigenous researchers:

> *"…there was so many Aboriginal researchers involved in the project, in the facilitation of the projection... That there, there were few, few elements in the project, or if any that didn't have Aboriginal voice in them."* ***Indigenous researcher***

> *"My experience was positive because it was an Aboriginal person and Aboriginal led research and I think that made a difference."* ***Past participant***

They suggested that projects led by Indigenous people were more likely to embed Indigenous conceptual frameworks and ethical practices:

> *"If it's Aboriginal led, so you've got an Aboriginal CI then it's built in and it generally, you know, that if an Aboriginal CI's running the research then they're gonna have culturally appropriate ways in which they're gonna feedback to community. Just, this is my experience."* ***Community coordinator turned researcher***

Indigenous researchers adopting Indigenous standpoints reflected on their own ethical approaches and on their role in the development of research:

> *"**I'm creating this research because it's a gap that I see, but is it something that the community needs as well?"** My whole kind of notion is, and the research is based on that history as **I need to be led by community when I'm developing my own research ideas.** And I still felt like **it was partially, swayed by what my supervisors wanted and what I kind of saw was a, was an issue.** But really like one member of community isn't enough to form a project. So I had an issue with that."* ***Indigenous researcher***

Some Indigenous researchers wanted to do research 'in collaboration with their communities:

> ***"I'm doing research with my community, not about my community." Indigenous researcher***

Many Indigenous researchers interviewed in this study purposefully conducted their research privileging Indigenous voices:

> *"But the one thing I did do in the thesis as a way of privileging the, the Indigenous voice, and again I do this in all of my research, even when I'm teaching, first thing I do when I get up there is I'll start talking in [language] …Get into the real stuff, the real knowledge."* ***Indigenous researcher***

Indigenous people innately understood Indigenous values systems and would overlay these on institutional ethical requirements:

> ***"…you go back to the, the Aboriginal lens of, of, what? Respect and all that sort of stuff is…" Community coordinator turned researcher***

Participants paid tribute to Indigenous organisations that lead Indigenous health research and brokered relationships with mainstream institutions and guided them through ethical research processes with their communities:

> *"But there are also great examples where they have, you know, actually sat down and, not always but mostly there is a strong Aboriginal research in that unit or in that organisation that's guiding that process."* ***Community coordinator turned researcher***

Community based Indigenous researchers were eager to promote community participation and ownership of their research. They made a concerted effort to inform and involve Indigenous community members in their research processes:

> *"…it's built into that research that at every step of the way they're either involved in it or their getting feedback immediately after any step, every single step. So they're actually driving it themselves to be honest."* ***Community coordinator turned researcher***

They wanted their community to support their research and feel valued for their contribution:

> *"…make community feel like they're connected with my project. And I think the other thing, to, to, they, I think actually feel good supporting me, like, (laughs), I don't know, you know because they, they're involved. And so they're on the journey with me, I'm not actually alone."* ***Past participant turned Indigenous researcher***

Community priorities were addressed by research conducted by Indigenous organisations and Indigenous researchers because they listened to what the community wanted. They actively took direction from Indigenous community members, and this fostered community ownership and investment in the research. Indigenous researchers and organisations would often wait until they were invited to support research proposed by their communities:

> *"…we're just saying, no, you choose, you tell us what, you know, your community, how do you want to structure this. And we'll always do what the ACCO and the community want."* ***Community coordinator turned Indigenous researcher***

> *"A lot of the research we do only because we have been asked to do it. It's not what we set out to do."* ***Indigenous researcher***

> *"…so it comes from an Aboriginal woman, woman who's grown up in the community, understand the community needs, is the one that proposed that initial idea."* ***Indigenous researcher***

In some examples research priorities were proposed and driven by Indigenous communities themselves. Indigenous peak bodies and other research programs by Indigenous researchers supported community-driven research by delivering research capacity building workshops:

> *And so now* ***what we've done is facilitated some workshops****, Aboriginal people to look at the data. We got ethics clearance for those researchers to show Aboriginal*

> *community data and* ***for the community to prioritise what they want to do and how it fits within the guidelines.*** *"* ***Indigenous researcher***

An Indigenous researcher established community driven research practices because they believed 'institutionalised' Indigenous health research conceptualised and driven by universities was fundamentally unethical and exclusionary and therefore could not deliver adequate outcomes for the community:

> *"So we've gone the other way. We've been in community and come back, whereas most people are building from an established body of work. And I, my argument is that, well, that's all institutionalised and that model is actually not going to be able to reach it back. That's good for some research problems. But if you're dealing with our marginalisation and exclusion where it's antithetical to an institutional base."* ***Indigenous researcher***

Community driven collaborative research approaches were widely supported with participants advocating for more support for Indigenous communities to conceptualise their own research and determine their own research priorities:

> ***"I think community have to be empowered [pause] to make a decision about um, what gets researched in their community. …rather than someone with his own research project come in and be of benefit."*** ***Past participant turned Indigenous researcher***

From the experience of participants, a more invested and empowered community encouraged broader community acceptance and support for research findings:

> *"I think the best one is, the tackling Indigenous smoking. In fact I can't, that, that's something I'm proud to say I was a part of at some level with [Indigenous organisation].* ***Because it was community driven. Even the research connected to it was very heavily community driven. Which made communities want to change,*** *which the data started to show a decrease within people smoking."* ***Community coordinator***

Respondents recognised the importance of building the research capacity of their Indigenous communities to ensure they had the adequate expertise to contribute, control, and critique Indigenous health research. They advocated for more Indigenous people to study higher research degrees to be able to disrupt inadequate structures and call out systemic inequalities. Indigenous people needed institutional support to develop research tools to be recognised as equals:

> ***"What can we do? We're doing it, like, we're doing PhD's, we're learning the language that we need to challenge their systems****. So, that's what we are doing*

> *and that's gonna be hard and we've seen some really terrible things within the [academic institution].* ***And we weren't strong enough, at that time, to challenge them. But I think the, the tools that we've learned and now, like, we're building a team within the [Indigenous organisation]*** *… But it would be the community that will go to [the academic institution] and say: "You're operating unethically in our community". And that's what has to be done. (Pause)* ***And I think we're doing it, we're getting all of the tools that we need to go in an actually do that. You have to learn their system to be able to challenge it, I think."*** ***Indigenous researcher***

According to experiences of Indigenous participants shared decision-making was often promised in ethics applications but infrequently put into practice. Yet, to create equal partnerships researchers and institutions needed to share control of research:

> *If you're a white fellow and you wanna work in that Indigenous research space and do it ethically and morally, in a sound way, you've actually got to surrender that.* ***You've got to surrender that privilege, you've got to give it up."*** ***Indigenous researcher***

Indigenous people wanted academic institutions to hand the reins to Indigenous research over to Indigenous researchers. They wanted non-Indigenous researchers to take a step back from Indigenous health research. To allow Indigenous researchers to fill the void:

> ***"So, as part of that ethics, is also the university relinquishing the power that they have."*** ***Indigenous researcher***

> ***"…if you've got a white researcher than they need, they need to step back from the project and get someone else in to do the work I guess."*** ***Indigenous researcher***

### Making researchers accountable

There were some examples of Indigenous-led monitoring and evaluation of ethical research. A few Indigenous organisations developed internal functions to review and approve research projects and monitor research partnerships. These accountability mechanisms have arguably been developed to shift control of research back to the community. An Indigenous community organisation incorporated research review and monitoring processes into a staff member's responsibilities because they felt it was important for them to have oversight of research that took place in their community:

> *"…****in my role at [Indigenous organisation] we have probably 15 active research projects happening****. And, so* ***I have to oversee those****. And we probably get at least two requests a week to review potential research opportunities for our sector. I have to say most of those we wouldn't recommend probably. …****we do it because***

***we think it's really important that someone has oversight." Community coordinator turned Indigenous researcher***

Community-led organisations (with the resources) actively created their own space to scrutinise research from a local cultural perspective. They reviewed research proposals to ensure community decision-making and cultural protocols were integrated into projects:

> *"Well they questioned the research, they questioned the project, they questioned the manager, they- they went through the normal grilling of doing all the checks. So looking at all the cultural protocols, all the cultural safety stuff, who are you talking to?" Community coordinator*

Within these community-controlled models researchers were expected to adhere to community accountability frameworks and report back to Indigenous partners regularly throughout their research. Accountability mechanisms were established to ensure researchers reported back and did what they said they were going to do.

One Indigenous community had several meetings with researchers to review findings in real time and provide input into how results were released and presented. After they get ethics approval it is up to academic researchers to follow through with their proposed ethical procedures. Moreover, there were limited tools to evaluate the ethical performance of researchers: An Indigenous researcher noted that further development of Indigenous community research protocols and research governance models were needed to prevent research exploitation:

> *"…overarching, we don't have any governing process around ethics protocols. And this is something that I've tried to develop and convince community they need to do to stop getting this type of exploitation happening. 'Cause I've been there many times when the exploitation's taking place." Indigenous researcher*

## Partnering with Indigenous organisations

The role of Indigenous community-controlled organisations (ACCOs) as community decision-makers was recognised by most participants. Aboriginal bodies specialising in health were especially relevant. One Indigenous researcher believed that Indigenous communities were 'highly self-regulated' suggesting that communities themselves would determine the protocols and processes that researchers should undertake. An Indigenous community coordinator talked about the importance of organisations being able to review and take control of research on behalf of the community. They outlined how their Indigenous organisation managed research approvals through their existing governance structure:

> *"The best-case scenario is that, [Indigenous organisation] has been consistent in this, a research sub-committee which reports to the board. And in the end. We have, we think the board should make a decision on whether research [is approved]…"* ***Indigenous community coordinator***

However, who was able to represent and speak for Indigenous organisations was also a question that was posed by several participants. Situations where non-Indigenous staff of Indigenous organisations approved research projects without including Indigenous community members was seen as problematic. An experienced facilitator of community research projects thought proposed research needed to garner broad community support:

> *"As I said, as I said if you've got a non-Aboriginal CEO that person may go in there thinking, "Okay****, I know what's best for this community, I've been in this job for five years."*** *****That's not how research should work****. Research is about capturing the stories of individuals and communities.* ***I don't believe that one person should be going in at any point of research, saying what's best for everyone." Community coordinator***

Others scrutinised the research knowledge and experience of some Indigenous organisations and raised concerns about how researchers instigated community research projects. They were apprehensive about the level of research expertise within community organisations and queried who had the authority to provide community research approvals:

> *"…****they need to meet and engage with the right people****, not just, you know, just because someone works for an Aboriginal organisation doesn't make him good at research."* ***Community coordinator***

Likewise, it was argued that organisations were merely a mechanism to organise and represent the broader Indigenous community, and that ensuring community voices were heard was more important than the actual entity:

> *"…[P]eople have this misconception out there, that if you're working with an Aboriginal organisation, then you're representing the community, I don't agree with that. Organisations are a structure, communities are humans."* ***Community coordinator***

An experienced non-Indigenous academic talked about the inconsistency of community approval processes, one size did not fit all. Navigating additional organisational administrative procedures within different community settings caused consternation because it could potentially delay the research and overburden research staff:

> *"But, you know, some you would write and you would get a letter back in,* ***in a couple of days say yes****, this sounds really good. We'd be really interested to do this.* ***And others say, well here's our forty-page form and uh, it's got to be submitted by such and such and the meetings are held quarterly." Researcher***

This perspective fails to comprehend the importance of community agency and respecting the rights of communities to be informed about proposed research programs before they approve them. There is a misguided underlying belief that these processes are unnecessary because researchers and institutions know what's best for communities.

The structure of Indigenous organisations provides a logical and suitable way to facilitate research with Indigenous communities. And many do. However, the way this happens varies depending on the resources and capacity of each organisation. And many require additional support to evaluate and contribute to external research agendas.

### Establishing Indigenous research reference groups (IRRGs)

Indigenous advisory groups or Indigenous research reference groups (IRRGs) were often established to help guide and oversee research projects in Indigenous communities. Advisory groups were often used so Indigenous partners could formally contribute to research. Indigenous advisory or reference groups usually comprised of staff, board members of participating Indigenous organisations, and Indigenous community members with relevant topic or research expertise. Some institutions and some Indigenous organisations had established ongoing research sub-committees for the purpose of supervising research. Others were created specifically for individual research projects. Though, all had a similar role to monitor research and advise researchers.

There is a growing number of research institutions and Indigenous organisations developing their own internal Indigenous advisory groups to review research proposals and manage research. These findings illustrate how these committees operate and function according to the experience of Indigenous participants. Indigenous-led steering committees or advisory groups comprising Indigenous elders and community members were established by some researchers. These groups were empowered to review and provide feedback on research practices, including engagement and research design, as well as raise concerns:

> *"****I think even just having a steering committee.*** *I think it would be good like if someone,* ***someone had an issue with a research project*** *that someone was conducting interviews like a participant that is like an Aboriginal person.* ***You know***

***maybe an elder or someone that that person can talk to that about their concerns." Indigenous researcher***

Indigenous research reference committees were formed first and foremost to protect the local Indigenous community. One community coordinator explained the role of an advisory group in their community:

***"Well they questioned the research, they questioned the project, they questioned the manager, they went through the normal grilling of doing all the checks.***

Some advisory groups were not Indigenous specific but incorporated Indigenous people as members. A non-Indigenous participant described how they had established an advisory group, with Indigenous representation, supported by donors, from the beginning to monitor the research:

*"…we have had an advisory group all, all along. And that was in part put in place by our donors to make sure that we weren't wasting our, their money. From day one it has had at least one, usually two Indigenous people."* ***Non-Indigenous researcher***

Some respondents suggested Indigenous advisory groups had no real veto power over funded research:

*"And, so,* ***your subcommittee is really not worth the piece of paper it's written on*** *because they know ... It's actually ... It doesn't have no power. And actually, you can't, you can't actually sit there and actually disagree or refuse something because you've got a vested interest."* ***Community coordinator turned researcher***

Respondents wanted advisory committees to be valued and to be acknowledged as authentic contributors. To move beyond tokenistic endeavours and rhetoric:

*"…so how do people value what we do as advisory groups and- because it's not just that we're here to do the tick box thing. It was to be a- a real thing."* ***Community coordinator***

Some participants felt reference groups didn't have the power to hold researchers accountable. The authority of Indigenous advisory committees was questioned by some respondents. Participants discussed the limited control reference groups had over researchers:

*"But I think the difficulty I have, like,* ***who holds them accountable*** *is the thing and* ***what's that mechanism that controls them****. Like is it a kind of like reference group? Or It needs to be uh.* ***It needs to be something that has powers. Not just a***

> ***reference group*** *where we'll just check in to see if it's all right. They need to have some sort of power. To say yes or no. And that be it."* ***Past participant***

Another participant's experience as a member of a reference group left her with concerns about the research. She felt that reference groups were not being utilised properly and were undervalued:

> *"Because what's happening with this project is- is* ***there are some red flags popping up.*** *So, where there's an Aboriginal advisory board involved in this project, it's like um, I think* ***there's not a lot of understanding around the way to work with the Aboriginal community, and the advisory group. And that you're there to seek their expertise and guidance…" Community coordinator***

Some researchers selected Indigenous committee members without adhering to local cultural consent protocols. Formalising Indigenous consent processes within institutions without appropriate permission.

Conflicting interests were also identified as a challenge for research committees based in Indigenous organisations, placing a burden on committee members from outside of the organisation:

> *"It's the same as the subcommittee out. It's, you know,* ***leveraged to death…*** *You know?* ***[committee member] works for the organisation;*** *[he] just thinks about what ... You know?* ***[staff member's] part of the research*** *... So, who do you actually have on there?* ***Who's going to critically analyse stuff?*** *Me. And I can't just take that all on. It's just like, "Whoa!"* ***Because it's not fair." Indigenous researcher***

Participants felt that advisory groups needed broader representation and needed the authority to make decisions on behalf of Indigenous partner organisations. Institutionally embedded Indigenous panels were seen by some as a ploy to approve Indigenous health research more easily. Some participants felt that Indigenous advisory groups within mainstream institutions undermined Indigenous community governance. They also challenged the identity of individuals on these groups and questioned their accountability to the Indigenous community:

> *"****I think they employ people like who's up there with weak identities****, but although they identity as Aboriginal,* ***they validate an Aboriginal approval. Even though they're not part of our community****." Indigenous researcher*

Some universities have also established their own internal mechanisms for Indigenous-led ethical review of research. A researcher working at a research institution described how they

decided to develop an Indigenous research reference group to review research proposals. This group was established in partnership with an Indigenous organisation:

> *"…it was decided at that point that we could establish a group called the Aboriginal reference group and to invite key representatives from key peak bodies to provide representation on this statewide committee.* ***And from there we would collaboratively develop terms of reference for the group*** *and establish a way forward,* ***which had to be endorsed by the [Indigenous organisation]."*** ***Researcher***

## Empowering Indigenous researchers

Including Indigenous investigators on research projects was an effective way to share control over heath research with Indigenous communities'. One Indigenous respondent in this study believed that Indigenous investigators were naturally more accountable to community protocols:

> *"…that's why I think Aboriginal CI's (laughs) know what they gotta do... to really make this work with community and feedback to community."* ***Community coordinator turned researcher***

A non-Indigenous researcher clearly described the different levels of accountability expected between her and her Indigenous colleagues. They recognised the additional responsibilities Indigenous people carried because of their relationships with their Indigenous community:

> *"…****being Aboriginal men or Aboriginal you're held to account by the community****. As a non-Aboriginal person I don't have that same level of scrutiny. …what holds me to account is my colleagues and my friends, and you know my relationship with the community."* ***Non-Indigenous researcher***

Indigenous academics also described the internal struggle between their various community and academic responsibilities. At times academic expectations made it challenging for Indigenous researchers to uphold their commitment to community values and protocols:

> *"…****that's the big challenge for us as Indigenous researchers is how do you find that fine line between the two?*** *How do you dip into both so that you're creating material that's gonna be useful and accessible to community, but also it's gonna give you some standing as an academic? …****it's bloody hard to, to, to stand with community and stay with community and get ahead as an academic." Indigenous researcher***

Academic institutions expected their Indigenous researchers to know what the community wants, suggesting consultation wasn't necessary:

> *"…But it's not fair to put so much pressure on them to just know what the community wants. And to feel like even though they might know that, to go and*

*not feel like they've necessarily had that consultation process."* ***Indigenous researcher***

The accountability of Indigenous researchers was a contentious issue for many participants. It wasn't always clear to participants how some Indigenous researchers based at universities met Indigenous community obligations and research priorities:

> ***"Like you go in as an Aboriginal researcher with an idea of a great project. But it doesn't necessarily mean it's going to meet the needs of community." Indigenous researcher***

Indigenous academics were also advised not to be complacent when doing health research with Indigenous communities. Indigeneity does not guarantee ethical research practices. Indigenous organisations (or partners) with community obligations should be included to ensure research was carried out appropriately:

> *"…I think as soon as the researcher has gone, no matter what cultural background, they're from the research is out of mind, if it's not by an Aboriginal organisation. Some Aboriginal researchers get away with that as well. You know, it's not like just cause you're Aboriginal, you're going to do it all really well. The guidelines are on a bit of a spectrum where you're meeting it well compared to just kind of, scraping it through."* ***Indigenous researcher***

It was important for researchers to stay accountable and follow community approval processes, even if they were Indigenous people:

> ***"I don't think its good enough personally, to say that I'm an Indigenous researcher and that I should just go forth and do my research. I think I should have someone that checks my work and checks my project" Indigenous researcher***

Indigenous respondents described how some Indigenous advisory group models incorporated into institutional ethical review processes. In one setting an institution supported the Indigenous review of applications and also supported the concept of an independent model. On this occasion the institution engaged an Indigenous researcher based at an Indigenous organisation to support recruitment of Indigenous members to their HREC:

> *"I have worked on building capacity within the [institutional] HREC to review actual research and they've got a community member already on there, but I've also put [Indigenous community member] on there as a young Aboriginal leader, emerging leader. Onto that HREC so, you know she then reviews [applications]…"* ***Indigenous researcher***

As a result of this partnership the institution was open to exploring how they could support a transition into an independent ethics committee controlled by the Indigenous community, which they could utilise to review the health research they were doing:

> *"[the institution has offered to] house our research and governance office within the office that just looks at assessing Aboriginal research applications and then if we can, if we're successful in getting the funding from government and I think it will happen, it's not if it's when then that can be moved out to an independent, as an independent group. But we needed to have it sitting within an existing [institution], it costs a lot of money to run a research and ethics, you know, office."*
> ***Indigenous researcher***

Collaborative arrangements between research institutions and Indigenous organisations clearly had the potential to strengthen HREC review of Indigenous health research proposals and empower Indigenous communities in the process.

On the other hand some respondents' criticised university based Indigenous advisory groups because of their perceived lack of autonomy. Another regional university delegated the review of Indigenous health research ethics applications to their Indigenous health research group. An Indigenous community member involved in this advisory model applied rigorous cultural assessment of research proposals but felt the institution was combative to this approach:

> *"Different people would comment, but, you know, some of the Aboriginal ethics applications, I was in shock horror; I was in shock horror that Aboriginal people could let this go through, and probably why they shut us down at [the academic institution] because I was questioning many, it was actually about questioning too much stuff about ethics..." Community coordinator turned Indigenous researcher*

### Disempowering Indigenous communities

According to many of the Indigenous people involved in this study too many Indigenous health research projects get funded, reviewed, and approved without appropriate Indigenous contribution. Indigenous health research is still being controlled by non-Indigenous researchers and institutions. Indigenous people are still regularly excluded from contributing to the design, development, and direction of Indigenous health research projects. Indigenous organisations and Indigenous researchers have been used tokenistically, disempowered from making decisions, consulted too late, used for their community networks, and been undervalued for their contribution:

> ***"But they can't see the benefit in actually working with us and valuing our contribution. So rather than that, we'd just get excluded." Past participant***

Researchers continue to exclude Indigenous people from Indigenous health research. Frequently driven by mainstream research agendas, researchers continue to conceptualise (and receive funding for) Indigenous health research without partnering with Indigenous communities:

> ***"…lots of people who have no relationship with Aboriginal communities get approved for grants" Indigenous researcher***

> ***"It will be an Aboriginal research grant and they have no background in Aboriginal research and don't have these connections and then you get two years to complete your project. …*** *[researchers] push ahead for getting ethics as soon as they can to get the data and to write the thing up."* ***Indigenous researcher***

Indigenous respondents implored researchers to engage with communities properly to gain a thorough understanding of their research needs before they designed their Indigenous research projects:

> ***"By undertaking community consultations and understanding what the community's needs are. Not going in and dictating what they think is best for them." Community coordinator***

Similarly, a past participant of an Indigenous health research wondered if the research priorities were actually community priorities:

> ***"…is it in line with the community's priorities? …are [you] collecting something that this community wants to know?"*** ***Past participant***

Unfortunately, the findings reinforced the stereotype of institutions imposing preconceived Indigenous health research programs onto Indigenous communities. Paternalistically determining what's important for Indigenous communities and excluding Indigenous perspectives manifestly disrespects, undervalues, and minimises the authority, expertise, knowledge, and contribution of Indigenous communities. According to some respondents researchers sometimes researchers failed to engage with Indigenous communities to identify research priorities, and pre-planned their research:

> ***"We had no say in how it was going to be done or anything they already had their plan."*** ***Community coordinator***

Paradoxically, one researcher thought the act of engaging with communities before any research funding is confirmed might be considered unethical conduct:

> ***"…just the whole thing that they require you to consult with the community prior to putting anything through, prior to knowing whether, you know, you've got stuff fixed in stone, I think it's quite an unethical thing in the first place." Researcher***

Government funding processes sometimes caused issues due to accelerated timelines for research proposals. After research was approved and funding secured some researchers would then seek out relationships with relevant Indigenous communities to contribute to their research within their expected timelines:

> *"…so you don't have to act non-professionally just because you've got tight timelines, but* ***you should probably not apply for that grant in the first place. If you don't have any relationships to call off****. And that's where people get in trouble. So if you've got already a great network and you can tap into that, you can probably work with a timed timeline. But the government is really bad with it. They will all of a sudden give a researcher, you know, $200,000 to I'm just thinking here. To do a project with injecting drug users and can you have it done by the end of the financial year? Well no."* ***Indigenous researcher***

Participants observed institutions that successfully obtained funding grants, attempt to impose predetermined research projects on Indigenous communities:

> ***"…trying to sell an already designed research [project] yet knowing it's actually could be of great value, but then trying to sell how you work with the Aboriginal organisation." Indigenous researcher***

Some Indigenous respondents claimed that in their past experiences some researchers used their academic authority to exclude Indigenous people from research projects:

> *"Yeah, because that's the other thing is we've been excluded off Aboriginal research projects."* ***Community coordinator***

Many Indigenous people felt they risked being rejected and outcast if they disagreed with or challenged the authority of non-Indigenous researchers with superior institutional status:

> *"So, the process at the moment is if you don't agree with what they're saying in the lens by which they're noticing or writing out their data, then you just get excluded."* ***Past participant***

Indigenous researchers themselves were wary of slipping back into disempowwering 'default positions' within institutional settings. The existing systemic power imbalance traditionally privileged western academic knowledge systems. One Indigenous researcher made the following observation about underlying inequalities:

> *"…**when you're working in a colonised space, it's really easy to think that you've actually broken free of that colonised space**, that you've actually gone beyond it, and that you're entering that decolonised space, **but then one little tiny thing can happen and you're back there where you started from**. So, it's like a default position, it's like a default setting on your computer. **Bang, you slide back into this old default setting again… But it's still there and it's still the default setting of passive play of believing that white fellas have power over you**, and that you don't have any rights next to them. So that default setting is always there, **and it clicks back in when you're not even aware of it**. **…that same default setting doesn't just apply to community, it actually applies to us as researchers as well." Indigenous researcher***

Instead of elevating Indigenous people's voices in academic spaces sometimes researchers blocked them to 'protect their patch'. Institutions maintained control of knowledge production and reinforced their academic superiority. Indigenous people wanted to tell their story but felt their voice was diminished or reinterpreted through researchers:

> *"…**a lot of that has been done through a process of excluding and barricading that space so that it's reserved for white experts.** That white expert space has to be dismantled. It has to be eroded. And those researchers who are actively doing that need to be aware of what they're doing. And I think a lot of the times they are, they know what they're doing. **But it's about protecting their patch." Indigenous researcher***

An Indigenous researcher felt institutional ethical processes routinely undervalued and underestimated the role of Indigenous community research partners.

> *"**I see it in the ethics process**… which assumes, and it's a prejudicial assumption. It assumes that an Aboriginal community organisation kind of do their own research. **It assumes that we are a junior partner in the university-based research. It assumes that we cannot be equal partners." Indigenous researcher***

Some Indigenous researchers had mixed feelings about their roles. At times they were uncomfortable with how they were being asked to perform within academic structures. Traditional academic knowledge systems were a barrier for authentic Indigenous voices. An Indigenous researcher struggled to participate in the academic system because they did not want to be seen to endorse 'mainstream' academic structures:

> ***"…the other thing, I suppose, that I often struggle with myself is I think, you know, by getting in there and being a part of the system, a lot of the times you just feel like you're validating what they're doing." Indigenous researcher***

Some Indigenous higher research degree students and early career researchers encountered challenges because of existing hierarchies. Indigenous PhD candidates brought on to research

projects were sometimes overawed by their supervisors. These circumstances created an unavoidable power dynamic within the student-supervisor relationship that had the potential to subdue the voice of Indigenous students:

> ***"And the power differential in that relationship when you're a PHD student… And it's five professors on the thing. It doesn't work well on the other particular personality. And so that seems that happened to Aboriginal people who are within the system that I know in the system." Indigenous researcher***

In relation to a previous research experience, an Indigenous participant believed the Indigenous people involved in the project were just used to extract information from the community:

> ***"…these Aboriginal people they were like puppets. So they came down, they presented it all, load all the information, took it back and give it took the white fellas to interpret. That's what happened, yeah." Community coordinator***

In one example an Indigenous researcher felt that Indigenous perspectives were tokenised:

> ***"There were some Aboriginal people involved but it was very tokenistic …I took it as you know using Aboriginal peoples voices and experiences to drive their own agenda rather than wanting to benefit the community." Indigenous researcher***

Often Indigenous people involved in research had little control over actual decisions. In addition, many Indigenous people felt their inclusion in research was tokenistic. Some believed they were used as 'window dressing' just to satisfy the *guidelines*:

> ***"Even though we tried to factor it into that project by saying, ah yes, [Indigenous researcher] is a co-researcher, Indigenous, from the community you know, cultural advisor. It was all just ... It was window-dressing." Indigenous researcher***

Another Indigenous researcher declined to get involved in one project because they felt they were only being recruited to carry the burden of Indigenous community consultation:

> ***"Yeah, I declined just like yesterday, an offer being on a clinical trial because I thought I would end up as the Aboriginal personnel in that and all of the community consultation and absolutely everything forward to me and it'd be up to me to work out how they can get their link today and all the other stuff, that they want to do." Indigenous researcher***

## Summary: Chapter ten

Some institutions worked with Indigenous organisations, Indigenous advisory committees, and Indigenous researchers to co-design Indigenous health research and inform their research agenda. A number of Indigenous communities and Indigenous people accepted these opportunities, especially when it aligned with their own priorities. Co-design processes afforded partner communities a certain level of input and control over the research.

Indigenous participants wanted institutions to hand the reigns of Indigenous health research over to Indigenous communities. They advocated for community driven research. Research that was led by Indigenous people that were obligated to their Indigenous communities. They felt research controlled by the Indigenous community was more likely to respect community protocols and deliver benefits for the community. When health research was actually led by Indigenous partners (not just informed by Indigenous people) it obviously gives them more control over research decisions. It addresses the power imbalance that exists in most research driven by universities and institutions.

Researchers partnered with Indigenous organisations to support their health research proposals and engage Indigenous communities. Indigenous advisory groups are also regularly used as a mechanism for Indigenous communities to contribute to research. Yet Indigenous participants suggested some researchers did not use them effectively or value them appropriately.

These complex matters lead to complex questions for academic researchers. How are Indigenous researchers defined by formal academic structures? How are Indigenous researchers defined by Indigenous research institutions and structures? Who determines their legitimacy? Is it Indigenous communities or the researcher themselves? What additional obligations (if any) do Indigenous researchers have? How are academic and community obligations ranked according to priority?

These questions can often lead to tension within Indigenous communities about the role of Indigenous researchers. Uncertainty about Indigenous researchers competing cultural and academic priorities led to many and varied opinions about their roles.

Indigenous communities keep Indigenous researchers accountable because there are additional cultural responsibilities and obligations that go beyond institutional ethical frameworks.

Many institutions were unaware of existing institutional barriers that exist for Indigenous people pursuing research careers. Despite the existence of multiple guidelines and frameworks about Indigenous health research many universities are yet to address the underlying structural inequalities that make it impossible for them to conduct Indigenous health research ethically. Without sufficient Indigenous research leadership and mentorship, academic power imbalances are reinforced making it difficult for Indigenous students to validate their role and research position.

Funding bodies awarding Indigenous health research funding to academics without evidence of Indigenous community support is a systemic issue. Unobligated researchers compete for funding with Indigenous organisations and representative bodies potentially impeding the development of community driven research. Researchers that are given funding without engaging with Indigenous communities not only undermines the *Guidelines* but also bypasses existing Indigenous community approval and review mechanisms.

Furthermore, compounding the problem, Indigenous community organisations and/or Indigenous academics are commonly approached to help complete pre-packaged research projects after the fact. Audaciously, once they've been funded, researchers have been known to burden Indigenous people with their predetermined research agenda. Single-minded and pushy researchers are academically incentivised to push the research through, and they use resources they control to garner the support of trusted Indigenous community organisations. Due to their social responsibility many organisations choose to carry this burden, protect their community, and facilitate and monitor research. Research institutions transferred their ethical obligations to researchers. Researchers then transferred their ethical obligations to Indigenous counterparts.

Community organisations that are empowered as equal research partners have the opportunity to shape and control the research, as well as protect their communities. Indigenous advisory groups were not always used by research projects to get feedback and

advice. They were often used as a mandatory step for researchers to get their proposals approved through their universities

Researchers acknowledged the decision-making authority of Indigenous communities either through recognised collectives, or by engaging with respected Indigenous leaders. Ethical equal partnerships inevitably required researchers to respect the decision-making protocols of Indigenous partners. These findings reveal how some Indigenous communities expected to contribute to research decisions. It also highlights how some researchers attempted to obtain collective consent from Indigenous partners.

However, according to Indigenous participants the power dynamic within relationships was often imbalanced. Many participants provided examples of researchers conceiving proposed health research and seeking funding without any contribution from Indigenous people. In some cases, researchers disregarded Indigenous community decisions about proposed health research. Some researchers undermined Indigenous community decisions and rationalised their authority using existing institutional hierarchical systems.

Some researchers felt it was illogical to engage with Indigenous communities before a research plan had been set. I would argue that this perspective suggests Indigenous communities should rely on the ethical review process to protect their interests. An area that is underwhelming in relation to Indigenous research expertise and representation. A system that is heavily weighted in favour of institutional knowledge based upon western knowledge constructs. This perspective unwittingly disregards the rights of Indigenous communities to be informed and engaged through the conceptualisation of research.

Institutional structures made it difficult to create equal partnerships with Indigenous communities. Some participants challenged institutions to disrupt their systems to give Indigenous communities more control over Indigenous health research. These findings examined how researchers recognised and respected potential Indigenous research partners; how they created equal partnerships; and how Indigenous research partners were excluded and disrespected. However, the inequity between dominant institutions and Indigenous communities was arguably reinforced through research partnerships.

Institutional power imbalances that exist between non-Indigenous researchers and Indigenous researchers, and between Indigenous communities and institutions, perpetuate

systems that create inequities. Conditions for mutually beneficial partnerships with Indigenous communities need to be explored further by researchers and universities.

# Chapter eleven: Protecting Indigenous participants and communities

Community coordinators and researchers were specifically asked how Indigenous communities facilitated culturally safe research as part of expanding on emerging concepts in earlier interviews. Researchers were obligated to protect the Indigenous people who participated in their studies and to ensure no harm came to the broader Indigenous community. Researchers in this study partially met these obligations by partnering with trusted Indigenous organisations, recruiting key local Indigenous people, including elders and community leaders, and establishing advisory groups to facilitate, support, and guide their research.

In many circumstances Indigenous communities had established their own processes for overseeing, monitoring, and gatekeeping researchers. So, researchers also had to navigate and respect these protocols in order to conduct research ethically and safely within these communities.

Despite efforts by both mainstream research institutions and Indigenous organisations to protect Indigenous communities through their systems, during the interviews, participants recalled previous research projects that they believed had caused harm to Indigenous people.

## Understanding the Indigenous community context

A few respondents recalled Indigenous community ethics committees specifically established by Indigenous community organisations and traditional owner groups to manage and review university research proposals. :

> ***"I do remember this ethics committee being set up purely to oversee what projects [were approved] ...The Indigenous organisation] knocked back projects as well…" Past participant***

These models had existing relationships with or were driven by, Indigenous communities, but had also developed trusted reputations within the academic community. These community ethics committees had created internal organisational processes for screening researchers to protect the Indigenous community:

> ***"I think [the Indigenous organisation] themselves at that point or maybe leading up to that, they had their own ethics on research. So [the Indigenous organisation] wouldn't let anything through unless it went through that committee first." Past participant turned Indigenous researcher***

In some jurisdictions Indigenous research advisory groups formalised pre-ethics processes to support stronger research proposals and ethics applications. An Indigenous researcher involved in one of these highlighted the benefits of this approach:

> *"…looking at the [Indigenous research advisory group] now that **we do have some consistency in terms of where we are progressing the applications**, but also from a standpoint were not commenced in 2018. Just looking at some of the **applications you can see the difference between providing adequate feedback** was about a consultation process to the end result following the recommendations. So, not only is it serving its purpose for **looking at more culturally specific suitability of the research applications, but also the standard of the [peak body ethics] application has been a lot better." University based Indigenous researcher***

In the experience of some participants, Indigenous reference groups reviewed methodology to ensure it was culturally safe for Indigenous participants. Community ethical appraisal was carried out alongside formal ethics procedures:

> *"…**through our own reference group**, um, who, um, who looked at the project and who, then checked how it was designed that had Aboriginal research ... uh, had people from community from [Indigenous organisation] and also outside of [Indigenous organisation] who were Aboriginal researchers themselves. So they would, **they looked at the method too, uh, to check on that**. …but it was also, um, then talked through with, um, the Aboriginal research project or the reference group early on before we started, uh, **to check our methodology and make sure it was safe." Indigenous researcher***

Several participants said that community-based ethics committees needed an equivalent (or greater) authority to human research ethics committees. Community driven review processes ensured potential proposals were interpreted and assessed according to their own ethical worldview and also empowered those to alter or veto research proposals:

> *"…pulling together an Aboriginal reference group and just informing them of what you're going to do is not research governance. And that tends to be what happens. Research governance is that you would put to your Aboriginal reference group your questionnaire. And give them the opportunity to make changes on that and tell you what you should or should not be doing and what is or is not appropriate." Indigenous researcher*

One community was in the process of developing a research body to effectively assess if researchers were a good fit with their community:

> ***"They're trying to establish that body that will have the correct training, that will be able to ... And they want people to come and meet with us before any research is done in [traditional owner] country." Past participant***

Some researchers were ignorant about potential issues that might be raised through an Indigenous ethical process. In effect they didn't know what they didn't know about Indigenous communities. An Indigenous respondent recalled *"the horror when we raise[d] [an ethical issue], and they had not even thought about it."* Another Indigenous researcher recalled the general lack of awareness researchers had about relevant concerns and issues in their community:

> *"But also, current, current traumas within the community, or current concerns within the community. Or areas of well-being that are currently compromised in the community.* ***But they didn't even know that they were doing the wrong thing****."* ***Indigenous researcher***

Some Indigenous researchers were criticised for failing to recognise what were perceived established protocols. A few participants described how Indigenous *community* ethics processes were different to academic institutional ethics:

> *"…And, and when I say formalised, um, I knew that those were gonna be the questions that the research subcommittee, uh, were gonna ask me. And they did ask me those questions. And, and not once, but twice. Uh, and, you know****, that was sort of different than the, the conventional kind of process really. It wasn't, it wasn't just [academic institution] ethics. That was actually the easy one. It was, it was our community ethics where, where for me, you could say it, it was culturally formalised. Like that was, that was really the test for that was just how cultural integrity, there's that cultural safety****…" Indigenous researcher***

Many if not most of the Indigenous respondents in this study assessed the 'moral' integrity of researchers and institutions from an Indigenous worldview. Researchers adhered to ethical guidelines from an institutional standpoint, but this didn't necessarily mean they understood how to integrate ethical practices from a cultural standpoint.

## Respecting cultural protocols

Respondents noted that in some discussions non-Indigenous researchers seemed unaware of unique protocols and specific issues of different Indigenous communities. Furthermore, respondents also noted that some non-Indigenous, and non-Indigenous researchers disregarded advice from Indigenous communities about how to adjust their research. An Indigenous researcher believed all researchers needed to have a general level of cultural and community awareness before conducting research within Indigenous communities stating that *"…so much knowledge and understanding's come before you can even enter a community to do a research project."* Respondents suggested that researchers participate in mandatory

cultural awareness training and basic training before they began any research with Indigenous communities:

> *"[P]eople have gotta have some kind of cultural awareness or kind of understanding before they probably, [laughs], come in and work with the community, maybe."* ***Past participant turned researcher***

Participants suggested that cultural awareness training would be valuable for all researchers (both Indigenous and non-Indigenous). In the broader context there are other stakeholders such as government and funding organisations involved in research with Indigenous communities that would benefit from specific training around Indigenous research ethics and cultural awareness:

> *"Lack of education because the cultural awareness training, the online module for [state government department] doesn't go into research or research ethics. In a way that makes you click and think we need to take this into account if we do research. So, the lack of capacity opportunities for education for government staff."* ***Indigenous researcher***

Cultural respect and cultural integrity were innately understood as part of a cultural ethical process. This included knowing the right research questions to ask and "knowing not to step over that line":

> ***"So that, for me that's what cultural respect was. It was a process of, of gradually coming to the right research questions." Indigenous researcher***

Researchers were oblivious to actions, which were seemingly innocuous, but were perceived as insensitive to the Indigenous people involved in their research. In relation to the protection of specific Indigenous knowledge a lead researcher pressured an Indigenous colleague to accelerate community engagement and overrule community protocols:

> *"And I said to her "But there's stuff in there that's sacred or secret information, it's gender-restricted knowledge" I said "I can't make those decisions." I said "That's, you know, that's the participants and the [pause] you know, particularly the elders in the community who were the, you know, the gatekeepers on that knowledge. They're the ones that need to make that decision.""* ***Indigenous researcher***

A fundamental part of cultural respect and integrity is listening to your elders. Indigenous elders played an important advisory role in Indigenous communities. Researchers were expected to listen to elders and consider their feedback. Elder guidance and mentorship of researchers were key aspirational goals for many Indigenous participants.

> *"The white researchers are ones that need,* ***well we all need an elder to be guiding our research.*** *But I think that white researchers in particular, need to have a little bit of extra time to be sitting down with the community. And I think, I feel like a white researcher should take twice as long to do a research project in the community."* ***Indigenous researcher***

Researchers needed to listen to elders before they discussed their research. As part of customary cultural protocols they were expected to 'listen before they spoke':

> *"And then you got the younger ones that get up there and talk, sometimes there it's not appropriate unless they're asked.* ***You have to sit back and listen.*** *Until you ... you know, and then you can,* ***if you're asked, then you answer a question.*** *And that's not suppressing people.* ***It's actually protocol, of how you do stuff."*** ***Community coordinator***

Recognition, acknowledgment, and respect for Indigenous eldership was consistently emphasised by community members as a fundamental principle of Indigenous cultural protocols. Many respondents felt researchers should allocate specific roles for Indigenous elders to guide and support their research projects:

> ***"I think it's guidance by a local Elder throughout the process. It's universities recognising the voice of the Elders.*** *And you know as an academic having an Elder support you should be recognised as something greater."* ***Indigenous researcher***

Endorsement had the potential to elevate the standing of research projects in the eyes of the community. In contrast some perceived the addition of *Elder's councils* in research as potentially tokenistic. The inclusion of Elders just to *rubber stamp* research was a concern for one Indigenous coordinator. They felt it was important for Elders to be respected and taken seriously:

> ***"There's been more take up of elders' councils.*** *In different orgs and bodies. However, to some degree it feels fairly tokenistic. At different points, just talking to some of the elders who are involved in some of those process. They were, you know, rubber stamping stuff."* ***Community coordinator***

An Indigenous researcher involved in a university study thought the actions of another Indigenous researcher were disrespectful to Elders:

> ***"…[T]he researcher, who was an Indigenous researcher didn't offer them a cup of tea. And like, these are elders, they're not just you know. Just put the recorder on, or I brought let's go, kind of thing" Indigenous researcher***

Indigenous people, involved in Indigenous health research within their communities, were often responsible for upholding local community protocols. These obligations sometimes conflicted with university research requirements:

> *"We're more accountable to community than we are to the University."* ***Indigenous researcher***

> *"You know,* ***we have obligations and responsibilities in our community. And the beautiful thing about our culture is our respect protocols****. It's the biggest thing. …so we know that that we know what our responsibilities are if we're working, and it's always going to be around advocating for our community.* ***It's always going to be a cultural safety thing****, but it's also um, you know, the* ***decolonisation of the systems****…"* ***Community coordinator***

Logically, some participants felt that Indigenous researchers were more likely **to uphold cultural protocols** because of they were accountable to their communities:

> *"So whilst I sort of, I could say to you I don't have 100 percent in my head about ethics per say. I do know the difference between right and wrong and you have the cultural awareness and the [Indigenous organisation] background."* ***Community coordinator***

In their eyes the consequences and outcomes of research, good or bad, lay on their shoulders. They were risking their own personal community credibility:

> *"…you're the one that's accountable to the community, and people, people don't understand that. Yeah, and it's just, and it'll give you a bad name because they won't, they don't see it as the university, they just see it as you."* ***Indigenous researcher***

A few respondents suggested that responsibilities to community were far more important to Indigenous researchers then their research obligations:

> ***"…as Aboriginal people, we're doing all this community stuff and all this… You know, it all adds up and it all eats into your time but it's a responsibility you take seriously and you want to do it. But it's not accounted for in that, percentage of load..." Indigenous researcher***

Some Indigenous researchers felt a deeper moral obligation that went beyond the ethics process. They were self-regulating through their own 'cultural' compass:

> *"I think Linda Smith really nailed it on the head when she said that you know,* ***this isn't just an ethical obligation, it's a moral obligation as well****. It does come back to what's your moral standing on this?* ***So it's much more than just the governance of ethics and jumping through the academic hoops, it's about what are you prepared to do morally?****"* ***Indigenous researcher***

Some Indigenous respondents believed that Indigenous researchers already held additional moral responsibilities when they were conducting research with their own Indigenous communities. Broader obligations were embedded in their community, family, and cultural relationships and these were often upheld through distinct local cultural protocols.

Whereas non-Indigenous researchers were perceived to have the luxury of coming in and out of the community, generally Indigenous researchers had ongoing community responsibilities beyond the research. An Indigenous researcher described how a non-Indigenous research colleague struggled with the extra cultural load that came with the cultural obligations (based on the kinship system) that was expected of them:

> *"…**even though she'd been slotted into our kinship system**, she didn't really understand or follow that script. And even though we kept trying to remind her that this is the reason why you've been slotted in. **You have a responsibility towards that group of people that you're aligned with. I'm aligned with the other set of people in the community, and that's how we create the balance."***
> ***Indigenous researcher***

## Creating culturally safe research

Indigenous people involved in this research wanted Indigenous health research to be conducted by 'culturally competent' researchers in 'culturally safe spaces'. Culturally safe spaces seemed to be created in various ways. As mentioned in previous chapters Indigenous communities ensured research was safe by assessing and 'tuning' researchers and funnelling research proposals through community protocols before agreeing to participate. But what did institutions and researchers do to ensure 'culturally safe spaces' existed? Research ethics were construed by some as a tool for protecting Indigenous participants and communities:

> ***"[E]thics… is there to protect the community. It's there to ensure that safe practices are followed. But even in that there are different interpretations based on white and black people." Indigenous researcher***

Universities were expected to collaborate with Indigenous communities to develop research that was culturally safe for Indigenous community members and potential research participants:

> ***"I think universities specifically need to be creating a safe space where community can talk about what they feel is needed in research." Indigenous researcher***

Another Indigenous researcher discussed the importance of being transparent about the purpose and the potential risks of research. This researcher incorporated cultural support mechanisms into their research design in case any participants became distressed:

> *"…**I think one of the things is to be really open and transparent** about, um, you know, the fact that it, that it is research and that it's Aboriginal design, but it, it's still, uh, um, a research project and to **be really upfront about what the research is trying to find out. You know, what the risks are.** Like with the, the men and women, you know, we had to, you know, we had to sit up and talk at a community presentation about the project [discussing research participant requirements] … **"Um, and, um, you know, that, that there's a small chance that, that you, you might feel some distress about that. And we, we have our, our counsellors here if that was to occur. But it's really important that, that you know that."" Indigenous researcher***

Many participants relied on, Indigenous organisations to protect Indigenous communities because they trusted them. They had long established community responsibilities, community knowledge, and community networks:

> *"It's [Indigenous organisation], so, you know, and you've got access to a lot of people there, and I just would not like for our people to be put in unsafe situations without having that, looking out for them, looking out for the community." Past participant*

In one region an Indigenous organisation facilitated research conversations with the Indigenous community and various Indigenous community stakeholders. This created a safe environment for the community to ask questions about potential research:

> *"[we often] get invited into those [Indigenous organisation] discussions and we can talk about what we're doing and why we're doing it and what does community think about that? Is that something they would support or they want to support? …It seems to be quite successful. And I think as long as it's done in a safe, facilitative way by Aboriginal people, talking to Aboriginal people then it'll happen. And we had mainstream stakeholders for that particular consultation that I'm think of come in and we introduced them and now they've gone on to form partnerships and relationships directly with the ACCO..." Community coordinator turned researcher*

Indigenous community members would also participate in Indigenous advisory groups to ensure research was conducted in a culturally safe way in their Indigenous community:

> *"…sometimes it- you might- you might not just want to be part of it for the benefits. But you might just want to be a part of it because of the safety, the cultural safety for the community." Community coordinator*

An Indigenous researcher described how strengthening engagement and broader commitment over time was of greater importance than completing rudimentary cultural safety programs:

> *"…if they try and step into a community or an ACCO cold then they're not gonna succeed. We know that. So they have to take it, they have to back it up quite a number of steps... and say how are we going to invest in, in the community and in ACCOs in other Aboriginal organisations. So that we build trust, we invest, we spend the time working with them as equal partners in our research framework. …that beats doing formal cultural safety training hands down." Indigenous researcher*

Some participants worried about *culturally unsafe* institutions competing for and receiving Indigenous health research funding. The status, research track record, and reputation of larger research institutions were attractive to research funders. However, they also took research opportunities away from smaller community research programs:

> *"My concern is, the ones that I have the issues with. This is a huge org and I'm thinking ok and these people are now entering the Aboriginal space. They're not culturally safe and then you're going to take funding, if there's a fight for funding." Indigenous researcher*

Indigenous participants wanted researchers to work within community timelines not academic or funding timelines. 'Slowing down' was an important indicator that researchers were listening and responding to community input. Working at the pace and within the flow of the community also signalled that they were willing to adapt and prioritise community needs:

> *"You know, he came and he worked with the, the flow and the time of community."*
> ***Past participant turned researcher***

Some researchers adapted their projects to work within community timelines. When talking about a previous research project where they were challenged by the local community, an Indigenous researcher thought it was important to slow the research down:

> *"Well I think like with that example it just means pausing and not pushing."*
> ***Indigenous researcher***

Indigenous communities involved in research wanted to have thorough engagement. They actively slowed down research processes to comprehensively discuss and consider projects until all their concerns were satisfied. Many Indigenous researchers in this study consciously

adjusted to extended community timelines during the conduct of their research which often caused tension with their academic supervisors:

> *"I found that with my project, like, **I have to work at the pace of the community. And my supervisors have found that really difficult to adapt to.** …I've had to meet with some of them [community members], like, four or five times, just to keep talking about the project and, **addressing the fears** and stuff around research but then like, my supervisors and that team went: **"Why can't we just get in there and do the data collection?"** and I'm: "Well, you can't". So, it's a different way of working and **you can't rush the pace of the Aboriginal community otherwise the integrity of the research, at the end, will be compromised.**" **Indigenous researcher***

Moving between academic and community responsibilities was reported by some respondents as being time consuming and draining for researchers:

> *"…the difference of the way or the pace in which I'm operating inside there, compared to out here, and basically, in two different time-zones. And, and it's, you know, exhausting. It takes me ages to, um, tune back in with, really, what is two different worlds." Indigenous researcher*

## Protecting Indigenous participants

Researchers tried to protect Indigenous participants of their studies in various ways. Often research teams would invite Indigenous community partners to develop or co-design strategies to safeguard and protect Indigenous communities involved in research. An Indigenous researcher sought advice from trusted people in their network to ensure their research report respected the experiences of Indigenous people that had dealt with trauma:

> *"So how I spoke about the trauma that people had in our report that um, some people talked about, you know, people, um, very close friends of theirs died by suicide. And so they're very to, how did I write that up? **I run it by a few trusted people within the network and 'Oh this, this has come up.' How do you talk about, it's quite confronting**." **Indigenous researcher***

Unfortunately, respondents described how some investigators used practices that actually harmed and *re-traumatised* Indigenous research participants:

> *"But I've recently heard about some research that was undertaken at an Aboriginal conference. …and the researcher supposedly, I don't know enough about it, **but they used practices that re-traumatised the participants.** …But also current, current traumas within the community, or current concerns within the community. Or areas of well-being that are currently compromised in the community. **But they didn't even know that they were doing the wrong thing**." **Indigenous researcher***

In the same vein, respondents commented on how sometimes researchers unwittingly harmed and hurt Indigenous participants because they used inappropriate methods in the conduct of their research:

> *"…you know, I guess, and when it comes to Aboriginal health, we're talking, you know, very, um, personal information is shared and, um, that's... uh,* ***I guess the, the trauma that gets unravelled with certain questions. …You know, um, trauma and dealing with grief and loss and all that. So those things are being questioned and I'm not having the support after the fact cause it's just a phone call. I don't [pause] It's not face to face…" Past participant***
>
> *"But it's just we're at this point in history now where people are still unknowingly doing these things, or unknowingly re-traumatising someone, or unknowingly, you know, just mistranslating things." Indigenous researcher*

The way researchers translated findings could also potentially cause harm to the broader Indigenous community. Responding Indigenous researchers commented on their awareness of researchers misinterpreting information and commented on the harm that this could lead to, however unintentional:

> *"…the way in which you write that up and brought that up and may be harmful to the community, you also may misinterpret that data. …research governance for that is incredibly important." Indigenous researcher*

Indigenous partners and contributors felt a sense of personal responsibility for keeping Indigenous people safe and expressed their anxieties accordingly:

> *"…I don't want to do the wrong thing by people. I want people to be safe and I want my research to help people. I don't want to, you know, damage." Past participant turned Indigenous researcher*

Some participants believed Indigenous researchers constantly examining sensitive issues in their own community were at risk of being re-traumatised. A non-Indigenous researcher was particularly concerned about their Indigenous research colleagues, and the constant strain that being involved in or facilitating research in their own communities could cause:

> *"And so, I'm always mindful of that. You know,* ***are the people that are doing research, are they okay?*** *Like you know,* ***are we supporting them and protecting them and looking after them*** *like 'cause you don't want to traumatise and re traumatise people in this environment and this can be a very challenging environment for Aboriginal people because you know of the intergenerational trauma.* ***The likelihood that they know people in the system and, I think it's really, really important to be mindful of that.*** *And to take good care of our colleagues and just be thoughtful that you know* ***by stretching them, that feeling you know,***

***constantly putting them out there all the time can be really hard on them." Non-Indigenous researcher***

## Summary: Chapter eleven

Respondents clearly understood that researchers and universities had responsibility for ensuring research did not 'traumatise' or 'harm' Indigenous participants. They also recognised that Indigenous communities played an extremely important role. Institutions made researchers accountable through HRECs and institutional processes. Indigenous communities made people accountable through cultural obligations. Together, they ensured research was safe for Indigenous communities to participate. However, some researchers chose research topics that had more potential to cause harm to communities.

Many researchers reported partnering with Indigenous organisations and Indigenous researchers, or with Indigenous advisory groups to ensure their research was culturally safe. Researchers acknowledged the value of Indigenous advice for strengthening their research practices in Indigenous communities. These findings also demonstrate that Institutions relied upon Indigenous organisations, reference groups, and researchers to make research safe by providing the appropriate cultural expertise and guidance.

Indigenous communities trusted Indigenous researchers from their communities because they had cultural obligations. Some Indigenous researchers carried additional burdens and responsibilities that other researchers did not. Indigenous community facilitators and Indigenous partner organisations also held these cultural responsibilities. If research failed in their community, from a cultural perspective they were often the ones that were held accountable.

After 'becoming known' in the community and developing trusting relationships some non-Indigenous researchers identified that they had fundamentally changed their approach to research with Indigenous communities. The development of authentic trusting relationships with Indigenous people influenced some to take on duties beyond the scope of the academic research. They became 'obligated' allies. Ultimately, some researchers broadened their accountability to prioritise these 'new' obligations to the Indigenous community and ensure their research was 'culturally safe'.

Alternatively, some researchers were blind to the cultural obligations that existed within communities. In some cases, respondents indicated that non-Indigenous academics were unaware of the community and cultural responsibilities many Indigenous people carried.

Some Indigenous respondents commented that non-Indigenous researchers could offload additional 'cultural loads' to Indigenous partners, Indigenous community facilitators, or Indigenous advisory groups. This position contradicts the acknowledgement of their importance previously mentioned by many respondents.

Respondents reported that Indigenous communities wanted researchers to slow research down and better adapt to the rhythm of the community. They further reported that they wanted researchers to adhere to community research approval and review processes in addition to institutional ethical review systems.

However, researchers also developed trusted relationships with Indigenous communities by 'becoming known' and being culturally accountable. Researchers reported a greater feeling of obligation to Indigenous communities due to the strong relationships they made.

# Chapter twelve: Valuing the contribution of Indigenous people

This chapter reveals how Indigenous participants, communities, organisations, and researchers were recognised and acknowledged for their contributions by researchers, and their parent institutions. Indigenous people contribute to research in various ways. For instance, communities are often invited to participate in research projects to provide their knowledge and/or share their experiences. To understand how researchers valued the contribution of Indigenous people I asked interviewees how researchers included Indigenous people in the analysis and interpretation of research data.

## Valuing an Indigenous worldview

Indigenous experiences and knowledge should be valued equally with western forms of knowledge. Participants expressed how important it was for academic institutions to respect the knowledge of Indigenous communities, including Indigenous traditional owners, Indigenous community organisations, or other distinct Indigenous collectives. It wasn't always easy for researchers that are used to having a lot of autonomy and control in an academic environment:

> *"…**the hardest thing to overcome, is you've actually got to listen to Aboriginal people.** And then you've gotta take that on board. You've gotta hear what they're saying, and then it's gotta go into your brain, and **you've got to process it** and **appreciate it and be respectful of it**, and **then you've got to act on that**."* ***Indigenous researcher***

It wasn't just about respecting Indigenous cultural knowledge it was about validating an Indigenous worldview in research:

> *"So when people are a part of that whole process, and understanding that they're not gonna be giving [pause] passing on knowledge and information, **not only just about cultural, or it's not even just about sacred things. It's about a particular worldview and that is enabling in people** but a lot of time, you know with professional people, or whether they're health workers or other professionals, write this in this professional industry style. And, … **that's seen as something as important at a high level, but not so much where that knowledge and that guidance came from." Community coordinator***

Alternatively, the desire for external validation of Indigenous knowledge was identified as a form of mainstream integration that wasn't necessarily appropriate. An Indigenous researcher suggested that Indigenous knowledge should be respected by mainstream academics:

> *"…in an ideal world it would be that **Indigenous knowledges experiences and perspectives are equal to Western.** And by having them in a tertiary setting that is typical you know, Western institution of knowledge. That kinda brings up that value. …**all we can do is try and get our voices in there somewhere." Indigenous researcher***

Indigenous people want to be treated like people, not as numbers convenient for funding and research reporting:

> *"**Those fellows need to remember, their numbers, are human lives.** And I think that the community needs to see them doing that, to be able to get them, to be able to get I suppose accepted within communities. To be able to collect the content to be able to get, get that information, to put out a research pro- program or process. **…No, most researchers come in and we are a number.** And numbers in different forms. Numbers in collecting the data, numbers in them being able to secure funding, you know, all those kinds of things and **we're more than numbers, we're actually, we're people. We're lives, we matter." Community coordinator***

Respect should be given to Indigenous community members for sacrificing their time. They expected Indigenous community members to be valued for their participation and knowledge and to be reimbursed for their time:

> *"For example for Koories it was about the principles about **engaging community, the community owning it, the community being key informants and being reimbursed for that**. And the research was. One of the key things that we had, the differences but the research that we do in [Indigenous organisation] **has to be an outcome, which suits [Indigenous organisation] and the community." Community coordinator***

Indigenous communities did not want to just contribute to the research, they wanted to take ownership of the research. At times Indigenous people have felt underappreciated and unrecognised for their contribution to research:

> *"'Cause I've done so much volunteer work. We all have. As Aboriginal people we all do mountains of volunteer work. Yep, it never gets recognised, but we know that because we've got the skills. …So I think, you know, even though at that level of understanding of how important it is for us as Aboriginal people to do our own research work, that's not properly acknowledged or understood." **Indigenous researcher***

This participant said it was important for Indigenous people to be 'allowed to have a voice' because an Indigenous lens provided more substance and authenticity within Indigenous research:

> *"**Respecting their contribution**. Understanding the issues they face on a daily basis. **Allowing them to have a voice.** I think that's so important, I mean I know that when I kick up research papers, and I have in the past, **where I've looked at non-Aboriginal people who have researched us versus an Aboriginal person who's done research. They're two different formats.** … **Aboriginal people, even though they may be employed within the Universities, have a different approach and it feels more real. And the substance seems more powerful. Community coordinator***

The protection of knowledge was reiterated through experiences of Indigenous informants. There were different perspectives from Indigenous informants about how knowledge was protected, produced, interpreted, and translated back to communities. Data sovereignty was touted as a tool for protecting community collective knowledge.

Respondents argued that Indigenous data were owned by the 'community' and protected by Indigenous organisations and other groups that represented their interests. Indigenous participants consistently asserted that the community maintained rights over any Indigenous knowledge shared within research:

> ***"Our data we own. It's not negotiable we own it." Community coordinator***

Yet, many others regarded Indigenous knowledge as a 'collective knowledge' that no one person could 'own'. Indigenous people were simply 'custodians' of knowledge. These types of custodial arrangements recognised the intergenerational transfer of cultural knowledge and acknowledged collective custodianship. Equally, some members of the group were seen as holders or keepers of certain knowledge:

> *"[E]ven though I'm Indigenous, even though my Indigenous community is giving me this information, **it's still their knowledge. And it's still their cultural knowledge. …This is knowledge that's been handed down as well. So, they're keepers of knowledge** and of their history as well, and so, **you're not just asking them for what they know, you're asking them actually for what a community knows." Past participant turned Indigenous researcher***

Another Indigenous community coordinator described themselves as 'delivering a message' on behalf of the community:

> *"**Around the Indigenous cultural intellectual property.** So, we've been sharing our knowledge and expertise, and we're bringing it because of where we come from, this- the community's position, which actually belongs to the community, not us. We're just delivering a message and providing you with some information. Because*

> *this is how we operate, and this is how we work with the community."* ***Community coordinator***

Some Indigenous communities protected Indigenous knowledge by 'gate keeping' it from researchers. Accessing community data (or knowledge) was often protected by unspoken protocols. Similarly to notions of 'becoming known' and 'tuning' mentioned previously, some participants would not share any collective knowledge with researchers until they trusted them. An Indigenous community coordinator said some researchers expected them to automatically open up 'access' to the community:

> *"…**what they've expected is us to, to open their doors and build their bridges, and I don't agree with that**. You've got to earn the right for that information. I'm not giving it up to you for free, like I'm not giving it up for free anymore."* ***Community coordinator***

An Indigenous researcher felt personally responsible for protecting and 'safeguarding' people's knowledge. Another Indigenous researcher included specific clauses to protect cultural knowledge through recorded interviews to ensure they could not be adapted without consent:

> *"I was just really concerned about people, you know taking, you've seen media stories, people taking like bits …so that's why I specifically said it's their property and you can't, no like we can't alter it without their permission because [otherwise] it's just opening the door for people to manipulate knowledge." Indigenous researcher*

An Indigenous researcher believed the community retained ownership over collective knowledge and that they had no right:

> *"Even though I'm Indigenous, even though my Indigenous community is giving me this information, it's still their knowledge."*

### "It's not their story to tell. It's ours."

During the interviews Indigenous informants identified occasions when researchers and universities had acquired Indigenous knowledge without appropriate community approval. Generally, most Indigenous participants thought non-Indigenous researchers should not interpret Indigenous knowledge and tell Indigenous stories without some oversight or contribution from Indigenous people. Some Indigenous communities believed researchers were 'stealing' knowledge and taking it out of context:

> *"Well, some people say manipulation, some people say it's, they have started to say it's stolen knowledge. They're stealing our knowledge, and they're writing it in a, in a way that they feel is appropriate for mainstream Australia to understand but not taking into context that* ***it's not their story to tell. It's ours****."* ***Community coordinator***

Knowledge production was a sensitive topic because of how universities have historically conducted research *on* Indigenous people and not *with* Indigenous people. Universities and governments were still intrinsically distrusted by many Indigenous communities because of their past research actions. Considering their historical track record some queried if institutions were able to be act impartially. In one example provided by an Indigenous community coordinator, an academic demanded ownership of research done about Indigenous women's business:

> *"…my friend's got an incident going at the moment about that crap. She's in charge of our women's business [withheld].* ***[the researcher is] ... now trying to take it off her, and call it her research.*** *And all she could contribute was this stuff out of old ... what old white men wrote in the 1800s and that. And in 1540s upwards."* ***Community coordinator***

Indigenous respondents were used to foster trust with Indigenous communities and encourage participation in research. Some researchers took advantage of community confidence in Indigenous co-researchers to *extract* knowledge. In fact, Indigenous community coordinators were expected to facilitate the extraction of community knowledge:

> ***"We were the go betweens. We were like the go betweens. We were expected to, you know, get, extract information from them and that." Community coordinator***

Indigenous community research partners were keenly aware of the value of their knowledge to institutions. If researchers wanted Indigenous information, then at the very least, researchers and institutions, needed to give something back in return:

> ***"If they're coming here to take information, then the least ... They need to be contributing to something else." Past participant***

Intellectual property rights were an issue for most Indigenous people involved in research. Many were wary of unscrupulous researchers *taking ownership* of their Indigenous intellectual property:

> ***"We're offering this information, we're offering our expertise and you know, we're- we're supporting and guiding you. And all of a sudden they're taking ownership of our IP." Community coordinator***

Similarly, a community coordinator expressed their fears about losing control of intellectual property when entering into research projects with institutions. They considered knowledge through a rights-based lens and identified the power and value that knowledge holders possess:

> *"Because what they're doing,* ***as soon as you give 'em that information, there goes your intellectual property rights, and copyright, on that that stuff.*** *And that's what we've gotta be more diligent with. Is protecting our intellectual property right,* ***because as soon as they write their book or whatever that becomes theirs. Not ours, so we've lost it." Community coordinator***

Researchers sometimes used inapt data collection methods to take advantage of Indigenous community members. An Indigenous academic described how researchers attended a conference exclusively to collect information from Indigenous participants:

> *"Yeah it was exclusive. These people, and this is a conference that was meant to have, didn't actually give anything back.* ***They didn't show any or come and talk. They just were there, just to take the research." Indigenous researcher***

An Indigenous researcher believed they had to protect information from non-Indigenous researchers who aimed to use community knowledge to advance their careers:

> *"…for white fellow researchers out there, it's a,* ***it's a body of knowledge*** *that's just full of stuff* ***that they can grab hold of****, yeah. And then ma- make themselves famous with it. So I thought no, I'm not doing that."* ***Indigenous researcher***

Researchers not reporting research findings back to communities was another bone of contention. In their role as a community coordinator one participant reiterated that ***"(r)esearch is just not taking on the knowledge and information and walking away"*** but importantly, findings need to be given back to the community. Knowledge gained through research ought to be shared with Indigenous communities for them to interpret and apply as they determine:

> *"…that's the other thing that doesn't happen often enough is* ***the researchers they just don't go back enough****. And keep informing community, investing in the, you know, those updates with community because, ,* ***they're quite happy to sit there and listen and take a lot of information for our people but they don't want to go back and talk about it." Community coordinator turned researcher***

Deeply embedded moral reservations about using Indigenous collective knowledge within academic settings was shared by many Indigenous people. An Indigenous researcher felt torn between advancing their academic career and developing useful research for their community:

> *"…**that's the big challenge for us as Indigenous researchers is how do you find that fine line between the two?** How do you dip into both so that you're creating material that's gonna be useful and accessible to community, but also it's gonna give you some standing as an academic? …because I know the track record is, **it's bloody hard to, to, to stand with community and stay with community and get ahead as an academic." Indigenous researcher***

When individuals used the knowledge gained from research to necessarily advance their careers it also had the potential to affect their relationships with partner Indigenous organisations. This could lead to sentiments of *leaving the organisation behind* as the following example shows:

> *"**Now, [Indigenous researcher] don't work at the [Indigenous organisation], right**? Because now, he's become ... **got a doctorate, and that's wonderful** and it's good, it's really good ... But, now, he's now moved into a, into a different place that actually caters to what his now **new knowledge** is. His **new knowledge as a researcher,** his new knowledge is where it can take him." Community coordinator turned researcher*

Inversely, other researchers refuted the notion that knowledge could be *taken* from Indigenous communities at all. Whilst acknowledging the problematic historical issues, one Indigenous researcher thought claims of overresearching were exaggerated. They also believed that knowledge was recorded and observed, not *taken* from the community. According to them communities had an incomplete understanding of research and were apprehensive because of previous bad experiences. There was also a community misconception that 'researchers are getting rich':

> *"**And so people keep saying that researchers are taking away what's ours.** Well of course we're not. Because whatever happened there that we observed happened there and they keep doing it. **We're not taking anything away from them, all we're doing is taking away observations.***
>
> ***…We're not taking anything from them. So they seem to think that we're stealing knowledge or something. We're not stealing their knowledge…" Indigenous researcher***

The question remains how the intellectual property rights of individuals, and communities, are protected in a system where knowledge is routinely exploited, and processes of knowledge production are incentivised. What happens when knowledge is transferred to researchers in academic settings? What obligations do they have to Indigenous knowledge holders? Which collective groups benefit and are these benefits distributed equally? Researchers controlled how research information was translated and they decided what story it would tell. Most Indigenous key informants worried about researchers interpreting Indigenous knowledge through a white lens and had experiences with non-Indigenous researchers where this happened. Lack of control made them worry about how Indigenous communities were being portrayed:

> ***"So we don't have any idea about the narrative, like, the information that they've taken from our community, and then the story that gets told about us." Indigenous researcher***

Some Indigenous participants got angry with researchers that reinterpreted their knowledge from a non-Indigenous standpoint:

> *"... the way he's [the researcher] written it.* ***He went ahead with that, and the way that they allowed him to write it.*** *And, he just had* ***lack of knowledge*** *and he's just taking it* ***from a white person's view****. And it was all... and it's about our site. He wouldn't know what was important. And, I don't know, I just ...yeah, that one makes me wild when I talk about him."* ***Community coordinator***

Indigenous participants felt like they weren't in control of telling their own stories. They thought research papers written by non-Indigenous authors didn't reflect 'who we are':

> *"And then they would, you know,* ***publish these papers that really didn't reflect who we were*** *and how we approach things and what was culturally appropriate.* ***Because at the end of the day they're painting the picture of who we are."*** ***Community coordinator***

Some researchers responded negatively to criticism and often used their authority to defend their position. One past participant was excluded from authorship because they disagreed with the deficit approach of a research paper:

> ***"…when I got the paper to review after the research project I sort of edited it and said, you know, I'm not happy with the story, stop saying we're the deficit you need to change the lens in which you're looking at it and so I got excluded off of that." Past participant***

For the most part Indigenous research participants felt they had limited control over how their experiences were interpreted and translated through academic publication. An Indigenous researcher steadfastly believed that non-Indigenous researchers had no place interpreting Indigenous knowledge. They experienced significant backlash when they challenged the authenticity of academic conjectures:

> *"And that's the way I look at it. No matter who they are, they [add] no value.* ***Because they're making assumptions, they write stuff.*** *It's a bit like these researchers that do the native title one for your family research.* ***And half of it's wrong. You know, and then they're passing that up as truth,*** *and when you challenge 'em they get very nasty.* ***I've challenged 'em a few times…" Community coordinator***

In part, participants thought community members would refuse to share any information with researchers they did not know or before a relationship had been established.

> ***"…if it were me or, and if I think about my grandparents, you know they'd be holding onto information because they don't trust you." Past participant***

Others would protect information by restricting how much they shared. An Indigenous community coordinator felt researchers would misinterpret what they were saying so they would only give them *"what they need"*:

> ***"And I don't let them over talk, and I only give 'em only what I believe is what they need. Not too much. So you give 'em this much. You don't give 'em too much. Because you know that their interpretation's gonna be totally different to yours."***

Sharing knowledge through postgraduate research was another conundrum brought up by several Indigenous researchers who reflected on this phase of their careers. They felt conflicted about documenting and recording their own or their community's knowledge due to strict PhD candidature requirements. They had to consider how to 'confine' the information they would share through the process. Effectively they felt they had to choose between protecting their Indigenous knowledge or using it to advance their career:

> *"…when you're actually creating that document that record, that thesis,* ***all the time you've got it in the back of your head, how much do I actually divulge here?*** *And what can I leave out and still get this through? And what, what happens to that knowledge, then, that I do leave out? How do I make that judgment call? And I think one of the ways that I did it when I was doing my PhD was* ***I told myself that even though there's not a lot that's been published out there about my community, about my cultural knowledge, you know, my group, [Indigenous nation removed], there hasn't been a lot of research.*** *We haven't been done to*

*death like a lot of the communities have in the north. But I thought,* ***I'm still only going to go for, I'm gonna try and confine this as much as I can, particularly around the cultural knowledge,*** *I'm gonna confine it as much as I can to what's been published."* ***Indigenous researcher***

The process of submitting information to academic institutions was questioned and raised ethical concerns about rights over intellectual property:

> *"…****when I go and submit my thesis, I'm supposed to turn over my data to the university****. …****It's like I don't really want that in their hands.*** *…but even in that, like the ethical storage of data, like who has ownership of the data?* ***Who remains the owner of the data? Like is it fair for these institutions to be getting our data?*** *And even historically understanding what some unis have in their bloody* ***archives, is like you don't understand the impact of the storage of like of artifacts and stuff. They don't get how to store this." Indigenous researcher***

Some Indigenous researchers staunchly withheld information because they considered the protection of community knowledge more important than advancing their career:

> *"So if there's stuff that I know that that would be really rich and informative to this project,* ***if there hasn't been anything published on it before, I'm not going there****.* ***That's my way of safeguarding the information.*** *Or I'm just gonna mention it in a really vague way.* ***Because for me, again, the thesis is just a document." Indigenous researcher***

The uncertainty around intellectual cultural property rights, the lack of proper agreements, and lack of trust caused some participants not to fully divulge their knowledge:

> *"****There was nothing signed or anything about it, no intellectual property rights or copyright.*** *That's why it's ... when they do that you don't tell them nothin'. Do like Mum used to do and make out she knew nothin'. She'd act dumb with 'em. Well not dumb. She was just very ...kept their stuff here. And that wasn't none of their business.* ***Because you don't trust 'em. So what information do you give to them?" Community coordinator***

## Academic recognition of Indigenous contributors

Given they had control of the academic narrative Indigenous informants expected researchers to modify their writing in response to community feedback:

> *"…but they have to take on the feedback and if they're not happy with the story that's coming out or the way that they've interpreted that information, then it has to be changed before they do anything else." Indigenous researcher*
>
> *"The information that they get back from doing their community report or whatever needs to be taken on board. …don't ask for feedback if you're not open to receive it." Past participant*

Respecting and incorporating the views of Indigenous researcher's transforms research reports and papers into *community documents*:

> *"Since my co-researcher has come along with this first rough draft document, I've done, you know, the last four weeks I've done a whole heap of work on it intensively, every day, and* ***I've put a whole heap of language into it, our language, not just as labels but as part of the interpretation of what the project's about.*** *So I've changed words like, you know, simple words in English* ***into something really meaningful and rich. Through our language.*** *I said so,* ***it's our project now*** *it's not an English written language pro- uh, it's not an English written project. That comes from a researcher's point of view,* ***this is now a community document." Indigenous researcher***

Indigenous communities want to interpret research findings and tell their own stories. This included critical review of papers before they were published:

> ***"And you know how you put in a paper to be published and they give you feedback and you have to make that feedback before it's allowed to be published. It needs that sort of relationship." Past participant***

However, there were occasions where Indigenous communities were left out of the research publication and dissemination process. :

> ***"…but it's surprising how I think how few communities really do receive back info, especially before it's published." Indigenous researcher***

Some believed that we need to move beyond recognition of Indigenous contribution and advocated for more Indigenous lead research authorship. More control so that researchers couldn't fly in and fly out. Though researchers might not be ready to give up their authority:

> *"****Yeah, well non-Indigenous people, they need to understand that they might be writing that up, but they have to consult us****. Every little part of it. They have to also include us in that. So our name needs to go on there. …****But we need more handle on that research, and more input, that way then people, they can't run off but, the thing is that they want control of that research…" Community coordinator***

Many Indigenous community participants were indifferent about the supposed benefits of being recognised for their contribution through publication. Academic authorship was not a significant incentive for them. Instead, they were intrinsically motivated to contribute to research because of their community and cultural obligations:

> ***"It comes from a different place when we do research, so ... Yeah, it's not about publications either, like white people and publications." Indigenous researcher***

> ***"So there's a real disconnect and that's why we don't care at [Indigenous organisation] whether we publish or not. …'Cause they [researchers], you know, you live through your publications. You've got to generate. …So even if it doesn't work out for them they've gotta publish something." Community coordinator turned researcher***

However, Indigenous authorship and co-authoring with community partners was a consistent theme throughout the interviews. It was clearly important and beneficial for some Indigenous knowledge holders and contributors to be recognised through authorship and to build upon an Indigenous knowledge base within the academy:

> ***"If you want to develop you do things like get them to be a co-author on your paper. That way you, you work with them to write an academic paper and that can be a really developmental thing and it leaves them with a publication." Indigenous researcher***

> ***"It's always good to publish, by the way, I'm very strong on that because it means that we're building the evidence." Indigenous researcher***

Many researchers collaborated with Indigenous people by co-authoring research publications. Researchers who published with their Indigenous research partners fostered relationships based on mutual respect:

> *"He [non-Indigenous researcher]* ***always named us on, publications anything that he wrote.*** *And always put himself last. Amazing. …he led a lot of the good research that I was part of. …****he always respected my knowledge****. I know he would have respected others knowledge. …****he would always ask for my permission to use my work****. …****So he would listen to what we were thinking*** *and then see how he could apply whatever theory or methods to how the conversation was going."* ***Past participant***

One Indigenous researcher sought permission from the research sub-committee and chief executive officer from their Indigenous organisational research partner before publishing:

> ***"…that's really important 'cause now when I'm writing up papers, um, you know, the first thing I did was ... I've written two papers. I think I ran it through, the CEO and the, the research committee that it was okay to write those papers." Indigenous researcher***

Additionally, when they realised the significance of community contribution the same Indigenous researcher went back and retrospectively gave community contributors the opportunity to be acknowledged:

> ***"…the dilemma was that I wanted to really honour the knowledge that was shared to me by some focus group participants. …'cause like it was sort of***

> ***community knowledge so I wanted them to be acknowledged for that. …I'm wanting us not just to take, you know, the kudos for the [research]." Indigenous researcher***

Indigenous community research partners were comfortable with researchers presenting the findings of Indigenous health research if they co-presented with an Indigenous community researcher or representative. Likewise, publications and reports required co-authorship with Indigenous partners:

> *"[Academic institution] have to publish a report, might be a presentation somewhere or it might go to a medical journal.* ***Yeah. But we're happy with that. But tell us. We want to present at an international conference.*** *Or, just tell us what's going on, and most times you know, when you say [researchers] is going to present.* ***Well someone from [Indigenous organisation] needs to stand next to you." Community coordinator***

Indigenous researchers and Indigenous participants want to actively be involved in interpreting results of Indigenous health research projects, including the academic publication process:

> ***"At the end, publishing it. They [Indigenous people] need to be in every step, I think. Because it'd be quite unethical to take something and, I don't know, twist it around or something I guess." Indigenous researcher***
>
> ***"Well, anything, like all the responsibilities, like the ownership, , the how it gets published... In what, in what context are we painted, if that makes sense." Past participant***

Still, there was community anxiety about how researchers conveyed Indigenous knowledge academically. They may have feared being misinterpreted or exploited. In fact, some Indigenous research partners wouldn't participate in research if they didn't have oversight over the translation of findings and interpretation of results:

> ***"We'll have final say over what's you know, released or what the results show." Indigenous researcher***

Unfortunately sometimes Indigenous communities were excluded from authorship. In many cases authorship was not readily discussed with Indigenous community research partners, and they were excluded or exploited during the publication process. Institutional barriers to Indigenous authorship were identified that privileged non-Indigenous academics or created opportunities for exploitation. Traditional procedures for recognising academic contribution through university structures often disqualified or downgraded the influence of Indigenous

people involved in the research. The system benefitted those with power and influence, which inadvertently inhibited Indigenous voices:

> ***"…you're actually perpetuating privileged knowledge here. Institutionalised knowledge…***
>
> ***…there was no one, there is not a study where an Aboriginal person's voice is privileged, you know, it's told through someone else in some way, shape or form." Indigenous researcher***

Traditional academic forms of reporting on Indigenous health research created institutional and financial barriers for Indigenous communities to access results and utilise relevant findings. Paywalls blocking access and overly technical publication, made it even harder for Indigenous communities to engage with research done about them:

> ***"And it's like what is that person getting, getting back? And like all these journals. Even the stuff that you publish will be behind a paywall. A journal that you have to pay for. …It's written in a way that no one can understand." Indigenous researcher***

The integrity of some researchers was also scrutinised. Troublingly, some researchers were accused of illegitimately manufacturing authorship and exploiting journal publication criteria for their own benefit. One Indigenous academic believed their non-Indigenous research partner engineered themselves to be the lead author on any potential publications. This left the Indigenous academic feeling used and undervalued:

> *"…the first named person as CI (Chief Investigator) on an ethics application, the underlying assumption at a system, systemic level is that* ***whoever is named first as the CI is the one who will have primary authorship rights. …I got 'sucked in'. I got just rolled… I was horrified by it.*** *You're just administer- you're administering the process. But it's much more than that. And I didn't know that. …It was flawed, it was a flawed process.* ***Yeah. Yeah, it was a flawed process. Because then, and how, how can you then go on to say, throughout a document, that's got a white fella's name on it, that this is about privileging Indigenous voices.***
>
> *…at the beginning stages of the project,* ***when we first did the first field trip we didn't even really talk about authorship.*** *And that's the other bit that I keep thinking, I'm such an idiot, I got sucked in." Indigenous researcher*

Some participants revealed that researchers had manipulated authorship just to satisfy journal requirements and meet research outputs:

> ***"It's occurred over the years when if it's an Indigenous specific journal for example, but they need an Aboriginal lead author on the paper and they just***

> ***switch names around just for the purpose of getting it published and maintain the status of the grant funding for the big author. Which is still going on these days." Indigenous researcher***

Another Indigenous researcher recalled a scenario where Indigenous investigators were originally excluded from the authorship process. However, the journal wouldn't accept their paper unless an Indigenous researcher was recognised as a lead author leading to questionable practices:

> *"I remember having an experience a few years ago where they had a grant submitted for an Aboriginal specific project, which was going to lead to a paper and stuff like that. And the normal investigation is done, but* ***the journal wasn't going to publish it because it wasn't an Aboriginal author*** *on the paper and at the last-minute ladies* ***changed the lead author to an Aboriginal person so they could publish the paper****… …Because if you're an Aboriginal person who's underdeveloped in terms of their research capacity or understanding of it,* ***you can be used as a pawn pretty much to come through the process and have an Aboriginal person attached to it." Community coordinator***

## Creating data governance arrangements

Early in the interview process respondents were asked about the concepts of Indigenous intellectual property rights and data ownership in relation to research they had been involved in. To achieve theoretical saturation additional questions were asked about data sovereignty in subsequent interviews with researchers. Researchers were specifically asked if they formally recognised Indigenous knowledge that contributed to their research. The following responses from participants in this study reflect a range of views that emerged on data governance.

Some Indigenous communities expected to retain full ownership over any information they shared through research and negotiated these positions with universities:

> ***"[The Indigenous organisation's] position on research is it's got to be beneficial to us and we have to own it. We've got really simple rules about research in our community. We have to own it. We want to be transparent, and we own the data." Community coordinator***

Indigenous communities entered into various agreements with researchers to protect their knowledge. Indigenous organisations also understood that they were obliged to protect community information. Some Indigenous organisations utilised intellectual property right frameworks and memorandums of understanding to protect their data:

> *Yeah, the reason it [MoU] was decided was because [Indigenous organisation] was worried that [academic institution] would appropriate, the knowledge from that and that they would use the data, or the, the knowledge in a way that would be contrary to what [Indigenous organisation] would, would see in that cultural knowledge.* ***So it was really for their, their safety, for the organisation's safety and, and data sovereignty if you will."*** ***Indigenous researcher***

An Indigenous community coordinator was part of an advisory group that developed specific protocols for authorising access to community data so they could keep researchers accountable to their community:

> *"****So what they wanted to do was put in some protocols around that group being consulted around the data. And who could access it and have it be shared.*** *So it was more making the researchers accountable to the community in terms of who accessed that, and if they got the proper permissions to you know,* ***share that data." Community coordinator***

They described how the group safeguarded Indigenous community knowledge by scrutinising data governance processes:

> *"****Especially the data governance.*** *I believe they wanted to really, they would not let up about that. They wanted to make sure, it's all around how many studies do you want to do on Aboriginal people? How many academics have studied Aboriginal people and culture, we know.* ***What are you doing with that data? Who are you sharing it with, and who has access to it? We need to be part of ... you need to get permission. So that's what they advocated for." Community coordinator***

A unique model to protect the data of individuals was developed by an Indigenous researcher. Through their institution they created processes for using community research data that allowed individuals to retain control over their data.

> *"****So the community the individuals own the data.*** *So we create the teaching resources and the community, like* ***the individuals have to sign off*** *that they're happy with the final product.* ***As it is a post-consent form.*** *And , it's their choice if they wanna give them to the community organisation to use or not, or they can give them to other unis or they can, you know, it's completely fine by them but they've consented that we can use them… … if they've got a cousin that works at another uni and they wanna use it, then yeah, it's,* ***it's their property so they can. And we can't alter it until, unless we get their permission." Indigenous researcher***

This approach seemed to give participants control over how their personal information was accessed and used. Another Indigenous-led project described by a past participant used a similar approach where certain information was not able to be published until participants

approved. The Indigenous ethics committee protected the knowledge of research participants by enacting a strict consent process:

> *"That was probably one of their criteria that we either own it or we're called owners and **you can't publish it without us signing off** and you know, all of this sort of stuff. So there will ... I think that the ethics committee at [Indigenous organisation] were, they were pretty strict, they were pretty strict. Yeah. Ownership and all of that was to go through them." **Past participant***

In another example, an agreement was established between an Indigenous organisation and an Indigenous researcher to share ownership of a useful tool that was developed through collaborative research:

> ***"Checks and balances and we have a good process [between the Indigenous organisation and the Indigenous researcher] that allows when people ask for that measure to be used…" Indigenous researcher***

This Indigenous scholar developed the tool through their PhD research which meant specific agreements had to be negotiated between their administering university and their Indigenous community research partner (whose data was being collected) to allow them to access the data for their PhD thesis:

> *"And then the [academic institution] side was that [Indigenous organisation] would allow me to ... so that the, the data would be used in a way that was going to allow me to have access to that so that I could complete the PhD and write up reports or papers but that **they would be provided to [Indigenous organisation] for feedback and endorsement.** But that I would have the right to use that so that like at last minute, you know, if I had I don't know some kind of conflict with one community member they couldn't turn around after six years and say, "No, you're not allowed to use this." You know?" **Indigenous researcher***

In this scenario the Indigenous community had control over how the data would be managed and accessed through their agreement with the PhD student. However, it also demonstrates the power of academic institutions and their role in the production of (Indigenous) knowledge. An Indigenous researcher acknowledged the uncertainty between the intellectual property rights of researchers and the intellectual property rights of participants but agreed that cultural knowledge should remain the property of Indigenous contributors:

> ***"It's not always black and white. It's also balancing out by cultural, you know, acknowledgement of cultural knowledge and cultural intellectual property rights." Indigenous researcher***

Conflict over data ownership often created tension between researchers (both Indigenous and non-Indigenous), Institutions, Indigenous organisations, and Indigenous participants and communities. Clarity around data ownership was a consistent issue raised by participants:

> *"So we wanted to, **one of the things around the data was who owns it**, and the [local community group] who's just a group of , community members, Aboriginal, non-Aboriginal, had very- had big concerns about **what was going to happen around with the data collected, and who was going to access it.**" **Community coordinator***

## Summary: Chapter twelve

Indigenous participants willingly shared information and contributed to research projects they believed would benefit them or their community. However, issues around intellectual property and efforts by Indigenous communities to protect knowledge also created barriers for sharing knowledge. Respondents expected researchers to appreciate Indigenous people for their involvement beyond academic acknowledgment.

The potential for conflict between individuals and collective holders of Indigenous knowledge was evident. This issue seemed particularly relevant for researchers working within Indigenous communities where data ownership and intellectual property arrangements were unclear or not established. Data governance arrangements between researchers and Indigenous communities were outlined by some participants, but many relied on an informal shared understanding. In some cases, protocols for data ownership were formalised in research agreements or through memorandums of understanding (MoUs).

According to some participants researchers failed to understand protocols for acknowledging Indigenous contributions to knowledge production. Although Indigenous knowledge and Indigenous data have been used interchangeably there are obviously some fundamental differences between Indigenous knowledges and knowledge or data about Indigenous peoples generated through research. There are also potentially different interpretations of Indigenous data considering the Indigenous context within which they are collected. However, arguably this doesn't alter the underlying principles and practices for protecting the interests and rights Indigenous contributors to knowledge produced from research – regardless of whether contributions are derived from traditional cultural knowledge or other non-cultural knowledge or experiences. The common denominator is the intrinsic value Indigenous people, communities or organisations bring to the knowledge production process.

Despite the emphasis on sharing authorship with Indigenous research partners, there were some systemic issues with the publication process that influenced how this was put into practice. Some researchers only shared authorship when it benefitted their own scholarship. Journal requirements for Indigenous authorship sometimes led to exploitation of early career Indigenous colleagues or non-research community members. Sometimes Indigenous people were included in research activities such as recruitment, data collection, and community engagement but were not recognised as authors or in the academic publication of research.

Additionally, participants experienced or observed researchers taking knowledge without permission. Others described how people without community ties exploited research processes to take community knowledge without any consequences.

In contrast, respondents reported many occasions where they were valued as co-authors and recognised for the knowledge they contributed by researchers. Many researchers collaborated with Indigenous colleagues based on mutual respect for their respective expertise and knowledge. Respondents reported that Indigenous people were invited to co-present at conferences and co-author publications of research they had been involved in. Clearly, Indigenous people were valued when they participated in these academic activities. These findings show Indigenous respondents want to be part of telling the story and to be recognised as authors of research.

Institutions, and researchers, Indigenous organisations, Indigenous communities, and Indigenous people all 'value' Indigenous knowledge and utilise Indigenous data for different reasons. To Indigenous people knowledge is sacred. The reciprocal nature of creating and exchanging knowledge was a concept mentioned by different Indigenous participants throughout the interviews. The process of knowledge exchange put simply is 'give' and 'take'. In a research setting, trust needs to be built between the researcher and the Indigenous people before the exchange of anything.

In summary, there was a mixed response, with conflicting experiences and opinions in relation to this issue. To what extent Indigenous people are valued within research It is not clear from this study. Participants presented a range of experiences portraying how Indigenous people were acknowledged/or not for their contribution to research. Some people had overwhelmingly positive experiences of respectful and appropriate recognition from researchers while others were left feeling unrecognised and devalued. What is clear is that when Indigenous knowledge holders were recognised for their contribution it 'transformed' academic research into 'community' research.

## *My experience as an ethics committee member*

*It seemed strange to me that in all of my time as an ethical reviewer I was only ever asked to review Indigenous research proposals. In some way this made my role feel tokenistic. Is an Indigenous perspective valued or obligatory?*

*I was advised to remove a lot of 'unnecessary' details from my own ethics application to avoid raising questions or forcing ethics committee members to review information they had limited understanding of i.e. Indigenous research methodologies. It poses the question, how can HRECs review Indigenous research if they don't understand Indigenous methodologies?*

*During my candidature I was invited to sit on three ethics committees. I sat on two. But only for a short while. I could not keep up with all my other responsibilities. In the reviews I did I was tough if I could not clearly see a benefit. If I could not see how Indigenous people were involved. I don't remember being trained so I was going on my cultural intuition a lot of the time. There were times when the committee would not blink an eye and I would think 'What's going on here?', so I would speak up, because I had to.*

*The last ethics review I did, an Indigenous colleague, about my age, had put in an ethics application on behalf of her teaching associates. It was for an Indigenous curriculum evaluation project. When I read the application I realised that her name was nowhere to be found in any of the leadership roles. Puzzling? Also she was not listed as a potential author. From what I could gauge she was involved in the project to pull it all together. She was the only Indigenous person in the team! The usual scenario.*

*I asked her why she wasn't recognised as a lead and a potential author. She had no idea that she should even consider those roles! I told her to go back and talk to her colleagues.*

*It seemed so simple to me that the only Indigenous person, part of an Indigenous curriculum project, should be recognised as a lead and author, and valued for their contribution?*

*We can do this better…*

## Chapter thirteen: Giving back to Indigenous communities

To get a better understanding of the perceived impact of Indigenous health research we asked past participants, community coordinators, and researchers who participated in this study how research benefitted Indigenous communities from their perspective. Respondents were asked how researchers reported back and asked if there were any barriers to reporting back to communities. Finally, researchers and community coordinators were asked for examples of capacity building activities in relation to research they were involved in.

Participants in this study recognised the value and impact of research for Indigenous communities but specific details about how this occurred were less forthcoming. Although it was generally understood that research was valuable participants in this study found it difficult to clearly define the benefits of health research to Indigenous communities. Participants, researchers, and communities all benefitted from research in different ways. Research benefit seemed to vary depending on the context and type of research being carried out. There were also secondary benefits (such as additional funding, employment, access to research expertise) that research provided that weren't necessarily the focus of the research.

This raised broader questions about the perceived benefits of Indigenous health research. Who are the main beneficiaries of research conducted with Indigenous communities? Who determines what potential research outcomes are for each project? How do different stakeholders (including researchers, research institutions, community partners, participants, local Indigenous communities) benefit from the research? How are benefits shared (or not shared) between partners?

### Meeting reciprocal obligations

The expectation of reciprocal obligations was a fundamental aspect of a trusting relationship. The promise of mutual benefits motivated Indigenous communities to participate in health research. An equal research partnership ensured academic objectives and cultural obligations were both met:

> *"And that's the way the relationships are then driven and drawn on and that's cultural 'cause we're looking for that reciprocal relationship…" Community coordinator*

Indigenous communities expected researchers to give back, whether through project activities, or in other ways. Researchers needed to clearly outline how their research would benefit their community:

> ***"I wanna hear in their words how they believe the community's gonna benefit from their research." Indigenous researcher***

Some Indigenous communities agreed to research because they could use and co-opt researchers for other community activities. They were interested in what skills and expertise researchers could bring to their community – participating in the research was a necessary compromise. Indigenous respondents discussed how prospective researchers would be assessed based on what they could do for their community:

> *"And it sort of happens informally. People especially that come through the [Indigenous organisation]. They have to do work in the community. If they're coming here to take information, then the least ... They need to be contributing to something else."* ***Community coordinator***

In addition, Indigenous people wanted to be acknowledged by researchers for their contributions, and they wanted proper compensation for their time:

> *"…it's like there's the expectation that as Aboriginal elders, or as Aboriginal community members, do they give up their time for free? It's actually that there needs to be recognition that if we're gonna have Aboriginal consultation, that there, there needs to be reimbursement. Like you can't take our knowledge, and then not give something in return. And just because research might be benefiting our community, doesn't mean that we have to give up our time for free."* ***Past participant***

Many researchers undoubtedly felt a sense of moral duty to give back to Indigenous communities. In the process of research there are many opportunities to contribute back to the community. Impactful research that provides solutions for health problems is obviously of enormous benefit to Indigenous communities. At the very least research projects need to leave Indigenous communities with more knowledge than they began with:

> ***"Yeah. It's not just about them taking, taking, taking and not giving anything back." Community coordinator***

## Translating research into outcomes

Strategies for knowledge translation were expected in university ethics applications and this was a common theme in the research. Participants felt emerging knowledge needed to be

shared with relevant groups for research to be useful and strongly advocated for research to inform community best practices:

> *"And I think that **research on the ground has to be translational**. , I think the days of just doing high end academic research, uh, yeah, that might be some need for it, maybe but for the most part I reckon **95% of the research has to be translational research**, developmental research with immediate application upon identifying best practice models in that research and **then immediate dissemination of the knowledge across a sector**. **Because, , that's where it becomes meaningful and that's where the community can see an immediate benefit."** **Community coordinator turned Indigenous researcher***

Indigenous-led research institutions and other research bodies stimulated a knowledge translation and exchange research agenda. Participants believed that learnings from research could and should influence policy and practice, which in turn would improve community services:

> *"So you do the research you write it up and then bring it back policy and practice change would be, and **so there is the flow onto how services can be improved in the community**. But that being sort of **translating research into policy and practice**, there's a big emphasis on it. About how much that actually happens in the last five or 10 years. They talk more and more about how you've got to show that in your [Indigenous research institute] applications, with your ARC applications."* ***Indigenous researcher***

Community-based Indigenous research partners clearly wanted to use the findings of research. Through their research, some researchers provided support for communities to build further capacity to interpret, translate, utilise, and review research data:

> ***"We're trying to help them develop their own reporting and monitoring systems. So that they can follow up themselves. …so we're helping establish that. … People should be empowered to be able to follow their own data." Researcher***

Indigenous organisations expected research projects to leave their communities with something substantial to build upon:

> ***"What are you going to leave with us when you go? And what are you leaving us for us to manage and look after, you know, how do we value add to this? Community coordinator***

Participants thought it was important for researchers to share research findings with Indigenous communities so they could reinterpret and use the information. An Indigenous

researcher recognised the potential value of research for Indigenous organisations when they were involved in interpreting the results:

> *"**Data's just data but you contextualise... and say, is this what you're seeing?** …And so that's how we looked at the data, then went out to the ACCOs and said is this what you're seeing? **'Cause this is what the data's saying.** And we went, and they went [pause] yup we're seeing it (laughs). **Do you know why? Look, we've some great ideas why."** **Community coordinator turned researcher***

This interaction reinforces how important it is for research partners to interpret results because they had the greatest insights to give. In our roles as researchers we are expected to make sense of data from an objective position. In Indigenous research it is constructive for translation of results to be grounded in the experiences of Indigenous participants, especially in relation to qualitative research data. Indigenous participants understood the importance of local interpretation of research data. It also indicates how Indigenous communities could utilise research to identify community solutions. Many believed Indigenous partners held responsibility for how information was shared with the broader Indigenous community: More than that, Indigenous institutions wanted to be involved in disseminating research:

> ***"…Well, if we're going to be part of research, we have to get it out there. We have to be in control of how it gets out there". Community coordinator***

Similarly, a non-Indigenous researcher described how a national research project they were involved in supported the establishment of regional committees to regularly monitor results in different jurisdictions:

> *"**[We've] set up jurisdictional committees to review and monitor the data. It's either quarterly or six monthly. And they're going, in each of the states, and territory, apart from South Australia." Researcher***

A community coordinator suggested research fact sheets could be used to support relevant future funding applications for Indigenous communities:

> *"Maybe even break it down to the community about how this research can benefit their organisations and the communities within their own towns and to give them, I suppose, even a, a fact sheet on how they can extract information to use that research to benefit through funding and all those kinds of things." **Community coordinator***

Unfortunately, not every Indigenous community had the necessary tools to utilise research data effectively. In response some academics actively aimed to increase community research capacity to evaluate and 'follow' their own data:

> ***"…we're trying to help them develop their own reporting and monitoring systems. So that they can follow up themselves. …so we're helping establish that. … People should be empowered to be able to follow their own data." Researcher***

However, despite consensus about the importance of knowledge translation, exchange, and impact there was clearly recognition that a lot of research failed to deliver any outcomes for many communities:

> ***"I fully recognise that. There's** a lot of research that's led to nothing." Non-Indigenous Researcher*

Academics and research institutions were challenged to better demonstrate how they deliver tangible outcomes:

> *"I'll bet you there's **not many that can actually say how they've benefited the Aboriginal community** in which they got the participants' information from. **It benefited the PhD person** and it **benefited for the research for big institutions**. **How much of its gone back?" Community coordinator turned Indigenous researcher***

According to Indigenous respondents research reports were too often 'left on the shelf'. Institutions and organisations were criticised by respondents for their lack of research impact. Many participants believed researchers and communities had a responsibility to use research findings:

> ***"How do we help Aboriginal people take control of the research so that it benefits them and it's not just gonna sit on a shelf and collect dust." Past participant***

## Summary: Chapter thirteen

Fundamentally, Indigenous communities deserve to receive some form of benefit or outcome from health research they contribute to or participate in. Indigenous participants voiced how important it was for any researchers to meet their reciprocal obligations with participating Indigenous communities. The notion that researchers *give back* to the Indigenous communities that contributed to their research was clearly supported, although examples of *how* researchers did this in practice was less evident.

Indigenous community research partners wanted to know how they could utilise the findings of research. Many participants reflected on capacity building activities as outcomes of research. Others believed that collaboration with academic institutions provided access to different capacity development opportunities for Indigenous communities. Similarly, employment opportunities arguably contributed to the skill-base of the broader Indigenous community.

Researchers frequently approached Indigenous organisations to facilitate the dissemination and translation of research findings back to Indigenous communities. Empowering Indigenous communities by supporting community-led research and privileging Indigenous voices fosters stronger community support and ownership.

The potential to exploit and over research Indigenous communities, without delivering any outcomes, continually emerged as an issue. Some researchers were shamed for doing research with Indigenous communities without meeting their reciprocal obligation to provide benefits. Whilst others felt guilty or *yuck* when they didn't give anything back to the community.

The ostensible 'shelving' of research findings is perhaps one explanation for the failure, at times, of Indigenous health research to deliver outcomes for Indigenous communities. There was an underlying insinuation that it was unethical to carry out research that resulted in another report that just sat on the shelf. Indigenous people did not want to participate in research that was purely for academic purposes.

In conclusion, Indigenous communities often received some secondary benefits, but they wanted more out of health research. Furthermore, researchers had a core ethical

responsibility to ensure that any Indigenous health research they undertook was worthwhile, could be used, and produced practical outcomes for Indigenous people.

## Chapter fourteen: Institutional ethical review

Respondents described their experiences in relation to the ethical review process. The findings also revealed how institutions defined, reviewed, and approved ethical research with Indigenous communities. Each institution developed and applied their own ethical frameworks to comply with ethical standards determining how ethics application, submission, and review processes would be carried out.

According to the 2003 *guidelines* participating Indigenous communities should be engaged and provide formal support before researchers undertake the formal ethical review process. This process gives Indigenous communities the opportunity to inform, contribute to, critique, design, and endorse proposed research before ethics application are submitted. In the experience of some respondents this did not always occur. Indigenous community approval processes often interpreted Indigenous ethical guidelines differently to university ethical review committees. This sometimes caused an inconsistent approach to ethical review processes.

Several respondents expressed frustration with how current university ethical review systems were implemented. Lack of Indigenous involvement in ethical review within institutions (HREC) and/or lack of community oversight and endorsement of ethical review applications (community approval) were clear barriers to ethical research with Indigenous communities. Practical strategies were suggested for improving ethical review procedures and strengthening Indigenous participation in them.

Respondents' experiences of the ethical review process showed that human research ethics committees, Indigenous researchers, non-Indigenous researchers, and Indigenous communities interpreted the values and ethics guidelines differently. Many respondents called for increased Indigenous representation on HRECs to influence how the Indigenous guidelines were interpreted by universities:

> *"**Each HRECs different, how they interpret the NHMRC (National Health and Medical Research Council) guidelines is different.** You know? So some, some are more rigid then others. …I think the way HRECs apply, you know, structure and apply their interpretation of NHMRC guidelines and protocols is where it sits, so we have to influence HRECs. **We've got to get more Aboriginal people onto HRECs and we've got to get them to agree to, to change and be more flexible."***
> ***Community coordinator turned researcher***

There was obvious tension about dominant research institutions reviewing and approving Indigenous community health research. The credentials and the capacity of universities to review Indigenous health research were queried. Many Indigenous researchers found it patronising to seek approval from a non-Indigenous institution to do research within their own Indigenous community:

> *"…**so do I need to go to a uni and then ask them permission to do research with my own mob**, and then fill out their forms and then send them back to them and then wait for them to say it's okay, **when really what I should be doing is just sitting down with my elders**, and asking them and telling them and then getting feedback. **You know? You have to do both**." Indigenous researcher*

Indigenous researchers disputed the right of predominately non-Indigenous HRECs to approve community research. They also felt the process for getting Indigenous community approval was not given enough respect by the academy:

> *"…**it's weird that Aboriginal researchers have to put in an application to, to white people**, if it's all right if we do research on our own community. Like, that's weird. But there's no, well, we, like, we come and we get our, permission from [the Indigenous organisation]." **Indigenous researcher***

Some participants expressed their lack of confidence in academic ethical administrative systems to protect Indigenous communities in the research process:

> ***"I think it's pretty clear that many communities now don't trust university ethics systems." Indigenous researcher***

HRECs are required to consider the guidelines in their assessment of Indigenous health research projects. Yet, some respondents thought some HRECs focused on bureaucratic details that were not relevant to the *guidelines*. One researcher believed the ethical review process had *"nothing to do with ethics".* This was reiterated by many researchers involved in this study who felt frustrated by university ethical processes:

> ***"It's extraordinarily frustrating, and ethics committees, I don't know, it's like they're trying to get you to shoot yourself in the foot sometimes. (laughs)" Researcher***

Some believed the preoccupation with procedural red tape could result in harmful ethical issues rather than prevent them. An Indigenous researcher considered specific changes suggested by an HREC, unethical to Indigenous participants in their project:

> ***"[I]t would be absolutely unethical for me to follow the structures of our ethics committee in showing Aboriginal people the garbage that they expect us to show them. That they call plain English statements." Indigenous Researcher***

To overcome the institutional emphasis on procedural issues some researchers would simply comply with instructions to attain ethics approval, then adapt their practice to what they thought was *"the right thing to do"* once they were in the field:

> ***"So that's, that's when I just go, yes, yes, of course, and go and do what is the right thing to do." Researcher***

In essence researchers thought the process of ethical review was merely monitoring completion of administrative tasks, which they felt was immaterial to the actual ethical practices of researchers:

> *"…**this is no longer an ethics system that we experience here in the university**, nor is it anything to do with ethics in, when you run up against the state health department ethics committees, that's **got nothing to do with ethics.** And because there is some unethical research, not from our university, necessarily..."* ***Indigenous researcher***

From an institutional standpoint the evaluation of ethical conduct was viewed as being reduced to examining research topics and policing ethical *procedural* compliance:

> ***"…these committees are not dealing with ethics; they're actually just policing the kind of research that can be done and who can do it." Indigenous Researcher***

The original ethical intent of the guidelines seemed to get lost when they were institutionalised. Due to the nature of their role, HRECs prioritised the administrative aspects of their review which was to the detriment of Indigenous health research proposals:

> ***"...find out about the actual, real ethical propositions of the research that's being undertaken as opposed to the pedantic processes**. …And I'm sure that's not what the ethics committee who sits there think what they're doing **but it's the way that it's being structurally framed." Researcher***

Researchers seemed to be frustrated with the overly pedantic and paternalistic review of their ethics applications. They felt some feedback was trivial and burdensome:

> ***"…they reviewed our, our response and had 26 questions. And it was silly stuff. And the ethical question, the questions about the ethics of the things, were basically meaningless." Researcher***

Protecting against risk is a serious consideration for universities. Therefore, it is logical for ethical processes to emphasise protecting against risk through legal frameworks. Universities

have a primary legal obligation that is prioritised and safeguarded through ethics. In short, a number of respondents believed the ethics process had become focussed on mitigating risk and being an insurance policy to protect researchers and the institutions they represented against complaints and potential legal challenges:

> *"And the other thing that I think they really do, it seems more,* ***less about the ethics and how you're applying them in the research, more about risk protection of the university.*** *So, you know, a legal [pause] they're protecting their own butts. To ensure that, you know, you're not gonna go out there and do something that is going to then come back on the university and have some sort of legal recourse. And a lot of what the ethics questions come about and their retorts, to me,* ***feel less about acting in an ethical manner. And more about acting in a risk-averse manner." Indigenous researcher***

## Capacity to apply the guidelines

Researchers involved in Indigenous research are required to comply with university ethical processes to have their research approved. However, it was argued that some HREC committees did not have the expertise and experience required to review Indigenous health research proposals.

Respondents noticed that some HRECs lacked the necessary Indigenous membership to interpret the guidelines appropriately. The *guidelines* were subjectively applied by HRECs and required Indigenous input to enhance their effectiveness. At the very least ethics review committees needed members with knowledge about Indigenous health research. A few respondents commented that some HRECs weren't adequately equipped to assess Indigenous health research proposals implying they had a superficial understanding of the *guidelines*:

> ***"…but it's about that HREC having people informed about Indigenous health research and the guidelines to know, to prompt to have a community reporting mechanism, but that's pretty flimsy." Indigenous researcher***

From their perspective extensive training was required to set a high standard for ethical review. Indigenous members of research committees needed to be skilled up and supported to uphold community obligations to protect Indigenous knowledge. As an example a respondent suggested that when they first started on the AIATSIS ethics committee the training was inadequate for the role they were expected to fulfil:

> ***"…the level of training that we got was just scratching the surface. And it was kind of, it was almost a bit belittling. And that sets the bar then, for the whole committee, in terms of what our responsibilities are and what the expectations that are placed on us as guardians of Indigenous knowledge." Indigenous researcher***

Many Indigenous respondents claimed training for HREC members on the *guidelines* was poor. In their experience training lacked depth which they felt diluted HREC obligations to uphold the values in the *guidelines*. Many Indigenous researchers who had previously participated in ethics review committees believed comprehension of the guidelines were inconsistent and varied according to membership:

> ***"…I've worked as a reviewer for an HREC. An advisor to an HREC. …some advising as well as chairing that HREC. So all different ones and involved in reviewing for an Aboriginal-led HREC and I think that there's not an across the board understanding of people on HRECs of the guidelines." Indigenous researcher***

Many participants suggested compulsory ethics training for researchers and HREC members to embed a more consistent and shared understanding of the Indigenous *guidelines* across the academy. An Indigenous researcher argued specific training was required and said committees needed more members with experience working in Indigenous communities:

> ***"So I think we desperately need that on mass education of academic stuff. About Aboriginal ethical guidelines." Indigenous researcher***
>
> *"…we do need some arrangement for research on Aboriginal people so that there are people on the committees who are,* ***they don't have to be Aboriginal or Torres Strait Islander, but they do need to be very experienced researchers in the Indigenous world.*** *So that we don't have to go through this nightmare. So something like that has to happen and I think actually that* ***everybody who serves on an ethics committee should first of all do a course on ethics so that they understand the difference between ethics and their personal biases." Indigenous researcher***

Some Indigenous-led ethical review models have been developed by mainstream institutions and Indigenous communities to address the lack of understanding and better inform researchers about the *guidelines*. An institution that established their own Indigenous advisory committee found that it provided secondary benefits for their organisation. The introduction and influx of Indigenous knowledge and expertise provided greater education and mentoring opportunities for non-Indigenous academics, which was a welcome but unexpected outcome:

> ***"…a really nice by-product [of an institutionally based Aboriginal research advisory committee] that I guess as head of research that I have observed is an increase in knowledge and understanding so it has also provided an educational opportunity for researchers within the network to learn more…***
>
> ***…but it also provides a learning opportunity, and it informs the feedback and forms, you know, future applications we'll submit or design of future studies. So, I think the by-product of this process has been a valuable educational process, particularly for non-Aboriginal researchers." Researcher***

Non-Indigenous researchers were criticised for being uninformed and apathetic about the *guidelines.* Some Indigenous academics were tired of preparing the ethical foundations for lazy researchers:

> ***"The other basic things is some people don't, some people don't… have never ever, ever read the Aboriginal ethics guidelines. And I know they've just been updated, but they've never ever read them. …they don't actually go on and read them. They, they just don't do that." Indigenous researcher***

An Indigenous researcher often felt conflicted about providing support because it took time away from their own research. They refused to support non-Indigenous researchers who failed to take the time to review the *guidelines* and resented researchers that expected them to fulfil their ethical obligations*:*

> *"…[a] non-Indigenous researcher who had come to me, he literally came to me saying, I'm really nervous coming to talk to you**. And he was like, I know I should know more and I don't and I don't want to make a fool of myself**, but I'm probably going to, which to me is like, it's sort of quaint and nice and honest, but it's really boring too. **It's like go do your homework and then come to me. They expect me to do your homework with you because I've got an actual proper research job too. Just like you.** And I'm not coming to you going, oh I don't know the guidelines. So I gave him the Lowitja material and the NHMRC material cause the new NHMRC just wasn't, yeah, going to cut it…" **Indigenous researcher***

However, most Indigenous people involved in research indicated that they wanted to inform and educate researchers because ultimately, they wanted researchers to conduct research the *right way*. It was important to build the capacity of individual researchers to ensure they conducted quality research. Indigenous people wanted research projects to provide an accurate portrayal of their community. An Indigenous researcher believed part of their role was to build the capacity of other researchers:

> ***"…but half my work is helping other people to do their work in a way… I trained actually as a researcher to be a serious researcher. All I can think is I can only be***

***that serious researcher if I help bring other people along…In in that sense it is a privilege building capacity of other people, especially that person who was so open…" Indigenous researcher***

## Mandatory high-risk review

Through the ethical review process many participants strongly disagreed with the way Indigenous health research was automatically placed in the high-risk category. An Indigenous researcher argued it was unnecessary for every Indigenous specific project to be grouped into this category. The Indigenous participants in their study were all highly regarded community members and as such in their opinion further scrutiny was not needed. But from an institutional viewpoint, Indigenous participants in their research were automatically viewed as 'highly vulnerable'*:*

***"High risk, right? And they had Aboriginal and Torres Strait Islander people there with the criminally insane, and I don't know, all these other highly vulnerable categories. And my research project largely involved talking to, , highly effective and responsible Aboriginal leaders." Indigenous researcher***

One Indigenous researcher felt automatic inclusion of Indigenous health projects into the high risk category was demeaning to the Indigenous participants in their research:

***"…So I was filling out the ethics forms, and I refused to tick that box, because I wasn't gonna put the kinds of Aboriginal and Torres Strait Islander participants into that category. The people I work with are not going to be classified as vulnerable in any way. I mean, they're actually highly effective operators and you know, a damn sight more literate than the idiots on our ethics committees, frankly." Indigenous researcher***

There were also those that believed some HRECs had covertly prejudiced understandings about Indigenous people, which manifested into an inherently paternalistic perspective through the ethical review process:

***"I remain convinced today, most of the questions have nothing to do with ethics and most of it's based on a really, I think racist view of Indigenous people as vulnerable." Indigenous researcher***

The imposed preconception that Indigenous people were *vulnerable* and a biomedical weighted approach potentially contributed to a perception of a fundamentally paternalistic approach to the ethical review of Indigenous health research. The practice of paternalism and *protection* hypothetically prevented Indigenous researchers (and non-Indigenous researchers) from dealing with challenging problems in Indigenous communities. In some

circumstances ethics committees were considered to be overly protective when reviewing culturally complex Indigenous research topics because they were worried about being accused of being overtly 'racist'. Ironically, this approach seemingly had the opposite effect:

> ***"...all the white people who sit on these ethics committees think that we're unethical 'cause we wanna look at these [sensitive] issues****, and you know why? …[they] do not want anyone to think that they're accusing Aborigines of drinking too much or bashing their missus, because you know they think they're white liberals.* ***They think they're really supportive of Aboriginal people, so anybody in the university who wants to do research on these difficult issues must be unethical because "We're not racist." It really is that stupid." Indigenous researcher***

Some respondents thought the ethics process had become too political correct. In one example an Indigenous researcher claimed a university ethics committees made it unreasonably difficult to approve research they thought was important:

> *"****So how is it ethics and how is it research to try to stop us from doing research on matters that Aboriginal people want research, like alcohol and family violence?*** *I don't care what their views are on these matters, they're supposed to be an ethics committee.* ***But you know what they are? They're a censorship committee. They just bring all their own prejudices to the table.*** *Yeah, people carrying on about university censorship and freedom of speech over here is not actually where it's occurring.* ***It's political correctness gone mad." Indigenous researcher***

Although university HRECs aimed to protect Indigenous communities, these systems sometimes prevented research on challenging subject matters deemed important to those communities. Furthermore, the censorship of Indigenous health research possibly had the opposite effect to what was intended.

> ***"...they're [HRECs] just know-it-alls with no comprehension of the fact that they might be causing real harm in the way that they are talking about Aboriginal communities." Indigenous researcher***

HRECs had the power to approve Indigenous health research but some respondents did not appreciate *institutional* scrutiny of cultural approval processes. The mandatory requirements to assess every Indigenous health research project as high risk reinforced paternalistic review processes:

> ***"There's no way in the world that I would ever do this work without somebody's permission. What do they think that you can just rock up to a community that have never met you before? And do research?" Indigenous researcher***

One senior researcher experienced patronising feedback from ethics committees on multiple occasions, which effectively eroded their trust in ethical review systems.

> ***"…the sorts of questions that I've been asked by ethics committees over the years that I've worked here at [academic institution] are beyond insulting. …they are insulting to my intelligence, they're insulting to Aboriginal and Torres Strait Islander people, and they show absolutely no comprehension of the actual research process." Indigenous researcher***

In contrast, some respondents found the ethical review process useful for guiding and validating their research practices with Indigenous communities. Feedback from well-informed HRECs added value to research and could assist researchers to fulfil ethical obligations in practice:

> *"**The thing I always say is doing a process, whereby you do the right process adds value to your research**. And so it is a value adding exercise when you go through the appropriate ethics process. And we do talk to the community, we do have a reference group that can be a governance group that does, that isn't just you can form it retrospectively of what's been done. **That sort of thing adds tremendous value to the research." Indigenous researcher***

## Scientific biomedical based ethical review

Other problems emerged with how institutions reviewed Indigenous health research projects. HRECs were usually led by members with backgrounds in traditional academic disciplines. HREC members from medical and science disciplines had distinct views about research that wasn't always congruent with other disciplines. These views were often the most dominant and dictated how Indigenous research proposals were evaluated internally. Researchers from traditional disciplinary backgrounds tended to have fixed views on how research should be conducted because of their own ontological and theoretical approaches:

> ***"...[with the HREC] sitting in the medical faculty, but even the way that the ethics applications are set out it's got, the ontology behind it.** So the way that it's framed eschews things that different disciplines don't do. So for example, in anthropology you don't go in there with a hypothesis and already assume you know the answer and you'll just go and test it. **You go in there; you might be focusing on an issue or a [pause] and generally you find out what's happening…***
>
> ***But it's not set up in the same way of, you know, aim, hypothesis, method**, da da da da, in the same drawn out way that a lot of other disciplines particularly scientific research occurs. **There is a difference to it, and it certainly is not reflected in the way that you have to write an ethics application." Researcher***

The focus on the scientific method was demonstrated by different players in the research including research staff, ethics committees, and third-party stakeholders. In many circumstances compatibility with community cultural protocols were secondary or not considered at all:

> ***"…so, I had no safety precautions, or any cultural considerations in that project. Unsafe research as far as I'm concerned, for mob. But in the eyes of a psychologist ethics committee, totally fine." Past participant turned Indigenous researcher***

Different researchers carried out Indigenous health research according to their disciplinary training and likewise HREC members reviewed projects according to theirs. It was clearly understood that ethical review committees had the power to approve research on behalf of the institutions they represented. However, their capacity to provide approval on behalf of Indigenous communities or to verify and validate community approval was questionable. An Indigenous researcher implied that ethical approvals were cleared institutionally without being discussed with Indigenous communities externally:

> ***"…for their ethics application they have ticked off what they needed for that but does anybody that makes that decision about whether that research is ethical or not actually care what the community think?" Indigenous researcher***

Without specific Indigenous health research expertise HREC review of Indigenous health proposals were lacking, inappropriate, and arguably unjust. A community coordinator argued for HRECs to diversify and turnover their membership to rejuvenate their committees and to let Indigenous people have a go:

> ***"It's the same old people in there, on the same old committees, that are making these decisions, that need to step down and let fresh blood in. And the way that they're looking at it, they're not [pause] and they do that for a reason. And that is to hold people back." Community coordinator***

## Complex, multi-jurisdictional, and extended ethical review

Research projects that comprised multiple sites, and/or within different jurisdictional regions, usually required ethical approval from multiple bodies. Many researchers involved in this study believed ethical processes for these types of projects could be centralised in order to remove duplication and streamline processes. It was also suggested by some researchers that ethical approvals provided through universities were adequate for multi-sited research, and additional approvals were time consuming and onerous. In contrast, some respondents believed additional regional approvals were required to maintain the autonomy of relevant

regional, and jurisdictional authorities and respect community approval mechanisms. Demonstrating these contrasting perspectives, one respondent explained how their colleagues felt additional regional approvals (and the prerequisite responsibility to engage with relevant communities) were unnecessary because they had already secured university ethics approval for a national project they were conducting:

> *"And I said, well, we haven't actually built that relationship yet with the health workers that you want to interview.* ***We haven't even gone through the ethics process over in Western Australia.*** *"Ah, but we've got the social behavioural research ethics approval from our institution at [university], that's enough." And I said no actually, it's not.* ***If you look at the NHMRC guidelines, they very clearly state that it's a multiple layered process, that you should never expect that there'll just be one round of ethics approval. And we are working on a national project here that's not based in South Australia alone." Indigenous researcher***

The ethical process for Indigenous health research frequently took more time to complete due to various reasons including increased documentation, complex nature of proposals, multiple sites, locations or jurisdictions, unfamiliar research methods (to reviewers), lack of HREC capacity, amendments procedures, and mandatory requirements mentioned earlier. Most researchers willingly complied with requirements and genuinely wanted to practice ethical research. Yet they also bristled at the additional burden to achieve ethical approval for Indigenous research:

> ***"[T]here's a special set of guidelines and you've got to do all this extra work." Indigenous Researcher***

HRECs asked researchers to submit multiple variations to general research materials for projects that covered different sites with numerous participants which deterred people from conducting Indigenous community research:

> ***"It's gonna be a different message for young people. It's gonna be a different message for elders, we're getting elders involved. So I'm thinking, oh man, I've got, I'm gonna have… literally hundreds of documents on this… It is a massive barrier." Community coordinator turned Indigenous researcher***

In general, institutions implemented rigid interpretation of the guidelines from a technical standpoint focused on process. HREC's required a lot of research documentation to be finalised through the ethical review process but this wasn't always possible for researchers partnering with Indigenous communities. These requirements sometimes restricted researchers from engaging with Indigenous communities and with Indigenous research

partners on their own terms. The ethical administrative process wasn't nimble enough to adapt to community activities which were often informal. Hard institutional ethical standards were incompatible with flexible practical relationship-based protocols between researcher-community:

> ***"Well, you could guess it and put it in the HREC but what actually in reality was completely different and that meant that we had to submit amendment after amendment after amendment, to make sure that we covered ourselves. And then as soon as we get here and even an ACCO won't ever be able to anticipate what community will want to do. So that's why there's always amendments along the way." Community coordinator turned Indigenous researcher***

Researchers often couldn't include everything within their ethics applications because Indigenous community partners had to listen to their community in real time and could not predict every possible activity necessary to ensure culturally safe research. Therefore, to do Indigenous health research ethically researchers were often required to submit amendments. The amendments required often did not sufficiently reflect community cultural processes. Further revision then often lengthened the process:

> ***"[B]ut we can't keep putting in amendments... and getting them approved. It's just ridiculous." Community coordinator turned Indigenous Researcher***

Researchers and community coordinators of Indigenous health research projects had to navigate comprehensive multi-layered approval mechanisms. National projects with multiple sites across different jurisdictions were required to seek numerous approvals from both formal ethics committees and Indigenous communities. A non-Indigenous researcher illustrated the point with their project:

> *"…the biggest problem we faced with the ethical guidelines was on the [national project]. Where we'd selected 30 sites, randomly, across the country and* ***we had to get 72 ethical clearances before we could undertake that study****." Non-Indigenous Researcher*

Presumably, each ethics application required community support. Without clearance from the various groups at different jurisdictional levels projects got delayed:

> ***"[T]hey said, well you might have community approval, and you might have state affiliated approval, but you haven't got regional approval yet, so. You, you know, it's just got to delay for us." Non-Indigenous researcher***

Some respondents were frustrated by national research approval processes that were multi-layered and time consuming.

> *"…but if you're trying to collect national data, which we wanted to,* ***the barriers that get put there*** *at the jurisdictional and the regional and the community and the multiple levels like that* ***really impede the progress."*** ***Non-Indigenous researcher***

> ***"So another thing is we don't just do one ethics application at the university. There are now ethics committees, behind ever- every corner. So we have to do for one recently we had to do three or four." Indigenous researcher***

Any research project that had multiple sites or that involved multiple communities usually required complex and lengthy ethics approvals from multiple jurisdictional and Indigenous community authorities. An Indigenous researcher involved in this study felt that the lengthy ethical delays to important research was actually unethical:

> ***"…that's another thing that's highly unethical. The pressure that's put on us by ethics committees and the delays, I mean I have waited six months with, you know, letters going backwards and forwards to ethics committees to do res- to get research started. I've wasted six months with idiots on a research committee, that's six months of a three year research program gone." Indigenous researcher***

A non-Indigenous researcher expressed concerns about the increasing complexity of community approval processes. They argued for centralised processes for ethical review:

> *"****Look, there are centralised processes, why aren't we using them? …Why don't they do an attachment of the additional things they wanna know?*** *…And that's the other thing that it does when there's this many layers, no one wants to fund research, you know, apart from the ARC and NHMRC, no one wants to fund more than a year of research.* ***By the time you get through these layers of ethics committees, it's six months into your research, you've only got six months to do the research, then you go back and feed the research back. When are you actually supposed to do the work?" Researcher***

Some academics urged communities to trust researchers because they were trained professionals:

> ***"Have faith in researchers as being professionals. We've all studied, we've all trained, we've all done our ethical based study. , otherwise we wouldn't be in the position of doing the research in the first place." Researcher***

### Indigenous HREC members

Indigenous membership (or lack thereof) on university ethics committees emerged as a issue through this research. Researchers and community coordinators involved in this study were asked what was needed to improve Indigenous representation on university ethics committees. NHMRC guidelines recommend that HREC's comprise *"at least one person who*

*performs a pastoral care role in a community, for example, an Aboriginal elder, a minister of religion"* (National Health and Medical Research Council, 2023b). Despite this requirement some respondents were aware of universities that did not have Indigenous HREC members. Some also acknowledged struggles to maintain Indigenous representation on HRECs. In Victoria, Indigenous community members had aspirations to increase Indigenous membership on HRECs:

> ***"…I'd love to get other Aboriginal community members onto other HRECs across Victoria's [HRECs]. There's a big gap." Community coordinator turned Indigenous researcher***

The lack of Indigenous people on HRECs had the potential to diminish the quality of ethical review. Indigenous people had different experiences and perspectives that were important to incorporate into the review of Indigenous health research proposals. Fundamentally, respondents argued that Indigenous people were required to interpret the *guidelines* from an Indigenous standpoint:

> *"[Y]ou actually have [Indigenous] people who, who actually then do the interpreting to people on the ethics committee. You know? I mean, you've got your researchers, but you've got your [pause] you know? You really need to understand about this. You have your [Indigenous] interpreters…"* ***Community coordinator turned Indigenous researcher***

Isolation was another barrier to Indigenous involvement in institutional ethics committees. It was intimidating for some to participate in a HREC as the only Indigenous voice. One Indigenous respondent who was a member of a university ethics committee regularly felt isolated and outnumbered. Consequently, they were deterred from expressing their views in this space:

> ***"And often, how often do you find yourself in a position where you're the only Aboriginal voice? On a committee of 10 people, 12 people… It's a deliberate power game, yeah, it's a power game."*** ***Indigenous researcher***

### Indigenous community-based HRECs

There was a renewed call for community-based ethical review models in the responses from the research enquiry. Some Indigenous communities clearly wanted to control their own formal ethics committees. An Indigenous respondent stressed that an Indigenous community-controlled HREC was an essential component to a key Indigenous health policy in their state:

> *"**And we need an Aboriginal HREC here. …it's in the Korin Korin Balit Djak (Aboriginal health strategy) it's a priority that we have to have** and that's in there because that's what I've put, you know, in there as part of the consultation process **we need to have an Aboriginal HREC in Victoria**." **Community coordinator turned Indigenous researcher***

Indigenous communities wanted support to develop independent community-controlled HRECs for Indigenous health research and some communities were already involved in investigating different models:

> *"**[W]e build an Aboriginal HREC and an office that's independent and get that funded separately through government and then we have our own**. …we're not saying it has to be [Indigenous organisation] **but we are saying that we need an Independent Aboriginal HREC** and how that might look I don't know but definitely something we've got to work towards. And that's what we're trying to do now." **Community coordinator turned Indigenous researcher***

Research institutions were criticised for not providing enough resources for Indigenous-led committees. An Indigenous respondent thought it should be mandatory for Indigenous-led committees to *pre-review* research proposals before an ethics application was submitted. In their time as a member of the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS) national ethics committee, they grew frustrated because not enough researchers were using this body:

> ***"It was good. It was, you know, again, it was a way of me feeling like I was contributing something back at a national level. But I'm aware that there are not actually many people using the process. …And the amount of funding that they've got to actually run those meetings is pitiful. So they can't even have six face to face meetings a year anymore. They can only have two." Indigenous researcher***

Other respondents had successfully established Indigenous community-based ethics committees that were compliant with NHMRC requirements for ethical review. These were ostensibly created to formalise community review processes in an effort to coordinate Indigenous health research in certain regions. In a few cases formal criteria for committee membership was adapted to acknowledge the importance of Indigenous 'Eldership'. The advice and feedback of elders was acknowledged as an appropriate substitute for other criteria in an Indigenous community cultural context. In the following statement Indigenous 'Eldership' was clearly recognised as an important element to be included:

> *"[We established] the Research Ethics committee at the [Indigenous organisation]. And we done it exactly the same way as an institutional ethics committee would be [but]* ***instead of having a minister of religion****, because that [pause] all that, all that was there for was to have, someone who represented the community. So,* ***we applied to actually have an Elder****. …So, we had an elder; a lawyer with research experience; we had a doctor; and we had laypeople as well. So, it was a proper instituted committee."* ***Community coordinator turned Indigenous researcher***

Whilst Indigenous communities obviously benefitted from high quality, ethical Indigenous health research from institutions, it was also an industry. While universities seemed to have the most to gain (at least in the shorter term), Indigenous organisations too had incentives to partake in research. Some questions were raised about the representativeness, legitimacy, and autonomy of voices from Indigenous communities. Indigenous people based in organisations were potentially inclined to approve research because of their organisational role. This placed the burden of responsibility for objective ethical review on the shoulders of *neutral* Indigenous community members on Indigenous advisory committees:

> ***"[Indigenous researcher's] part of the research [pause]. So, who do you actually have on there [Indigenous advisory committee] who's going to critically analyse stuff? Me. And I can't just take that all on. It's just like, "Whoa!" Because it's not fair. …And actually, you can't, you can't actually sit there and actually disagree or refuse something because you've got a vested interest." Community coordinator turned researcher***

An Indigenous organisation had to navigate this issue when establishing their own committee to reflect their own cultural structures:

> ***"…We changed the role of committee and we said headed up by an Aboriginal person. Probably a board member. Who is the head of the ethics committee? A conflict of interest had to be sort of dealt with." Community coordinator***

It was also recognised that independent models had the potential to reduce the burden on existing Indigenous organisations by taking over the responsibility for assessing regional research proposals:

> ***"…[M]aybe if they had that committee it would take the pressure off organisations. But I mean the question I would ask, is does that community stand alone, or is it affiliated with something, affiliated with an organisation, and then how would that work, or how would they represent community…" Community coordinator turned Indigenous researcher***

As an alternative to HRECs, some participants had suggested the development of local advisory groups. These could also be used to determine how research should be conducted

in local communities. A community coordinator outlined how Indigenous community-obligated researchers, based within an Indigenous organisation, might review research to ensure that Indigenous community protocols were adhered to:

> *"**Locally owned ethical research groups,** and as I said, I'm not quite sure how they work, would work but maybe it's something like, **where we have two Aboriginal researchers, who sit with community, working through our processes before the application is actually approved as ethical.** That's one way, I'm sure there's other ways, but **that's for me, community owned and driven." Community coordinator***

While formal community-based ethics models were obviously worthwhile and in demand they required a significant amount of effort and resources to develop and maintain. Unfortunately, the absence of core funding caused a significant drain on community capacity and they weren't able to be sustained:

> *"**So we've had a couple of go's of doing our own ethics committee**, just a wonderful exercise to go through such challenging [HREC requirements]. [It wasn't sustainable] Because **we were bombarded with research** and just the time to do it. Yeah. Yeah. **Limited resources and trying to get everyone together and just the logistics." Community coordinator***

Indigenous communities needed resources for the development and the operation of an independent model of community ethical review. To deliver a legitimate model they required Indigenous community members with the expertise to understand research and provide appropriate advice, which required training and investment:

> ***"I know communities have talked about their own ethics research committees. Which could be quite useful and develop up this kind of stuff. But I think too, that requires communities to have that expertise then, in terms of just understanding the research, and it could just be one person, I mean it doesn't have to be everyone." Community coordinator turned Indigenous researcher***

## Summary: Chapter fourteen

When ethical review was undertaken through institutions the *guidelines* were sometimes defined in what appeared to be an overly paternalistic way. Many HRECs reinforced a Western understanding of the *Guidelines* because they were heavily influenced by traditional academic disciplines. The absence of Indigenous members meant Indigenous ways of knowing were undervalued or missing from institutional ethical review processes and highlighted the potential power imbalance within traditional academic structures. Furthermore, committees without Indigenous representation were unable to scrutinise ethics approaches with an Indigenous lens.

The mandatory categorisation of Indigenous research as 'high risk' reinforced a paternalistic approach. While it was obviously necessary for some projects to be identified in such a category, making this categorisation compulsory resulted in an inequitable additional onus for every Indigenous research project. This created another hurdle for Indigenous health research proposals to clear. Indigenous community-led research proposals were inadvertently discriminated against because they were subject to full HREC review (which lengthened the approval process), even if their projects were considered low risk. Furthermore, Indigenous led research and Indigenous researchers were concerned about the additional scrutiny on them undertaken by HRECs that were potentially uninformed, underprepared and undermanned. Consequently, many Indigenous researchers felt disempowered and disadvantaged through the ethical review process.

The absence of Indigenous perspectives in the ethical review process was a potentially systemic issue. Some HRECs were not fulfilling NHMRC requirements to have at least one Indigenous person on their committees. While some respondents had participated in the ethical review of research proposals both formally and informally, they highlighted the lack of consistent Indigenous participation in HRECs. Without Indigenous input and oversight of research projects, ethical review of applications had the potential to become unnecessarily complex and misguided. Failure to ensure comprehensive Indigenous involvement in the ethical review of applications was perhaps fuelled by ignorance, and reinforced by contrived righteousness, in time honoured institutional structures that ironically created structural barriers to achieving ethical Indigenous health research. HRECs failed to recruit community members to participate, and/or there was a lack of training to upskill Indigenous community

members to participate in HRECs. Therefore, universities and the academy need to make a concerted effort to build the capacity of and support for, Indigenous communities to not only participate in *institutional* ethical review structures but to create their own tailor-made community-based *Indigenous* ethical review models.

These findings revealed an inherent and systemic lack of understanding about Indigenous people, Indigenous health, and Indigenous research within University HRECs. Subconscious racial bias was structurally embedded within conventional institutional ethical review systems. Some HRECs clearly lacked the education and knowledge about Indigenous people, their culture, history and society. As a result, some researchers involved in this study ignored HREC suggestions and feedback they deemed inappropriate or unethical.

Despite their necessity, independent Indigenous-led ethical review mechanisms were underutilised and underfunded. These findings demonstrate the lack of systemic support for Indigenous people involved in ethical review, and Indigenous models of ethical review. Although the AIATSIS ethics committee was clearly highly respected, at least one Indigenous reviewer (involved as a respondent) claimed it wasn't used enough by research practitioners and their institutions.

Likewise, the burden of duplicate approval processes has been identified as a barrier to Indigenous health research by some academics. Research projects that comprise multiple communities across multiple sites are required to navigate multiple approval processes within each jurisdiction, overburdening researchers with administrative ethical procedures. The impact of duplicate processes has been well described in the literature for many years.

In essence, the role of HRECs was chiefly to ensure researchers addressed ethical concerns before the commencement of the research through the approval process. Unfortunately, HRECs do not have the resources to monitor the ethical conduct of researchers whilst they were conducting research in Indigenous communities. HRECs do not have the resources to review completed projects consistency with ethics applications. Therefore there are no sanctions available for research that has not been conducted ethically or has complied with community undertakings in the initial research application. Sometimes ethical values were lost in translation and HRECs did not often have the relevant capacity to appropriately assess compliance with the *guidelines* once the research had commenced. Some institutions had

Indigenous people on their committees and others established their own Indigenous advisory groups. Finally, HRECs relied heavily on researchers (it was their responsibility) to self-regulate and on participating communities to report back on their behaviour:

> ***"…but then it's difficult for an ethics committee to monitor whether that actually occurs, because a lot of this is self-regulation and it's about your own personal [accountability]." Indigenous researcher***

Ethics committees were expected to have a deeper understanding of Indigenous people and Indigenous health beyond just the implementation of the *guidelines*. Some researchers felt they weren't adequately supported by their institutions to fulfil the additional ethical *guidelines* required to undertake health research with Indigenous communities. Institutions expect researchers to respect and adhere to Indigenous ethical values, but resources and support for capacity development (to ensure it was upheld in practice) were rarely provided.

# Chapter fifteen: Unethical practices in Indigenous health research

The following chapter provides an insight into how some researchers practiced unethical research from an Indigenous perspective. There is no suggestion that these findings are generalisable however they are noteworthy. There might be instances of duplication in this chapter but that only serves to demonstrate the interrelatedness and complexity of the concepts discussed. Furthermore, it is critically important to consider the implications of these ethical challenges.

Common themes emerged related to researchers that inadequately put the *guidelines* into practice or worse, breached ethical standards. Some respondents interpreted the practices of some researchers as unethical. Though these might be isolated occurrences, they warrant the review of current ethical complaints and monitoring procedures and may require development of specific strategies to prevent reoccurrences. These findings revealed that some researchers were unaware of, ignored, and dismissed relevant cultural protocols. And some researchers were seemingly resistant to advice from communities, because thought they knew better.

## Researchers bending the rules…

Some researchers tried to expedite the ethical review process by downplaying Indigenous specific elements in their research. Some researchers purposefully avoided the mandatory 'high risk review' required for Indigenous health research by not declaring Indigenous components of their research. This allowed them to undertake a 'low risk' review and avoid a longer review process:

> ***"…[S]o some people don't go through the process, because it slows the whole thing down. Yup. And you end up with multiple ethics applications. The process of an Aboriginal ethics if its Aboriginal specific, it does need to be full, have a full review. So there is no low risk that you can then say this can be proved out of session. So everything has to go to a committee." Indigenous researcher***

In some circumstances researchers underemphasised the relevance of their research for Indigenous people to avoid the additional scrutiny. An Indigenous researcher believed some researchers strategically avoided Indigenous ethics in their research. From their previous experience reviewing ethics applications occasionally researchers elected not to address the *guidelines* despite knowing they were likely to have high participation from Indigenous people and their research would be potentially significant to Indigenous communities:

> *"So there are researchers who ended up doing stuff saying they know full well when they do kidney, you know a bit of kidney research or something,* ***that is going to end up having a lot of Aboriginal people in that research. …they'd want to avoid the Aboriginal ethics*** *because* ***[they would say] well it's not an Aboriginal specific project"****.* ***[But] …if you have a high disproportionate number of Aboriginal people within your participant growth, you need to have Aboriginal ethics****." Indigenous researcher*

Even more worryingly, this Indigenous researcher suspected that some researchers exploited the ethics amendments process with the intention to bypass the *guidelines*:

> *"And then* ***there's also amendments*** *that would appear to have been things that I wanted to not put in the full application in the first place.* ***So it's, if you play it tactically you put through what you know you can get approved and then it's easy to get an amendment for the stuff that might not be so nice.*** *I understand that's horrible but* ***that's what I suspect happens****." Indigenous researcher*

This practice was corroborated by others who had participated in ethical review committees. In their experience some researchers used the amendments process because it was less time-consuming and 'easier' to get the projects approved:

> ***"Yeah. It's easier to ask for an amendment. So, they do that's why ... and so I've seen those as well, which has come through and has been such a big amendment." Indigenous researcher***

Many people that participated in this study thought the guidelines were undervalued and disrespected by researchers. They believed some researchers had an indifferent approach to the guidelines because they were an 'afterthought':

> ***"…And they're an afterthought.*** *And you can tell immediately when you read applications, if it's an afterthought or a beginning thought the ultimate irony is, if it's a beginning,* ***if you begin at the beginning, the research is quicker." Indigenous researcher discussing their role reviewing HREC applications***

An Indigenous researcher was tired of the blasé attitude to the *guidelines*. Some academics treated the *guidelines* like a mere 'academic hoop' to be cleared. This seemed to demonstrate a lack of understanding about the importance of the *guidelines* for Indigenous communities:

> *"****Because I'm so fed up with that attitude****, 'cause you see it all the time, where that's how people treat it, it's [ethics are]* ***just an academic hoop to jump through****,* ***it's got nothing to do with community and nothing to do with culture."*** ***Indigenous researcher***

Institutions and academics were accused of seeing the *guidelines* as 'lower-level' and not valuing the *guidelines* in the same way as other critical policies such as the National Statement*:*

> *"…**people get defensive** because they know when you say that actually in NHMRC guidelines, **they know they should have known that** they shifted defensiveness. About why they bunny hop them. **They're still seen as lower-level guidelines to the national statement guidelines."** **Indigenous researcher***

Some respondents accused researchers of 'cutting corners' to fast track their applications:

> ***"…it means researchers will cut corners then cause they won't allow the time to do proper process." Indigenous researcher***

Respondents were aware of researchers recruiting Indigenous people being recruited to retrospectively integrate the guidelines to their already commenced research projects. In one example an Indigenous researcher was allegedly recruited to 'retrofit' the Indigenous ethical guidelines:

> *"And I got invited into it, which in some ways I still regret cause **I was put in the position of having to retrofit**, that word was used. Yeah. **Help us retrofit to the guidelines.** Yeah. It's awful isn't it?" **Indigenous researcher***

Many in this study believed researchers were given a long leash to loosely interpret the guidelines. An Indigenous researcher argued *"the guidelines are so flexible and they can be bent to suit anybody's needs".* Researchers were able to use their words to adapt and translate their proposed research into an acceptable Indigenous ethical framework:

> ***"…the guidelines are written in such a way that you can interpret them anyway and academics have wordsmiths…" Indigenous researcher***

Experienced researchers were able to skilfully craft their ethics applications to simplify complex research activities:

> *"I think we need to take into account, especially when it comes to Indigenous programs or projects. 'Cause I think **there's a tendency to just write certain words in there or rephrase things that are complex that allows it to low end of the spectrum…" Indigenous researcher***

The ethical process was reduced to an academic hurdle that researchers needed to get over before they can do their research. This sometimes resulted in researchers treating it as a tokenistic 'tick a box' exercise to get approved:

> ***"I think they only tick the box. I think they're only, a lot of that ethical stuff is only tick the box, yeah we'll tick that. And we've done this, and we've done that, and now we're just gonna do it how we want it." Indigenous researcher***
>
> ***"In the same way that bureaucracy sort of, you know, the job they should be doing is only measured in a tick the box as opposed to what they should be doing." Researcher***

Alternatively, academic timelines were often rigid and imperative. Requirements stipulated by institutional and funding bodies of research often motivated academics to accelerate their research processes. This contradicts the required ethical processes for community engagement. Researchers are often caught between two vastly different expectations in relation to community research programs. Both Indigenous and non-Indigenous researchers thought that the pressure to meet tight academic timelines had the potential to encourage some scholars to unduly 'push' research through:

> ***"…[I]t can be hard and fast, research. It's in and out. You know. Project's done. But, community's always there. (Laughs)." Past participant turned Indigenous researcher***

Participants believed that research primarily focused on academic deadlines resulted in research activities being progressed too quickly for communities. From their perspective this compromised the cultural safety and integrity of the research:

> *"…**it happened really fast. And it's been- these are my objective observations. It happened really quick.** It was promoted as a good thing, as a benefit for Aboriginal people like we said. But then the reality and the implementation of **it was too quick, not a- not briefed enough. None of the information that you would normally, the cultural safety stuff wasn't there." Community coordinator***

Fast research didn't allow enough time for Indigenous communities and participants to be fully informed and failed to fully consider Indigenous perspectives about research proposed by outsiders:

> ***"[S]o it happened too quick. And there wasn't enough lead in time.** Have a yarn to the community, or even get to get local community involved. …**You want to achieve that, but are your timelines realistic?** And are you factoring in that community engagement, and that with our mobs, into your [research]? …So, what happens next? They comp- they compromise the integrity of the project by focusing on that. Focusing on deadlines. **All of a sudden, that becomes the focus. …voices are getting lost. Not being heard." Community coordinator***

Researchers 'rushed' through promised community engagement and consultation processes because they were anxious about meeting research funding obligations:

> *"…[the researcher] was rushing the process. Rather than us working with the community and going over stuff and educating them and checking to make sure that they were fully up to speed with the ethics principles and their rights as participants* ***she was trying to rush that through all the time. So she was getting very edgy after about two days. All she wanted to do was start recording data. And she even was saying at the time, "Oh, my funding body aren't gonna be happy if I don't come back with some data."*** ***Indigenous researcher***

Some respondents believed that some academics were guilty of *pushing* through their research and glossing over ethical procedures in communities in order to meet academic timelines:

> *"…I could see really quickly, he was kinda trying to push me through the process, and so you know, hurry up, we've gotta get this through, you know, let's, let's get this done, let's, let's do this quicker than what you're doing. And every time I brought up the uh, the matter around community consent and community involvement and endorsement, I could tell it was kind of, you know, it kind of seemed glazed over a little bit. And I thought yeah, well you know, that's fair enough, he's a white fella, so of course he's gonna glaze over, 'cause he doesn't understand this stuff."* ***Indigenous researcher***

In some instances, Indigenous communities were pressured and persuaded by researchers to formally support their proposals:

> *"And it's hard, because* ***as a researcher you need to get that form [for community support] signed*** *before you can go through ethics, so it's like (laughs) ...* ***sign my form I'm gonna deal with this later*** *definitely not the right attitude to have, but you can see how researchers are like "Oh, I've gotta get [permission]..."""* ***Indigenous researcher***

In fact, respondents reported that in their experience some researchers disregarded community approval processes altogether:

> *"But for purposes of expediency, yeah. The thing of uh, asking for forgiveness rather than permission, is a very common practice in research mode? And so it's the competitive nature of it that it can turn, it's not healthy. It's not healthy mentally for people in that system, it's just how the whole thing kind of works."* ***Indigenous researcher***

Although not related to an Indigenous *health* research project another incident demonstrated how research ethical approval could be exploited. A researcher was accused of deliberately

misinforming the community about the true purpose of their research. After the study gained formal community support the scope and nature of the project changed. This caused the Indigenous people involved in the study to withdraw their approval and contest the findings and validity of the research:

> *"**And he told me, when we signed off, he told me that he just wanted to have a look at, he was just looking into Aboriginal sites and farming people, on how they react to those sites on their properties. Which I thought was quite harmless. Soon as he got that letter he changed it all and he was all over our country like flint.***
>
> ***And he just wrote up all the stuff, he decided that he was gonna research us all, and he refused to interview me any further on that research,** and he went off and got the people down the South East and that are not from our Country and they spoke on it. And they were all paternal, and they didn't come from there, **and I can just imagine what they done…***
>
> ***And yeah, he didn't interview us, and then he turned around and said that we weren't from there. 'Cause he don't know our ties.** And he did all our trade routes and everything, but he thought, by and **he's only another middle-aged white man. Writing about our country, and our people. ..Copying what's out in those bloody old books. Research stuff. And talking to the people who aren't the traditional [owners]... those peoples from that country. Yeah. It's really interesting. The way in which he did it…***
>
> ***And then he went in there and said, "Oh well, [this participant] give me permission." After I wrote a letter and said I was withdrawing from it. He still continued to do it, and they ignored it. The ethics he broke was absolutely disgusting, but [the academic institution] were known for it.** And [Indigenous researcher] should know better. **But these white fellas they are able to manipulate people like that."** **Community coordinator***

Researchers were so adept at addressing the *guidelines* that they could:

> *"**They can make the most innocuous seem, seem fabulous**. It's amazing to see how some people can describe things. They should get a literary award for the best way to describe an [pause] you know **a five minute conversation with an Aboriginal person that you can make the description of it. Just this is wonderful, haven't, they done the best possible thing. So it's about how you describe those things."** **Indigenous researcher***

Research institutions and Government departments have been reported as classifying their projects as evaluation or quality improvement to avoid the ethics process:

> ***"…there are a lot of health departments, health academies that have other processes in place to set up quality improvement. But is that sort of the low hanging fruit …a lot of services take that low hanging fruit by wording it a certain***

***way so that it will be classified as research of quality improvement." Indigenous researcher***

In addition, while sometimes research theory and methods included in the application sounded appropriate, the methods and process described were not always implemented in the research. Although *nobody wants to do the wrong thing,* sometimes actions outlined in applications were no longer viable. In practice it was sometimes necessary for researchers to adapt to the needs of the community:

> ***"Sometimes when you do the theory for a project, the methodology, especially if it's international it reads really good and nobody wants to do the wrong thing. But as you get as you travel through the real on the ground stuff and you're talking to people and you find little road bumps or even blocks then you've got to negotiate your way around them…" Community coordinator***

## Researchers not listening…

At times researchers progressed their research without listening to Indigenous communities. They ignored local community decisions and dismissed advice and feedback about their research. University researchers who did not listen to Indigenous communities were accused of being arrogant and dismissing cultural protocols. Many experienced researchers did not heed community advice or failed to ask for advice because they were too proud and overly confident in their 'tried and true' methods:

> ***"What is okay for one group in you know one country may not be true for someone else from another part of the state. …allowing yourself as a researcher to be vulnerable. And say I don't know, can you help me? Can you guide me? And I think a lot of senior researchers won't do that, you know." Researcher***

In the experience of an Indigenous researcher some researchers would exploit their academic position when their authority was threatened. They also implied researchers rejected the notion cultural protocols were relevant to academic ethics:

> ***"They don't listen, half of them. Even those that do listen. It's like they've got, again, this little default setting in their brain where they're saying, but I'm in charge. I'm the one that's , in a superior position here. I'm the one who has all the rights. This, you know, this, this is just a, an academic process, it's got nothing to do with culture it's got nothing to do with community." Indigenous researcher***

In a blatant example of perceived entitlement, a researcher carried out a project after explicitly being told not to by the local Indigenous community. Despite their rejection they

apparently used institutional workarounds to continue the research without the proper community approval and consent:

> ***"[The researcher] got the answer, which was no, but she continued to do the project anyway." Indigenous researcher***

Some researchers had a patronising attitude towards Indigenous community ethical processes. They belittled and disregarded the additional community obligations expected by Indigenous ethics committees:

> *"[Some researchers view ethics] as being a headache and not wanting to do ethics, and there is also some researchers, and I say this as a member of that ethics committee, up there patronising and* ***I've wondered whether they are as patronising to a non-Aboriginal ethics committees as well as they are to Aboriginal ethics committee, very shocking type of telling us what our job is and what we will be doing..." Indigenous researcher***

### Researchers not following processes…

Many Indigenous communities determined their own research protocols but researchers didn't always follow them. After ethics approval was provided researchers didn't always apply them in practice. Alarmingly, in the following case senior academics used their status to get around applying research practices they had previously agreed to. An Indigenous early career researcher implored senior researchers to adhere to ethical protocols but was powerless to make them comply:

> *"I think there were about eight or nine, you know, professors from around the country working on this project and I was their little Indigenous research fellow.* ***And when it came to the ethics protocol, I wanted them to follow the protocol. They didn't want to follow the protocol.*** *So I tried and tried. There was one person who was kind of there with me, you know, supporting me, one of the professors.* ***But at the end of the day, she still folded when her other professor buddies were putting pressure on her." Indigenous researcher***

The power imbalance in research settings between researchers and Indigenous communities often made it difficult for Indigenous people to monitor researchers. When reflecting on their various experiences in research participants in this study discussed how cultural protocols were not upheld:

> ***"…if we set the benchmarks as an Aboriginal community in terms of Aboriginal health, and community control is a measure. And that's the very basis of what we- how we operate as an Aboriginal advisory group. Clearly this is an example***

> ***of not upholding those principles, and this is where we don't have the service that we would've expected to come out of this." Community coordinator***

Some researchers arguably found it difficult to take advice from Indigenous people because it challenged their self-belief in their academic *superiority*. They resisted critique from Indigenous communities because they wanted to preserve their authority and felt their academic expertise entitled them to determine the best course of action. This sometimes resulted in Indigenous researchers or experts being excluded from Indigenous research projects by their academic colleagues. An Indigenous academic thought their credentials were seen as a *threat*:

> *"**And I think that's when I first realised what a threat you are as an Aboriginal person to non-Indigenous researchers.** You, I've seen it many times since then, how once non-Aboriginal people find out what your qualifications are, what your experience is, and who you are, **nine times out of ten, they're gonna see you as a threat, rather than as an asset. Or as someone who they could partner with.**" Indigenous researcher*

Researchers were accused of dismissing and disrespecting Indigenous community expertise, knowledge, and advice on a range of research activities:

> ***"…no one's listening to us around protocols around the data collection. Even the language [how it's used]... So we've been told as the Aboriginal advisory board, "That's- that's not your [pause] that's not what you do."" Community coordinator***

However, through their authorised representatives Indigenous communities still had the power to provide and withhold collective consent. To this end Indigenous community-controlled organisations disengaged with researchers who ignored or attempted to circumvent community mandated processes:

> ***"…they're going directly to ACCOs and they [the ACCOs] don't want to talk to them, for obvious reasons – because they don't want to follow the proper processes." Community coordinator turned Indigenous researcher***

### Researchers know best…

From an institutional standpoint there was a potential for researchers to be driven by academic ambition and purpose, facilitated by clear hierarchical academic structures. It was perceived by the respondents that some academics believed that their academic credentials had earnt them the right to determine how to conduct research within the academy and *out in the field*:

> ***"[T]hey come from a very individual world, yeah. Where you learn the system that you work in and you learn how to work the system so that it works for you. That's how you're trained as a white fellow." Indigenous researcher***

As a result, some researchers thought additional ethical guidelines for Indigenous health research were an unnecessary hurdle. In the experience of an Indigenous researcher some older academics in particular believed Indigenous specific guidelines shouldn't apply to them. They felt their research qualifications and experience justified their methods, and that the general ethical protocols were adequate protection:

> ***"…non-Indigenous researchers believe and are schooled in believing and are positioned and reinforced to believe that they are experts in research, and they can make the decisions about research design.***
>
> ***…And they're very surprised when they come to us, either as the Indigenous health discipline for advice on how to meet the guidelines after the project is designed.***
>
> ***…We have not had generational shift among the mainstream body of academics. Partly because new ones come in and the old ones think it doesn't apply to them." Indigenous researcher***

In an Indigenous health research setting experience demonstrates very clearly the imperative for Indigenous people to provide cultural knowledge and expertise in the critical ethical review process and to inform researchers about appropriate practices. Yet, the findings from this research indicates that some researchers have still not recognised the importance of these expectations. Another scenario described by a non-Indigenous researcher exemplified the belief that the guidelines were inessential. Their colleagues were unable to understand why the researcher intentionally put a project through an Indigenous ethics process when they didn't have to:

> ***"…I've had other people say to me who work here, who aren't involved in this particular project going your mad [for seeking additional ethical approval], it's secondary analysis. What are you doing? You know, they just don't get it." Researcher***

Unfortunately, sometimes researchers demonstrated a self-righteous attitude when they conducted research with Indigenous communities. They thought they knew what was best for Indigenous communities. They often used this overly confident approach to talk their way around different challenges:

> ***"[O]ver the years I've seen people come in and talk about what was best for us, you know, they hire a researcher and they were able to talk their way around, this is why we do it. And people just accepted that…" Community coordinator***

Sometimes researchers used academic language full of jargon when they engaged with Indigenous people. Indigenous people got turned off and felt belittled when researchers *talked down to them*:

> *"**Talking down to people.** …speaking in say research language, you know terms [pause] you know every industry has different words they might use as a part of that industry. **So if you're communicating with people, every day people, you know what I mean? Like that could be seen as talking down, and so if there are elders there, you know what are they talking about?** So it makes them feel silly, and what are they doing there? How can I come [pause] **So they don't say anything." Community coordinator***

### Researchers doing whatever they want…

An Indigenous researcher thought many non-Indigenous researchers weren't motivated to follow Indigenous community processes, and thought systems for academic promotion were stronger incentives for many researchers. Systemic privileges were already *baked in* for certain researchers who were motivated to meet benchmarks to elevate their academic status:

> *"**'Cause you know. Every other white fellow, they're not doing this [following community protocols].** They're just sailing in here, doing what works for them and pumping out the research work and getting themselves up to a professorial level 10 times faster than what you and I will. **'Cause they know how to tick the boxes and the boxes are there for them already. Those boxes, those boxes of reputation. Yeah. They're not there for us." Indigenous researcher***

An Indigenous researcher had been burnt a few times by misjudging the character and ethical integrity of researchers who made ethical promises but failed to deliver in practice:

> ***"I'm really aware that I still get caught from time to time. You still get sucked into thinking you're working with someone who's really decent. …You talk about it all, and it sounds wonderful, and you think, "Oh yeah, this is a really good white fella that I'm working with." Once it comes to putting it [ethics] into practice that all just goes down the drain a lot of the time still." Indigenous researcher***

In an alarming example a professor misled an Indigenous community partner in an attempt to garner their support. They dishonestly co-opted them onto a project that had not yet received ethical clearance:

> ***"The professor there, he didn't get proper ethics. I've dropped like a hot potato and you know, he didn't, he just, he told lies. …He, yeah, he didn't go through with it, it was unethical… …ethics was not approved. And he told us it was..." Indigenous researcher***

This study clearly revealed expectations (from Indigenous researchers, past participants, community facilitators, and non-Indigenous researchers) for researchers to follow Indigenous protocols for research with Indigenous communities. However, in the experience of some respondents, researchers thought they could conduct research with Indigenous communities because they already held academic qualifications. Unfortunately, a prevailing sense of entitlement seemed to justify the conduct of some researchers. An Indigenous respondent experienced in ethical review criticised researchers who sought 'forgiveness rather than permission' when they undertook Indigenous health research.

There are limited systems in place for monitoring researcher ethical compliance (with research integrity processes relying heavily on self-reporting) exist but evidently institutions are not equipped to monitor ethical conduct. Some Indigenous groups have self-funded research monitoring practices (Lowitja institute ethics awards, AHMRC ethics committee) these normally sit outside academic structures and therefore have limited power. Further discussion about how monitoring and reporting on researchers' ethical conduct is in the following section.

## Reporting on ethical conduct in Indigenous health research

Primarily, researchers are responsible for ensuring ethical protocols, as they apply to Indigenous health research, are implemented. University ethics committees considered the *guidelines* in their review processes, and also had ethical compliance and reporting processes to maintain researcher accountability. Researchers were expected to report back annually on any ethical issues to HRECs. The institutions do not the monitor the veracity of researcher statements in annual ethics reports. According to some respondents there were some researchers that brazenly dismissed, did not report and/or downplayed ethical violations. A non-Indigenous researcher was openly ridiculed by peers for even considering reporting a violation:

> *"And I've actually had people say are you insane **you're reporting that as a protocol violation. That's just par for the course.** You're like 'not that is not what we said we would do. That didn't happen in that way' and **I've actually had senior***

***academics saying to me, you're being ridiculous that's so not enough to worry about." Non-Indigenous researcher***

The ramifications of reporting on ethical violations encouraged researchers to conceal problems rather than deal with them. Conversely, an Indigenous researcher thought identifying ethical issues within their research was a good thing to do. They saw it as an opportunity to remedy any problems rather than ignore them:

***"[T]he researchers who do report protocol violations, …they will have admitted something has gone wrong and the ability to say something has gone wrong in my research project. I think there's something that's a very good thing we'll do. Most won't, most senior research will be just smooth over that little back and act as if it's not there, sort of thing." Indigenous researcher***

Interestingly, whilst some respondents thought researchers didn't report breaches to avoid consequences others thought HRECs had limited power to enforce any punishment. Participants with experience on ethics committees said it was difficult for HRECs to monitor and police ethical violations. When they were notified about violations HRECs provided advice to researchers about how to resolve issues and improve ethical conduct. However, it was likely many researchers were not reporting breaches. :

***"And so, the ethics committee can't really do a great deal with protocol violation, but I don't, and when you get them, that's great. And you meet and you talked about it, who then gives some advice? I suspect there's a lot more protocol violations…" Indigenous Researcher***

From the interviews it wasn't clear what consequences or penalties researchers faced (if any) for violating ethical protocols. The HRECs also relied on Indigenous communities to inform them about breaches because they didn't have the capacity to monitor researchers:

***"[T]here's no real recourse when things aren't adhered to. As HREC, we will rarely hear if those researchers have met the Aboriginal guidelines, they put in an annual report and it can be written in such a way that it all sounds fine and we'd have no time and we're not resourced, and we won't really ever know like lucky Koori grapevines pretty good.***

***You will know some things, but that doesn't mean you've got the evidence to bring in recourse and revoking an ethics clearance. So, I've definitely seen that happen where I'll know, yeah, that doesn't add up…" Indigenous researcher***

The previous example shows institutions have limited control over the behaviour of researchers, or indeed the will or commitment to address unethical behaviours especially if

their behaviour, right or wrong, goes unreported. Even when HRECs are aware of ethical issues their ability to reprimand or revoke ethical clearances is constrained.

Conversely, another Indigenous researcher criticised excessive bureaucratic interference. To them ethical requirements were merely a compulsory institutional hurdle and they had no real bearing on the ethical conduct of researchers. They anticipated there would be a stark difference between how they addressed the *guidelines academically*, and how they integrated them into their research *practically*:

> ***"I'd be happy to report on any changes on my annual report back to the HREC. Like, this is what we changed... this is why we changed it. I'm happy to do that. But I'm not happy to put in dozens of amendments. So we've gotta meet the requirements of the the HREC but I know how we're gonna do it [research methods or practice] is gonna be so different [in the community context]." Community coordinator turned Indigenous researcher***

On a few occasions ethical issues were raised through *Indigenous advisory groups* but it was unclear how these were escalated or managed. In reference to a past project an Indigenous community coordinator recalled that *"…from the advisory point of view, there's some red flags"* that caused apprehension about research progressing. In some cases community members raised formal complaints about researchers. An Indigenous researcher submitted a written complaint and withdrew from a project because of strong objections about the behaviour and decisions of their academic colleague:

> ***"So that's what I've done, I've written to the ethics board up at [research institution] and put in a complaint, made it into a complaint, now, not a request for mediation now, it's a complaint. To say that I'm withdrawing my consent to continue working on this project with her." Indigenous researcher***

When agreed ethical protocols weren't followed or when *bad* things happened complaints were made to institutional human research ethics committees. An Indigenous researcher was upset with their research partner, and put in a complaint, because they failed to engage appropriately with their community:

> ***"The first meeting, not one person from [the academic institution] turned up; not one senior person, white fellows who would run the project with [Indigenous organisation]. And they put [Indigenous staff member up] ... And I just, I, I was [livid]. So, I went back to [the academic institution], and I done an ethics complaint.***

> ***…when I complained, [the senior researcher] went off her head. But she knows it didn't follow ethical protocol, so it would have mucked up their research.***
>
> ***[After the formal complaint]…they've changed the way they actually now roll it out. And they're not talking to the community anymore. Oh, it's absolute shit." Indigenous researcher***

This situation highlights the control some institutions have over the complaints process, and how researchers might exploit this to avoid following ethical practices that delay their research. Some issues raised by participants weren't necessarily regarded as violations by some researchers and it was assumed researchers chose not to report on these to their institution. According to an Indigenous researcher most complaints about projects they received were verbal and were consequently resolved before they were submitted in writing:

> *"…That gets reported at times.* ***So it's not necessarily protocol or violation of doing the wrong thing, but it is a issue of concern that has happened.*** *And I don't know how often researchers report some of this stuff and I know how they empower the community to raise concerns and to actually felt to comply.* ***So there's very, very few complaints come through. People tend to [provide] verbal complaints rather than written complaints that you would get phone calls about it, but not not anything put in writing as well." Indigenous researcher***

Some respondents felt that more needed to be done by institutions to monitor and investigate unethical research practices. A more thorough and rigorous process for resolving ethical violations was recommended by one Indigenous researcher. They proposed the establishment of a dedicated complaints body that could independently manage and investigate grievances between researchers and Indigenous communities:

> ***"There should be a body that you can go to to complain, an Aboriginal body that you can go to kind of lodge complaints about poor research practices. And act and advocate on your behalf and they'll take the complaints seriously and investigate it." Indigenous researcher***

Ultimately, the formal procedures and processes are only effective if they are regulated, evaluated and reviewed because as one Aboriginal researcher put it *"…if you're good at writing. …you're gonna say whatever anybody wants to hear."*

## Summary: Chapter fifteen

Research funded by the NHMRC must comply with the *guidelines*. As part of compliance, university-based HRECs ensure researchers follow the *guidelines* through their ethics processes. These findings reveal that the ethical review and approval process, could not always prevent unethical practices by researchers.

Although ethics committees reviewed and provided feedback about research proposals from an objective position, researchers had the responsibility to consider how to apply these in practice.

According to respondents' experiences some researchers considered the Indigenous *guidelines* superfluous. Furthermore, it was alleged that some researchers downplayed the significance of their projects to Indigenous communities to reduce further scrutiny and avoid the *guidelines*.

Although the *guidelines* were applied through HRECs, institutions lacked the resources and capacity to effectively monitor ethical practices and relied heavily on researchers self-policing, or on external parties (such as Indigenous partners, and advisory groups) raising issues. The combination of these factors resulted in some noteworthy gaps for implementation of the *guidelines*.

Understandably academic leaders in research are critical in upholding ethical values in research. They determine the research methodology and the methods and likewise they select the ethical approach. Lead researchers have the agency to determine and propose an appropriate ethical approach and they are currently empowered by their institutions who reinforce and endorse their ethical position in their review processes. Lead researchers are in the driver's seat when research is conceived, developed, and ethically reviewed. They actively made decisions about how research would be carried out from theoretical and practical perspectives.

Senior academics have a degree of influence over early career researchers. Hierarchical levels of authority are the backbone of traditional academic structures leading to certain power dynamics. Early career researchers, striving to prove themselves within the academy, were often apprehensive about raising ethical concerns because of the implications on their career. Presumably many young researchers felt they would not be considered for future projects if

they were perceived as 'difficult' by their peers and superiors. They didn't want to get a reputation for rocking the boat.

The advantage of flexible guidelines is negated through systemic pressures that require academics to adopt a structured approach when addressing them. Researchers under pressure to meet academic obligations will, more often than not, opt to take the *path of least resistance* or indeed seek to circumvent the correct protocols to get their research approved. Once researchers had complied with the initial university ethics procedures institutional accountability mechanisms were mostly limited to annual self-reporting. Without effective monitoring, evaluation and accountability mechanisms the values and ethics *guidelines* are susceptible to exploitation.

The *guidelines* were downplayed because they were considered an unnecessary additional responsibility for some researchers. Many researchers felt they had already earned the right to determine how to conduct their research projects within Indigenous communities because they were academically trained. Some researchers thought the *guidelines* were additional hurdles that overburdened and delayed their research projects. Furthermore, it was reported that many were dismissive of Indigenous *ways of knowing* (a central principle of the *guidelines*) because they seemingly conflicted with their own traditional academic processes.

Problematically, some researchers retrofitted research projects to address the *guidelines* for their ethics applications, without adapting their actual research practices. At times the efforts to apply the Indigenous ethical guidelines seemed tokenistic and performative. It appears some researchers complied with the necessary procedures merely to get their research approved. They considered bureaucratic systems for meeting these requirements overly restrictive.

Troublingly, some researchers used strategies to avoid complying with additional Indigenous ethical protocols. On occasions they used specific tactics to avoid the prescribed ethical requirements related to the Indigenous ethical *guidelines*. Some researchers exploited the use of the amendments process to avoid thorough ethical review. More concerning was the apparent and widespread acceptance and awareness of these loopholes within institutions with no apparent efforts implemented to counteract them. Numerous respondents recalled research projects where ethical concerns were raised formally by Indigenous research

partners and collaborators, Indigenous advisory committee members, and community participants.

A problem with current systems is that violations in the ethical conduct of research do not attract suitable sanctions. In addition changes to the original ethical protocol are sometimes not reported during the research process. The problem seems to be fourfold. Firstly, most universities have insufficient ethical monitoring systems when it comes to Indigenous health research. Secondly, ethical breaches are seldom reported to institutions by Indigenous participants and partners. Thirdly, and most alarmingly some academic environments fostered a culture that concealed ethical violations, and failed to adequately penalise researchers for reported breaches. Fourthly, researchers did not respect the importance of reporting changes to the original protocol possibly because it meant amendments would be required that could interrupt their research. The acceptance of ethical breaches, and blatant disregard for reporting on these, was a troubling revelation. Researchers' failure to take responsibility for reporting ethical breaches, and/or changes to the research protocol make it difficult to measure the scale of ethical misconduct in Indigenous health research. Further evaluation of monitoring systems would be required to assess the problem and consider whether this is a universal issue.

Although HRECs can be notified about ethical issues their ability to reprimand or revoke ethical clearances is constrained. Other than provide constructive feedback to researchers it was not apparent what, if any, steps or sanctions HRECs undertook or imposed when ethical breaches in research practices were reported. There was an existing underlying power dynamic that reinforced the authority of research institutions and researchers through the ethical process. Institutions ultimately controlled the process as to how ethics would be reviewed and researchers controlled how they would be applied. However, due to the constant flow of ethics applications most HRECs are focused on the ethical review process and thus don't have time or funding for monitoring ethical conduct. As mentioned previously, supervisory functions are poorly funded so institutions don't prioritise these within their systems.

Many respondents recommended researchers within institutions undertake cultural awareness training, delivered by Indigenous communities, before they carried out health research with Indigenous people. Although Indigenous communities obviously shared a lot

of common health concerns, each community functions and deals with these in their own way. This requires a certain level of adjustment by researchers to ensure their research is suitable for and relevant and specific to, each individual community.

In the interviews, participants explained the degree to which researchers complied with administrative and institutional monitoring processes for ethics (such as ethics application, reporting, and complaints systems). Importantly, ethics training was identified as a necessary activity to enable researchers to properly understand and embed Indigenous ethical values within their research appropriately.

The research sector clearly required support from the Indigenous community to understand and adhere to specific cultural protocols especially in relation to ethics, and to contribute to various components of Indigenous health research. Yet the increasing *demand* from institutions (driven by legislative and bureaucratic policies) to seek Indigenous advice and involvement (informally and formally) in their research agenda exhausted the limited capacity of Indigenous organisations. The *guidelines* encouraged researchers to get advice and guidance from Indigenous communities. The demand for time, resources, and energy from the Indigenous community to provide this guidance created a tension between researchers (who needed this support to commence their research) and Indigenous community members (who had other community obligations and priorities). Indigenous researchers too felt burdened when they had to train researchers in these issues on top of their existing workloads.

In response to these issues, many Indigenous communities developed their own processes for monitoring academic researchers. However, Indigenous community processes were often independently financed and rarely funded by research institutions. It is clear more investment is needed to build the capacity of Indigenous communities to participate in all elements of the Indigenous health research agenda. This could be achieved through development of targeted research training. Further, to be effective Indigenous community-led monitoring needs be more highly respected as an authority in the research process.

Indigenous academic leadership often disrupted and challenged institutional norms that had previously privileged many non-Indigenous researchers. However, some non-Indigenous researchers pushed back against the requirement to incorporate Indigenous critical feedback

of their research practices. In some cases Indigenous academic expertise appeared to threaten the status quo, and made some researchers more protective of their own standing within the broader academy. Indigenous people were not always viewed as colleagues or potential research partners instead they were viewed as competitors that threatened academics' status as the *expert.* Non-Indigenous researchers sometimes used their academic rank to justify ignoring advice from Indigenous advisory committees, Indigenous community coordinators, and Indigenous research colleagues. This approach effectively disregarded protocols for community engagement and undermined the cultural authority of Indigenous organisations, and Indigenous community leaders, and advisors.

Indigenous community protocols for research applied to all researchers, including Indigenous researchers. However, Indigenous researchers were sometimes wedged between their academic responsibilities and their community responsibilities. According to some respondents some Indigenous researchers did not *position* themselves within an Indigenous worldview in the conduct of their research at all. Individual Indigenous researchers are not immune to academic pressures and Indigeneity does not ensure above standard ethical processes.

Many of the ethical issues discussed apply across the board to all researchers, including Indigenous researchers. I believe that every researcher must consider their positionality in order to conduct their research with integrity and transparency and to allow accurate scrutiny and critical review. Indigenous people involved in research are often caught between two worlds and must uphold many different responsibilities in their various roles. When some Indigenous people take on positions of influence outside of their communities, it can create dynamic situations that make it difficult to uphold community obligations. Dissecting impartiality and subjectivity can be almost impossible for institutions without understanding the cultural context of different Indigenous communities.

In my opinion this is a systemic *institutional* problem rather than an *Indigenous* problem. Institutions often don't have the internal expertise to understand the complex relationships and protocols that exist within different Indigenous communities. Problems arise when individuals are relied upon to provide advice about how to navigate these systems, or when advice from Indigenous staff members conflict with advice from Indigenous community experts. Strengthening ethical conduct requires strengthening academic institutional respect

for Indigenous cultural authorities that exist outside the academic environment. Universities should not rely solely on internal systems for oversight of Indigenous research.

The benefits of Indigenous people leading research are clear to see. Many Indigenous researchers have conducted high quality research that has immense impact on grassroots communities because of their unique insights and position as *insiders*. Indigenous academic leaders that can go between the Indigenous world and the academic world, and respect both are invaluable for advancing the Indigenous research agenda. There are also professional academics, regardless of positionality, that provide high quality Indigenous health because of their exemplary research skills, and their respect for community protocols.

As Onemda at the University of Melbourne so aptly identified many years ago (Vichealth VicHealth Koori Health Research and Community Development Unit, 2000) *"we don't like research…. But in Koori hands it could make a difference"*. The shift in the Indigenous perspective of research in the last 20 years exemplifies the importance of Indigenous people being in *control* of research done *with* Indigenous people. For Indigenous health research to be truly ethical, institutions must empower Indigenous people, communities, and their authorised representative organisations, to participate in and contribute to Indigenous health research as equal partners.

Institutions expected researchers to be accountable to the *guidelines* without providing the necessary support to do so. The *guidelines* have the potential to lose their purpose when they get operationalised through excessive administrative requirements. Instead of creating an environment that encouraged Indigenous research ethical accountability, institutional responses were perceived by some to generate further administrative burden on researchers which they considered to be counterproductive. It is conceivable that excessive administrative requirements have the potential to encourage researchers to take shortcuts in the ethics application process which could lead to unethical research practices.

Due to regulations universities were required to enforce the Indigenous ethical *guidelines* through their systems. However, they arguably failed to provide adequate support for their researchers to comply with the *guidelines.* Researchers were expected to build extensive relationships with Indigenous communities but this was rarely funded. This sometimes led to researchers' conceptualising Indigenous health research projects without adequate input

from Indigenous communities. In some circumstances community feedback in the review process was overlooked. Institutions ignored Indigenous guidance and failed to incorporate advice into their internal ethical review processes which reinforced institutional power imbalances. At the time of undertaking this research universities were still seemingly reluctant to share their control over Indigenous health research. Further, research funding systems did not provide the sufficient resources to Indigenous communities to oversee and implement the core values contained in the *guidelines* into research practice.

# Chapter sixteen: Indigenous ethics at the cultural interface

This chapter summarises the findings using the methodological tools described previously in the methodology and methods chapters. Further in-depth analysis on the findings is presented using theoretical concepts, (Charmaz, 2006) conditional relationship tables (Scott, 2004), and multiple conditional matrices (Strauss & Corbin, 1998). A summary of additional significant quotes is in Appendices I and J.

The following section focuses on the underlying conditions, actions, and consequences within an ethical landscape. These actions are influenced by the structural forces from both within the academy and from within the Indigenous community. The conceptual framework of a conditional matrix was used to identify the systemic conditions and structural forces that exist within two different worlds, the academic institutional setting, and the Indigenous community setting. This framework is a core component of grounded theory and is also recommended analytical tool for interpreting data arising out of CRGM (Malagon, et al., 2009).

## Critical race grounded analysis

Data analysis, and interpretation was carried out in accordance with critical race-grounded methodology (Malagon et al., 2009). CRGM uses critical race theory to expand the opportunity "to consider the influence of structural processes of domination" and reflect on "both social and structural processes that shape the social phenomena we explore in our research" (Malagon et al., 2009, p. 264).

Using a modified grounded theory approach I developed a coding framework to support theoretical development. The framework involved seven levels of non-linear coding, analysis and conceptualisation described by Charmaz (2006) as; line-by-line (LBL) coding; incident coding; 'in vivo' coding; and focused coding. These codes were then analysed, interpreted, and concept mapped using different analytical tools such as conditional relationship guides, and conditional matrices. NVivo computer software was also used to support qualitative data analysis. A comprehensive preliminary codebook is in Appendix K.

**The first level of coding required extensive line by line analysis** of the interview transcripts. Grounded theory requires researchers to form a close relationship with the concepts and

themes emerging from the data. Line by line coding helps break up the data and discover ideas (Charmaz, 2006). It's also an opportunity to define actions important to the research.

As line by line coding progressed the **second level coding** began simultaneously. **Incident coding** identified common liminal actions occurring within the data (Charmaz, 2006). The occurrence of similar incidents would be cross checked with each other and a set of properties for each incident was defined. As the number of different incidents grew, a catalog of different identifiable events was created in the research.

Throughout the coding process **'in vivo' coding** was used to ensure emerging concepts were grounded in the participants experiences, this was the **third level of the coding framework** (Charmaz, 2006). *'In vivo'* coding retains the language and terms used by participants to preserve their meanings, views and actions. These terms have come directly from the data and are not altered in any way. Concepts emerging can be general terms everyone knows, innovative terms created by participants and insider shorthand.

Preliminary coding and analysis identified multiple potential concepts. **The IRRG data analysis workshop** assisted with theoretical sampling by identifying concepts that required further investigation. This required revising questions and themes (see Appendix G) to explore potential theory. To fulfil these requirements interviews were done in phases until theoretical saturation had been reached and no new relevant concepts were emerging.

**The fourth level of coding involved identifying focused codes**. After multiple levels of coding common themes started to emerge and became more apparent as I moved across and between the data (Charmaz, 2006). Assumptions were made about the most significant codes, with frequent codes also being noted and interpreted. Constant comparison methods were undertaken consistent with grounded theory (Bryman 2004, Liamputtong 2010) where themes were drawn out of the data, but, the broader social context was also considered according to abductive coding techniques of critical race-grounded methodology described earlier (Malagon et al., 2009). Comparing data to data helped bring commonalities to the forefront of the analysis.

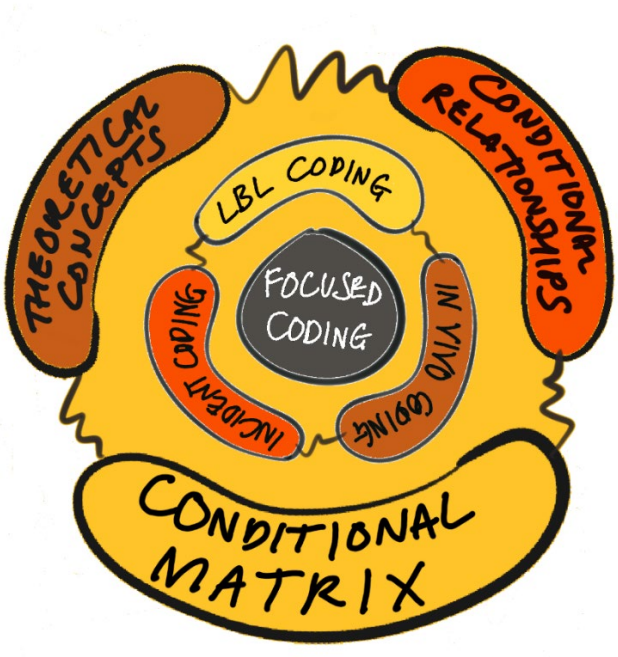
The **fifth level of analysis involved the development of theoretical codes**. These theoretical concepts were further fleshed out and explored through additional interviews, inclusion of a university as a recruitment site, and collaborative workshops with the IRRG. Theoretical

codes "specify possible relationships between categories you have developed in your focused coding" (Charmaz, 2006, p.63). Theoretical concepts were developed that provided theoretical direction for the analysis (Charmaz, 2006).

**The sixth level the conditional relationship guide** was used to further understand the interrelated conditions and interactions between theoretical concepts (Scott, 2004). The conditional relationship guide identified relationships, conditions, interactions, and actions, and consequences for the various concepts that emerged (Scott, 2004). Conditional relationship tables are a grounded theory analytical device that was used to understand the relationships between different conditions that emerged from the data. These tables helped conceptualise the actions and interactions identified through the coding process. These tables demonstrate the different interactions between focused codes and theoretical concepts and are presented in Appendices L and M.

**Finally, conditional matrices** (Charmaz, 2006, Hildenbrand, 2007, Strauss & Corbin, 1998) were used to understand the different social levels and interactions between these levels in relation to the analysis and codes. Figure 5 provides a visualisation of this process.

*Figure 5 Illustration of the coding and analytical process*




In summary, combining and intertwining the components of critical race theory (CRT) and grounded theory (GT) required thorough examination of the emerging data to scrutinise the

dominant structural forces that exist within the research sector. Themes were considered within the broader social context according to the abductive coding techniques of critical race-grounded methodology (Malagon, et al, 2009). The most significant and frequent codes and theoretical concepts occurring in the data were contextualised using my cultural knowledge and my experience as an Indigenous community member and researcher. This led to the development of several conditional matrices capturing the conditions, actions and interactions, and consequences happening with Indigenous ethical health research practices within the broader academic structural setting.

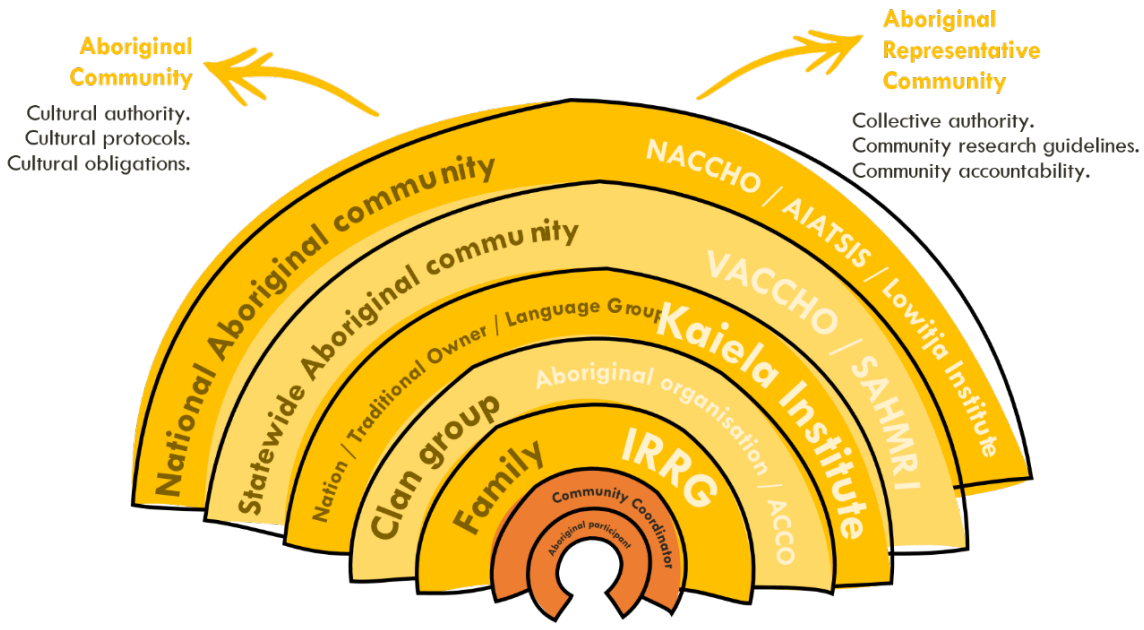
## Indigenous structural forces

Indigenous communities comprise bodies with distinct cultural or representative authority, responsible for protecting Indigenous communities' rights and wellbeing, and upholding Indigenous community obligations and protocols.

Multiple systems and structures have been grouped into a multi-layered Indigenous decision making matrix (see Figure 6). The matrix has been divided into two parts to describe interrelated but distinct purposes. Firstly, sovereign traditional owner groups or recognised cultural authorities with inherent cultural rights (some recognised through native title). Secondly, Indigenous community organisations usually focused on specific service delivery. These collectives are normally membership based with corporate board governance structures recognised under the Corporations (Aboriginal and Torres Strait Islanders) Act (Australian Government, 2024).

From an Indigenous standpoint (what Indigenous communities do) these are Indigenous structures that operate in direct response to the Indigenous ethics process (such as Indigenous ethical review or community approval) and responsibility for activities indirectly relating to the ethics process (such as community engagement).

*Figure 6 Indigenous (cultural) structural forces*



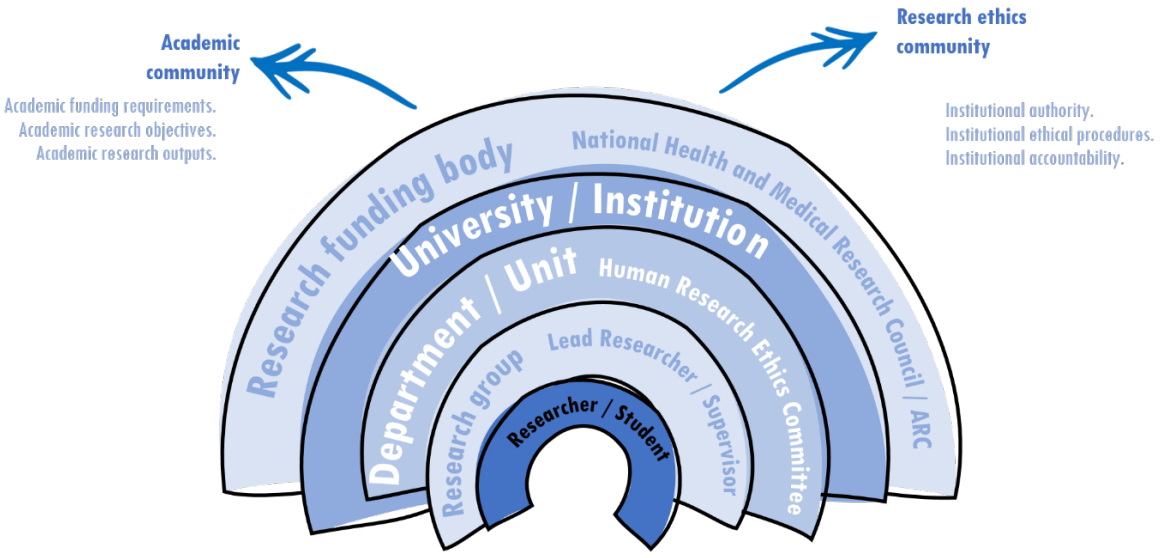
## Institutional structural forces

Academic or institutional structural forces (what dominant structures do) have been divided into research ethics related systems and general academic structures related to ethical practices required by the *guidelines.* Institutional structural forces (Figure 7) are played out through traditional academic structures and actioned by key academics within these structures.

In general academic systems influence how Indigenous health research projects are funded and conceptualised. Funding requirements, research objectives, and research outputs influence the practices of researchers, (influencing their ethical conduct). University research departments along with lead investigators also determine how to engage with Indigenous communities on Indigenous health research programs and contribute to upholding ethical standards within their institutions.

Institutional bodies, the NHMRC and Australian Research Council govern research ethics nationally (outer levels in Figure 7), universities and research institutions are the level below. Until you reach individual levels (inner circles Figure 7). The *guidelines* are stipulated (not necessarily enforced) by universities through institutional policies and through administrative procedures (HRECs). Researchers submit their ethic applications to HRECs.

*Figure 7 Institutional structural forces*

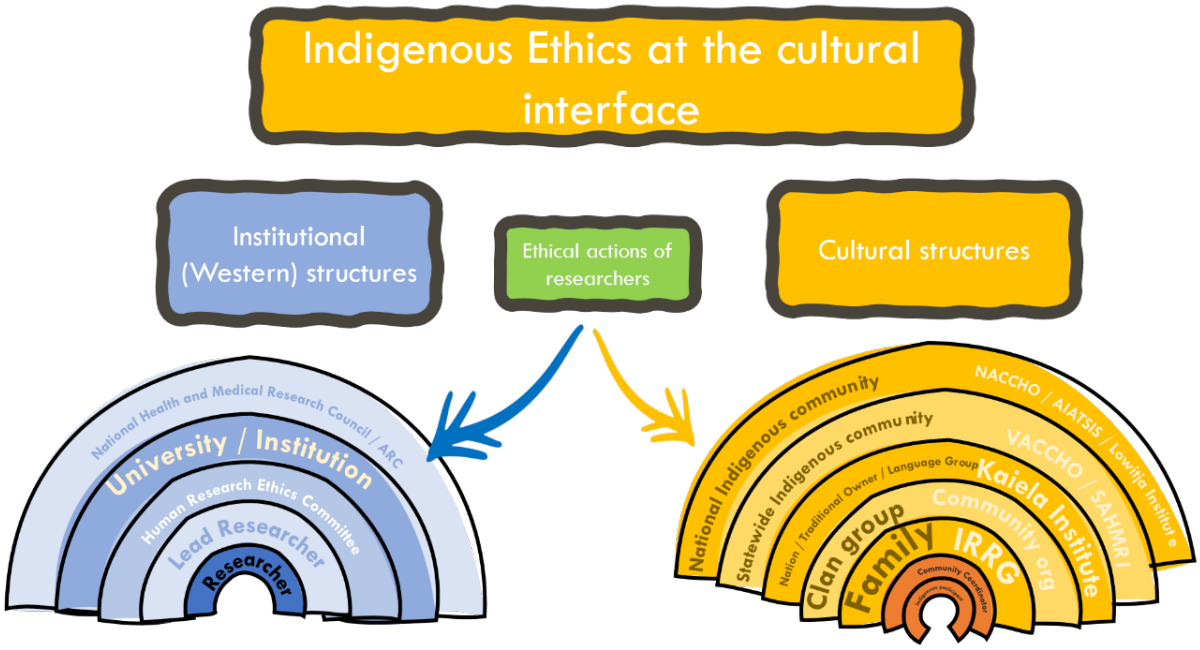


## Indigenous ethics at the cultural interface

Although institutions provided the ethical infrastructure, it was researchers who were responsible for determining how they *practiced* ethical values through their actions. Which could be on a spectrum from great to poor. It is the responsibility and the willingness of the researcher to be rigorous in the authentic application of the ethical values, as this research shows this does not always happen. Ethical practice therefore relied heavily on the personal accountability of individual researchers. Conducting ethical Indigenous health research means abiding by ethical values according to an Indigenous community, and these are often inconsistent with those directed by institutions.

Figure 8 identifies Indigenous structural forces and institutional structural forces, and positions researchers (and community coordinators) between these two systems within and an Indigenous ethical research context. Ethical actions of researchers occur within *two worlds* and encompass complex intersections between these worlds and even within them. The structural forces from both the research academy and from Indigenous communities influence and shape the conditions that researchers operate within.

*Figure 8 Indigenous ethics at the cultural interface*




Researchers' determined what course of ethical action to take place by submitting ethics applications through their institution (ethical review) to meet ethical compliance requirements (institutional structural forces). Researchers proposing to carry out Indigenous health research were also required to address the Indigenous ethical guidelines through an

institutional process. However, they must also uphold predetermined ethical practices in the conduct of their research. The final part is where gaps between ethical intentions and ethical conduct sometimes appear. There was a difference between the procedural administrative tasks associated with ethical compliance (controlled by institutions) and the demonstration of values-based ethical practices (monitored by Indigenous research partners, community coordinators, Indigenous communities, and researcher self-compliance). Whilst they have been theoretically linked through the ethics process they are distinctly separate.

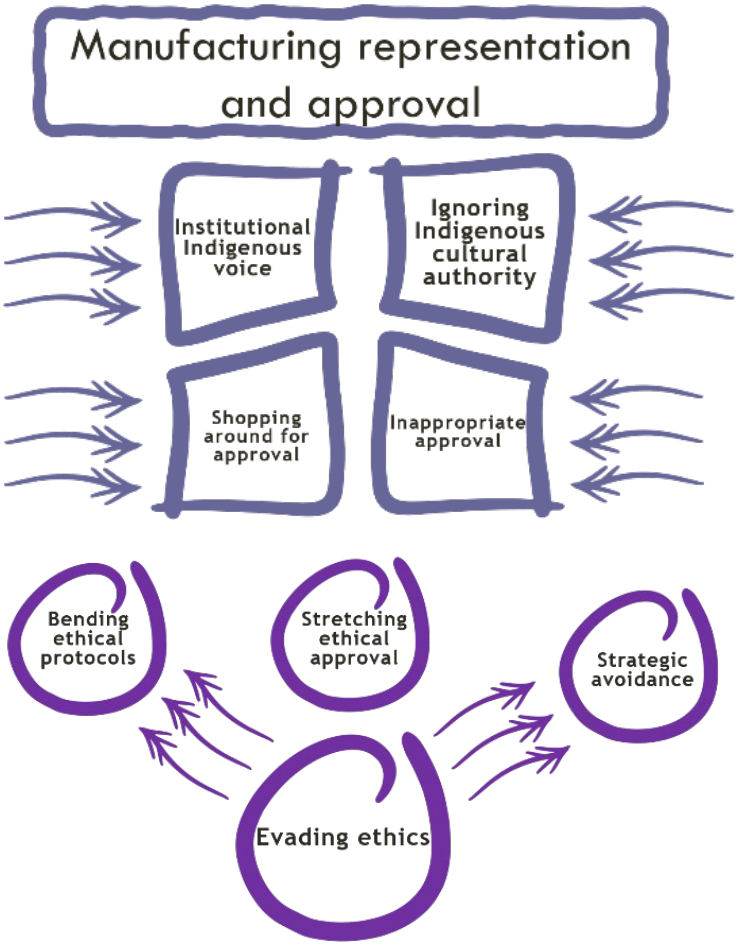
In addition, translation of the *ethical protocols* into practice could lead to contested practices between different stakeholders involved in Indigenous health research. In this analysis, codes clearly emerged revealing the outcomes of different researcher actions. Focused codes were selected because they demonstrated actions important to the ethical process. The conditional relationship guide further defines conditions for these according to a set list of questions. Structural forces (institutional and Indigenous) and conditions contributed to researcher actions that lead to different ethical consequences. Actions and consequences are described further in the conditional relationship guides in Appendices L and M.

Five theoretical conceptual models were constructed to further explain what was happening. Conceptual mapping supported the development of five theoretical conceptual models; evading ethics, manufacturing representation and approval; cultural ethical readiness; brokering research; and creating culturally safe research (see Figures 9 and 10).

Manufacturing representation and approval (Figure 9) describes conditions where Indigenous support for Indigenous research is provided through institutions; or where Indigenous cultural authorities advice is ignored; where Indigenous approval is given without appropriate authority; and finally when researchers 'shop' around research proposals to different stakeholders within Indigenous communities.

Also in Figure 9 shows how researchers evaded ethics through; strategically avoiding the *guidelines* by omitting Indigenous specific information in their research proposals; stretching ethical approval (to incorporate Indigenous specific components) by using the amendments process to avoid full ethical review; and bending ethical protocols and rules knowingly, or ignorantly.

*Figure 9 Theoretical concepts: Manufacturing representation and approval, and evading ethics*

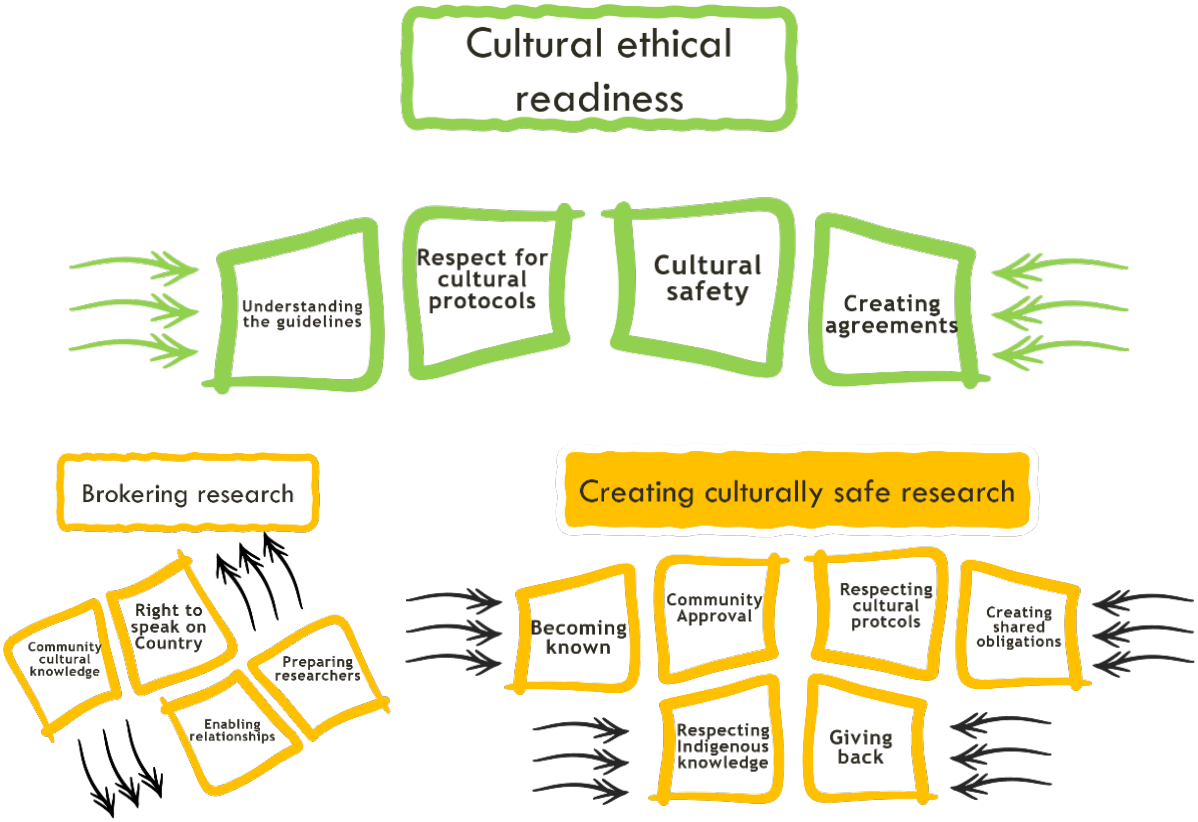



Cultural ethical readiness defines the ideal conditions for institutions before they conduct research involving Indigenous communities. Key features include; understanding of the guidelines; respecting cultural protocols; being culturally safe; and creating agreements.

The brokering model contains the following conditions; community cultural knowledge; the right to speak on country (either having the right or knowing someone who does); enabling relationships; and preparing researchers (see Figure 10). This concept could be understood as the bridge between 'institutional' readiness and 'creating culturally safe research'.

Finally, the last theoretical concept are conditions for culturally safe research. This concept relates more to community expectations whereas the 'cultural ethical readiness' concept relates to institutional internal readiness. This theoretical concept includes 'grounded' codes from the findings and comprises; becoming known; community approval; respecting cultural protocols; creating shared obligations; respecting Indigenous knowledge; and giving back.

*Figure 10 Theoretical concepts: Cultural ethical readiness, brokering research, and creating culturally safe research*




## The intersection between *Indigenous* ethics and *institutional* ethics

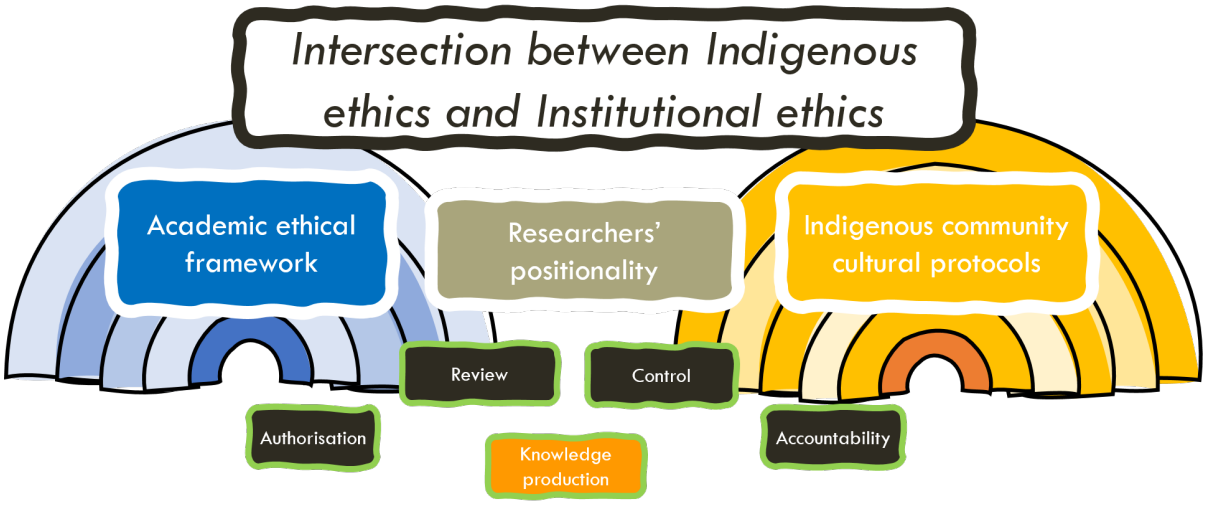
In the conduct of Indigenous health research there are Indigenous community cultural obligations to consider and there are academic ethical obligations to fulfil. *Academic institutions* operationalise ethical frameworks determined by legislation, *researchers* define appropriate ethical actions in the conduct of research with Indigenous communities, and *Indigenous communities* determine necessary cultural protocols, advise researchers, and monitor research in their communities. However, the latter two are often aspirational rather than operational. This description alone reveals the power imbalance between Indigenous 'rules' and 'Western' rules.

Researchers (both Indigenous and non-Indigenous) work and operate within these two frameworks. If we generalise, Indigenous researchers may hold stronger obligations with Indigenous communities through their cultural authorities or through their community organisations. Vice versa non-Indigenous researchers may be more focused on academic requirements. However, these findings also demonstrate the opposite; some non-Indigenous researchers become obligated to cultural and community frameworks; and under certain

circumstances some Indigenous researchers are not connected to the Indigenous community they are conducting research with (Gower, 2015), and as such might prioritise adherence to academic requirements.

Indigenous structural forces intersected with institutional structural forces in four key areas relevant to the Indigenous ethical *guidelines*; ethical review; Indigenous community authorisation and approval; research governance and control; and monitoring and accountability. In addition, the primary purpose of research is the production of knowledge. This goal creates further tension at the cultural interface contributing to a contested ethical space (see Figure 11).

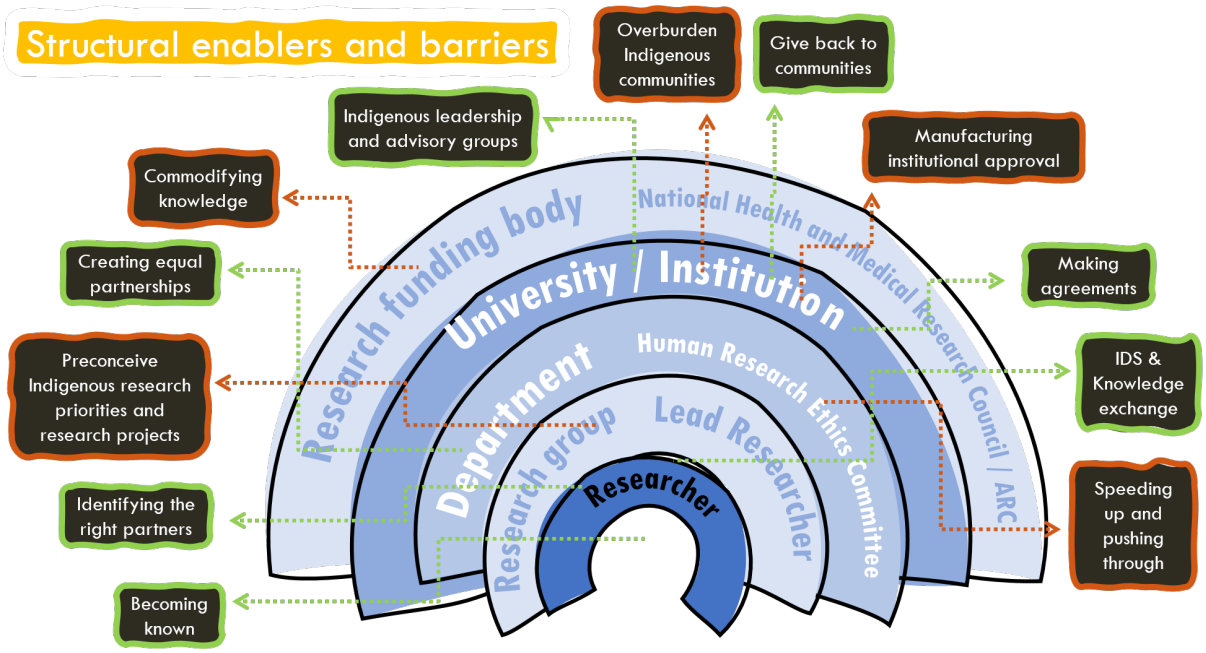
*Figure 11 Intersection between Indigenous ethics and institutional ethics*




The intersection between these two worlds caused an overlap in roles and responsibilities between researchers, Indigenous community partners, institutions, and Indigenous communities in meeting the ethical *guidelines*. Dual systems also highlighted the disparity in resources, and infrastructure.

The actions of researchers were influenced by different systemic pressures within the four intersecting areas described previously. Researchers sometimes prioritised institutional ethical compliance requirements. Competing priorities created gaps for implementation of the ethical guidelines. These are the structural conditions that contribute to unethical/ethical activities. Figure 11 encapsulates the enablers and barriers to practicing the ethical *guidelines* Indigenous health research as a result of institutional structural forces.

*Figure 12 Structural enablers and barriers*




*Note 5 The green and red labels represent enablers and barriers.*

Systemic barriers make it harder for Indigenous communities and institutions to monitor implementation of the *guidelines.* Within the ethical review system the guidelines were interpreted differently by academic reviewers and Indigenous communities, researchers strategically avoided them (sometimes undertaking amendments to do so) and stretched ethical approval. There was a lack of Indigenous participation in institutional ethical review.

The authenticity of Indigenous representation, approval, and consent was contested. Lack of agreement making evidently restricted the rights of Indigenous communities involved in research. Multi-layered approval processes through institutions and Indigenous communities, across different jurisdictions contributed to a complex authorising environment for Indigenous health research.

Existing power structures within academic environments disempowered Indigenous people, and communities. Institutions ultimately controlled the Indigenous research agenda; Indigenous knowledge production, translation, and dissemination; and Indigenous data and knowledges. Monitoring and accountability of researchers was lax with ethical non-compliance, breaches and complaints being resolved ineffectively.

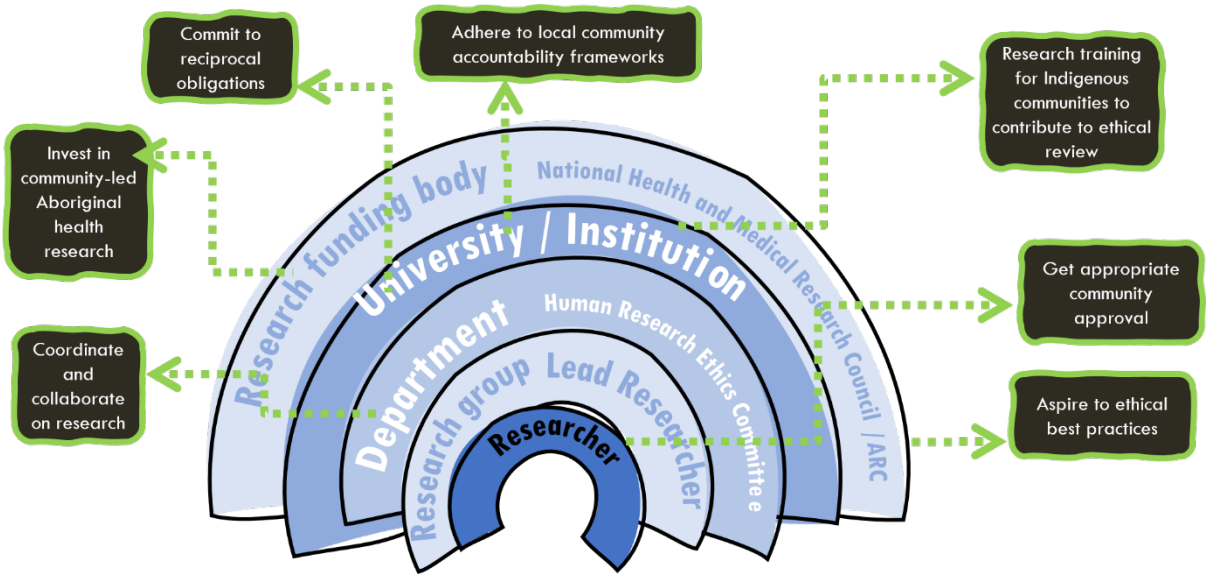
It is unethical to do Indigenous health research without Indigenous partners, authority, representation, and control. However, it could be argued that standards of compliance and

regulation remain distinctly separate from compliance with Indigenous community cultural protocols. Institutional HRECs lacked Indigenous membership and accountability mechanisms were disconnected from Indigenous people and communities. Researchers were sometimes the lone connection between these two compliance systems and Indigenous ethical compliance arguably relied on researcher reflexivity and self-reporting.

These discussions reveal to what extent the *guidelines* are operationalised by researchers conducting Indigenous health research; explain how researchers interpret and apply the NHMRC six values; describe how Indigenous protocols for Indigenous research (including Indigenous representation, approval, and consent processes) are applied (or not); critique and scrutinise systemic drivers of inequality causing institutional power imbalances between Indigenous communities and research institutions; and identify effective ethical approaches for Indigenous contribution and participation in Indigenous health research.

However, universities, research institutes, funding bodies, and researchers have the potential to strengthen outcomes for Indigenous health research through a number of enabling factors (see Figure 13).

*Figure 13 Role of universities, research institutions, funding bodies, and researchers*

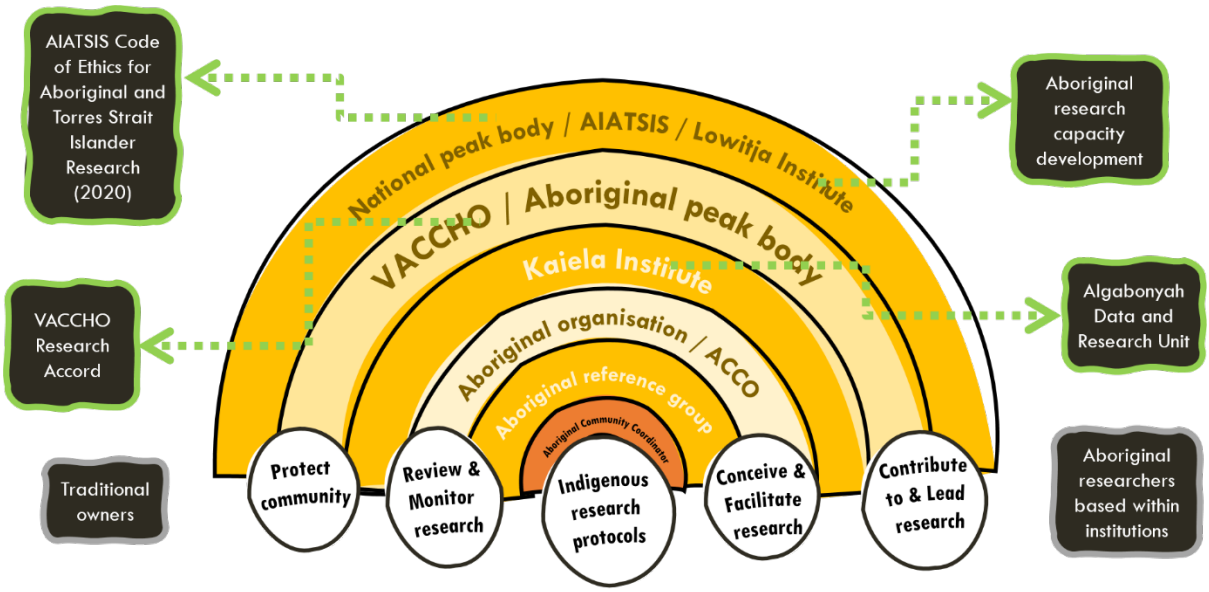



Empowering Indigenous community research partners and meeting Indigenous community obligations to support reciprocal outcomes and benefits. The development of formal agreements was paramount for creating equal partnerships, empowering Indigenous leadership and advisory groups, and valuing and protecting, and sharing control of Indigenous

knowledge. Indigenous communities, and Indigenous organisations are already invested in Indigenous health research.

Indigenous communities support implementation of the *guidelines*, and uphold cultural protocols that complement them, with limited resources and without adequate capacity development. Without appropriate resourcing Indigenous Communities can be overburdened by obligations to monitor research (see Figure 14).

*Figure 14 Role of Indigenous communities in Indigenous research*




## Kinaway, Djillay-Ngalinya, and Community Control: Some conceptual models:

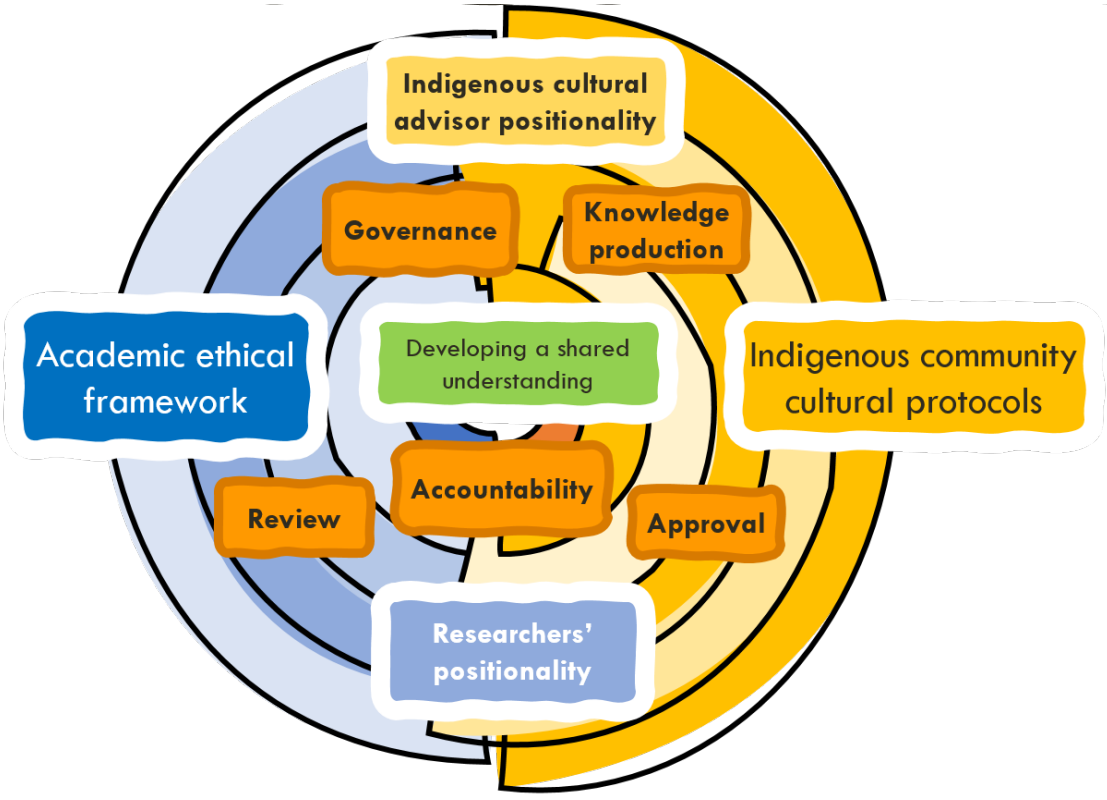
In an ideal scenario (after appropriate engagement has happened) a research agreement should be developed. A negotiation is required between researchers and Indigenous communities involved in research in these domains; monitoring and accountability, approval, review, knowledge production, and governance.

Each of these key domains should be considered from the Indigenous perspective and adhere to specific community cultural protocols identified by the 'Indigenous cultural advisor', which could be an individual, a structured group, or an Indigenous research partner, or the Indigenous community organisation involved in the research. The Indigenous cultural advisor would facilitate the negotiation between the research team and the Indigenous community within each of these domains. This should be confirmed through a research agreement that upholds the rights of Indigenous community partners.

In Gunai brabiralung mukdhang language 'Kinaway' means 'reciprocal exchange'. This expands upon the 'Western' notion of exchange to include cultural obligations that are expected to be fulfilled as part of a relationship. This model (Figure 15) aims to centralise the concept of 'reciprocal exchange' within the research negotiation. Research negotiations should provide clarity about obligations, expectations, and contributions to the research. A clear understanding about what is 'given' by each group and what will be provided in 'return'. To establish an equal partnership researchers and Indigenous community partners must respect obligations from both sides. Indigenous community partners should understand their rights and expectations in relation to knowledge produced from the research.

This model would be more effective in an environment where Indigenous self-determination exists or where institutions and governments respect the authority and decision-making of Indigenous communities. This conceptual model could encompass all Indigenous governance systems, including the Indigenous community-controlled health sector and could potentially contribute to a decolonising approach to broader research systems. Indigenous communities involved in research, and Indigenous researchers could adapt and use this model in consideration of research proposals.

*Figure 15 Kinaway: conceptual model for negotiating reciprocal obligations, and research agreement making*



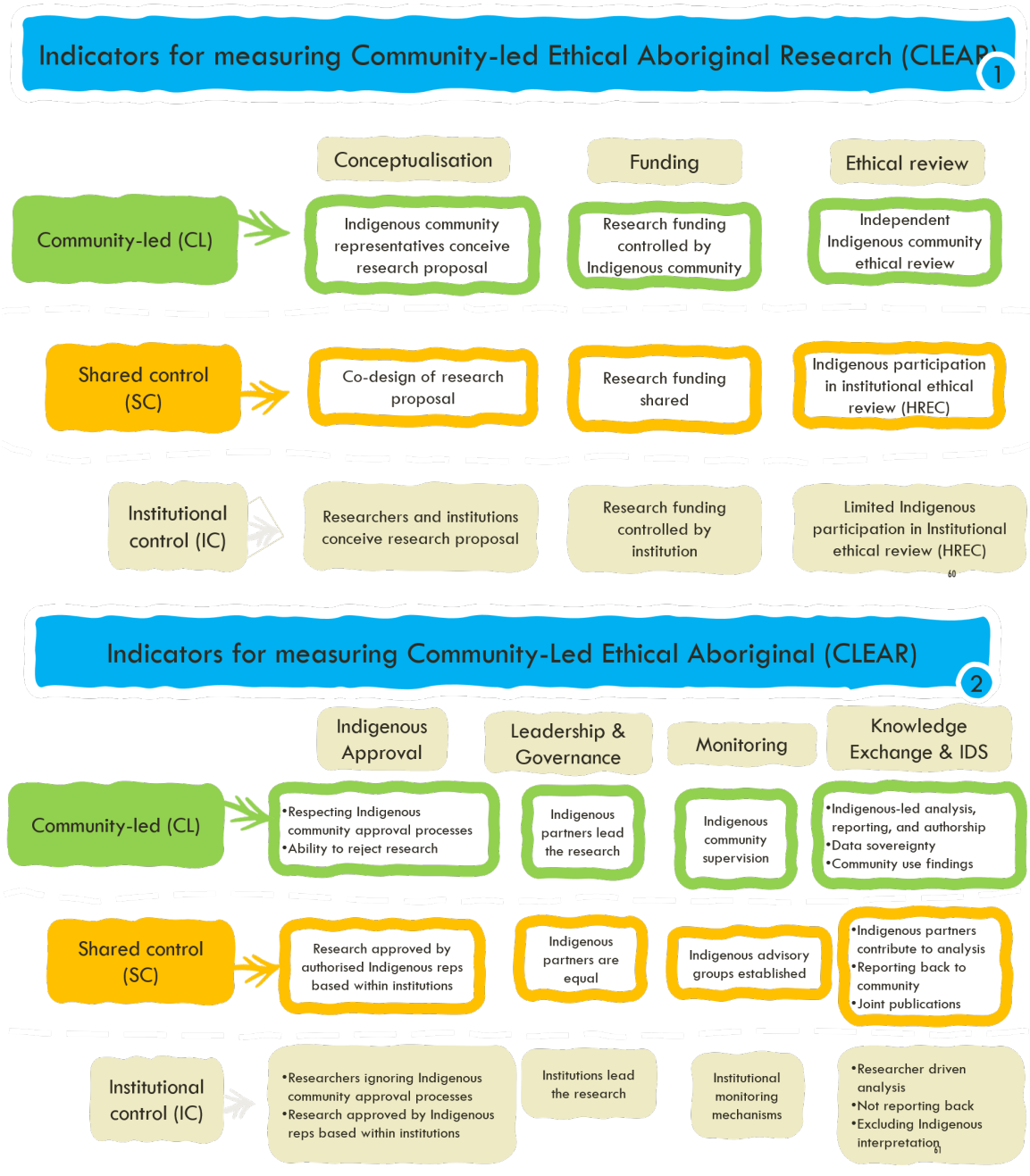
The idea of best practices in Indigenous health research has been promoted by various scholars (Huria et al., 2019, Brunger et al., 2020). Luke et al (2020) queried if the 'Western' philosophy of best practice is appropriate in an Indigenous context. Luke et al (2020, p.2) argue that "Western evidence-based practice places too strong a value on Western methods and scientific rigour of research evidence". Others still have attempted to examine and measure how Indigenous ethics have been put into practice (Bainbridge et al., 2013, Chenhall et al., 2011, Dudgeon et al., 2010, Gower, 2015, Maclean et al., 2015, Pyett et al., 2008, Wand & Eades, 2008). What is not debatable is the large contribution from Indigenous research institutions, bodies, groups, and academics to Indigenous health research in the last twenty to thirty years at least (Aboriginal Health & Medical Research Council, 2023, Australian Institute of Aboriginal Torres Strait Islander Studies, 1999, 2012, 2020, Onemda VicHealth Koori Health Unit, 2008, 2010; VicHealth Koori Health Research and Community Development Unit, 2000, South Australian Health and Medical Research Institute (SAHMRI), 2014, Victorian Aboriginal Community Controlled Health Organisation, 2023) and the development of tools to measure, appraise, and apply ethical research in Indigenous communities (The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE), 2015, Huria et al., Laycock et al., 2011, National Health and Medical Research Council, 2005, 2018b, The Lowitja Institute, 2014). I argue that as Indigenous researchers we have a responsibility to build upon and consolidate 'cultural' best practices to ensure certain standards (defined by Indigenous communities) for Indigenous research are met.

Ngalinya-Djillay[13] (see Appendix N) is an ethical spectrum for being 'good' in Indigenous research. This spectrum distinctively identifies unethical researcher actions and behaviours, as well as best cultural practice. These are not comprehensive or rigorous by research standards, they merely aim to add to the discussion and provoke an idea that could be further explored. There is potential value in establishing best practices in Indigenous ethical research but best practice frameworks should be designed by Indigenous researchers with an Indigenous lens and supported by Indigenous community-led organisations (Luke et al., 2020). I would also add Indigenous cultural authorities should be included and recognised as 'knowledge holders' or 'cultural experts' in the development of 'Indigenous best practices'.

[13] Ngalinya means beautiful in Yorta Yorta language. Djillay means good in Gunai brabiralung mukdhang.

Still to transform Indigenous research into ethical research we need to extend beyond best practices. Indigenous communities need to be empowered to lead research (Biles et al., 2022, Burchill et al., 2023, Clapham, 2011, Duke et al., 2021, Mckenzie and Bandler, 2023, Onemda VicHealth Koori Health Unit, 2008). Through this research, a set of indicators for Community-Led Ethical Aboriginal Research (Figure 16) have been developed to measure how much control Indigenous communities have over research. Indicators have been identified for *conceptualisation, funding, ethical review, approval, leadership and governance, monitoring, and knowledge exchange and Indigenous data sovereignty.*

*Figure 16 Indicators for measuring community-led Indigenous research*



# Chapter seventeen: Discussion

The discussion includes the following sub-chapters; *Structural power and privilege; Structural capacity to deliver ethical Indigenous health research; The myth of objectivity and difference blindness; (Re)interpreting the guidelines; Knowledge production, Indigenous data, and Indigenous knowledges; and Transformation and Structural reform.* An additional chapter is included on the *Evaluation and revision of the 2003 NHMRC guidelines*.

The following discussions will describe the structural issues relevant for ethical Indigenous research, discuss an Indigenous translation of the *guidelines*, challenge and disrupt accepted practices, and finally highlight opportunities for academic structural reform and community empowerment. The arguments within should provoke a discussion on the best way forward for not only 'ethical' Indigenous health research but for community controlled Indigenous health research.

## Structural power and privilege

These findings demonstrate structural power imbalances affecting ethical Indigenous research practices within the academy. Traditional academic institutions arguably perpetuate systems that maintain the 'status quo' by privileging some groups and disadvantaging others. Institutional power, paternalism, and privilege created barriers for implementing the Indigenous ethical health research guidelines.

Through the institutional ethical review process, HRECs often lacked the required experience and expertise to review Indigenous health research proposals. It would be fair to say the lack of Indigenous representation on institutional HRECs, and the lack of members with Indigenous health research expertise and experience, led to inconsistent ethical review of Indigenous health research projects across the academy. As a result many universities reviewed the Indigenous ethical values according to their own institutional values, experience, and capacity.

Academic institutions were primarily established to contribute to knowledge to society privileging 'Western' scientific disciplines. Current systems of ethical review are arguably based on 'Western' concepts and favour scientific biomedical review model and as a result undervalue Indigenous perspectives. Indigenous scholar Grenz (2023) claims institutional ethical review processes are systemic barriers for Indigenous-led research with Indigenous

communities. Grenz argues that HRECs "processes and assessment criteria are still created mainly for non-Indigenous researchers. They don't account for years of developing trusts and nurturing relationships in ways that go well beyond ordinary research partnerships" (2023, p.221). Grenz suggests Indigenous community-led peer review as a solution to "let Indigenous academics stand before our co-researchers – our communities – and be wholly and solely accountable to them. The ethics of research projects between Indigenous researchers and Indigenous communities should be reviewed only by those communities" (2023, p.221). Burchill et al (2023) also argue for Indigenous-led HREC's for similar reasons. According to Burchill et al (2023) fundamental reform of Indigenous health research was required to strengthen Indigenous community participation in research governance and oversight. Burchill et al (2023) study implied that community controlled organisations were a robust mechanism for Indigenous oversight of research and strengthened researchers' alignment to local protocols.

In the ethical review of Indigenous research proposals the technical and bureaucratic administrative processes often superseded any cultural considerations. Gorman (2011) described the problematic relationship between researchers and HRECs and the broader context of research governance. HRECs have been prone to "ethics creep" which has been described by Canadian researchers Guta et al (2013) as the increasingly bureaucratic and expanding reach of ethical review bodies. In an Australian context, I would argue 'ethics creep' has been displayed by HRECs in their overzealous nature to 'protect' Indigenous communities. This is evident in the experiences of Indigenous and non-Indigenous researchers that participated in this study. The increasingly regulatory nature of ethical review of Indigenous research in Australia has been criticised by researchers. Hawkes et al (2017), criticised university ethical procedures, challenged the historical reputation of universities (in relation to perpetuating racist stereotypes), and connected this to the current 'paternal' approach to Indigenous ethics. Paternalistic ethical review processes inevitably evoke negative sentiments for many Indigenous researchers because of the historical overresearching of Indigenous peoples (Hawkes et al, 2017). Universities have been accused of over regulating Indigenous ethics to the point where these "bureaucracies' strict, inflexible adherence to formal ethical codes frequently disempowers Indigenous peoples by questioning and often limiting their ability to negotiate the terms of their relationships with

research academics by and for themselves and their communities" (Hawkes et al, 2017, p.22). Institutions were overly focused on compliance requirements related to Indigenous health research:

> ***"There is a problem with the system. This is not about ethics anymore. For years this has not been about ethics." Indigenous researcher***

Due to past practices of exploitation, many Indigenous communities had an inherent lack of trust in universities, and in their capability to ethically review Indigenous research (Grenz, 2023). Universities ultimately still have control over the Indigenous health research agenda. Indigenous scholars argue that non-Indigenous researchers and non-Indigenous institutions are controlling Indigenous health research agendas (Burchill et al., 2023). Structural power imbalance was unintentionally reinforced through ethical procedures. Demonstrating cultural ethics was constricted and twisted to ensure compliance with procedural ethics. The practice of Indigenous cultural ethics intersected with administrative ethical requirements without institutional acknowledgement of the inherent difference between these two processes.

There has been significant investment in Indigenous research but structurally academic institutions are difficult to change. Indigenous leaders must be empowered to support institutional reform rather than reinforce traditional academic power structures. Universities that are interested in Indigenous health research must commit to Indigenous research philosophies, methodologies, principles, and practices and invest in community partnerships not just academic ones. Indigenous communities invited to participate in research were not normally in control of decisions about the research. In an academic research context, researchers had the decision-making power. There was an obvious disconnect between academic decision-making processes and Indigenous community decision-making authority.

Grounded Indigenous researchers had overlapping obligations within two worlds, and were required to reinterpret, redefine, and demonstrate cultural obligations within a western ethical research framework. Indigenous community partners, community coordinators and Indigenous researchers were continually forced to validate and modify Indigenous ways of knowing, being and doing within dominant western constructs.

The academic peer review system preserves and privileges existing members of the academic community. Peer review and supervision are proven models but they inherently benefit those that are already privileged. Institutional barriers for already disadvantaged and disenfranchised groups. A critical mass of Indigenous scholars is required to create a balanced peer review model that values and includes Indigenous experiences, worldviews, standpoints, and knowledges. This system doesn't exist yet because of systemic inequality.

Solar and Irwin (2010) identify power structures influence over socioeconomic status within society as a social determinant of health. They conceptualise power as structural determinants *"that generate or reinforce social stratification in the society and that define individual socioeconomic position"* (2010). Academic hierarchical structures could be identified as *structural determinants* of power with entrenched systems of privilege and entitlement. Current academic systems reinforce the power imbalance between Indigenous communities and institutions.

The marginalisation of Indigenous peoples from academic power structures, is demonstrated through limited Indigenous led research within universities and lack of Indigenous involvement in institutional ethical review potentially contributing to systemic exclusion. Guta et al (2013) recognised the power of ethical review bodies in the knowledge production chain stating that:

> *"We understand **ethics review sit at the crossroads of power/knowledge** within current systems of university and hospital-based academic knowledge production. **Ethics review determines what is possible in the production of knowledge: what can be done, what can be asked, by whom, and for what purposes.** The restricting of research may be understood as oppressive and dominating to certain forms of truth, especially those that do not promote objectivist knowledge rooted in the scientific method" (pp. 307-308).*

Richard Bell's artwork "Aboriginal Art – It's a White Thing" (2003) serves as a poignant critique of the commodification and control of Indigenous art by the predominantly white art market. This work is part of Bell's broader engagement with issues of identity, colonialism, and the politics of art (Bell, 2002). Bell's work suggests that the control of Indigenous art extends beyond mere aesthetics, touching on deeper issues of power, representation, and cultural appropriation.

Using Bell's artwork as an analogy for 'white' control of Indigenous research, we can draw parallels to how Indigenous knowledge and methodologies are often framed, interpreted, and valued through a predominantly 'Western' academic lens. Just as Bell critiques the external control and commodification of Indigenous art, there is a critique to be made of the ways in which Indigenous research is conducted, published, and utilised, often without adequate involvement, recognition, or benefit to Indigenous communities themselves.

This analogy highlights the importance of decolonising research methodologies and advocating for Indigenous-led research practices that prioritise Indigenous epistemologies, values, and sovereignty. We need to shift towards Indigenous autonomy and self-determination in both the cultural and academic spheres, challenging structures of power that have historically marginalised Indigenous voices.

Targeted investment to build research expertise within Indigenous communities is required to address the power imbalance. The concept of Indigenous-led research has been identified as a core component of a 'culturally adaptive governance' framework for equitable research by Duke et al (2021).

However, we must also consider the academic structural reform required to create space Indigenous academic leadership, and recognise Indigenous knowledge systems as different but equally valid to 'Western' knowledge systems. In my experience as an Indigenous academic there were still clear barriers for expressing Indigenous ways of being, doing, and knowing within academic structures. This is consistent with the experiences of prominent Indigenous scholars Fredericks (2009) Aileen Moreton-Robinson.

Universities must relinquish some of their power (within academic structures such as; HREC processes; Indigenous research funding programs; research ethics training; academic leadership pathways) to Indigenous communities, academics, and community controlled organisations, to enable a better foundation for ethical Indigenous health research. Universities must also invest in an Indigenous academic workforce, grounded in their Indigenous communities, to transform institutions from the inside out.

## Structural capacity to deliver ethical Indigenous Health research

Universities that undertake Indigenous health research have an obligation to create culturally safe research with Indigenous communities. Before institutions considers a program of

Indigenous health research they should have a broad understanding of the priorities, needs, issues, and challenges of Indigenous communities. To do this institutions need to establish relationships with Indigenous cultural authorities to understand and contextualise these needs. They need to create systems within their institution to educate researchers about the Indigenous *guidelines* and support widespread implementation. An agreed understanding of what constitutes ethical behaviour is the platform from which Indigenous health research should begin. This can only happen with the support of Indigenous peoples and Indigenous communities.

The system is currently not equipped (underfunded) to support adequate and appropriate Indigenous involvement. Institutions expected their researchers to be accountable to the g*uidelines* without providing them with the necessary support to do so. The purpose of the g*uidelines* seemed to get lost when they were operationalised. Instead of creating an environment of Indigenous ethical accountability, institutional responses generated further administrative burden on researchers. Institutions were not adequately building their ethical research capacity or providing the additional resources required (such as support for extensive community engagement) to ensure they upheld ethical practices. Institutions were overly focused on compliance requirements related to Indigenous health research.

Formal research agreements were critical to establish parameters, gaps, and rules between Indigenous communities and research institutions. Indigenous academics have called for stronger Indigenous research governance and oversight over Indigenous research (Huria et al., 2019, Burchill et al., 2023, Duke et al., 2021). However, it is unclear how many institutions actually used formal research agreements in their research with Indigenous communities.

What is clear is that not every institution has the capability or the capacity to undertake the extensive ethical steps required. This research reported that institutional awareness of the *guidelines* moved between institutional blindness and institutional hyper-visibility. Some institutions were not prepared for conducting Indigenous health research. Unfortunately some institutions lacked the cultural capacity to engage in Indigenous health research.

In contrast some Indigenous organisations were still overburdened by requests to facilitate research, some weren't ready to provide the necessary support, and some actively did not

want to participate in research. Due to the assumed importance of Indigenous health research there seemed to be an underlying expectation that Indigenous communities use their resources to contribute to the Indigenous research agenda.

The consideration of the additional guidelines for research with Indigenous peoples meant more administrative burden, lengthier review and approval, and required more project resources to uphold in practice. Combining increased administration with institutional pressure to meet academic targets meant researchers chose to avoid high risk ethical review. Researchers contested the value of additional guidelines specifically for Indigenous health research and found ways around being reviewed against them, and practicing them. Researchers felt they had the qualifications to undertake research with any community due to their formal training. As researchers they were empowered by institutional structures, the compulsory nature of the *guidelines* arguably challenged their position and status. Requirements to seek external advice and support from Indigenous communities further exacerbated this notion.

As an Indigenous researcher and as a community member involved in the community controlled health sector current systems lack the capacity to monitor the active demonstration of ethical practices in Indigenous health research. Researchers were able to exploit loopholes and limitations of institutional reporting and monitoring systems. Despite the reluctance of researchers, ethical responsibilities did not just disappear. Due to their non-negotiable community obligations Indigenous communities often absorbed the additional burden and responsibilities dropped by researchers and institutions.

Alternatively, Indigenous communities that ensure relevant Indigenous ethical values and principles have been embedded in systemic review processes were undervalued. From an Indigenous standpoint there was a convergence of purposes within researcher-community relationships that included but was not limited to ethical review. In that sense it might be necessary to reimagine the roles of Indigenous communities in ethical review. The research sector might need to expand the roles of Indigenous research committees, especially those based within institutions, to better incorporate community identified research objectives and accountability, rather than focusing primarily on attaining ethical and community approval.

The concern is that the ethical *guidelines* have been developed to ensure researcher accountability to institutions and universities. Accountability to Indigenous communities is a secondary priority. This requires an Indigenous monitoring and accountability system to ensure researchers are accountable to the Indigenous communities. Lack of accountability to Indigenous communities is a limitation of the current institutional framework, and a glaring systemic gap that needs to be addressed. Huria et al (2019) have developed a best practice framework for reporting on health research involving Indigenous peoples that includes measures for the following areas: governance; prioritization; relationships; methodologies; participation; capacity; analysis and interpretation; and dissemination. This is a useful mechanism to begin to address this gap but structural reform is required for tools like this to be implemented.

## (Re)interpreting the *guidelines*

This sub-chapter focuses on the inherent cultural and community obligations carried by Indigenous people through their, identity, their connection to Country, and their connection to community. It will also describe how cultural obligations and academic obligations intersect and are contested within an Indigenous research context.

Indigenous communities define, interpret, and deconstruct the ethical *guidelines* through their own cultural values systems. Consent and approval processes are relevant to Indigenous values of respect and responsibility. Relationality and cultural positioning are important elements for building trusted relationships with Indigenous communities. The concept of reciprocity should be easy to understand but takes on a different meaning in an Indigenous community context. In the context of Indigenous health research some communities' established independent mechanisms to monitor and guide researchers through their own protocols.

### Building trusted relationships through community responsibility

More often than not Indigenous community protocols were unspoken, and undocumented, and could only be navigated through building relationships. The NHMRC (1991, 2003, 2005, 2007, 2015, 2018, 2018), the Australian Institute for Indigenous and Torres Strait Islander Studies (2001, 2012, 2020), and numerous national and state Indigenous, and non-Indigenous, peak health organisations in Australia (Watson et al 2010, Laycock et al 2011, AHMRC 2013, SAHMRI 2014) strongly advocate for working in partnership with Indigenous

communities to identify priorities before any research begins. Building relationships and trust is recognised as a crucial part of the research journey (National Health and Medical Research Council 2005). The importance of trust between Indigenous communities and researchers (and institutions) is well documented (Guillemin et al., 2016ab, 2018).

Cultural obligations are an important part of kinship systems. Researchers that 'became known' to Indigenous communities sometimes innately assumed cultural obligations of their Indigenous community partners. Cultural obligations became a cornerstone of trusted relationships.

Researchers became obligated to contribute to the greater good of an Indigenous community as part of their maintenance of community relationships. Indigenous communities that deconstructed the ethical process in their own worldview, were able to reframe the position of researchers they engaged with and transform research principles into practice.

Creating equal partnerships in a cultural setting meant relinquishing control and privileging Indigenous led research. Community cultural obligations often superseded research objectives. Timelines for research would often be slowed down to incorporate adherence to cultural protocols which created tension for researchers driven by academic timelines. Researchers had to incorporate cultural obligations into their research design. Taking responsibility for cultural obligations associated with Indigenous communities they are building relationships with. Beyond the objectives and purposes of the research. This supported authentic relationships based on mutual obligations, rather than competing ones. Sharing resources with Indigenous communities supported their capacity to engage and contribute to research.

This is where Indigenous and academic positionality and self-reflection are evidently required when it comes to Indigenous health research. Everybody has a position and biases that influence their decisions. The explicit cultural positioning of Indigenous communities is one of the strengths of Indigenous research approval and review processes. Research is immediately positioned within a framework that scrutinises the real world practical benefits for that specific Indigenous community. Cultural positioning clearly positions Indigenous people within a cultural responsibility framework. Indigenous people on Indigenous advisory

groups within universities should be required to have their cultural positions ratified by relevant Indigenous organisations.

Fronting up and being part of the community, not just for the purposes of research, solidified relationships with communities. Understanding, respecting, and contributing to community networks based on social obligations strengthened accountability. It broadened understanding of the complex relationships between different community groups. Making connections between different groups to strengthen outcomes of research. Creating opportunities for solidarity and collective unity through research.

### Indigenous cultural authority, representation, and collective consent

Indigenous identity, representation and authority is complex and place dependent. It is not in the scope of this study to define Indigeneity in an Australian context however, Indigenous identity has been defined by the Commonwealth government using a (probably outdated) three part criteria that determines a person is of Indigenous status if they are (1) of Aboriginal and/or Torres Strait Islander origin (2) identify as Aboriginal and/or Torres Strait Islander and (3) is accepted by an Aboriginal and/or Torres Strait Islander community (Department of Aboriginal Affairs, 1981 cited in Australian Bureau of Statistics, 2013, p.5). Academics and institutions have also expanded and redefined Indigenous identity in different contexts (Ganter, 2008, Gorringe et al., 2011, Peters-Little, 2000). Peters-Little in particular talks about the construction of Indigenous identity, critiques notions of pan-Aboriginality, and argues the "structure of 'community boards' is based on western notions of representativeness." (2000, ch.6 para.1).

As an Indigenous researcher I have culturally positioned myself in this research. I have clearly identified the Indigenous nations I belong to and reinforced my cultural and family obligations. This positioning along with my research experience and knowledge allows me to analyse these findings to scrutinise and determine relevant criteria for authentic, authorised, Indigenous institutional representation in Victoria, Australia. Furthermore, these options could be relevant and adaptable and potentially form a basis for further action, locally, nationally, and internationally.

In Australia, there are various formally recognised Indigenous bodies with different levels of authority for community decision making. As mentioned previously, some of these have

even developed their own community research approval processes. It is recommended that researchers receive endorsement from these bodies for their research as part of the ethics application process. However, this can be a lengthy process.

Different communities have specific cultural and community obligations that cannot always be easily understood or interpreted through mainstream institutions. Indigenous people also have dynamic interconnected community and cultural relationships influenced by lore, political history, kinship and family connection, and a range of other factors that are important considerations for any decision-making. Indigenous communities, and the cultural authorities mandated by them, must determine who is authorised to represent them and speak on their behalf. This is not often understood by mainstream institutions and researchers.

Most research institutions were unaware of complex Indigenous community political environments that were different for each region. Understanding community relationships and networks is vital for identifying appropriate Indigenous organisations to partner with. There are usually multiple Indigenous collective entities within a region, and sometimes there are competing interests and circumstances that muddy the waters for unaware external researchers aiming to establish Indigenous projects. Regional Indigenous priorities are sometimes aligned and sometimes disjointed with the intent of the research and it isn't always clear to outsiders which groups are able to authorise the research. It is not the role of researchers to establish who has the authority; this is up to communities to determine. However, researchers with established relationships within the community, logically are better placed to understand the community protocols of authority.

Indigenous peoples had inherent rights based on their ongoing spiritual, cultural, emotional, and physical connection to Country. These rights were underpinned by intricate cultural obligations passed down from generation to generation. Many Indigenous communities viewed and interpreted the ethical process from a cultural standpoint. The *guidelines* were broad enough to allow local (re)interpretation but the nuance of this in practice was often overlooked by researchers. Researchers were expected to respect cultural authority including elders, aunties and uncles, and acknowledged community leaders. Understanding and respecting kinship relationships was crucial for developing respectful relationships.

The development of overlapping multi-layered complex Indigenous approval processes has exasperated many researchers. National ethical clearances have been suggested by some to reduce administrative burden on researchers working across multiple sites and regions (Studdert et al., 2010). This issue demonstrates the tension between institutional and Indigenous approval systems. A national approval system potentially undermines local community protocols and decision making. I fear this approach would allow researchers to bypass appropriate engagement and approval processes with Indigenous communities in different regions. From my perspective respecting Indigenous community decision making processes is more important than reducing red tape.

Considering the structural forces described earlier in this thesis a multi-levelled approach is justified. Furthermore, multilayered approval processes through a rights based lens, preserves local and regional autonomy, and upholds their decision making rights. Independent Indigenous approval models are a necessary component for Indigenous structural forces to uphold Indigenous cultural and community obligations at different levels. These systems have also been recognised as critical for strengthening researchers' engagement with Indigenous communities. Local Indigenous research protocols translate and deconstruct ethical values into cultural practices for researchers to follow. Cultural 'message sticks' with messages carved with local designs informing you of the protocols of this Country.

Respecting cultural authority meant respecting Traditional Owners, recognised cultural bodies, and recognised community leaders. It meant respecting Indigenous cultural authorities and decision-making processes. Valuing and acknowledging contribution of Indigenous knowledge holders, especially elders. Respecting and understanding the diverse cultural protocols of Indigenous communities. Slowing down research to suit community timelines.

While they have a rich political history and have previously rightfully amplified Indigenous voices, in a modern context the nature, purpose, and responsibility of many Indigenous organisations have shifted to a service delivery model. Government funding strategies and changing policy environments have accelerated the transition of many Indigenous organisations from Indigenous political bodies to Indigenous service providers. Indigenous

community controlled organisations have rightfully adapted to ensure their survival through receiving government funding to sustain vital community services.

Native title has resulted in the formal establishment of Indigenous 'traditional owner' representative structures based on cultural heritage, and familial Connection to country. This has further complicated the Indigenous authorisation and approval landscape for researchers. There is now a large range of different bodies that represent Indigenous groups based on service delivery, cultural heritage, advocacy, all with different governing structures. However, traditional owner groups, or language groups, or nations are unique because of their inherent sovereign rights. Furthermore, the political landscape in Victoria (and some other states) has created opportunities for Indigenous communities to transform and clarify their Indigenous decision-making structures.

In contrast to community research approval processes, some institutions established formal semi-permanent Indigenous advisory groups to streamline internal research approval processes. How these groups were established was not examined in this study. The independence, cultural authority, and mandate of groups established within university hierarchical structures was questioned by Indigenous respondents in this study. This raises further questions about collective consent processes and approval for Indigenous health research.

In some circumstances Indigenous organisations established relationships with universities to support and guide Indigenous research programs. Community accountability mechanisms for groups established within institutions were not clear from this study. Approval for Indigenous health research within these mechanisms is contentious. It is important for both non-Indigenous and Indigenous stakeholders with interests in Indigenous health research to position themselves, academically and culturally, to ensure Indigenous communities can hold researchers, institutions, and organisations, accountable.

Institutionalisation of Indigenous decision-making has the potential to undermine the rights, interests, and self-determination of community mandated Indigenous bodies (such as Traditional Owner Groups or Indigenous peak representative bodies) and are at arm's length from community accountability mechanisms.

The concept of Indigeneity and how this relates to Indigenous health research is another issue. Indigenous researchers are complex, diverse, independent, united, cultural, technical, political, apolitical, scientific, and community grounded. Not every Indigenous researcher has the same protocols, authority, connections, and knowledge. There are common causes and some shared values to be certain however, we are also part of the academic system and the competitive environment. So Indigenous academics are motivated by different purposes. This is why positionality and reflexivity is important for Indigenous researchers too. When we locate ourselves in our research it becomes very clear who we are accountable to and what our cultural obligations are. Every Indigenous researcher has the autonomy and right to express their individual Indigenous perspective and worldview however an Indigenous researcher that is recognised, accepted, and obligated to a distinct Indigenous community should be recognised as community grounded researcher. The following proposed criteria (adapted from these findings) could be useful for Indigenous communities to define 'community grounded' researchers that belong to them:

1. *known to and belongs to an Indigenous community*;
2. *has been authorised to represent their Indigenous community*;
3. *has the recognised expertise to conduct Indigenous research on behalf of their Indigenous community*;
4. And *is socially and culturally obligated to their Indigenous community*.

Any Indigenous person can become a researcher and conduct research on any topic they choose but which Indigenous researchers have been given the authority and mandate by their community to represent them in the research sector. This is an important distinction that institutions and Indigenous communities should recognise.

To be clear I support Indigenous researchers, Indigenous academic excellence, and research capacity building. However, I also support the development of researchers grounded in Indigenous communities. Indigenous research capacity needs to be built within communities and not just within universities.

So institutions must prepare and understand the Indigenous community governance landscape. With the advice of Indigenous communities, institutions must respect Indigenous self-determination and consider how they attain appropriate Indigenous community approvals for research. Who has the right to speak for Country or has the authority to provide community approval potentially has multiple answers within multiple contexts intersecting

between traditional ownership, community control, and Indigenous institutional representation. Indigenous collective approval for research could be given by Indigenous community controlled organisations, Indigenous peak representative bodies, Recognised Aboriginal Parties (RAPs) or traditional owner groups, and Indigenous advisory groups amongst many other options. Respondents also noted that the level of community support for existing representative groups, where they exist can wax and wane depending on political and/or other circumstances. An understanding of these complex community relationships is usually required to create genuine community backed relationships. Independence and objectivity in Indigenous health research is multilayered and needs to be contextualised to demonstrate transparency and accountability.

Concepts of Indigenous approval, representation, authority are extremely complex due to historical, political, and modern factors. These factors need to be understood, or better yet explained by Indigenous communities and knowledge holders to navigate community decision making processes. Indigenous identity, cultural authority, and cultural protocols are interrelated concepts that are part of community collective decision making. There is an authorising environment, dependent on local cultural authority, that intersects with (and from an Indigenous community perspective supersedes) the ethical approval process. This a complicated additional process that requires specific knowledge of relevant cultural protocols for researchers to navigate.

### Community cultural reciprocal obligations

There are cultural obligations that Indigenous communities expect researchers to uphold. Specific community-designed cultural protocols, related to community cultural obligations and responsibilities that researchers are expected to adhere to. Researchers are expected to formalise their support from communities, and co-establish Indigenous advisory groups to ensure these protocols are followed.

In order to respect these protocols institutions had to relinquish some control over the research process, they had to value Indigenous knowledge, expertise, leadership, and decision-making, they had to modify their research according to cultural advice, and they had to align with community flows and timelines.

Being part of an Indigenous community means being part of a cultural accountability framework based on social obligations and relationships. Unwritten cultural obligations that sit underneath the formal structures in a community. Through their relationships non-Indigenous people can also become part of this community network and become bound by the same obligations.

Likewise, if universities want to do research with Indigenous communities they must adhere to relevant social community responsibilities. This is a system that has been practiced over generations, but that has also been adapted to the modern context. Indigenous communities used their organisations to uphold protocols in research and manage complex relationships with research institutions.

Researchers and their institutions need to be more aware of the research burden they are placing on communities and the potential harm this might have. The added burden of community expectations was not fully appreciated and supported by institutional mechanisms. Indigenous researchers and community facilitators carried an additional 'cultural load' when they were involved in research conducted within their own Indigenous communities. These community cultural obligations aren't fully captured within the ethical review process. They are practiced within the evolving relationship between researchers and Indigenous communities.

Indigenous academics risked their personal community credibility and relationships every time they conducted research. This burden on Indigenous research committee members,

Indigenous research partners, Indigenous community coordinators, and Indigenous researchers, is not adjusted or reviewed for within ethical bureaucratic processes. Nor is it adequately funded or accounted for by research funding bodies. This is an area that falls through the gaps when it comes to research funding.

Although incorporating important concepts and principles the NHMRC *guidelines* (2003, 2018) still largely framed ethics through a 'Western' lens. From an Indigenous perspective reciprocity takes on a deeper meaning. Responsibilities, obligations and exchange were core elements of a circular accountability framework that elevates the concept of reciprocity. In my tribe we have an important concept called 'kinaway'. In our Gunai Brabiralung Mukdhang language this means 'reciprocal exchange' (Thorpe). Therefore, any researchers wanting to do research on our Country or with our people will need to uphold this value according to Gunai people. The current system is not set up for the translation of the values from the Indigenous community that is being researched. Without this understanding how can researchers meet this obligation? Reciprocal obligations need to be understood before the research is carried out with participating Indigenous communities. Put simply, reciprocity is the circular concept of giving back what you take out. It means compensating for the time and resources taken out of Indigenous communities to monitor and guide your research, by reinvesting your time and resources into Indigenous community driven initiatives. It could be argued that reciprocity draws upon the fundamental principles of beneficence and doing research for the 'greater good'. Indigenous communities shared their time, resources, experience, and knowledge so there was an expectation for researchers to return and share the benefits of research. Impactful, relevant, applicable research was needed to produce reciprocal community benefits.

Similarly, dissemination and translation of research findings back to Indigenous communities was important to share the benefits of knowledge exchange. When Indigenous community research partners could utilise the findings of research it expanded their knowledge, strengthened their services, and created solutions. Some communities also received secondary benefits from capacity building activities done in conjunction with research projects.

## More than an advisory group

The concept of the 'Indigenous advisory group' needs to be broadened to encompass the range of Indigenous contributors providing guidance to researcher and universities including, traditional owner groups, organisations, leaders, 'community coordinators', and community members. Previously, the representative and decision making roles of these groups have been discussed. However, they also provide cultural advice, mentoring, specific expertise on different issues, cultural awareness, staffing (community coordinators for example), access to community networks, research design, and whatever else is required within the partnership. They also often provide infrastructure and administrative support to research that often goes unaccounted for.

Some Indigenous communities have developed their own research capacity to address the needs of researchers and research institutions. Community driven independent models for review and approval of Indigenous health research proposals were established so that Indigenous organisations could have some level of control over research in their communities.

The investment and the commitment to 'advising' research from some Indigenous organisations is significant. Indigenous models for ethical review, approval, and monitoring of researchers are largely self-funded, or rely on existing resources unrelated to research. Indigenous organisations have existing cultural, community, and organisational obligations. Time invested in guiding researchers is time taken from other priorities.

These findings show that Indigenous community advisory roles (including formal reference groups) are incredibly valuable for both Indigenous communities, and universities. Universities and researchers receive cultural advice and guidance. Indigenous communities get stronger cultural protection and accountability. However, the onus is often on Indigenous communities to setup advisory groups to protect the community and guide researchers. The question is where do they get the resources to do this?

In the research context I've identified Indigenous community coordinators as important facilitators of Indigenous health research. Indigenous community members were often recruited as community research coordinators to help navigate engagement and recruitment. However, their roles might be more accurately described as community messengers or

translators. The role of messenger is a familiar one, and was reserved for the most trusted and best communicators of the group:

Researchers relied heavily on Indigenous 'community coordinators' to develop ethical relationships with Indigenous communities. Indigenous community coordinators helped navigate cultural protocols, identified Indigenous research partners, and established relationships between research institutions and Indigenous communities. Indigenous community coordinators were known, trusted, and obligated to their community. Researchers might not realise it, but it is the cultural obligations and responsibilities of Indigenous community coordinators and their connection with associated Indigenous organisations or traditional owner groups that created the accountability framework that Indigenous communities trusted.

Indigenous community coordinators were akin to messengers and translators. Two-way messengers that communicated and translated between two worlds, the Indigenous world and the research world.

> *"**Messengers were important in the tribe, and were generally chosen because of their ability to speak more than one language**. When on a peaceful errand, such as when sent to invite another group to share food, or to a corroboree, only one was sent. But when a fighting message was to be delivered, two messengers were used, as they had to go through enemy territory, and could assist each other.*
>
> *…**Messengers had to follow certain rules**. They had to be painted with certain colours and in a certain manner, which indicated the nature of their message. **They had to travel openly, and not by stealth**, and their camp fires had to be smoky, to indicate their whereabouts, and that they came in peace. Otherwise they could be attacked.*
>
> ***When close to the camp to which they were sent they had to sit down with their back to it.** After some time two (E)lders from the camp would slowly approach them, and enquire the nature of the message. The messengers were then invited into the camp, and, if they had to stay overnight, food and shelter was given to them.*
>
> ***Messengers sometimes used message sticks**. These were small notched sticks, each notch representing a number or a message, and could only be read by the man who made them…*
>
> ***Smoke signals were also neither a code nor a secret language**. They simply indicated the whereabouts of a man or group, who wished the others to know where they were." Massola (1969, pp. 20-21)*

Cultural protocols maintain their relevance for Indigenous peoples in a modern context. They demonstrate consistent, ongoing values that have sustained Indigenous peoples for generations. These values are still practiced and upheld and have evolved and integrated into modern expressions of Indigenous representation and identity.

Indigenous advisory groups supported researchers before ethics approval, identified appropriate approval processes, provided community legitimacy and accountability, embedded Indigenous protocols, scrutinised and critiqued the research from an Indigenous standpoint, improved research design, and supported dissemination of the results back to the community.

In essence Indigenous advisory groups accountable to Indigenous communities were collective structures specifically designed to embed cultural protocols into the research process. They had responsibilities to ***protect*** their Indigenous communities, to translate, interpret, and communicate, and ***engage*** with their Indigenous communities, they informed researchers about specific ***cultural protocols***, and they advised on appropriate practices that sustained ***community cohesion***.

## The myth of objectivity and difference blindness

Knowledge can always be contextualised to provide a different perspective. Knowledge is created, shaped, curated, and constructed. Critical academic discourse about knowledge production in academic settings explore the role of researchers in the process of attaining knowledge. In the development of grounded theory opposing philosophical views emerged in relation to knowledge production. The original proponents of grounded theory integrated an objectivist epistemological approach which framed research as a process of discovery. Objectivism proposes that it is possible to discover an objective truth or reality (Charmaz, 2016). Prominent academics Strauss and Glaser (1967 cited in Charmaz, 2016) developed formulaic grounded theory methods that could be systematically applied to theoretically reveal an objective truth.

The second school of thought suggests researchers were an integral part of an "interpretive process" (Charmaz, 2006) and were not just passive bystanders. Constructivism challenged objectivist ideology and outlined a philosophical pragmatic approach to knowledge. Scholars such as Strauss, Corbin and Charmaz, advocated for constructivist approaches that reflected

on the role of researchers in the development of new knowledge. Charmaz in particular expanded on this philosophy in her constructive grounded theory methods (2006, 2014, 2016, 2017).

These opposing philosophies are often mirrored within academic institutional settings. Using constructivist methodology allowed further examination of dominant structures that continue to perpetuate epistemological philosophical methods that privilege Western knowledge systems.

Charmaz's 'constructive approach' to grounded theory posits that researchers and institutions contribute to the 'social construction' of knowledge. Charmaz takes a symbolic interactionist and Marxist position. She argues that processes within institutional structures are driven by the actions of individuals and believes institutions remain dominant because:

> "…people act in their routine actions to perpetuate them, and then structures get reified and treated as if they're lasting forever and people will act that way towards them" (Gibbs, 2013).

Just thinking about ethical research systems there are multiple structures where individuals actions determine institutional responses. Human research ethics committees and ethical advisory groups are just two examples where individual actions influence ethical research through institutional structures. The NHMRC have established guidelines and universities have created systems at multiple levels in response but all of these require individuals to action processes.

The concept of impartiality also invites further discourse in an Indigenous research context. For many, perhaps unfairly researchers invoke images of colonial settlers recording their field notes whilst observing the Aborigines. How can *outsiders* provide an unbiased perspective given the ongoing (colonial and post-colonial) paternalistic attitudes of universities? If we agree that reality is socially constructed at least to some degree, then researchers are in a powerful position to construct these realities.

This is problematic in Indigenous research because many researchers are susceptible to unconscious bias meaning they often contextualise and interpret findings from their own worldview. Moreton-Robinson (2017), through the concept of relationality defined as "the interpretive and epistemic scaffolding shaping and supporting Indigenous social research

and its standards are culturally specific and nuanced to the Indigenous researcher's standpoint and the cultural context of the research" (p.69), constructs an 'Indigenous social research paradigm' that arguably contests the 'reality' constructed by Western scientific methodologies. Moreton-Robinson argues for "producing knowledge through research in a given time, place and land" (2017, p.71). I interpret this to mean positioning ourselves as Indigenous researchers' in the context of our Country, our people, our kinships, our knowledge, and our lore. I would argue that the concept of the 'community grounded' researcher aligns with the notion of relationality.

In contrast, institutions exploit the notion that all researchers' critical analyses are unbiased to justify their independence. It also permits institutions to act with an heir of moral superiority and judgement. Researchers use this to uphold their position and justify their research approaches.

Let me be clear I strongly believe and endorse using quantitative methods of inquiry in Indigenous health research. These are valuable research tools in our arsenal to measure and quantify social health issues in Indigenous communities. I also believe knowledge is constructed through analysis, and is shaped by subjective decisions made by those who control the research.

Good researchers try to eliminate as many biases as possible. However they still exist in our subconscious. Researchers make mistakes, they are human, and researchers' are not just empty vessels. They have an important role to analyse, interpret, and translate the data. This process, driven by methodology and methods, presumably is unavoidably done through the researcher's worldview to some extent. Researchers are not just mindless drones processing information. Just like anyone else, they have feelings, thoughts, values, and beliefs that influence their analysis. If you believe in the premise that knowledge is 'constructed' then it is logical to suggest that researchers' have the most control over what is 'constructed'.

Likewise how can research institutions be completely independent and impartial? They are a collective of ideals, united in some areas and divided in others. They are microcosm of the ideas, thoughts, beliefs, values of our society. The pursuit of independent free thought is a core value of modern academia.

Though driven by formal structures designed to promote objectivity ethical review committees naturally lean on the expertise of its membership, and often those come from traditional research backgrounds. The inherent bias and privileging of certain disciplines affected the way ethical applications were reviewed. The HRECs assessed Indigenous health research proposals according to their specific area of research expertise. If we only consider technical research expertise, the interpretation of ethical values into research practice depends on researchers' disciplinary background along with their research methods. The ethical review system is inherently biased because it is predominately controlled by researchers from within the system. It is a self-regulated practice that relies on institutional accountability.

The critical discourse for impartiality in an Indigenous research context is incomplete. If we consider a symbolic interactionist position than most research analysis is influenced in some way by our positions, and by our actions and decisions as researchers. If we push this notion further than we could argue that the absence of Indigenous positions and worldviews from ethical systems has an influence over how those systems are operationalised within universities.

Indigenous communities hold their own positions and values that influence the way research is reviewed and conducted. Similar to criticism about perceived institutional conflicts of interest, some felt Indigenous organisations could be susceptible to conflicts of interest when it came to Indigenous health research within their communities. However, as we discussed earlier the notion of academic objectivity, within an institutional context, is also vexed within Indigenous health research settings.

As a Gunai, Yorta Yorta, Gunditjmara, Wurrundjeri Woi-wurrung man the answer seems simple; we each need to position ourselves in the research context with transparency and clearly articulate our objectives. We reflect on our cultural position and our institutional position and respective power and privilege. The notion of impartiality for Indigenous people in multiple interconnecting positions complicates approval, collective consent, and ethical review processes. We need to be honest and recognise that in Indigenous health research there is no impartial position, everything needs to be placed in context. These issues demonstrate that the idealistic concept of objectivity from an Indigenous standpoint is complex and arguably unattainable.

Reflexivity and positionality are important philosophical tools that should be considered as part of an ethical approach to Indigenous research (Guillemin & Gillam, 2004, Maclean et al., 2022, Moffat, 2016). These concepts prompt researchers to reflect on their personal privileges, biases, positions, and values.

Who determines what the greater good is when it comes to Indigenous health research? The endeavour to achieve the greater good is driven by the concept of utilitarianism. But can there be an objective greater good? What Indigenous communities believe is the most beneficial outcome for all would probably be vastly different to an institution's idea. This discussion about what it is, is rarely thought about in ethical review settings. Yet, the uncompromising struggle of academia to achieve outcomes that have broad universal benefit fail to reflect current societal inequities. In an Indigenous context we need to adapt our approach to address current power imbalances and consider aspirational objectives that are specific to Indigenous peoples. Research can no longer use the utilitarianism argument to justify their research if their research fails to consider how tangible outcomes address the inequalities that Indigenous communities face.

### Knowledge production, Indigenous data, and Indigenous knowledges

Ownership and control of Indigenous health research knowledge was contested between Indigenous communities and academic institutions. Agreements about data ownership between researchers and communities seemed to be non-existent. There was a struggle over ownership of knowledge that emerged from Indigenous health research. However, this is rarely acknowledged or addressed and is sometimes blatantly ignored by those who have control over research. There are issues with the translation and handover phases of knowledge production. Outcomes of research are often not reported back to communities in a way that satisfies their expectations as Indigenous knowledge holders and contributors to research.

The fight for control over 'Indigenous' data through research created tension between traditionally dominant institutions and Indigenous communities. There has been a global movement towards Indigenous data sovereignty lead by Indigenous scholars in Australia, New Zealand, Canada, and North America (Kukutai & Taylor, 2016). This has also resulted in numerous principles focused on Indigenous data governance and Indigenous data sovereignty (Kukutai & Taylor, 2023, Te Mana Raraunga, 2018, Carroll et al., 2020).

There was a perception that institutions 'take Indigenous knowledge' without giving anything back. When institutions and universities restricted access to Indigenous knowledge and data it reinforced power imbalances and demonstrated the power structural institutions have over Indigenous knowledge and data. .Gatekeeping of knowledge directly conflicts with Indigenous cultural values of exchange and inhibits equitable benefits for Indigenous people that have contributed to the attainment of academic knowledge. Ironically an Indigenous community that may have contributed to research may not be able to access the findings of that same research. The systems restricting access to Indigenous knowledge are clearly a barrier for the ethical production of Indigenous knowledge. It becomes a story about us without us.

Indigenous knowledge is intrinsically important to the identity of Indigenous people, but it also has academic value. Indigenous health research has been used to collect Indigenous data and knowledges to build Institutional 'cultural capital'. Without protection Indigenous knowledge can be taken, controlled, misinterpreted, and exploited with impunity. The institutional hunger for Indigenous knowledge and 'picking brains' has not waned, so it is easy to understand why Indigenous people are so protective of their stories.

From an Indigenous standpoint our knowledge is our story. Our knowledge is who we are. It is our law and ceremony. It's our identity, our language, our songlines, our kinship, and our totems. It is in our Country, and it's in our people. It is not only cultural, it is political, historical, intellectual, generational, and experiential. It is our struggle. Knowledge is passed down from generation to generation. And if our people and our nations are to survive that's how it will always be. You can never take our voice. Because at the end of the day only we can tell our stories.

Some institutions still try to control Indigenous knowledge. Sometimes our story gets told without us. Researchers translated and interpreted and analysed results from Indigenous health research through a 'Western' theoretical framework. Institutional interpretation of research sometimes obscured Indigenous community perspectives. Indigenous communities have been subjected to years of being observed and studied by institutions (Burchill, 2023, Hawkes et al, 2017, Humphrey, 2001, VicHealth Koori Health Research and Community Development Unit, 2000). An historical pattern of dominant academic institutions studying Indigenous people and taking Indigenous knowledge has overwhelmingly privileged an outsider's perception of Indigenous people. It is part of a colonial legacy that has twisted

Indigenous knowledge through a non-Indigenous worldview. Maybe Indigenous research is a white thing?

> *"**Because for years they've been taking our, taking our knowledge and that, but they're not giving back.** So everything written about us is what we're still considered, perceived in this day and age. And, yeah, we're still way back there. And we're uncivilised, and all that c…p. So that's why we need to take more. …**a lot of 'em just want their name on our knowledge." Community coordinator***

Academic publishing, research funding, and university research metrics, fuels the collection and consumption of Indigenous data (content). These components of the machine, that is the academy, are part of an embedded paternalistic structure designed to consume, absorb, create, and (re)interpret knowledge. Some journals have further commercialised knowledge by charging fees. This is a barrier for access for many Indigenous people. It is clearly unethical to submit Indigenous health research to journals that restrict access using paywalls. Is academic publishing and the peer review system broken for groups that aren't represented within the dominant structures? Indigenous academics are still underrepresented, community researchers even more so. Community led knowledge production and reporting is one method that's been used to get around this issue.

There is a deep-rooted difference in the way Indigenous and non-Indigenous people value knowledge. Academic publication is a *'Western'* way of valuing knowledge, constructed by western values. Lack of Indigenous interpretation of results impacts the quality, and accuracy dependability of the research analysis.

Clear boundaries of ownership and control of data need to be outlined in any research agreements to protect the rights of Indigenous communities that contribute to research. Agreements need to consider current roles of different parties and be prepared for potential future roles where data and/or tools developed through research might be used.

Principles of Indigenous data sovereignty (IDS) also emerged when discussing how Indigenous knowledge was controlled within a research context. The concept of Indigenous data sovereignty aims to reposition how knowledge is valued and controlled within institutions (Maiam nayri Wingara Indigenous Data Sovereignty Collective, 2018). In Australia, the

Indigenous peoples globally have been tackling the issue of Indigenous data and developed frameworks for agreement making comprising custodial type arrangements for Indigenous

data (Kukutai et al., 2023, Kukutai & Taylor, 2016, Te Mana Raraunga, 2018, Carroll et al., 2020). The principles of ownership, control, access, and possession (OCAP) of Indigenous data could inform regional strategies for Indigenous communities that help provide a solution to this issue (First Nations Centre, 2005, 2007, Assembly of First Nations, 2007). Institutions will need to consider principles of Indigenous data ownership and implications for their data collection, management, and storage systems. The Indigenous data sovereignty movement within Indigenous communities is only getting stronger and the concepts within it have gained traction beyond the research sector. Governments, museums,, archives, libraries and other institutes that hold Indigenous items, data, or knowledge, must also be prepared to negotiate shared control, access, and ownership with Indigenous communities. Indigenous communities that contribute knowledge to universities deserve to benefit from the knowledge economy.

Indigenous intellectual property rights is an element of data collection and knowledge production that requires further examination (Janke, 2005). In Australia issues over ownership of individual and collective cultural and intellectual property rights are largely untested. There has been complex context-specific arrangements and an inconsistent application of data sovereignty principles in research agreements between universities and Indigenous communities. This has resulted in a lack of a shared understanding about data sovereignty ethics and how they should be applied in Indigenous health research.

Indigenous data sovereignty movement seems to be predominately located within academia. I have reservations about this given the history of research and the colonial history of dispossession. Indigenous traditional owner groups and cultural authorities (Indigenous knowledges) and Indigenous community controlled organisations (Indigenous data) need to be more involved in the discourse around IDS and IDG to strengthen the legitimacy of its arguments.

### Evaluation and revision of the 2003 NHMRC Guidelines

In 2013, the National Health and Medical Research Council commissioned an evaluation of the Values and Ethics Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003) and Keeping Research on Track (2005) companion document. The evaluation was conducted by the Lowitja Institute in collaboration with the Australian Institute for Aboriginal and Torres Strait Islander Studies.

A key objective of the evaluation was to provide advice on improving the guidelines effectiveness by scrutinising how they were applied in practice (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute). Another broader agenda of the evaluation was to align ethical guidelines with the Australian Code of Ethics (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute). The evaluation involved a comprehensive literature review (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, 2013), extensive community consultation, community workshops, and a survey (National Health and Medical Research Council, 2024a).

The evaluation found "lack of awareness" of both guidelines a recurring theme. (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, p7). The report also revealed 80 per cent of researchers referred to both guidelines (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute). The majority of survey respondents were researchers' and administrators' with only 6.5 per cent (n=15) of respondents identifying as Indigenous (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute). The evaluation did not collect evidence about how researchers applied ethics in practice (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute).

Despite these apparent limitations the sanctions suggested by the evaluators were comprehensive and consistent with previous critiques of Indigenous ethical research processes in Australia (Humphrey 2001, Anderson et al., 2003, Dunbar & Scrimgeour 2005, Henry et al. 2004).

The evaluation resulted in four key recommendations in relation to; revision of the documents; training for stakeholders (including the Indigenous community, HRECs; and researchers); HREC assessment and monitoring; targeted dissemination strategies to increase awareness amongst researchers (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute).

Most notably, the evaluation recommended the establishment of Indigenous specific HRECs in each jurisdiction empowered to monitor community engagement and approval processes outlined through the ethics process. It also suggested the inclusion of 'partnership' as an

additional value of ‘partnership’ (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute).

In 2015, the Indigenous Research Ethics Guidelines (IREG) working group was established by the NHMRC to revise the two guidelines in consideration of the findings of the evaluation (National Health and Medical Research Council, 2024a). In 2017, draft revised guidelines were released for a three month public consultation period. The draft suggested two changes to the core values. Firstly, the core value of ‘equality’ to be replaced with the value of ‘equity’. Secondly, for the value of ‘survival and protection’ to be swapped with ‘cultural continuity’. No other changes to the core values were suggested. Following extensive community feedback the revised guidelines were recommended for release by the Australian Health Ethics Committee (AHEC) in March 2018 (National Health and Medical Research Council, 2024a).

The updated guidelines (National Health and Medical Research Council, 2018) continue to be critically relevant and are pertinent for all Indigenous health research conducted in Australia. However, in my assessment, publication of the revised NHMRC guidelines (2018) only partially met the recommendations of the evaluation. The NHMRC administered a rigourous process to update the guidelines to ensure they maintained relevance and arguably, addressed aims to provide consistency of ethical review of research across institutions through better alignment with other ethical guidelines.

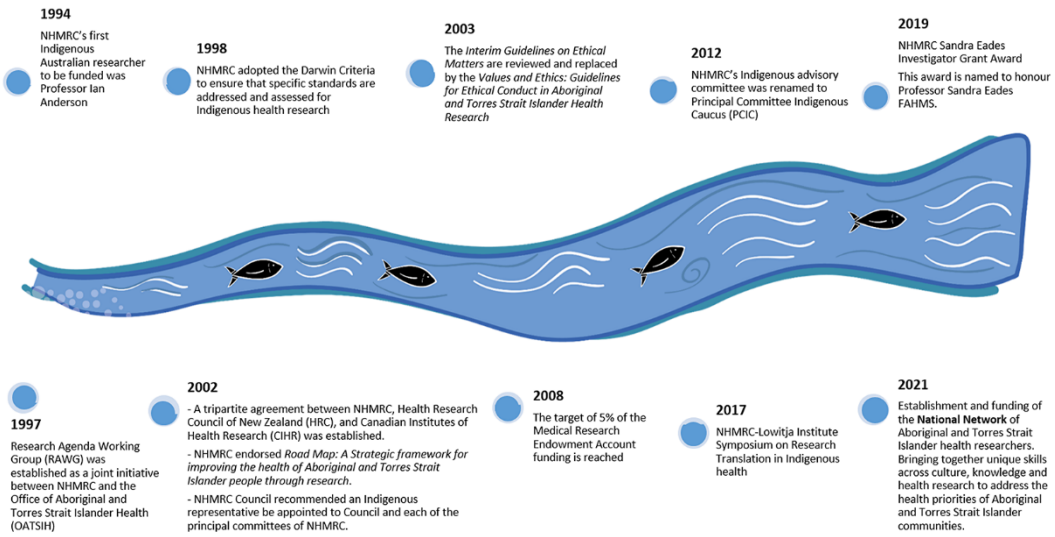
The evaluation revealed that over 50 per cent of survey respondents required a better understanding of how HRECs monitored Aboriginal health research (Australian Institute for Aboriginal and Torres Strait Islander Studies & The Lowitja Institute).

Significantly, it is as yet unclear if recommendations for the establishment of Indigenous HRECs to improve monitoring and assessment of Indigenous health research have been progressed by the NHMRC. Clear advice about how to strengthen monitoring and assessment was provided and included specific recommendations to support the establishment of Indigenous specific HRECs in every jurisdiction that did not already have one, develop a function to enable continuous monitoring of ethical research practice in HREC annual reports, and importantly the establishment of a community based research fund.

As of May 2023, only half of the states and territories in Australia (ACT, NSW, SA, and WA) had HREC's that specialised in the review of Indigenous health research (2024b). According to the NHMRC's latest report (2022b) only half (n=90) of the HRECs considering new research reportedly considered Indigenous health research proposals, with 94 per cent referring to the updated 2018 guidelines. Refining the definition of Indigenous research and examining what is meant by "involving Aboriginal and Torres Strait Islander peoples" could arguably provide a more nuanced understanding of appropriate implementation of the guidelines by HRECs.

There has been a steady development of Indigenous research leadership with several NHMRC funded initiatives and programs designed to build research capacity (see Figure). A national Indigenous researcher network and a national Indigenous research caucus are two key strategies supported by the NHMRC. The OCHRe national researcher network is a forum for sharing skills and knowledge and is led by prominent Indigenous academics supports collaborative opportunities (National Health and Medical Research Council, 2022a). The Principle Committee Indigenous Caucus (established in 2012) provides advice to the NHMRC Indigenous health research

*Figure 17 NHMRC Indigenous health research timeline of achievements from 1994 to 2021*

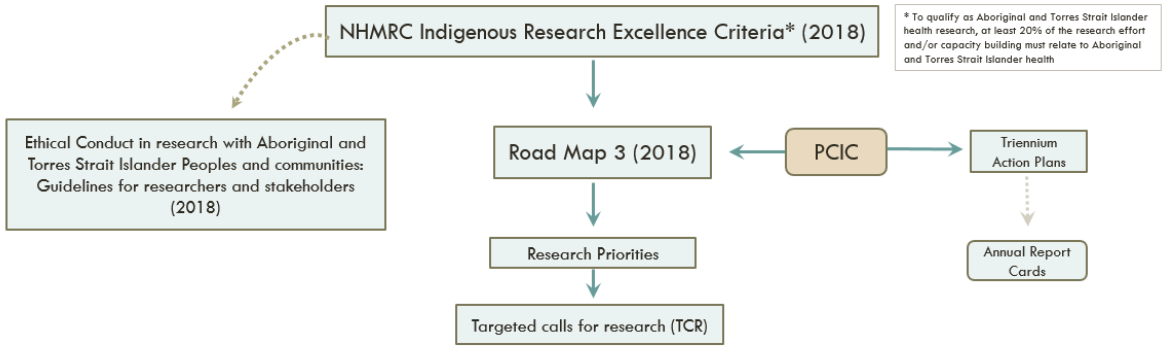



*Note 6 From https://www.nhmrc.gov.au/health-advice/aboriginal-and-torres-strait-islander-health/road-map-3*

NHMRC Indigenous health research funding rules are underpinned by the Road Map 3, a strategic framework for Indigenous health research that outlines the national Indigenous health research agenda (National Health and Medical Research Council, 2018d). The NHMRC

also have four criteria for research excellence built into the funding rules health research, community engagement, benefit, sustainability and transferability, and building capacity. Road Map 3 includes strategies dedicated to strengthening the capacity of Indigenous researchers. Notable key actions identified in the 2018-2021 action plan (National Health and Medical Research Council, 2018) included the implementation of a peer review program that evaluates the leadership and impact track records of researchers involved in Indigenous health research. The NHMRC (2023a) recently announced a review of their Indigenous Research Excellence Criteria (IREC). The IREC is relevant for NHMRC targeted calls for research in relation to Indigenous health research (see Figure 18).

*Figure 18 NHMRC Indigenous research excellence criteria*




*Note 1 Adapted from NHMRC (2023a)*

The NHMRC reported that in 2022 over 66 million dollars had been spent on Indigenous health research (2022a). Half of the Indigenous health research grants were dedicated to public health. More than a third of active Indigenous health research grants were led by Indigenous researchers (NHMRC, 2022a). The NHMRC roadmap holds targeted calls for Indigenous research.

The National Statement on Ethical Conduct in Human Research was also recently revised (2023b). The statement reiterates the importance of community engagement and cautions against overburdening Indigenous communities with research demands. The statement identified the issue of ethics review duplication but acknowledged that research with Aboriginal communities sometimes required specialised ethical review. Researcher and institutional integrity and accountability were core elements of the statement.

The updated national statement focuses on additional values such as 'justice' and 'beneficence' which aim to ensure researchers "provide fair opportunity for involvement and of Aboriginal and Torres Strait Islander Peoples" (2023b, p. 80) and research benefits enhance "capabilities, opportunities or research outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples" (2023b, p. 81). The statement clearly states that researchers involved in national, or multi-centred research seek local support to ensure their methods respect local cultural protocols.

In relation to HREC review of Indigenous health research the national statement specifically asserts that advice is sought from "people who have networks with Aboriginal and Torres Strait Islander Peoples and/or knowledge of research with Aboriginal and Torres Strait Islander Peoples; and people familiar with the culture and practices of the Aboriginal and Torres Strait Islander people with whom participation in the research will be discussed" (2023b, p. 80).

Interestingly, thirteen (13) HRECs were supported by institutionally based advisory groups, thirteen (13) were supported by external advisory groups, and fourteen (14) used other mechanisms that included advice from Indigenous HREC members or from HRECs specifically focused on Indigenous health research (see Figure 19).

*Figure 19 Mechanisms used by HRECs for the review of health research proposals involving Indigenous peoples*

*Note 7 Adapted from "Report on the Activity of Human Research Ethics Committees and Certified Institutions" by NHMRC, 2022, p. 14*

My findings presented throughout this thesis align with many of the findings in the evaluation. Including key themes such as monitoring and evaluation, training, and capacity building. My findings include additional information about the intersection between Indigenous ethics, and the role of Indigenous communities in supporting ethical research practices in their

communities. Of some concern, from the account of some participants, researchers strategically avoided the additional Indigenous guidelines through various methods. This issue should warrant further investigation and consideration.

Other scholars have attempted to measure the development of Indigenous health research, or scrutinise the effectiveness of the guidelines in other ways (Burchill et al., 2023, Duke et al., 2021). In 2023, a research group comprising prominent Indigenous academics published a protocol for a study to examine the implementation of Indigenous health research ethics through a mixed methods design (McGuffog et al).

However, the focus on Indigenous peoples' experiences of researchers' implementation of ethical practices gives this study a unique insight. The findings disclose specific issues that possibly could have only been revealed through this study design. I argue that this research complements and provides further nuances to the previous evaluation. Future review of the guidelines could combine elements of the previous evaluations with the in depth qualitative research approach of this study.

## Summary: Discussion

In summary, I argue that we can no longer rely on ethical guidelines to ensure that researchers are ethical in indigenous research. We need to ensure the research institutions such as universities are transformed to create the conditions in which ethical research occurs. Institutions must relinquish their structural power and privilege to empower Indigenous communities within the research process.

The *guidelines* are open to interpretation by researchers, institutions, funding bodies and Indigenous communities. This study found that researchers avoided the high risk review required for Indigenous health research proposals. Some researchers exploited administrative loopholes and stretched ethical approvals via the amendments process. Others demonstrated unethical practices in their research.

However, researchers also became trusted allies of Indigenous communities by developing authentic relationships based on shared understanding of cultural and academic obligations. The concept of reciprocal obligations underpinned the development of strong research partnerships between researchers and Indigenous communities. These were identified as fundamental principles for establishing equal partnerships.

This study aimed to better understand the role of Indigenous communities in ensuring researchers complied with the *guidelines* in their research activities. The cultural interface revealed the tensions in the contested ethical spaces between academic institutions and Indigenous communities. Indigenous community coordinators, Indigenous researchers, and Indigenous research advisory groups, are active within the cultural interface to ensure ethical research in Indigenous communities. Indigenous communities guide researchers through complex Indigenous community review and approval pathways.

Models of community-controlled Indigenous research governance have been established for approving research and monitoring researchers independently of the research sector. Some Indigenous organisations established research specific committees to manage and assess research requests.

The *guidelines* were (re)interpreted from an Indigenous standpoint. Relationships were put into a relationality context to better describe the community and cultural obligations researchers were expected to uphold. 'Kinaway' the concept of 'reciprocal exchange' was

defined through Gunai Brabiralung Mukdhang language. Indigenous cultural authority, identity, representation and approval processes were complex and multilayered.

Ethical standards are expected but not resourced. However, when universities commit to collaboration, co-design, and community research capacity development it creates opportunities for a shared understanding of ethical standards in both worlds.

There is an opportunity to further embed Indigenous research leadership within Indigenous communities by investing in community-driven research agendas, based on connection to place and Country. There is enormous potential for Indigenous communities to lead health research initiatives, provided they are given appropriate opportunities, resources, and support. The transformation of Indigenous governance models through various opportunities for Indigenous self-determination in different jurisdictions requires consideration in the development of future Indigenous research priorities.

The implications of this analysis is that we can no longer rely on just ethics committees and the use of Indigenous ethics guidelines to enable ethical practice in Indigenous communities. We need to transform universities and research institutes to create the conditions in which researchers can behave ethically, and to empower Indigenous communities to conduct their own research.

# *Kut bun: Our cultural obligations*

*I was introduced to research by my Aunty Lisa Thorpe. She is a true grassroots community researcher. She was influential in driving (creating) the community research agenda at the Victorian Aboriginal Health Service (VAHS) in the mid to late 90s that resulted in some ground breaking community-led research.*

*A lot of my values came from my experience working at the health service. It is here where I first learnt about ethics. Aunty Lisa was a staunch believer in community control and viewed the ethical review process as the way to achieve this in some small way. VAHS must have been one of the first blackfella health services that even entertained the idea of research.*

*I had grown up in a special environment where research was a tool. The health service was way ahead of its time.*

*I chose this topic because I had seen my community deal with ethical issues for a long time. I could see the correlation with our cultural obligations. But they are not the same.*

*Our cultural obligations are relational, deeply connected to place, layered with responsibilities to our family, and our community.*

*But there has been a lot of progress. Not even I can deny that.*

*However, this has not been an easy journey for me. In some ways I feel like this is the end of my career not the beginning.*

*It is not easy within these systems to hold on to your cultural values. But I hope that this work will contribute in some way to shifting the system to recognise our obligations…*

*This thesis was written; in the car; during my family holiday; on multiple writers retreats with blakademics; after the kids were asleep; after a research project was finished; after sitting on a HREC; after sorry business and healing; during the teaching block; in a First Peoples Assembly Chamber (where the decisions are made!); on my Country…*

## Chapter eighteen: Strengths and limitations of the research

This qualitative research presents a critical analysis of the ethical research practices concerning Indigenous health research projects and the role of Indigenous communities in ensuring compliance. In summary this research strengths are its privileging of Indigenous experiences, the innovative methodological approach, and the implications of the research.

**Below are the key strengths:**

This research used critical-race grounded methodology, an innovative methodological approach that combined critical race theory (CRT) with grounded theory (GT), providing a robust lens through which Indigenous ethical considerations are examined. The inclusion of an Indigenous conceptual framework using Indigenous standpoint theory privileged an Indigenous worldview. Experiential knowledge is central to both CRT and Indigenous standpoint theory.

Conditional Matrices and the Cultural Interface: The use of conditional matrices and the cultural interface for critical data analysis supported examination of the structural forces, conditions affecting Indigenous ethical at the cultural interface. These diagrams are visual tools for representing the intersections between different levels.

This research provides clear recommendations for improving Indigenous health research ethics, including the development of Community Controlled Regional Research Plans, increasing Indigenous membership on Human Research Ethics Committees (HRECs), and incorporating Indigenous community ethical review into research funding models.

Given the sensitive nature of this topic a high level of trust was required between the participants and the researcher. The transparent and honest experiential accounts from participants demonstrate that trust was present.

**Potential limitations** of this study are acknowledged and are identified below:

The use of semi-structured interviews as a method could be identified as a limitation. In hindsight I would suggest use of Yarning or deep listening.

The use of CRT in methodology comes with some methodological queries about its relevance in an Australian context. Indigenous institutional framework theory is a suggested

alternative for examining 'Western' institutions from an Indigenous perspective (Coates et al., 2022)

Due to the nature of this topic Indigenous people involved as participants in this study might have been more inclined to discuss negative experiences they've had with past research projects.

The research includes a limited number of past participants of Indigenous health research projects and only had participants from Victoria and New South Wales. The experiences of a broader participant pool, particularly from regional and remote jurisdictions, might offer different insights.

The inclusion of three non-Indigenous researchers may slightly dilute the findings. The methodological approach and methods for data analysis mitigated against this. Further research with non-Indigenous researchers would be a valuable to increase understanding about ethical practices with Indigenous communities.

## Chapter nineteen: Major contribution to further knowledge

This research reveals opportunities for structural reform and transformation for the academic sector, and for the empowerment of Indigenous communities within the Indigenous research sector. These are:

Innovative mixed methodology (Decol, IST, CRT, GT, CRGM) for potential application for Indigenous research on broader social structures.

Original critical race-grounded analytical approach using mixed methods, cultural interface model, semi-structured interviews, conditional matrices, theoretical sampling, and adapted collaboration method.

Recommendations for adaption might include yarning as a substitute for semi-structured interviews, potentially adapt conditional matrices with other Indigenous conceptual models such as Dudgeon, or Indigenous knowledge frameworks.

Suggested best practice model transform ethics from principles framework to best practice:

**Universities**

**To Indigenous communities**

- Affirms the role Indigenous communities should play and suggest ways they could strengthen their control over research
- Acknowledges the leadership Indigenous communities and Indigenous researchers with current bureaucratically administered ethical review structures
- Reveals the mentoring and brokering role of Indigenous organisations and Indigenous community advisors, and Indigenous researchers
- Identifies the significant contribution of Indigenous communities to research through academic leadership, cultural leadership,
- The dichotomy between Indigenous and non-Indigenous cultural ethical standards
- Acknowledges that community-led ethical review and research approval models protect Indigenous communities and provide advice and guidance to academic researchers

- Recognise the potential research impact of strengthened community-led and controlled research in collaboration with research institutions

**Implications for further research**

- Development of HREC training for researchers
- Implications beyond Australia. These findings are relevant to the Australian context but they could possibly have relevance in international contexts. Opportunities for international collaboration and knowledge exchange with Maori in Aoteroa, Canadian first peoples, and Metis first nations. Could have particular significance for jurisdictions with Indigenous or colonial-settler populations
- The research could be adapted to contribute to a review of the current ethical guidelines

**Funding gaps**

- Resources for communities to facilitate implementation of ethical practices
- Indigenous organisational research committees
- Indigenous research reference groups
- Indigenous community-based research coordinators or advisors
- Structural problem for achieving research impact and benefit.
- For Indigenous communities to implement the findings of relevant research

## Chapter twenty: Conclusion

In this research from an Indigenous standpoint, I applied critical-race grounded methodology to examine how researchers implemented Indigenous ethical *guidelines* into research practice and better understand the role of Indigenous communities in ensuring ethical research.

Three crucial methods were applied; theoretical sampling; conditional matrices; and collaboration. The data collection involved semi-structured interviews with Indigenous past participants, community coordinators, and researchers (Indigenous and non-Indigenous) involved in Indigenous health research. In addition, I used journaling through an aide-mémoire to reflect on my own experiences as an Indigenous man, an Indigenous researcher, and a previous member of several HRECs. This data informed critical analysis of the broader social structures that influenced the practical implementation of ethical Indigenous health research. Finally, the concept of the 'cultural interface', the seminal work of Nakata (2002, 2007a), was used as an analytical tool to examine the structural forces (Indigenous and institutional) impacting on the ethical research practices in research involving Indigenous communities.

The findings revealed the structural barriers and enablers for 'ethical' Indigenous health research and the challenges of complying with ethics through two different worldviews. Through the application of Indigenous standpoint theory this research provides a better understanding of the complex structural conditions related to Indigenous ethical processes that exist at the cultural interface between Indigenous and institutional systems. The *Indigenous ethics at the cultural interface* model demonstrates the important role that Indigenous community coordinators or brokers can play to support outside academics to conduct ethical research in Indigenous communities.

The findings also provide some indicators for Indigenous ethical research best practices, and creating culturally safe research spaces. Indigenous communities were recognised for independently, and institutionally, providing cultural guidance and advice on behalf of their communities, and models of community-controlled Indigenous research governance were also identified.

Despite the lack of Indigenous representation on university HRECs, the potential for Indigenous people to participate in formal ethical review of research existed.

Increasingly, Indigenous research advocacy, capacity building, and academic leadership from both within the academy and within the Indigenous community is being established. These entities have the potential to develop and implement a vast array of strategies, programs, initiatives and resources designed to improve the efficacy of Indigenous health research.

The ongoing support and commitment (financial and otherwise) through the NHMRC has contributed to significant progress in Indigenous health research over the last few decades. We are arguably nearing a critical mass of Indigenous researchers that could support transformation of the research sector. This must continue in order to elevate and redefine 'ethical' standards for Indigenous health research.

From an ethical standpoint Indigenous research would ideally be designed, funded, ethically reviewed, conducted, by researchers endorsed and trusted by Indigenous communities. Collaborative approaches with a non-Indigenous research sector vastly experienced in Indigenous health research is still of value and critical importance. Yet, as Indigenous research capacity grows, especially at the community level, more opportunities arise for Indigenous health research projects to be driven by local communities.

In my final summation I initially considered detailed recommendations for various components of the ethical research systems, for both Indigenous communities and institutions. However, this would have only fuelled incremental changes. Also, the objective of this research was to tackle the structural issues. To do that requires fundamental transformation. To that end I propose the following recommendations:

**Universities should:**

- Transform *guidelines* from principles into best practice framework.
- Support the development of 'community grounded' researchers.
- Negotiate research agreements with Indigenous communities based on the concept of 'kinaway' to set the 'reciprocal obligations' for their partnerships.
- Support Indigenous communities to develop 'whole of community' research plans.

- Develop stronger relationships with Indigenous community-controlled health services and Indigenous research organisations (such as the Lowitja Institute).
- Invest in the development of Indigenous leadership in research both in the university executive and in research teams.
- Foster leadership in Indigenous research ethics across its ethics systems.
- Support the development of research leadership and capacity in Indigenous communities and Indigenous community-controlled sector on research and ethical practice in research.

**Funders should:**

- Establish requirements for recipients of Indigenous health research grants to undertake ethical review with certified independent Indigenous community-led ethics committees.
- Establish additional Indigenous TCR rounds at the state level to complement national research targets.
- Establish funding programs that support the development of long term equitable research relationships between Indigenous communities and researchers.
- Continue to invest both financial and through continuing education, in Indigenous community research capacity building programs
- Additional allocation of resources within research grants to support community involvement in research, and for determining local priorities.
- Mandate formal research agreements with Indigenous community partners.
- Develop regional approaches for identifying Indigenous research priorities and targeted calls for research to reflect the diversity of Indigenous peoples.
- Dedicated funding for Indigenous communities to implement the findings of Indigenous health research

**Indigenous communities should:**

- Determine research priorities through regional coordination and planning (with the support of funding).
- Continue to build community capacity to undertake research and strengthen collaboration between Indigenous researchers and Indigenous communities.
- Identify Universities and Institutions with proven track records for Indigenous health research.

**General:**

- Support development of ethical research models that are truly collaborative and respectful of Indigenous sovereignty and knowledge systems.
- Continue to explore the development and implementation of a decolonising approach to ethics in Indigenous health research.
- Call for a renewed commitment to respecting, valuing, and investing in Indigenous knowledge and leadership in research.

## *How a young fella named Boondjil Noorook discovered Captain Cook*

*"Early one morning, a young fella named Boondjil Noorook was out spearing seals to get some ngulli [meat] for his family when he heard a big noise out in the ocean. Boom, boom, boom. Before long he spotted something strange, what looked like a big canoe with white wings on it coming in towards the coast.*

*Well, that was the Endeavour with Lieutenant Cook, later known as Captain Cook. This is when the Endeavour was coming from New Zealand and they were heading straight for Gunai country, the south-eastern parts of Australia, and doing the soundings with the ship's cannon.*

*Boom, Boom, Boom.*

*Boondjil Noorook spotted them out there and it looked like trouble. He went back to his elders and told them about it, what he'd seen. They said to him, "Send a smoke signal and a song and forewarn all the people up along the coast." The south-westerlies were blowing fairly strong and the Endeavour was turning up along the east coast.*

*So, this is a story about Boondjil Noorook discovering Cook."*

*Uncle 'Watbalimba' Wayne Thorpe (2022)*

*Figure 20 Gunai Elder Uncle 'Watbalimba' Wayne Thorpe with dancers*

*Note 2 From The Age. Copyright 2022. Justin McManus.*

# References


Aboriginal Health & Medical Research Council. (2023). *NSW Aboriginal Health Ethics Guidelines: Key Principles*.

Aboriginal Health & Medical Research Council Ethics Committee. (2013). *AH&MRC Guidelines for Research into Aboriginal Health: Key Principles*. Aboriginal Health & Medical Research Council of New South Wales.

American Indian Law Center. (1999). *Model Tribal Research Code. With Materials for Tribal Regulation for Research and Checklist for Indian Health Boards*.

Anderson, I., Griew, R., & McAullay, D. (2003). Ethics Guidelines, Health Research and Indigenous Australians. *New Zealand Bioethics Journal*.

Anderson, P. (2017, 21 March). Things have got to change. AIATSIS National Indigenous Research Conference, Canberra.

Annas, G. J., & Grodin, M. A. (1992). *The Nazi doctors and the Nuremberg Code : human rights in human experimentation* [Bibliographies, Non-fiction]. Oxford University Press.

Aristotle. (2009). *Nicomachean Ethics* (W.D Ross, Trans.). Oxford University Press.

Arnstein, S. (1969). A Ladder Of Citizen Participation. *Journal of the American Planning Association*, *35*(4), 216.

Assembly of First Nations. (2007). *O.C.A.P. Ownership, Control, Access and Possession. First Nations Inherent Right to Govern First Nations Data*.

Assembly of First Nations. (2009). *Ethics in First Nations Research*

Australian Bureau of Statistics. (2013). *Information Paper: Perspectives on Aboriginal and Torres Strait Islander Identification in Selected Data Collection Contexts*.

Australian Government. (2024). *About the CATSI Act*. https://www.oric.gov.au/catsi-act/about-catsi-act

Australian Institute for Aboriginal and Torres Strait Islander Studies. (1999). *Research of Interest to Aboriginal and Torres Strait Islander Peoples*. Canberra Commonwealth of Australia

Australian Institute for Aboriginal and Torres Strait Islander Studies. (2012). *Guidelines for Ethical Research in Australian Indigenous Studies* (Revised Second Edition, Issue. Australian Institute for Aboriginal and Torres Strait Islander Studies.

Australian Institute for Aboriginal and Torres Strait Islander Studies, & The Lowitja Institute. *Evaluation of the National Health and Medical Research Council Documents: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health research 2003 (Values and Ethics) And Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005 (Keeping Research on Track)*.

Australian Institute for Aboriginal and Torres Strait Islander Studies, & The Lowitja Institute. (2013). *Researching Right Way. Aboriginal and Torres Strait Islander Health Research Ethics: a Domestic and International Review*.

Australian Institute of Aboriginal Torres Strait Islander Studies. (2020). AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research. In *Canberra: Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), October 2020.* Canberra: Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).

Bainbridge, R., Tsey, K., Brown, C., McCalman, J., Cadet-James, Y., Margolis, S., & Ypinazar, V. (2013). Coming to an ethics of research practice in a remote Aboriginal Australian community. *Contemporary Nurse*, *46*(1), 18-27.

Bargallie, D. (2020). *Unmasking the racial contract: Indigenous voices on racism in the Australian Public Service*. Aboriginal Studies Press.

Bargallie, D., & Lentin, A. (2021). Beyond convergence and divergence: Towards a 'both and' approach to critical race and critical Indigenous studies in Australia. *Current Sociology*, *70*(5), 665-681. https://doi.org/10.1177/00113921211024701

Bell, R. (2002). *BELL'S THEOREM: ABORIGINAL ART - It's a white thing!* Retrieved 20 March 2024 from https://kooriweb.org/foley/great/art/bell.html

Bell, R. (2003). *Scientia E Metaphysica (Bell's Theorem)* [Acrylic on canvas].
Benveniste, T., Guenther, J., Dawson, D., & King, L. (2019). Race, Rules and Relationships: What Can Critical Race Theory Offer Contemporary Aboriginal Boarding Schools? *Journal of Intercultural Studies*, *40*(1), 32-48. https://doi.org/10.1080/07256868.2018.1552573
Brands, J., & Gooda, M. (2006). Putting the users of research in the driver's seat: the Cooperative Research Centre for Aboriginal Health's new approach to research development. *Australian Aboriginal Studies*(2), 27-35.
Briggs, C. (2014). *The Journey Cycles of the Boonwurrung: Stories with Boonwurrung Language* (Second ed.). Victorian Aboriginal Corporation for Languages.
Brinckley, M.-M., Bourke, S., Watkin Lui, F., & Lovett, R. (2022). Knowledge translation in Aboriginal and Torres Strait Islander research contexts in Australia: scoping review protocol. *BMJ Open*, *12*(7), e060311-undefined. https://doi.org/10.1136/bmjopen-2021-060311
Brunger, F., Russell, T., & Wall, D. (2020). Decolonizing Research Ethics: Best Practices for the Ethical Conduct of Research Involving Indigenous Peoples. In A. S. Iltis & D. MacKay (Eds.), *The Oxford Handbook of Research Ethics* (pp. 0). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190947750.013.47
Bryman, A. (2004). *Social Research Methods* (Second Edition ed.). Oxford University Press Inc.
Burchill, L. J., Kotevski, A., Duke, D. L. M., Prictor, M., Ward, J. E., Lamb, K. E., & Kennedy, M. (2023). Ethics guidelines use and Indigenous governance and participation in Aboriginal and Torres Strait Islander health research: a national survey. *Medical Journal of Australia*, *218*(2), 89-93. https://doi.org/10.5694/mja2.51757
Canadian Institute of Health Research, Natural Sciences and Engineering Research Council of Canada Social Sciences, & Humanities Research Council of Canada. (2022). *Tri-Council Policy Statement Ethical Conduct for Research Involving Humans*.
Canadian Institutes of Health Research. (2012). *Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches*.
Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J. D., Anderson, J., & Hudson, M. (2020). The CARE Principles for Indigenous Data Governance. *Data Science Journal*. https://doi.org/10.5334/dsj-2020-043
Casteel, J. K. (1998). The ethics of informed consent among storyteller cultures. *Int J Circumpolar Health*, *57 Suppl 1*, 41-42.
Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. sage.
Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). SAGE Publications.
Charmaz, K. (2016). Shifting the Grounds: Constructivist Grounded Theory Methods. In *Developing grounded theory : the second generation*. Routledge.
Charmaz, K. (2017). The Power of Constructivist Grounded Theory for Critical Inquiry. *Qualitative Inquiry*, *23*(1), 34-45. https://doi.org/10.1177/1077800416657105
Chenhall, R., Senior, K., & Belton, S. (2011). Negotiating human research ethics: Case notes from anthropologists in the field. In *Anthropology Today* (Vol. 27, pp. 13-17).
Chinn, P. W. U. (2007). Decolonizing Methodologies and Indigenous Knowledge: The Role of Culture, Place and Personal Experience in Professional Development. *Journal of Research in Science Teaching*, *44*(9), 1247-1268. https://doi.org/10.1002/tea.20192
Chun Tie, Y., Birks, M., & Francis, K. (2019). Grounded theory research: A design framework for novice researchers. *SAGE Open Med*, *7*, 2050312118822927. https://doi.org/10.1177/2050312118822927
Clarke, A. E. (2005). Situational analysis : grounded theory after the postmodern turn. In: Sage Publications.
Commonwealth of Australia. (2013). *Assessing the wider benefits arising from university-based research: Discussion paper*.

Delgado, R., & Stefancic, J. (2017). *Critical Race Theory (Third Edition) An Introduction* (3 ed., Vol. 20). NYU Press. https://doi.org/10.2307/j.ctt1ggjjn3

Denzin, N. K., & Lincoln, Y. S. (2008). Preface. In Y. S. L. Norman K. Denzin, Linda Tuhiwai Smith (Ed.), *Handbook of critical and indigenous methodologies / editors, Norman K. Denzin, Yvonna S. Lincoln, Linda Tuhiwai Smith*. Sage.

Department of Aboriginal Affairs. (1981). *Report on a review of the administration of the working definition of Aboriginal and Torres Strait Islander*.

Dodson, M. (2017, 21 March). Indigenous Education Research. AIATSIS National Indigenous Research Conference, Canberra.

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

Duke, D. L. M., Ekinci, E., Hachem, M., Burchill, L. J., & Prictor, M. (2021). Culturally adaptive governance—building a new framework for equity in aboriginal and torres strait islander health research: Theoretical basis, ethics, attributes and evaluation. *International Journal of Environmental Research and Public Health*, *18*(15). https://doi.org/10.3390/ijerph18157943

Dunbar Jnr, C. (2008). Critical Race Theory and Indigenous Methodologies. In Y. S. L. Norman K. Denzin, Linda Tuhiwai Smith (Ed.), *Handbook of critical and indigenous methodologies / editors, Norman K. Denzin, Yvonna S. Lincoln, Linda Tuhiwai Smith*. Sage.

Dunbar, T., & Scrimgeour, M. (2005). *Ethical Assessment of Indigenous Health Research: A Review of the Literarure*.

Elston, J. K., Saunders, V., Hayes, B., Bainbridge, R., & McCoy, B. (2013). Building indigenous Australian research capacity. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, *46*(1), 6-12. https://doi.org/10.3316/informit.206891696485660

First Nations Centre. (2005). *Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities*.

First Nations Centre. (2007). *OCAP Ownership, Control, Access and Possession*. N. A. H. Organization.

Foley, D. (2003). Indigenous Epistemology and Indigenous Standpoint Theory. *Social Alternatives*, *22*(1), 44-51.

Foley, D. (2006). Indigenous Standpoint Theory. *International Journal of the Humanities*, *3*(8).

Ford, C. L., & Airhihenbuwa, C. O. (2010). Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis. *American Journal of Public Health*, *100*(S1), S30-S35. https://doi.org/10.2105/AJPH.2009.171058

Fredericks, B. (2009). The epistemology that maintains white race privilege, power and control of Indigenous Studies and Indigenous peoples' participation in universities. *Critical Race and Whiteness Studies*, *5*(1), 1-12.

Ganter, R. (2008). Turning Aboriginal-Historical Bents.

Gibbs, G. (2013). *A discussion with Prof Kathy Charmaz on Grounded Theory [Video]* YouTube, Gibbs, Graham. https://www.youtube.com/watch?v=D5AHmHQS6WQ

Glaser, B. G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine. https://books.google.com.au/books?id=oUxEAQAAIAAJ

Gorman, S. M. (2011). Ethics Creep or Governance Creep? *Monash Bioethics Review*, *29*(4), 23-38. https://doi.org/10.1007/BF03351328

Gorringe, S., Ross, J., & Fforde, C. (2011). *AIATSIS Discussion Paper Number 28: 'Will the Real Aborigine Please Stand Up': Strategies for breaking the stereotypes and changing the conversation*.

Gower, G. (2015). *Ethical Research in Indigenous Contexts and the practical implementation of it* Edith Cowan University].

Grenz, J. (2023). University ethics boards are not ready for Indigenous scholars. In *Nature* (Vol. 616, pp. 221). England: Nature Publishing Group.

Guillemin, M., Barnard, E., Allen, A., Stewart, P., Walker, H., Rosenthal, D., & Gillam, L. (2018). Do Research Participants Trust Researchers or Their Institution? In *Journal of Empirical Research on Human Research Ethics: An International Journal* (Vol. 13, pp. 285-294).

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "Ethically important moments" in research. *Qualitative Inquiry*, *10*(2), 261-280. https://doi.org/10.1177/1077800403262360

Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H., & Rosenthal, D. (2016). “Doing Trust” : How Researchers Conceptualize and Enact Trust in Their Research Practice. In *Journal of Empirical Research on Human Research Ethics: An International Journal* (Vol. 11, pp. 370-381).

Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H., & Rosenthal, D. (2016). "We're checking them out": Indigenous and non-Indigenous research participants' accounts of deciding to be involved in research. *International Journal for Equity in Health*, *15*(1). https://doi.org/10.1186/s12939-016-0301-4

Guinier, L. (1991). The triumph of tokenism: The Voting Rights Act and the theory of Black electoral success. *Michigan Law Review*, *89*(5), 1077-1154.

Guinier, L., & Carter, S. L. (1994). The tyranny of the majority: Fundamental fairness in representative democracy. *(No Title)*.

Gunaikurnai Land and Waters Aboriginal Corporation. (2022). *Stories & Songlines*. Retrieved 1/03/2022 from https://gunaikurnai.org/our-culture/stories/

Guta, A., Nixon, S. A., & Wilson, M. G. (2013). Resisting the seduction of “ethics creep”: Using Foucault to surface complexity and contradiction in research ethics review. *Social Science & Medicine*, *98*, 301-310. https://doi.org/10.1016/j.socscimed.2012.09.019

Haney-López, I. F. (1994). Social Construction of Race: Some Observations on Illusion, Fabrication, and Choice, The. *Harvard Civil Rights-Civil Liberties Law Review*, *29*, 1.

Harding, S. (1991). *Whose Science? Whose Knowledge?*
*Thinking from Women's Lives*. Cornell University Press. http://www.jstor.org/stable/10.7591/j.ctt1hhfnmg

Hawkes, G. L., Pollock, D., Judd, B., Phipps, P., & Assoulin, E. (2017). Ngapartji Ngapartji: Finding Ethical Approaches to Research Involving Indigenous Peoples, Australian Perspectives. In *ab-Original: Journal of Indigenous Studies and First Nations and First Peoples' Cultures* (Vol. 1, pp. 17-41).

Henderson, R., Simmons, D. S., Bourke, L., & Muir, J. (2002). Development of guidelines for non-Indigenous people undertaking research among the Indigenous population of north-east Victoria. *Medical Journal of Australia*, *176*(10), 482-485.

Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., & Murakami-Gold, L. (2004). *Indigenous Research Reform Agenda. A Review of the Literature*.

Hildenbrand, B. (2007). The SAGE Handbook of Grounded Theory. In. SAGE Publications Ltd. https://doi.org/10.4135/9781848607941

Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2009). Te Ara Tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members.

Hudson, M. L., & Russell, K. (2009). The Treaty of Waitangi and Research Ethics in Aotearoa. *Journal of Bioethical Inquiry*, *6*(1), 61-68. https://doi.org/10.1007/s11673-008-9127-0

Humphrey, K. (2001). Dirty questions: Indigenous health and 'Western research'. *Australia and New Zealand Journal of Public Health*, *25*(3), 197-202.

Hunt, J. (2013). *Engagement with Indigenous communities in key sectors*. Australian Government

Huria, T., Palmer, S. C., Pitama, S., Beckert, L., Lacey, C., Ewen, S., & Smith, L. T. (2019). Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement. *BMC Medical Research Methodology*, *19*(1), 173. https://doi.org/10.1186/s12874-019-0815-8

Jamieson, L. M., Paradies, Y. C., Eades, S., Chong, A., Maple-Brown, L., Morris, P., Bailie, R., Cass, A., Roberts-Thomson, K., & Brown, A. (2012). Ten principles relevant to health research among

Indigenous Australian populations. *Med J Aust*, *197*(1), 16-18. https://www.ncbi.nlm.nih.gov/pubmed/22762218
Johnstone, M. (2007). Research ethics, reconciliation, and strengthening the research relationship in Indigenous health domains: An Australian perspective. *IJIR*, *31*, 391-406.
Kearney, J., & Janke, T. (2018, 29 January 2018). *Rights to Culture: Indigenous Cultural and Intellectual Property (ICIP), Copyright and Protocols*. https://www.terrijanke.com.au/post/2018/01/29/rights-to-culture-indigenous-cultural-and-intellectual-property-icip-copyright-and-protoc
Kinchin, I., McCalman, J., Bainbridge, R., Tsey, K., & Lui, F. W. (2017). Does Indigenous health research have impact? A systematic review of reviews. *Int J Equity Health*, *16*(1), 52. https://doi.org/10.1186/s12939-017-0548-4
Kok, M. O., Gyapong, J. O., Wolffers, I., Ofori-Adjei, D., & Ruitenberg, J. (2016). Which health research gets used and why? An empirical analysis of 30 cases. *Health Research Policy and Systems*, *14*(36).
Kovach, M. (2009). *Indigenous Methodologies. Characteristics, Conversations, and Contexts*. University of Toronto Press.
Kowal, E. (2008). The Politics of the Gap: Indigenous Australians, Liberal Multiculturalism, and the End of the Self Determination Era. *American Anthropologist*, *110*(3), 338-348.
Kowal, E., Anderson, I., & Bailie, R. (2005). Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research. *Australian and New Zealand Journal of Public Health*, *29*(5), 468-470.
Kukutai, T., Campbell-Kamariera, K., Mead, A., Mikaere, K., Moses, C., Whitehead, J., & Cormack, D. (2023). *Māori data governance model. Te Kāhui Raraunga*.
Kukutai, T., & Taylor, J. (2016). *Indigenous Data Sovereignty. Toward an agenda*. Australian National University.
Laycock, A., with Walker, D., Harrison, N., & and Brands, J. (2011). *Researching Indigenous Health: a practical guide for researchers*. The Lowitja Institute.
Liamputtong, P. (2010). *Research methods in health: foundations for evidence-based practice* Oxford University Press.
Ligita, T., Harvey, N., Wicking, K., Nurjannah, I., & Francis, K. (2020). A practical example of using theoretical sampling throughout a grounded theory study. *Qualitative Research Journal*, *20*(1), 116-126. https://doi.org/10.1108/QRJ-07-2019-0059
Luke, J., Verbunt, E., Zhang, A., Bamblett, M., Johnson, G., Salamone, C., Thomas, D., Eades, S., Gubhaju, L., Kelaher, M., & Jones, A. (2022). Questioning the ethics of evidence-based practice for Indigenous health and social settings in Australia. *BMJ Global Health*, *7*(6), e009167. https://doi.org/10.1136/bmjgh-2022-009167
Maar, M. A., Lightfoot, N. E., Sutherland, M. E., Strasser, R. P., Wilson, K. J., Lidstone-Jones, C. M., Graham, D. G., Beaudin, R., Daybutch, G. A., Dokis, B. R., Lesage, M. T., Raymond, M., & Williamson, P. (2011). Thinking outside the box: Aboriginal people's suggestions for conducting health studies with Aboriginal communities. *Public Health*, *125*(11), 747-753. https://doi.org/10.1016/j.puhe.2011.08.006
Macaulay, A. C., Delormier, T., McComber, A. M., Cross, E. J., Potvin, L. P., Paradis, G., Kirby, R. L., Saad-Haddad, C., & Desrosiers, S. (1998). Participatory Research with Native Community of Kahnawake Creates Innovative Code of Research Ethics. In *Canadian Journal of Public Health / Revue Canadienne de Sante'e Publique* (Vol. 89, pp. 105-108).
Maclean, K., Woodward, E., Jarvis, D., Turpin, G., Rowland, D., & Rist, P. (2022). Decolonising knowledge co-production: examining the role of positionality and partnerships to support Indigenous-led bush product enterprises in northern Australia. *Sustainability Science*, *17*. https://doi.org/10.1007/s11625-021-00973-4

MacLean, S., Ritte, R., Thorpe, A., Ewen, S., & Arabena, K. (2015). Assessing compliance with Aboriginal and Torres Strait Islander health research guidelines within systematic reviews. *Australian Indigenous HealthBulletin*, *15*(4).

Maiam nayri Wingara Indigenous Data Sovereignty Collective. (2018, 20 June 2018). Maiam nayri Wingara Indigenous Data Sovereignty principles. Indigenous Data SOvereignty Summit, Canberra.

Malagon, M. C., Huber, L. P., & Velez, V. N. (2009). Our Experiences Our Methods- Using Grounded Theory to Inform a Critical Race Theory Methodology. *Seattle Journal for Social Justice*, *8*(1).

Martin, K., & Mirraboopa, B. (2003). Ways of knowing, being and doing: A theoretical framework and methods for indigenous and indigenist re-search. *Journal of Australian Studies*, *27*(76), 203-214.

Massola, A. (1968). Bunjil's cave: myths, legends and superstitions of the Aborigines of south-east Australia / Aldo Massola ; photographs by John Gollings. In: Lansdowne Press.

Matsuda, M. J. (1987). Looking to the bottom: Critical legal studies and reparations. *HaRv. cR-cll Rev.*, *22*, 323.

Mayo, K., & Tsey, K. (2009). The research dance: university and community research collaborations at Yarrabah, North Queensland, Australia [Article]. *Health & Social Care in the Community*, *17*(2), 133-140. https://doi.org/10.1111/j.1365-2524.2008.00805.x

McGuffog, R., Chamberlain, C., Hughes, J., Kong, K., Wenitong, M., Bryant, J., Brown, A., Eades, S. J., Griffiths, K. E., Collis, F., Hobden, B., O'Mara, P., Ridgeway, T., Walter, M., & Kennedy, M. (2023). *Murru Minya*–informing the development of practical recommendations to support ethical conduct in Aboriginal and Torres Strait Islander health research: a protocol for a national mixed-methods study. *BMJ Open*, *13*(2), e067054. https://doi.org/10.1136/bmjopen-2022-067054

McLaughlin, J., & Whatman, S. (2011). The potential of critical race theory in decolonizing university curricula. *Asia Pacific Journal of Education*, *31*(4), 365-377. https://doi.org/10.1080/02188791.2011.621243

McManus, J. (2022). How a young fella named Boondjil Noorook discovered Captain Cook [Photo]. In. Melbourne: The Age.

Menzies School of Health Research. (2021, 12 May 2021). *Establishing a National Network for Aboriginal and Torres Strait Islander health researchers*

Mihesuah, D. (1993). Suggested guidelines for institutions with scholars who conduct research on American Indians. *American Indian culture and research journal*, *17*(3), 131.

Mitchell, J. D. (2014). Advancing Grounded Theory: Using Theoretical Frameworks within Grounded Theory Studies. *Qualitative Report*, *19*(36), 1-11.

Moffat, M. (2016). Exploring Positionality in an Aboriginal Research Paradigm: A Unique Perspective. *International Journal of Technology and Inclusive Education*, *5*. https://doi.org/10.20533/ijtie.2047.0533.2016.0096

Moodie, N. (2018). Decolonising race theory: Place, survivance and sovereignty. In G. Vass, J. Maxwell, S. Rudolph, & K. N. Gulson (Eds.), *The relationality of race in education research*. Routledge, Taylor &; Francis Group.

Moreton-Robinson, A. (2013). Towards an Australian Indigenous women's standpoint theory: A methodological tool. *Australian Feminist Studies*, *28*(78), 331-347.

Moreton-Robinson, A. (2016). National Indigenous Research Knowledges Network (NIRAKN)—Some Reflections and Learnings. *International Journal of Critical Indigenous Studies*, *9*, 1-9. https://doi.org/10.5204/ijcis.v9i2.135

Moreton-Robinson, A. (2017). Relationality: A key presupposition of an indigenous social research paradigm.

Morey, K. (2017). *South Australian Aboriginal Health Research Accord: Companion Document*. SAHMRI.

Morton Ninomiya, M. E., Maddox, R., Brascoupé, S., Robinson, N., Atkinson, D., Firestone, M., Ziegler, C., & Smylie, J. (2022). Knowledge translation approaches and practices in Indigenous health research: A systematic review. *Social Science & Medicine*, *301*. https://doi.org/10.1016/j.socscimed.2022.114898

Murray, G. (2024). *Myndie a Yung Balug Creation Story in Dja Dja Wurrung Country the home of Waa.* [Interview].

Nakata, M. (2002). Indigenous Knowledge and the Cultural Interface: underlying issues at the intersection of knowledge and information systems. *IFLA Journal 28*, *5*(6).

Nakata, M. (2007a). The cultural interface. *The Australian Journal of Indigenous Education*, *36*(S1), 7-14.

Nakata, M. (2007b). An Indigenous standpoint theory. *Disciplining the savages: Savaging the disciplines*, 213.

National Aboriginal Community Controlled Health Organisation. (2024). *Aboriginal Community Controlled Health Organisations (ACCHOs)*. National Community Controlled Health Organisation. Retrieved 17 March 2024 from https://www.naccho.org.au/acchos/

National Health and Medical Research Council. (1991). *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health*. Australia

National Health and Medical Research Council. (2003). *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. National Health and Medical Research Council

National Health and Medical Research Council. (2005). *Keeping Research On Track: A guide to Aboriginal and Torres Strait Islander peoples about health research ethics*. Australia: Australian Government

National Health and Medical Research Council. (2018a). *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*. Australian Government

National Health and Medical Research Council. (2018b). *Keeping research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*. Australian Government

National Health and Medical Research Council. (2018c). *National Statement on Ethical Conduct in Human Research*. Australian Government

National Health and Medical Research Council. (2018d). *Road Map 3: A strategic framework for improving Aboriginal and Torres Strait Islander health through research*. Australian Government

National health and Medical Research Council. (2022a). *2022 NHMRC Aboriginal and Torres Strait Islander Report Card of Achievements*. Retrieved 20 March 2024 from https://www.nhmrc.gov.au/aboriginal-and-torres-strait-islander-report-card-achievements-2022

National Health and Medical Research Council. (2022b). *Report on the Activity of Human Research Ethics Committees and Certified Institutions for the period: 1 January 2021 to 31 December 2021*. Australian Government

National Health and Medical Research Council. (2023a). *Indigenous Research Excellence Criteria (IREC) Review: Discussion paper*.

National Health and Medical Research Council. (2023b). *National Statement on Ethical Conduct in Human Research*. Australian Government

National Health and Medical Research Council. (2024a). *Ethical guidelines for research with Aboriginal and Torres Strait Islander peoples*. Retrieved 3 March from https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islander-peoples#download

National Health and Medical Research Council. (2024b). *Human Research Ethics Committees*. NHMRC. Retrieved 3 March from https://www.nhmrc.gov.au/research-policy/ethics/human-research-ethics-committees#download

*National Indigenous Research and Knowledges Network: Annual Report*. (2017).

O'Donahoo, F., J, & Ross, K., E. . (2015). Principles Relevant to Health Research among Indigenous Communities. In *International Journal of Environmental Research and Public Health* (Vol. 12, pp. 5304-5309): MDPI AG.

Onemda VicHealth Koori Health Unit. (2008). *We can like research... in Koori Hands: A Community Report on Onemda VicHealth Koori Health Unit's Research Workshops in 2007*.

Onemda VicHealth Koori Health Unit. (2010). An Onemda decade : ten years of progress in Koori health / [editorial team, Angela Clarke ... [and others]]. In. Melbourne: Onemda VicHealth Koori Health Unit,

The University of Melbourne.

Parker, L., & Lynn, M. (2002). What's Race Got to Do With It? Critical Race Theory's Conflicts With and Connections to Qualitative Research Methodology and Epistemology. *Qualitative Inquiry*, *8*(1), 7-22. https://doi.org/10.1177/107780040200800102

Parker, M., Pearson, C., Donald, C., & Fisher, C. B. (2019). Beyond the Belmont Principles: A Community-Based Approach to Developing an Indigenous Ethics Model and Curriculum for Training Health Researchers Working with American Indian and Alaska Native Communities. *Am J Community Psychol*, *64*(1-2), 9-20. https://doi.org/10.1002/ajcp.12360

Penman, R. (2006). *Occasional Paper No 16 Aboriginal and Torres Strait Islander views on research in their communities*.

Pepper, P., & De Araugo, T. (1985). *What did happen to the Aborigines of Victoria. Vol. 1. The Kurnai of Gippsland* (Vol. 1). Hyland House Publishing.

Peters-Little, F. (2000). *The Community Game: Aboriginal Self-definition at the Local Level*. Australian Institute of Aboriginal and Torres Strait Islander Studies.

Pyett, P., Waples-Crowe, P., & Van der Sterren, A. (2008). Challenging our own practices in Indigenous health promotion and research. *Health Promotion Journal of Australia*, *19*(3), 179-183.

Rigney, L.-I. (1999). Internationalization of an Indigenous anticolonial cultural critique of research methodologies: A guide to Indigenist research methodology and its principles. *Wicazo sa review*, *14*(2), 109-121.

Russell, C. (2020). Critical Race Theory in Indigenous Contexts. In V. L. Farmer & E. S. W. Farmer (Eds.), *Critical Race Theory in the Academy*. Information Age Publishing, Incorporated.

Sanson-Fisher, R. W., Campbell, E. M., Perkins, J. J., Blunden, S. V., & Davis, B. B. (2006). Indigenous health research: a critical review of outputs over time. *Medical Journal of Australia*, *184*(10), 502-505.

Schaap, A., Foley, G., & Howell, E. (2013). *The Aboriginal tent embassy : sovereignty, black power, land rights and the state*. Routledge.

Schokman, B., & Russell, D. L. (2017). *Moving beyond recognition: respecting the rights of Aboriginal and Torres Strait Islander Peoples*. Carlton: Oxfam Australia

Scott, K., & Receveur, O. (1995). Ethics for working with communities of Indigenous Peoples. *Can J Physiol Pharmacol*, *73*(6), 751-753. https://doi.org/10.1139/y95-099

Scott, K. W. (2004). Relating Categories in Grounded Theory Analysis: Using a Conditional Relationship Guide and Reflective Coding Matrix. *Qualitative Report*, *9*(1), 113-126.

Sherwood, J. (2013). Colonisation - It's bad for your health: The context of Aboriginal health. *Contemporary Nurse*, *46*(1), 28-40.

Singh, D. (2020). Racial complaint and sovereign divergence: The case of Australia's first Indigenous ophthalmologist. *The Australian Journal of Indigenous Education*, *49*(2), 145-152.

Smedley, A., & Smedley, B. D. (2005). Race as biology is fiction, racism as a social problem is real: anthropological and historical perspectives on the social construction of race. *The American Psychologist*, *60*(1).
Smith, L. T. (2000). Kaupapa maori research. *Reclaiming indigenous voice and vision*, 225-247.
Solar, O., & Irwin, A. (2010). *A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2*.
Solórzano, D. G., & Yosso, T. J. (2002). Critical Race Methodology: Counter-Storytelling as an Analytical Framework for Education Research. *Qualitative Inquiry*, *8*(1), 23-44. https://doi.org/10.1177/107780040200800103
South Australian Health and Medical Research Institute (SAHMRI). (2014). *Wardliparingga Aboriginal research in Aboriginal hands. South Australian Aboriginal Health Research Accord Companion Document*.
Stewart, P., Anderson, I., Dunbar, T., Shibasaki, S., Pyett, P., & Devitt, J. (2006). Aboriginal and Torres Strait Islander Participation in the Ethical Review of Health Research. *Aboriginal and Islander Health Worker Journal*, *30*(6), 22-25.
Stewart, P., Shibasaki, S., Anderson, I., Pyett, P., Dunbar, T., & Devitt, J. (2006). Aboriginal and Torres Strait Islander participation in ethical review of health research. *Australian and New Zealand Journal of Public Health*, *30*(3), 291-292.
Stokes, S. (2023). A Sense of Belonging within the Imaginative Constraints of Racial Realism: A Critical Race Analysis of Latinx Students' Racialized Experiences during the Trump Presidency. *International Journal of Qualitative Studies in Education (QSE)*, *36*(1), 26-41.
Straus, S. E., Tetroe, J., & Graham, I. (2009). Defining knowledge translation. *181*(3-4), 165.
Strauss, A., & Corbin, J. (1998). Basics of qualitative research techniques.
Strauss, A., & Corbin, J. M. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. SAGE Publications. https://books.google.com.au/books?id=nvwOAQAAMAAJ
Strauss, A. L. (1993). *Continual Permutations of Action*. Transaction Publishers. https://books.google.com.au/books?id=VdCWXXjdqxYC
Su, C. (2007). Cracking silent codes: Critical race theory and education organizing. *Discourse: studies in the cultural politics of education*, *28*(4), 531-548.
Te Mana Raraunga. (2018). *Principles of Māori Data Sovereignty*.
The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE). (2015). *CREATE Critical Appraisal Tool*. https://create.sahmri.org/?page_id=1476
The Lowitja Institute. (2014). *Ethics Hub*. Retrieved 2 August from http://www.lowitja.org.au/ethics
The University of Melbourne. (2012). *Research at Melbourne: Ensuring excellence and impact to 2025*. T. U. o. Melbourne.
Thomas, D. P., Bainbridge, R., & Tsey, K. (2014). Changing discourses in Aboriginal and Torres Strait Islander health research, 1914-2014. *MJA 201*, *1*, 51-54.
Thorpe, A., Arabena, K., Sullivan, P., Silburn, K., & Rowley, K. (2016). *Engaging First Peoples: A Review of Government Engagement Methods for Developing Health Policy*.
Thorpe, L. (2024). *BAIAME Murrangurrang: Baiame Always Forever (past; present; future) Ancestral Continuum.* [Digitised artwork combined with acrylic painting on canvas].
Thorpe, W. *Gunnai Brabiralung Mukdhang Language* [Indigenous language].
Thorpe, W. (2022, January 23). How a young fella named Boondjil Noorook discovered Captain Cook. *The Age*. https://www.theage.com.au/national/how-a-young-fella-named-boondjil-noorook-discovered-captain-cook-20211214-p59hgi.html
Tuhiwai-Smith, L. (2012). *Decolonizing Methodologies Research and Indigenous Peoples* (Second Edition ed.). Zed Books Ltd.
VicHealth Koori Health Research and Community Development Unit. (2000). We don't like research... : but in Koori hands it could make a difference / VicHealth Koori Health Research and

Community Development Unit. In: VicHealth Koori Health Research and Community Development Unit.
Victorian Aboriginal Community Controlled Health Organisation. (2023). *Marra ngarrgoo, marra goorri: The Victorian Aboriginal Health, Medical and Wellbeing Research Accord*. VACCHO.
Victorian Aboriginal Corporation for Languages. (2014). *Nyernila: Listen Continuously*. Arts Victoria. https://books.google.com.au/books?id=F77ZngEACAAJ
Walker, R. *Ethical Principles and Guidelines for Indigenous Research*. Commonwealth of Australia.
Walker, S., Eketone, A., & Gibbs, A. (2006). An exploration of kaupapa Maori research, its principles, processes and applications [Article]. *International Journal of Social Research Methodology*, *9*(4), 331-344. https://doi.org/10.1080/13645570600916049
Wand, A. P. F., & Eades, S. J. (2008). Navigating the process of developing a research project in Aboriginal health. *Medical Journal of Australia*, *188*(10), 584-587.
Watson, R., Adams, K., Fredericks, B., & Mahoney, R. (2010). *Strategic Directions Report for the Social Determinants of Aboriginal Health Project*.
West, R., Stewart, L., Foster, K., & Usher, K. (2012). Through a Critical Lens: Indigenist Research and the Dadirri Method. *Qualitative Health Research*, *22*(11), 1582-1590.
Wiles, R., Charles, V., Crow, G., & Heath, S. (2004). *Researching Researchers: Lessons for Research Ethics* BSA Medical Sociology Conference, York.
Williams, M., Carrigan, C., & Doherty, L. (2021). *Profiling Excellence: Indigenous Knowledge Translation* [Report].
World Health Organization. (2001). Helsinki Declaration. *Bulletin of the World Health Organization*, *79*(4).
Writer, J. H. (2008). Unmasking, exposing, and confronting: Critical race theory, tribal critical race theory and multicultural education. *International journal of multicultural education*, *10*(2).

Appendix A Guidelines for ethical research with Indigenous peoples in Australia, New Zealand, Canada (sorted by country and year)

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| NSW Aboriginal Health Ethics Guidelines: Key Principles | 2023 | Guidelines | NSW | Ethics | Net Benefits for Aboriginal people and communities<br>Aboriginal Community Control of Research<br>Cultural Sensitivity<br>Reimbursement of costs<br>Enhancing Aboriginal skills and knowledge | Replaces the AH&MRC Guidelines for Research into Aboriginal Health, 2016<br>Additional themes<br>Aboriginal Governance<br>AH&MRC Review |
| Marra ngarrgoo, marra goorri: The Victorian Aboriginal Health, Medical and Wellbeing Research Accord | 2023 | Research accord | Vic | Ethics | Aboriginal and Torres Strait Islander Leadership<br>Trust and Equity<br>Aboriginal and Torres Strait Islander Health Priorities<br>Cultural Safety and Humility<br>Knowledge, Equity and Recognition<br>Data Governance and Sovereignty | Aims:<br>To increase Indigenous-led research and enhance benefits.<br>To implement monitoring mechanisms.<br>To enhance research capability. |
| AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research | 2020 | Guidelines | Aus | Ethics | **Core Ethical Value**<br>Integrity<br>**Four principles**<br>1) Indigenous self-determination<br>a) recognition and respect<br>b) engagement and collaboration<br>c) informed consent<br>d) cultural capability and learning<br>2) Indigenous leadership<br>a) Indigenous led research<br>b) Indigenous perspectives and participation<br>c) Indigenous knowledge and data | Focused on Indigenous research in general |

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| | | | | | 3) Impact and value<br>a) benefit and reciprocity<br>b) impact and risk<br>4) Sustainability and accountability<br>a) Indigenous land and waters<br>b) ongoing Indigenous governance<br>reporting and compliance | |
| Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities | 2018 | Guidelines | Aus | Ethics | Spirit and Integrity<br>Cultural Continuity<br>Equity<br>Reciprocity<br>Respect<br>Responsibility | Replaced 2003 guidelines |
| Keeping research on track II | 2018 | Companion guide | Aus | Ethics | 1. Building relationships<br>2. Developing the research idea<br>3. Developing the project and seeking agreement<br>4. Data collection<br>5. Analysing the data and making sense of the findings<br>6. Report writing<br>7. Sharing and translating the results into action<br>Learning from experience | Replaced previous companion guide KROT |
| Maiam nayri Wingara Indigenous Data Sovereignty principles | 2018 | Communique | Aus | IDG | Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure. | Developed from Indigenous Data Sovereignty Summit |

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| | | | | | Data that are contextual and disaggregated (available and accessible at individual, community and First Nations levels).<br>Data that are relevant and empowers sustainable self-determination and effective self-governance.<br>Data structures that are accountable to Indigenous peoples and First Nations.<br>8. Data that are protective and respects our individual and collective interests. | |
| Rights to Culture: Indigenous Cultural and Intellectual Property (ICIP), Copyright and Protocols | 2018 | Website | Aus | IDG | True Tracks protocols<br>1. Respect<br>2. Self-Determination<br>3. Consent and Consultation<br>4. Interpretation<br>5. Cultural Integrity<br>6. Secrecy and Privacy<br>7. Attribution<br>8. Benefit Sharing<br>9. Maintaining Indigenous Culture<br>Recognition and Protection | |
| Wardliparingga: Aboriginal research in Aboriginal hands<br>South Australian Aboriginal Health Research Accord: Companion Document | 2017 | Companion document | SA | Research | Priorities: Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.<br>Involvement: The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.<br>Partnership: Research should be based on the establishment of mutual trust, and equivalent | https://sahmri.org.au/south-australian-aboriginal-health-research-accord |

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| | | | | | partnerships, and the ability to work competently across cultures.<br><br>Respect: Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.<br><br>Communication: Communication must be culturally and community relevant and involve a willingness to listen and learn.<br><br>Reciprocity: Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.<br><br>Ownership: Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.<br><br>Control: Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.<br><br>Knowledge Translation: Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice. | |
| AH&MRC Guidelines for Research into Aboriginal Health: Key Principles | 2013 | Guidelines | NSW | Research | Net Benefits for Aboriginal people and communities<br><br>Aboriginal Community Control of Research<br><br>Cultural Sensitivity<br><br>Reimbursement of costs<br><br>Enhancing Aboriginal skills and knowledge | Updated in 2023 |

Appendix A Guidelines for ethical research with Indigenous peoples in Australia, New Zealand, Canada (sorted by country and year)

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| Guidelines for ethical Research in Australian Indigenous Studies (GERAIS) | 2012 | Guidelines | Aus | Ethics | Rights, respect and recognition<br>Negotiation, consultation, agreement and mutual understanding<br>Participation, collaboration and partnership<br>Benefits, outcomes and giving back<br>Managing research: use, storage and access<br>Reporting and compliance | Updated in 2020 refer to AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research |
| Keeping Research on Track | 2005 | Companion guide | Aus | Ethics | Building relationships<br>Conceptualisation<br>Development and approval<br>Data collection and management<br>Analysis<br>Report writing<br>Dissemination<br>Learning from our experience | Updated in 2018 refer to KROT II<br>A guide for Aboriginal and Torres Strait Islander peoples about health research ethics |
| Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (2003) | 2003 | Guidelines | Aus | Ethics | Reciprocity<br>Respect<br>Equality<br>Responsibility<br>Survival and Protection<br>Spirit and Integrity | Updated in 2018 refer to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities |
| Māori data governance model. Te Kāhui Raraunga. | 2023 | Guidelines | NZ | Data governance | Nurture data as a taonga<br>Be accountable | Includes Māori Data Governance Pou: |

Appendix A Guidelines for ethical research with Indigenous peoples in Australia, New Zealand, Canada (sorted by country and year)

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| | | | | | Put iwi-Māori data in iwi-Māori hands<br>Use data for good<br>Decolonise data systems | Data capacities and workforce development<br>Data infrastructure<br>Data collection<br>Data protection<br>Data access, sharing and repatriation<br>Data use and reuse<br>Data quality and system integrity<br>Data classification |
| Principles of Māori Data Sovereignty | 2018 | Guidelines | NZ | Data governance | Rangatiratanga – Authority<br>Whakapapa – Relationships<br>Whanaungatanga – Obligations<br>Kotahitanga – Collective benefit<br>Manaakitanga – Reciprocity<br>Kaitiakitanga – Guardianship | |
| Te Ara Tika Guidelines for Māori research ethics: A framework for researchers and ethics committee members | 2009 | Guidelines | NZ | Ethics | Partnership, participation, and protection. Māori values of whakapono (faith), tūmanako (aspirations) and aroha (awareness). | Good to best practice model. Ethics linked to rights, roles, and responsibilities of Treaty of Waitangi. Maori ethical framework encapsulated by a quadrant matrix. |
| An exploration of kaupapa Maori research, its principles, processes and applications | 2006 | Guidelines | NZ | Research | **Tino rangatiratanga** (sovereignty, self-determination, governance, autonomy, and independence)<br>**Social justice** (Maori benefits from research. Capacity development of Maori researchers)<br>**Maori world view** | |

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| | | | | | **whakawhanaungatanga** (the process of identifying, maintaining, or forming past, present, and future relationships<br>**Te reo** (using language)<br>**Whanau** (family, establishing relationships) | |
| Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2 2022 | 2022 | Guidelines | Canada | Ethics | Respect for Persons<br>Concern for Welfare<br>Justice | Replaces TCPS (2014) and TCPS2 (2018) |
| Ethics in First Nations Research | 2009 | Guidelines | Canada | Ethics | **Sharing Power**<br>OCAP<br>Code of Ethics<br>Research Agreement<br>Data-sharing Protocol<br>**Using a Research Protocol - Guiding principles for Potential Researchers**<br>Community Engagement<br>Approval by Community<br>Research Paradigm Vetted by Community<br>Transparent Process<br>Respect for Local Protocols and Adherence to Research Protocols<br>Proper Time Commitment<br>Research Outcomes<br>Partnerships<br>Foster Indigenous Employment | |

Appendix A Guidelines for ethical research with Indigenous peoples in Australia, New Zealand, Canada (sorted by country and year)

| Key guidelines | Year | Document | Place | Focus | Core principles | Notes |
|---|---|---|---|---|---|---|
| OCAP: Ownership, Control, Access and Possession | 2007 | Guidelines | Canada | Data governance | **Ownership:** Refers to the relationship of a First Nations community to its cultural knowledge/data/information.<br>**Control:** The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information and data.<br>**Access:** The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them.<br>**Possession:** While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. | OCAP principles have been adopted in other guidelines and has influenced Indigenous data sovereignty movements globally |
| The CARE Principles for Indigenous Data Governance | 2020 | Journal article | Int. | Data governance | Collective benefit<br>Authority to control<br>Responsibility<br>Ethics | |
| Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement | 2019 | Journal article | Int. | Reporting on health research | Governance<br>Prioritization<br>Relationships<br>Methodologies<br>Participation<br>Capacity<br>Analysis and interpretation<br>Dissemination | Best practice model for reporting health research involving Indigenous peoples |

From “Aboriginal Health Ethics Guidelines: Key Principles”. By Aboriginal Health & Medical Research Council. 2023.
From “Marra ngarrgoo, marra goorri: The Victorian Aboriginal Health, Medical and Wellbeing Research Accord”. By VACCHO. 2023.
From “AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research”. By AIATSIS. 2020.

Appendix A Guidelines for ethical research with Indigenous peoples in Australia, New Zealand, Canada (sorted by country and year)

From “Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities”. By NHMRC. 2018.
From “Keeping research on track II”. By NHMRC. 2018.
From “Maiam nayri Wingara Indigenous Data Sovereignty principles”. By Maiam nayri Wingara Indigenous Data Sovereignty Collective
Australian Indigenous Governance Institute. 2018.
From “Rights to Culture: Indigenous Cultural and Intellectual Property (ICIP), Copyright and Protocols”. By J, Kearney, & T, Janke. 2023.
From “Wardliparingga: Aboriginal research in Aboriginal hands”. By K, Morey. 2017
From “AH&MRC Guidelines for Research into Aboriginal Health: Key Principles”. By Aboriginal Health & Medical Research Council. 2013.
From “Guidelines for ethical Research in Australian Indigenous Studies (GERAIS)”. By AIATSIS. 2012.
From “Keeping research on track”. By NHMRC. 2005.
From “Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research”. By NHMRC. 2003.
From “Māori data governance model. Te Kāhui Raraunga”. By T, Kukutai, K, Campbell-Kamariera, A, Mead, K, Mikaere, C, Moses, J, Whitehead & D, Cormack. 2023.
From “Principles of Māori Data Sovereignty“. By Te Mana Raraunga Maori Data Sovereignty Network. 2018.
From “Te Ara Tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members”. By M, Hudson, M, Milne, P, Reynolds, K, Russell, B, Smith. 2009.
From “An exploration of kaupapa Maori research, its principles, processes and applications”. By Walker, Eketone & Gibbs. 2006
From “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2 2022”. By Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council. 2022.
From “Ethics in First Nations Research”. By Assembly of First Nations. 2009.
From “OCAP: Ownership, Control, Access and Possession”. By First Nations Centre. 2007.
From “The CARE Principles for Indigenous Data Governance”. By The International Indigenous Data Sovereignty Interest Group. 2020.
From “Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement”. By T, Huria, SC, Palmer, S, Pitama, L, Beckert, C, Lacey, S, Ewen, & LT, Smith. 2019.

Appendix B – Methods audit trail

| Step # | Activity | Description | Methods |
|---|---|---|---|
| | **Research Design** | Research aims questions<br>Researcher positionality: Reflecting on cultural, political, and academic positions<br>Selection of CRGM<br>Incorporating CRT and GT principles.<br>Indigenous methodologies | Theoretical Framework<br>Positionality<br>CRGM |
| | **Ethical Research Protocol** | IRRG<br>IRRG Ethics Workshop<br>Data Analysis Workshop<br>KE and Impact Workshop<br>Community research approvals were received from each participating community site (x3) | **1. Collaboration through IRRG** |
| | **Data Collection** | Three community sites were recruited to participate in the study.<br><br>Participants were recruited through purposive sampling for insights into Indigenous experiences<br><br>Two methods of data collection – Semi structured interviews and aide-mémoire<br><br>Pilot interviews<br>Refined interview schedule for participant groups | **2. Theoretical sampling Theoretical saturation.**<br><br>Data Collection Methods: Culturally sensitive semi-structured interviews.<br><br>Aide memoire |
| | **Data Analysis and Interpretation** | Use of constructive grounded theory<br>Use of Nvivo software for preliminary analysis<br><br>Validating findings and ensuring accuracy through participant feedback. Constant comparison<br><br>Coding Process: From focused to theoretical coding, centered on CRT themes<br><br>Integration of CRT: Analysis focused on power, and structural forces within research institutions<br><br>Workshop with IRRG to interpret the data, confirm emerging concepts, and validate conditions and properties.<br><br>Aide-mémoire - reflect on learnings and consider my experiences throughout the research. | **3. Conditional matrices**<br><br>Conditional Relationship guides<br>Theoretical concepts<br>Cultural Interface |
| | **Limitations and reflections** | Limitations of this study. Challenges encountered in integrating CRT with GT. Areas for future research. | Aide memoire |

**Name:** Indigenous advisory groups

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**Modified On:** 10/5/2020 9:37:31 AM
**Modified By:** AT
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DIAGRAM

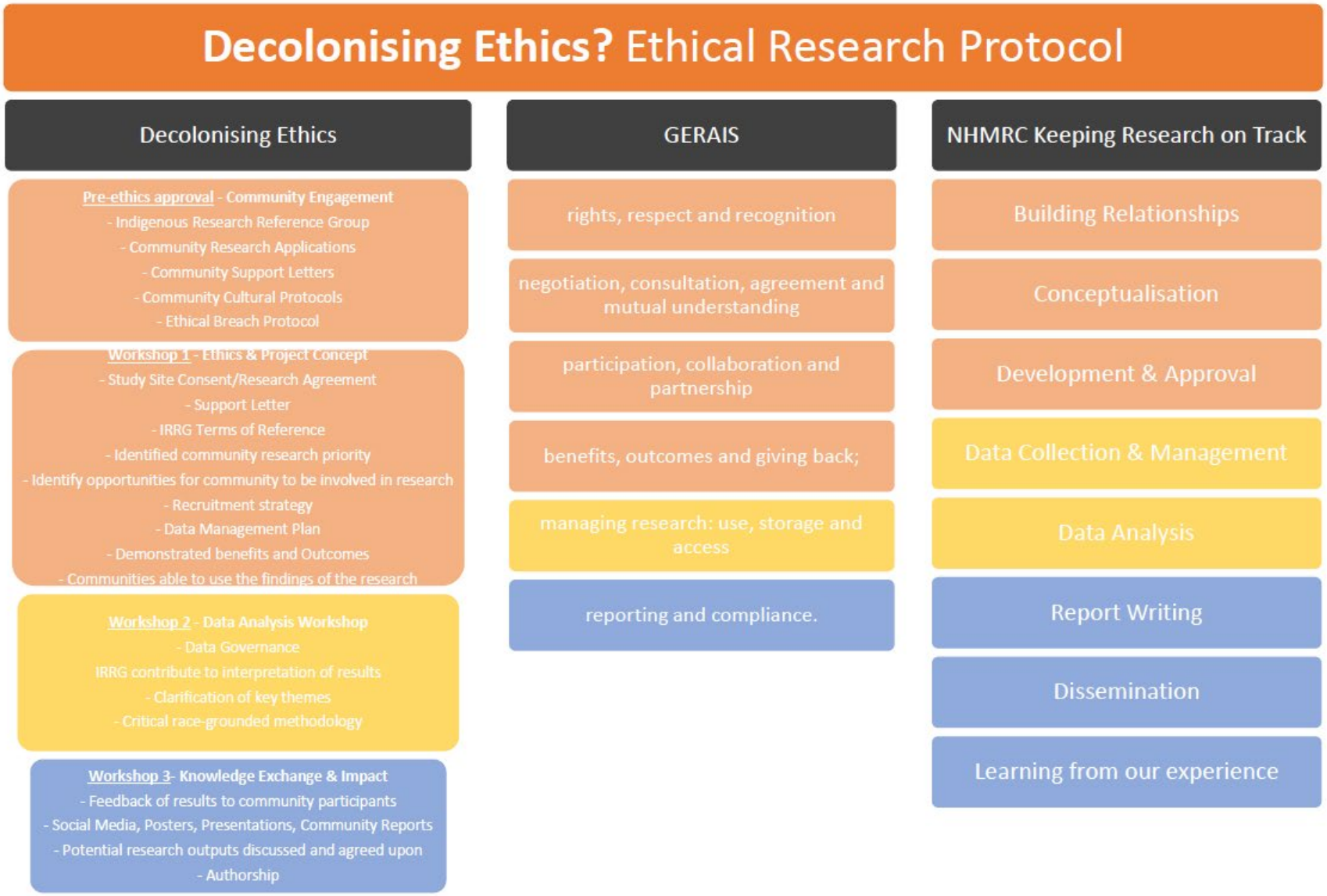
**IAG stucture**
Community vs Institutionalised IAGs
Tokenistic - Empowered
Statewide - Regional - Organisational
Terms of Reference

**Roles**
Pre-ethics
Aboriginal representation [Traditional owners - organisations - Peak bodies]
Advocacy
Safeguarding - protecting community - cultural safety - safe process -
Gatekeeping
Provide community and cultural accountabilty
Embed Indigenous protocols 'Cultural' ethics [assessing cultural validity and relevance] [AHMRC and AIATSIS]
Research governance - Screening for appropriateness - Interrogate the research
Approving/endorsing research
Reviewing ethics
Legitimising 'Indigenous' research
Improving research proposals
Building capacity
Research governance
Feeding back research progress/results

**Attributes**
Consistency
Credibility
Trusted network
Community expertise and relationships
Critiquing the research from an Indigenous standpoint
Negotiating the research
Facilitating collective consent

**Challenges**
Systemic barriers - Tokenised [lack of understanding of role] - afterthought - tick a box - paternalism - assumed academic superiority
Conflicting advice
Multiple authorities

Appendix D – Ethical Research Protocol



Appendix E

Indigenous Community Partner logo

Indigenous Community Partner logo

THE UNIVERSITY OF MELBOURNE

# Plain Language Statement

School of Global and Population Health, Faculty of Medicine Dentistry and Health Sciences

***Project: Decolonising ethics? A critical analysis of researchers intended ethical research practices and the role of Indigenous communities in ensuring ethical research***

Associate Professor Jane Freemantle (Responsible Researcher)
Tel: +61 3 8344 0640 Email: j.freemantle@unimelb.edu.au
Mr Alister Thorpe (PhD student) Email: athorpe1@student.unimelb.edu.au

## Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

## What is this research about?

Ethical frameworks for Indigenous[1] health research in Australia are well established. Yet there is limited research on how ethical principles for Indigenous health research are complied with in research practice

[1]As a Gunai, Yorta Yorta, and Gunditjamara man Alister Thorpe respectfully acknowledges the many distinct languages, cultural practices, and lore, of the First Peoples' of Australia. However, for this research the collective term 'Indigenous' will be used as it is frequently used in health contexts.

Appendix E

The purpose of this research is to is to explore how researchers comply with Indigenous health research ethics, and how Indigenous communities participate in the development, assessment, and monitoring of ethics. The aims of this study are to investigate;

- Indigenous experiences of researchers' application of National Health & Medical Research Council (NHMRC) ethical practices
- How researchers comply with Indigenous health research ethics
- The role of Indigenous communities in ensuring ethical research
- Barriers and enablers for Indigenous participation in the review of ethics
- How the NHMRC values and ethics guidelines address Indigenous human rights

### What will I be asked to do?

Should you agree to participate in this study you will be asked to share your experiences of ethical practices in previous research you have been involved in. This will be a face to face semi-structured interview and take up to one hour. We will take notes and if you consent, we will audio record your interview to ensure accuracy. You will be provided with the notes from your interview so that you can check them. The information provided by you will not be reported in a way that identifies you unless you specifically agree to this.

### What are the possible benefits?

This research aims to provide a better understanding of how researchers apply the NHMRC Indigenous Values and Ethics guidelines in practice. Indigenous community organisations could potentially use these findings to develop better strategies for ethical research in their communities. The research has the potential to be used to develop more effective and impactful ethical research policies that consider an Indigenous human rights perspective.

Participants will be offered $30 gift vouchers to compensate for sharing their knowledge in the research and will be reimbursed for travel expenses (up to $30).

### What are the possible risks?

Due to the small number of participants in this study it may not be possible to report on some findings without identifying you or the organisation you have participated in research with. If this is the case, we will ask you to approve the information before including in the thesis or any other publications.

In the final report, you will be referred to by a pseudonym. Any references to personal information that might allow someone to guess your identity will be removed.

An Indigenous Research Reference Group (IRRG) has been established to ensure community cultural protocols and values are respected throughout the study. The IRRG will provide expert advice about the content, methodology, strategies, and to advise on community engagement, and cultural protocols. Reference group members will be from

Appendix E
Indigenous communities in Victoria and will include community members from participating research sites.

All data, transcriptions, and journal notes will be stored securely and only accessible by the researchers listed.

### Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw at any time. You will have the option to withdraw any data collected about you up until reports have been approved and finalised. This means that any information you provide cannot be removed once it has been published.

### Will I hear about the results of this project?

After the study a community summary report will be provided to research participants and study sites. A knowledge dissemination strategy will also be developed in partnership with the IRRG – this may include community presentations, social media, posters, or other materials summarising the findings.

The findings of this research will also be submitted as the researcher's PhD thesis. Other potential academic outputs, including publication in peer reviewed journals, and conference presentations.

### What will happen to information about me?

All data collected about you will be kept electronically and stored securely on a University of Melbourne server for at least 5 years from the date of any publication, after which it will be destroyed. Any hardcopy data, including consent forms, and field notes will be kept in a locked filing cabinet at the University of Melbourne that only the PhD student will have access to. Digital data and audio files will be deleted and destroyed, and hardcopy files will be shredded and disposed of in confidential waste units, 5 years from the date of any publication.

### Is there any potential conflict of interest?

As an Aboriginal person, it is likely that the PhD researcher will have existing relationships with some participants from the community sites, but this will provide no benefit to the researcher. This perceived conflict of interest will be moderated by utilising the IRRG to target and make the initial approach to participants. The perceived conflict of interest will also be disclosed in the reporting of the research.

### Who is funding this project?

The University of Melbourne have contributed a RHD scholarship to the PhD candidate. The Lowitja Institute have also provided a PhD scholarship and project funding to the study.

Appendix E

### Where can I get further information?

If you would like more information about the project, please contact the researchers; Associate Professor Jane Freemantle j.freemantle@unimelb.edu.au, or PhD student Alister Thorpe ahthorpe@unimelb.edu.au or 03 8344 0640.

### Who can I contact if I have any concerns about the project?

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project.

## Appendix F Interview schedule

| Participant group | Question | Thematic focus |
|---|---|---|
| Past participant (pp), community coordinator (cc) | What good experiences have you had with research in your community?<br><br>What could have been done better in past research in your community? | Worldview |
| Researcher (r) | Can you tell me about your experience in Indigenous health research? | Worldview |
| Past participant (pp), community coordinator (cc), researcher (r) | In your opinion how can research demonstrate a commitment to working within the spirit and integrity of Indigenous peoples? | Demonstrating the values |
| Past participant (pp), community coordinator (cc), researcher (r) | Can you briefly describe how decisions are made about research in your community? | The role of Indigenous communities |
| Community coordinator (cc), researcher (r) | Can you give examples of how participating Indigenous communities support recruitment of participants? | The role of Indigenous communities |
| Community coordinator (cc), researcher (r) | What has been your experience of researchers willingness to modify research to fit with community aspirations? | The role of Indigenous communities |
| Past participant (pp), community coordinator (cc), researcher (r) | Can you describe any barriers to providing feedback to communities?<br><br>How was the research reported back to the community? | Learning from the experience |
| Past participant (pp) | How did you find out about the research (you participated in previously)?<br><br>Did you trust the researchers? Why/why not? | Community engagement |
| Community coordinator (cc) | How was the community supported to participate in the research?<br><br>Did you trust the researchers? Why/why not? | Community engagement |
| Researcher (r) | How was the community supported to participate in the research?<br><br>How did you gain the trust of the Indigenous community? | Community engagement |
| Community coordinator (cc), researcher (r) | How was the Indigenous community involved in the development of the research concept/aims/questions? | Conceptualisation |

## Appendix G Revised Interview schedule

| Participant group | Question | Thematic focus |
|---|---|---|
| Community coordinator (cc), researcher (r) | Was there any opportunity for community stakeholders to modify the research? | Conceptualisation & decision making |
| Researcher (r) | How have you recognized Indigenous knowledges that have contributed to your research? | Data sovereignty |
| Researcher (r) | Can you describe any barriers to ethical research with Indigenous health peoples? | Worldview |
| Community coordinator (cc), researcher (r) | What is required to support improved Indigenous representation on Human Research Ethics Committees? | The role of Indigenous communities |
| Past participant (pp), community coordinator (cc) | Can you describe the different roles you might perform when participating in, or coordinating, research in your community | The role of Indigenous communities |

Decolonising ethics?
A critical analysis of researchers intended ethical research practices and the role of Aboriginal communities in ensuring ethical research
Volunteers required
Have you participated in an Aboriginal health project since 2003?
Share your experience!
We are looking for Aboriginal community members aged 18 and over to take part in a health research study. Volunteers in the study will be asked about their experiences with ethical practices in past Aboriginal health research they have been involved in.
Volunteers will take part in an interview with an Aboriginal researcher that should only take approximately 60-90 minutes. Participants will be reimbursed $50 for their time.
For more information or to participate in this project please contact Alister Thorpe on 0432 631 608 or email: ahthorpe@unimelb.edu.au
OR Leave your contact details at reception.

Appendix I Findings – Demonstrating Ethical Indigenous Health research - Participant quotes in relation to focused codes and sub-codes

| Focused codes | Sub-codes | Significant quotes |
|---|---|---|
| ***Engaging Indigenous communities*** | Engaging with Indigenous organisations, engaging with known Indigenous community leaders, earning trust, fronting up, tuning, becoming known | "…if I was to go into a community that I didn't know you know, I'd try to make a connection with someone I know who's from that community, and if they can introduce me to the CEO of an Aboriginal organisation or, an elder, or, you know, a community member." **Non-Indigenous researcher**<br><br>"Or have you considered doing this with your research because you've actually bothered to build a relationship. So, I think that's something that's really important to remember that relationships in this space are important. **Non-Indigenous researcher**<br><br>"Luckily there was one Aboriginal organisation who was really keen to be involved. So it meant a couple of meetings taking the non-Indigenous researcher to a meeting. Oh, priming them on the way and negotiating how to do the meeting." **Indigenous researcher**<br><br>"Their relationships, their values, how they engage the Aboriginal people. Are they prepared because you know what happens, they'll come to you and say listen, I love [Indigenous organisation] you make all the decisions. Oh yeah, that's what we like hearing that. Sweet we will sign on. And then what happens down the track where we say we don't want that. Sometimes you've got to test that early and just come up with something, just test it." **Community coordinator** |
| ***Getting community approval*** | Collective Indigenous consent, contested collective approval, 'Black-fronting', informed consent, multilayered approval, developing agreements, objecting to research, right to speak 'on country', individual informed consent | "Just because you've got ethics from your institution, it doesn't mean that it's ethical in terms of what the community believes is what you need to do. So just 'cause you've got that tick off doesn't meant that gives you approval to go and do research in that community. You actually have to get that approval from the community to go and do research in there." **Past participant turned Indigenous researcher**<br><br>"It was myself, and [two other Indigenous community members]. That were the only three. …And the other blackfellas were all from [other Indigenous community organisations] and the rest were from government. More government workers once again. I said, 'Who's the community who you're talking to? What are you asking them?" **Community coordinator turned Aboriginal researcher**<br><br>"…but also the system, and I think the way that you know, we, so do I need to go to a uni and then ask them permission to do research with my own |

Appendix I Findings – Demonstrating Ethical Indigenous Health research - Participant quotes in relation to focused codes and sub-codes

| | | |
|---|---|---|
| | | mob, and then fill out their forms and then send them back to them and then wait for them to say it's okay, when really what I should be doing is just sitting down with my elders, and asking them and telling them and then getting feedback. You know? You have to do both." **Indigenous researcher**<br><br>"...I'd reckon- and I don't know obviously it was before it's time, but that [traditional owner] ethics group. I think that's really important piece of infrastructure." **Past participant** |
| ***Creating equal partnerships*** | Partnering with Indigenous communities, establishing Indigenous advisory committees, Indigenous co-researchers, Indigenous led-research, co-designed Indigenous research, excluding Indigenous communities, unequal partnerships | "It's, it's still the, the competition between the institution and the organisation. The institution still holds all the mighty power, and still ... It's everything, we will talk everything about the community engagement to the point it's actually... Give us the reins." **Community coordinator**<br><br>"That is what they're trying to do here at the [Indigenous organisation]. They're trying to have more control over the research that comes out of this community." **Past participant**<br><br>"The board are elected by the community and if we are going to do research in our community the board need to own it. As staff members we just can't say we are going to do this research. ...So, the research sub-committee which should have a board member, looks at it and goes through stuff that whether it's ethical, whether it's useful, whether it's worthwhile and then we would, we would say, yes, we agree or no forget about it. So that's the process. And on that committee are senior staff, whoever's involved." **Community coordinator**<br><br>"'Cause we feel like even some of our concerns would be stated, just not taken on board." **Community coordinator** |
| ***Protecting Indigenous participants and communities*** | Respecting community protocols, respecting culture, respecting Elders, becoming culturally accountable Creating culturally safe research, 'gate-keeping', slowing down, protecting participants, protecting Indigenous community partners, facilitators, and researchers | "And that's a major thing when you're doing that sort of stuff, is the cultural part of it. Cultural respect and knowing not to step over that line when you, when you're asking questions about different things." **Community coordinator**<br><br>"But we [IRRG] need to have as much authority as what the ethics committee does too. We need to say, well we don't agree with that. And stop it in its tracks. So you know, none of these are gonna be done, but if we don't like it, we gotta stop it." **Community coordinator turned researcher** |

Appendix I Findings – Demonstrating Ethical Indigenous Health research - Participant quotes in relation to focused codes and sub-codes

| | | |
|---|---|---|
| | | "You've got to answer to your Elders, which are the board, which I think is, is really, and that's my sense, it feels like it should be hard [to get research approved]." **Indigenous researcher**<br><br>"Our elders feeling that they are still able to make a contribution, and it's a valued one that's taken seriously. If you know what I mean. It's not token." **Community coordinator**<br><br>"[Y]ou know, you have these unbelievably dumb white advisors in communities. …So yeah, we have a pretty serious problem developing with people who actually have no clue about what research is, they're working on communities, and they've become the gatekeepers of these communities." **Indigenous Researcher** |
| ***Valuing the contribution of Indigenous people*** | Respecting Indigenous knowledge holders, exploiting Indigenous knowledge, academic recognition of Indigenous contributors, valuing Indigenous worldviews, Indigenous data | "…that knowledge whilst it's individual, it's cultural knowledge that is connected. Through a number of ancestors and family lines and so it's also, kind of collective knowledge." **Past participant**<br><br>"'Cause we're the custodians of the data. That's the other thing, we don't own it." **Indigenous researcher**<br><br>"It [MoU] protects our rights to a degree, and I think enough of a degree that, that we feel more secure. But it is interesting because I do have that question mark around data sovereignty and legal rights when it, when push comes to shove. I think that, I think that there's probably a lot of murky area that needs to be unpacked, you know." **Indigenous researcher**<br><br>"Data is owned by [Indigenous organisation]. …there is a memo that was put in to say that the data remains the intellectual property of [Indigenous organisation]. Before the research was undertaken. I think that ensures that the data stays safe, because it stays within our community. And it's not with them." **Indigenous researcher**<br><br>*[An agreement between a PhD student and an Indigenous organisation]*<br>If we were to use any of the data following the completion of the project, that there would be consultation between the two parties to ensure appropriate use and interpretation of the data" **Indigenous researcher**<br><br>"That is actually a tricky one because I wondered about like part of it was in validating [researchers] measure, and now it's like who owns that |

Appendix I Findings – Demonstrating Ethical Indigenous Health research - Participant quotes in relation to focused codes and sub-codes

| | | |
|---|---|---|
| | | measure? Is it [the Indigenous organisation]? Is it nobody? Is it [the researcher]?" **Indigenous researcher** |
| ***Giving back to Indigenous communities, participants, and partners*** | Reciprocal obligations, empowering Indigenous participants, partners, and communities, translating research into outcomes, shelving findings | "…it's about how you contribute and how he can see you're going to [make a contribution] …that's right for us." **Indigenous researcher**<br><br>"…we're still trying to come to terms with what we achieved as an Aboriginal advisory group. How we benefited the project. …it's around our professional integrity that's in question, and like- and the devaluing of us as an advisory group. **Community coordinator** |

Appendix J ***Findings –Ethical review of Indigenous research & Unethical practices - Participant quotes in relation to focused codes and sub-codes***

| Focused codes | Sub-codes | Significant quotes |
|---|---|---|
| ***Ethical review*** | Understanding the guidelines, academic interpretation, Indigenous interpretation, conflicts of interest, Indigenous community-led review, paternalistic review | "Or they want you to dumb down the plain language statement that's already plain language even more, 'cause how are those Aboriginal people from somewhere out there gonna understand that? You know, the same thing you would put through in another research area, and they wouldn't blink." **Researcher**<br><br>"I've got to the point, and I say it to people, you know, loudly, because I think it needs to be said. They cannot expect us to take their ethics process seriously when they ask such insulting, insulting questions about Aboriginal people and make such insulting assumptions about Aboriginal people. They're really, really insulting." **Indigenous researcher**<br><br>"I don't mind those ticks. I don't mind those checks. I think they're actually, I think they actually were really good for me. And they gave me confidence, really, in my research. So, I don't see anything negative with doing that." Past participant turned **Indigenous researcher**<br><br>"There's no question about whether or not you're gonna get the authority to do this. You will, because the university wants you to do the work." **Indigenous researcher**<br><br>"We really wanted to do it right but we changed it. On an ethics committee there's different people that you need. One of them was a priest or chaplain. We crossed that out and said Aboriginal elder." **Community coordinator** |
| ***Unethical practices in Indigenous health research*** | Avoiding and downplaying the guidelines, they didn't know they were doing the wrong thing, they're not listening, they don't want to follow the proper processes, researchers' know best, reporting on ethical conduct, bending academic compliance, | "NHMRC guidelines and Aboriginal Torres Strait islander health research guidelines easily accessible, well written, clearly explained in two documents promoted by HRECs that they must be answered with other little instructions. And usually, I can't contact person for assistance, and they are met poorly. They are met poorly." **Indigenous researcher** |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Aboriginal representation | | 13 | 55 |
| Black fronting | | 5 | 5 |
| Indigenous Advisory Groups | | 7 | 18 |
| Institutional Aboriginal research review | | 2 | 5 |
| Indigenous researchers | | 5 | 16 |
| Manufacturing representation | Manufacturing cultural legitimacy | 4 | 19 |
| Manufacturing approval | Pushing predetermined research, Rubber stamping | 4 | 18 |
| Tokenistic Indigenous involvement | | 7 | 13 |
| Devaluing contribution | | 2 | 7 |
| Ignoring advice | | 1 | 3 |
| Poorly informed | | 2 | 6 |
| Respecting Indigenous authority | | 6 | 13 |
| 'right to speak on country' | | 7 | 15 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Speaking for Aboriginal people | | 1 | 2 |
| Tokenistic representatives | | 4 | 6 |
| Traditional owner representation | | 1 | 4 |
| Accountability | | 5 | 24 |
| Cultural accountability | | 12 | 45 |
| Community accountability | | 4 | 8 |
| Fronting up | | 3 | 5 |
| Local accountability | | 2 | 5 |
| Personal accountability | | 2 | 2 |
| Institutional accountability | | 5 | 19 |
| Sharing responsibility | | 2 | 3 |
| Acknowledging Indigenous contribution | | 8 | 27 |
| Valuing Indigenous participants | | 6 | 14 |
| 'We are a number' | | 1 | 2 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Benefits of research | | 4 | 4 |
| Creating opportunities | | 2 | 8 |
| Giving back (reciprocity) | | 9 | 28 |
| Indigenous research benefits | | 9 | 21 |
| Mutual benefits | | 2 | 2 |
| Sharing benefits | | 2 | 2 |
| Tangible benefits | | 3 | 5 |
| Translating to outcomes | | 3 | 5 |
| Brokering research | role of peak bodies | 5 | 22 |
| Broken relationships | | 2 | 6 |
| Community facilitators | Sometimes not specifically funded - additional role for existing workers. They know what's gonna work | 2 | 9 |
| Multiple roles | | 3 | 12 |
| Endorsing research | | 1 | 2 |
| Facilitating relationships | | 3 | 4 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Pooling resources | Academic partners - funding - other resources. | 1 | 5 |
| 'Priming' researchers | Organisations and community members chaperoning researchers and institutions | 1 | 4 |
| Recognising opportunities | | 3 | 5 |
| Building Indigenous research capacity | ACCHOs and communities. Adding value. Localised capacity. Research capacity. Supporting Indigenous communities | 11 | 75 |
| Draining capacity | | 4 | 10 |
| Support to contribute to research | | 2 | 2 |
| Supporting Indigenous review of ethics | see annotation 3 | 2 | 3 |
| Systemic capacity | HRECs - Researchers - Research Integrity - Universities - Institutions | 5 | 18 |
| Training researchers | | 5 | 18 |
| Building relationships | Bringing people together. Existing relationships. Tuning. Making connections. Understanding community | 13 | 68 |
| Engaging community | Deep engagement. Engage the right people. | 7 | 21 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Engaging Indigenous Partners | Equal partners. Empowering Indigenous partners. | 4 | 21 |
| Informing community | | 8 | 22 |
| Existing relationships | | 7 | 16 |
| Making connections | | 2 | 10 |
| Tuning | | 2 | 14 |
| Understanding community | | 7 | 10 |
| Community ownership of research | Empowering Indigenous partners | 10 | 20 |
| Giving us the reins | | 3 | 4 |
| Complying with ethics | A systemic response. Privileges academics. Whose purpose does this serve? Academia or Community? | 6 | 16 |
| Acting compliant | | 2 | 10 |
| Administering | | 3 | 7 |
| Ammending | | 2 | 5 |
| Avoiding | Bending. Downplaying | 5 | 9 |
| Breaching | | 2 | 3 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Burdening researchers | When engaging with community members, ACCOs, workers, about research there are many complex layers and interrelationships between all these roles | 3 | 7 |
| 'Cajoling' | | 1 | 1 |
| Doing the right thing | | 1 | 3 |
| Dressing up | | 1 | 1 |
| Facilitating | | 3 | 5 |
| Fronting up | | 3 | 5 |
| Improving | | 2 | 2 |
| Interpreting | | 4 | 7 |
| Making complaints | | 4 | 6 |
| Modifying | | 3 | 7 |
| Not addressing | | 2 | 5 |
| Paying lip service | | 3 | 13 |
| Poor ethics | | 2 | 5 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Pushing | Quick ethics vs slow ethics | 5 | 16 |
| Retrofitting | Revising | 1 | 2 |
| Slowing | | 7 | 11 |
| They're an afterthought. | | 1 | 2 |
| Ticking the box | | 5 | 5 |
| Translating | | 3 | 10 |
| Conforming to the system | | 4 | 18 |
| 'Black fronting' | | 3 | 6 |
| Compliant | | 1 | 2 |
| Seeking validation | | 2 | 5 |
| Validating institutional exploitation | | 5 | 12 |
| Controlling the research | | 10 | 23 |
| Aboriginal-led research | Identifying research partners. Listening to Aboriginal researchers. Listening to the community | 12 | 40 |
| Clearly defined Indigenous roles | | 2 | 5 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Community control | | 8 | 25 |
| Community driven research | | 9 | 28 |
| Formalising protocols | | 1 | 11 |
| Identifying research priorities | | 10 | 57 |
| involved every step of the way | | 4 | 11 |
| Managing research | | 2 | 4 |
| Research governance | Research done right. Research done wrong | 2 | 4 |
| Researcher driven research | | 3 | 4 |
| Sharing the control | | 4 | 13 |
| Cultural ethics | Assessing cultural validity. Hidden Indigenous ethics | 5 | 11 |
| Obligating researchers | Researchers engage with communities and become obligated to research from and Indigenous perspective. Obligated to do research in a way that benefits the communities they work with and not the institutions who employ them. | 4 | 18 |
| Slow research | | 5 | 15 |
| Understanding the history | | 6 | 9 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Working at community pace | 'Community flow'  Researcher flexibility | 3 | 4 |
| Cultural safety | | 9 | 23 |
| Creating safe spaces | | 6 | 22 |
| Inappropriate methods | | 2 | 10 |
| Researchers Lack of knowledge | | 5 | 8 |
| Understanding socio-cultural context | | 6 | 10 |
| Decision making | Undermining community decisions. Ignoring advice | 9 | 33 |
| Creating boundaries | | 2 | 9 |
| Gatekeeping | | 7 | 24 |
| Power | | 4 | 11 |
| Fast research | | 3 | 12 |
| 'Compromising integrity' | | 3 | 6 |
| In and out ... | | 3 | 6 |
| Pushing research | | 2 | 4 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Rigid timelines | | 3 | 10 |
| Getting approval for Indigenous research | | 11 | 50 |
| Indigenous community approval | | 2 | 6 |
| Fractured decision making | | 2 | 10 |
| Institutional ethical approval | | 1 | 6 |
| Shopping around for approval | Replacing community representatives | 3 | 12 |
| Indigenous leadership | | 3 | 8 |
| Institutional leadership | | 2 | 5 |
| Mentoring Indigenous researchers | | 4 | 16 |
| Indigenous protocols | Avoiding protocols. Breaking protocols. Following protocols. Misusing cultural knowledge and artefacts. Respecting Cultural Authority. Risking cultural integrity. Silence - Not responding. Taking time | 14 | 50 |
| Avoiding protocols | | 4 | 4 |
| Breaking protocols | | 7 | 24 |
| Following protocols | | 5 | 5 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Risking cultural integrity | | 3 | 4 |
| Silence - Not responding | | 2 | 8 |
| Taking time | | 7 | 26 |
| Knowledge Creation | | 3 | 7 |
| Indigenous knowledge | Collective knowledge. Undervaluing | 4 | 10 |
| Interpreting the results | | 12 | 39 |
| Lost in translation | Making assumptions, using a western knowledge lens, passing off as truth | 4 | 7 |
| Using cultural language | | 3 | 13 |
| Protecting knowledge | Opposite of sharing - Retaining, withholding. Keeping secret/sacred. Knowledge that is not given until trust has been earnt. You don't know where that knowledge is going to go. None of 'their' business. | 3 | 11 |
| Sharing Knowledge | | 6 | 9 |
| Taking Knowledge | Extracting information and knowledge - picking our brains | 11 | 24 |
| Commodifying knowledge | | 3 | 7 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Stealing knowledge | Claiming someone elses knowledge without proper consent or acknowledgement | 4 | 7 |
| Using the findings | | 6 | 22 |
| Publishing research findings | | 7 | 19 |
| Culturally relevant 'publishing' | | 1 | 2 |
| Publishing with community | | 6 | 10 |
| Researcher driven publishing | | 3 | 9 |
| Shelving research | | 4 | 7 |
| Validating knowledge | | 5 | 17 |
| Making agreements | At the table. 'Living' agreements. | 4 | 9 |
| Negotiating the research | | 3 | 5 |
| Managing data | | 4 | 7 |
| Collecting data | | 4 | 5 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Data Ownership | | 11 | 42 |
| Data privacy and confidentiality | | 3 | 16 |
| Data Sovereignty | | 3 | 6 |
| Intellectual property | | 6 | 13 |
| Protecting our data | | 2 | 4 |
| Using our data | | 5 | 11 |
| Monitoring research | | 8 | 20 |
| Checking and reviewing processes | | 5 | 6 |
| Over researching | | 2 | 4 |
| Burdening Indigenous communities | | 3 | 10 |
| Burdening community members | | 2 | 4 |
| Coercive research | | 4 | 5 |
| Obligating communities | Railroading Aboriginal people | 5 | 12 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Extending research | | 2 | 4 |
| Overcommitting to research | Stretching research capacity | 6 | 18 |
| Participating in research | | 3 | 5 |
| Consent | | 5 | 8 |
| Collective consent | | 7 | 24 |
| Culturally Unlawful Consent | | 1 | 5 |
| Dynamic consent | | 2 | 3 |
| Gaining consent | | 2 | 7 |
| Informed consent | | 3 | 14 |
| Manufacturing consent | | 4 | 11 |
| Retrospective consenting | | 2 | 4 |
| Withdrawing Consent | | 3 | 6 |
| Harming participants | | 2 | 3 |
| Inappropriate participation | | 1 | 4 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Obligating participants | Need to reference cultural practices around cultural obligations | 2 | 5 |
| Recruiting Indigenous participants | | 4 | 12 |
| Opportunistic recruitment | | 1 | 4 |
| Power dynamics | | 4 | 4 |
| Contesting | | 1 | 6 |
| Disrupting | | 3 | 21 |
| Maintaining control | | 2 | 10 |
| Relinquishing power | | 4 | 8 |
| Systemic control | | 6 | 12 |
| Pre-ethics | Community research capacity. Don't have the time. Research ready. Under resourced involvement | 10 | 31 |
| Community research capacity | Including - ACCHOs - Peak bodies - Indigenous researchers | 10 | 50 |
| Don't have the time | | 3 | 5 |
| Research ready | | 4 | 14 |
| Under resourced involvement | | 5 | 13 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Protecting Indigenous community | | 8 | 13 |
| Operating defensively | | 1 | 2 |
| Protecting Indigenous participants | | 5 | 33 |
| Protecting Indigenous researchers | | 2 | 2 |
| Safeguarding community | | 3 | 10 |
| RECOMMENDATIONS | | 6 | 18 |
| Best practice model | | 3 | 10 |
| Ethical review systems | | 2 | 2 |
| Regional research registers | | 3 | 7 |
| Rejecting research | | 7 | 28 |
| Knocking back research | | 1 | 2 |
| Pushing research back | | 2 | 8 |
| Stopping research | | 4 | 12 |
| Reporting back to community | | 15 | 54 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Localised reporting | | 5 | 9 |
| Research conceptualisation | Designing research | 4 | 16 |
| Developed in partnership | | 4 | 6 |
| Modifying research | | 2 | 12 |
| Preconceiving research | | 7 | 25 |
| Reviewing ethics | | 5 | 18 |
| Gatekeeping research | | 2 | 10 |
| Indigenous-led ethical review | | 6 | 32 |
| Local ethics committees | | 2 | 5 |
| Seeking cultural ethical advice | | 3 | 10 |
| Unsupported | Not systemically supported - unstructured - unresourced - systemically exploited | 2 | 6 |
| Institutional ethical review | State government ethical review boards + University HRECs + Institutional Índigenous' ethics committees | 1 | 3 |
| HREC advice | | 2 | 15 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| HREC amendments | | 2 | 9 |
| HREC capacity to review Indigenous research | Oversimplification and generalisation of Indigenous issues. Lack of nuance when considering research. Lack of Indigenous representation. Paternalistic, demeaning and petty feedback. Systemic assumption of Indigenous vulnerability because of how the ethical frameworks are embedded (High Risk categorisation) | 4 | 24 |
| Contextualising research | | 1 | 5 |
| Disciplinary biases | | 1 | 8 |
| HREC interpretation of the values | | 2 | 4 |
| Flexible interpretation | | 1 | 11 |
| Paternalistic ethical review | | 2 | 19 |
| Multi-layered review | Complex - Multi-sites - Multi-projects - No standardisation | 6 | 25 |
| Lack of standardisation | | 2 | 11 |
| Multi-sited ethics | | 2 | 9 |
| Redundancy | | 1 | 3 |

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Time consuming | | 2 | 7 |
| Pushing research through | | 2 | 5 |
| Supporting researchers | | 1 | 3 |
| Student-led research | | 2 | 7 |
| Supervising Indigenous researchers | | 2 | 4 |
| Supporting Indigenous research | | 2 | 5 |
| supporting research | Aboriginal community supporting research. 'we don't want them to fail' | 2 | 4 |
| Systemic exploitation | | 7 | 23 |
| Exploiting community | | 5 | 25 |
| Exploiting Indigenous community relationships | | 3 | 12 |
| Exploiting Indigenous voice | Researchers using Aboriginal voices to drive their own agenda - manipulation 'using Aboriginal peoples voices and experiences' | 4 | 11 |
| Exploiting Indigenous researchers | Exploiting Indigenous research students | 5 | 21 |
| Feeling yuck | | 1 | 9 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Misleading research | Misleading researchers | 2 | 8 |
| Predatory research | | 3 | 4 |
| Systemic power imbalance | Institutional academic entitlement. Researcher privilege | 9 | 80 |
| Academic superiority complex | Academic hubris. Gatekeeping academic legitimacy | 8 | 33 |
| Academic hubris | | 4 | 5 |
| Gatekeeping academic legitimacy | HRECs + Funders + Institutions + Researchers | 1 | 8 |
| Decolonising research processes | | 3 | 5 |
| Imbalance of resources | | 3 | 4 |
| Institutional academic entitlement | | 8 | 37 |
| Protecting universities | | 1 | 5 |
| Marginalising Indigenous voices | | 7 | 26 |
| Positionality | | 4 | 14 |
| Conflicting interests | | 7 | 10 |
| Indigenous worldview | | 5 | 12 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Paternalism | Layers of paternalism = HREC - Researchers + HREC - Community + Researchers - Community. Assumption of research benefits | 12 | 37 |
| Dumbing down | | 2 | 10 |
| Privileging Indigenous voices | Capturing community voices. Giving them their voice | 8 | 26 |
| Researcher privilege | 'Protecting their patch'. Researcher entitlement | 7 | 46 |
| 'Protecting their patch' | | 5 | 11 |
| Structural disempowerment | | 5 | 8 |
| Systemic drivers of inequality | Isolating Indigenous researchers | 8 | 32 |
| Academic peer pressure | | 4 | 8 |
| Academically driven | | 4 | 8 |
| Capacity building | | 1 | 8 |
| Progressing their career | | 3 | 4 |
| Trust | | 8 | 18 |
| Building trust | | 6 | 12 |
| Built-in trust | | 5 | 9 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Distrust in mainstream | | 5 | 10 |
| Earning trust | Earning the right for information | 9 | 25 |
| Fulfilling promises | | 2 | 12 |
| Institutional trust | | 3 | 10 |
| Research was a dirty word | | 1 | 3 |
| Maintaining trust | | 4 | 14 |
| Researcher credibility | | 2 | 6 |
| Transparency | | 2 | 4 |
| Trusting Indigenous researchers | | 1 | 2 |
| Two ways | | 3 | 7 |
| Conflicting perspectives | | 3 | 7 |
| Two different time zones | | 2 | 4 |
| Understanding ethics | | 7 | 12 |
| Ignorance | | 3 | 5 |

Appendix K Codebook (Produced using Nvivo software)

| Codes | Description | Number of participants | References |
|---|---|---|---|
| Institutional visibility | Systemically disengaged - limited opportunities to share skills | 1 | 4 |

Appendix L Conditional relationships for focused codes

| *Focused Code* | *What* | *When* | *Where* | *Why* | *How* | *Consequence(s)* |
|---|---|---|---|---|---|---|
| Engaging Indigenous communities | Building relationships with Indigenous communities | At any time | Through appropriate community networks | Build authentic trusting long term sustainable relationships | Building trust, fronting up, becoming known | Becoming obligated<br>Identify appropriate partners<br>***Reciprocity i**<br>***Spirit ii**<br>***Equality ii** |
| Getting community research approval | Getting Indigenous community approval to conduct research | Before research commences | Through appropriate community representative structures | To complete ethical research applications | Seeking formal community approval<br>Becoming trusted<br>Following community research protocols | Indigenous community approval<br>Institutional ethics approval<br>***Responsibility ii**<br>***Survival ii & iii**<br>***Spirit i & ii** |
| Creating equal partnerships | Establish research relationships based on equal partnership | Before research is conceived<br>After engaging with appropriate partners | Within Indigenous community settings and within institutions | Respect Indigenous leadership, expertise, and knowledge<br>To empower Indigenous community leadership | Indigenous investigators<br>Indigenous community advisors<br>IRRGs<br>Agreements / MoUs<br>Joint funding<br>Co-designed research | Community-led research<br>Empowered partners<br>Collaborative research<br>***Reciprocity i**<br>***Spirit ii**<br>***Equality ii** |
| Protecting Indigenous communities | Protecting Indigenous participants, communities, and partners of research | At all times | Engagement<br>Approval<br>Recruitment<br>Data analysis<br>Knowledge production<br>Reporting | To prevent harm | Adhering to IRRG advice<br>Creating culturally safe research<br>Slowing down research<br>Creating agreements | Doing no harm<br>***Survival i**<br>***Respect i**<br>***Responsibility i** |
| Valuing Indigenous contribution | Valuing contribution of Indigenous people | Throughout the research | Data analysis<br>Data collection<br>Dissemination of findings | Recognise Indigenous contributors<br>Respect Indigenous knowledge | Community DMPs research agreements<br>Community reports | Recognition of Indigenous contribution to the research |

Appendix L Conditional relationships for focused codes

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | Indigenous Authorship | | Sharing authorship<br>Protecting Indigenous knowledge & ICIP | Valuing Indigenous knowledge<br>*Respect i<br>*Spirit i<br>*Equality i |
| **Giving back to Indigenous communities** | **Reciprocal obligations with Indigenous communities that have engaged in research** | **Throughout the research**<br>**After the research is completed** | **Within Indigenous community settings** | **To consolidate relationships, build trust and respect with Indigenous community partners** | **Respecting community obligations**<br>**Using research findings** | **Meeting reciprocal obligations**<br>**Translating research into outcomes**<br>***Equality i**<br>***Reciprocity ii** |

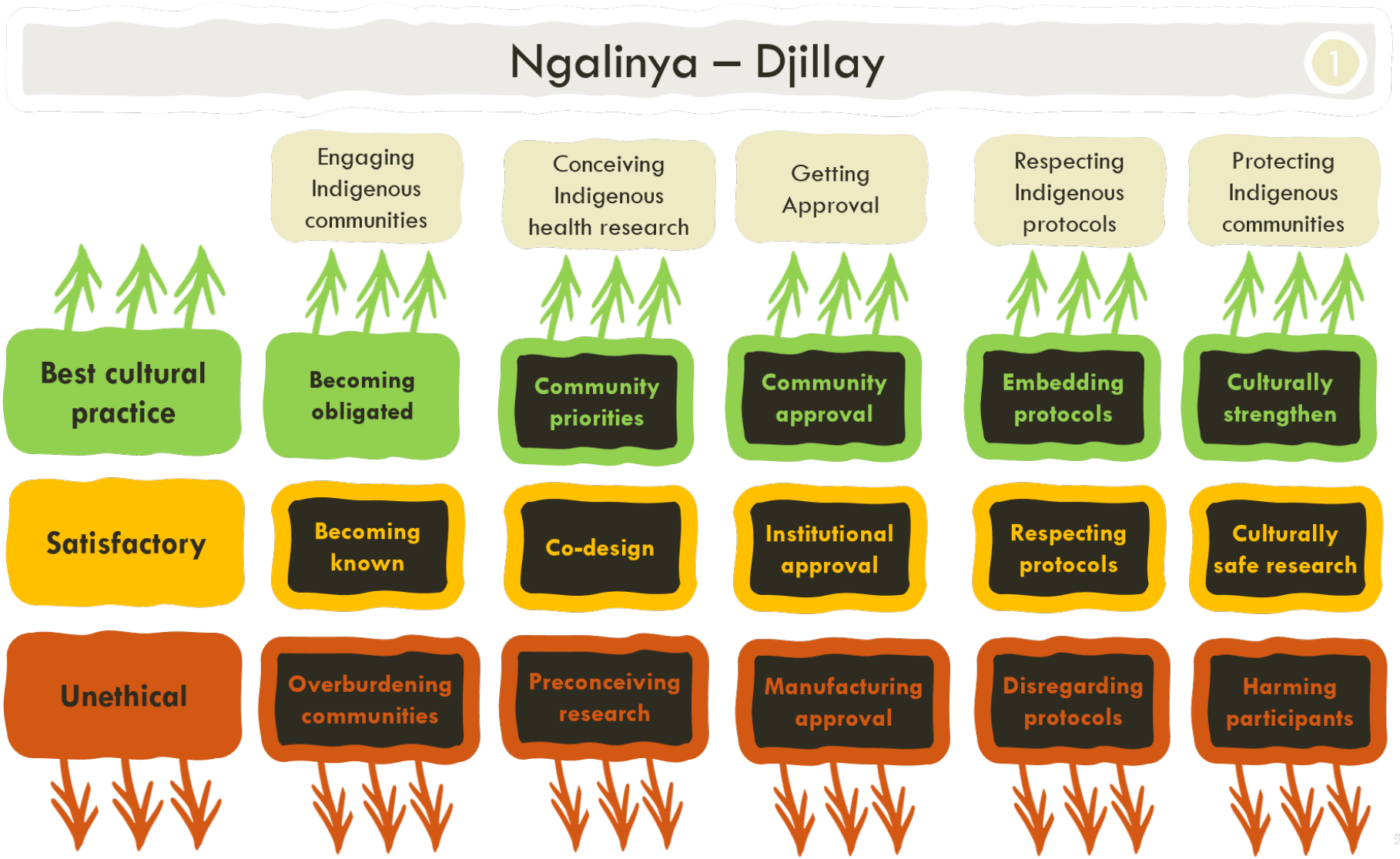
**Relevant values*

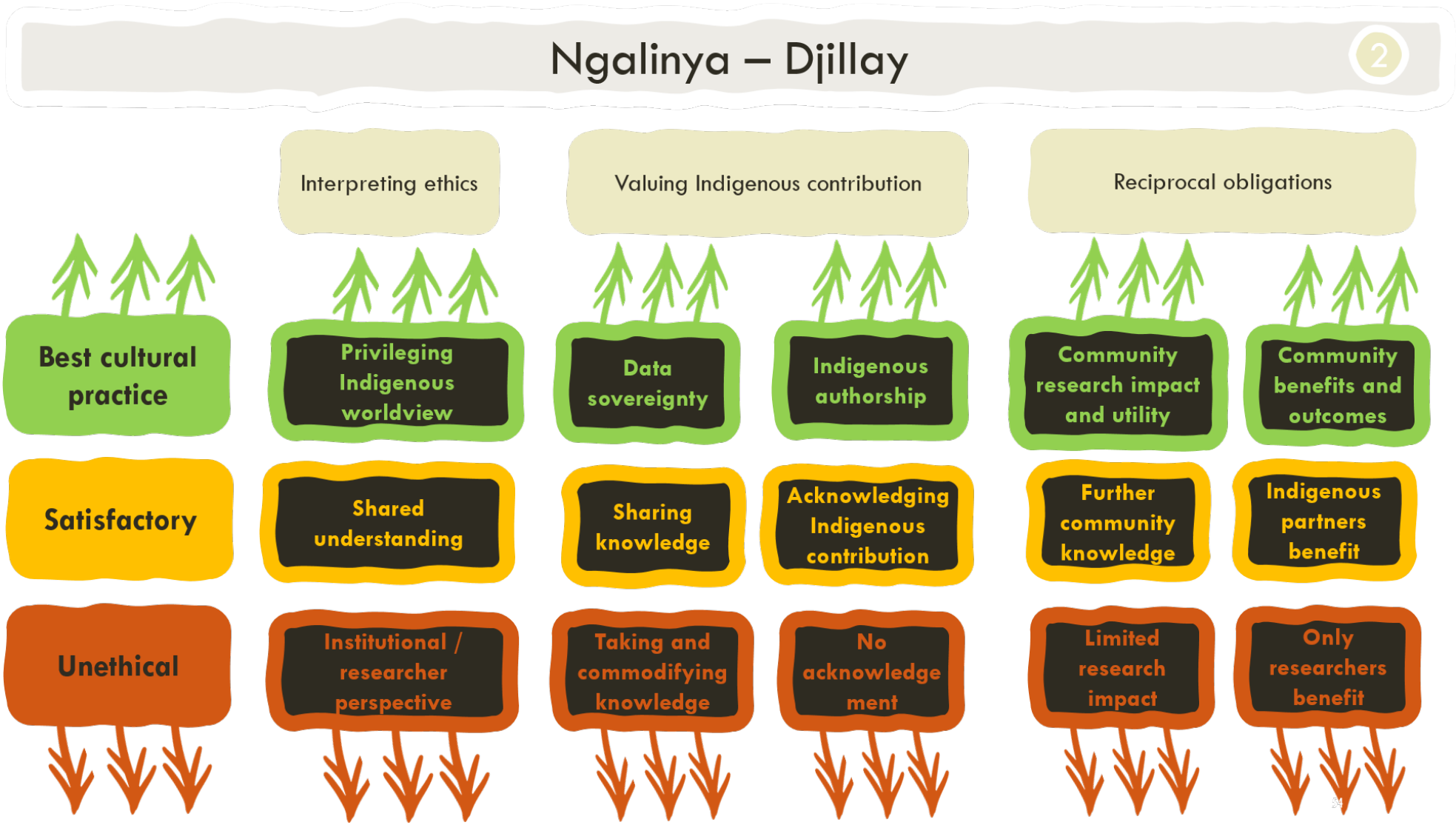
Appendix M Conditional relationships for theoretical concepts and other codes

| *Theoretical concepts* | *What* | *When* | *Where* | *Why* | *How* | *Consequence(s)* |
|---|---|---|---|---|---|---|
| Evading ethics | Strategic avoidance of the *guidelines* | Through the ethical review process | Through HRECs | Avoid *guidelines*<br>Avoid high risk review<br>Speed up approval | Downplaying or Omitting Indigenous components of application | Incomplete and false ethics applications |
| | Bending protocols | During the research | Engagement<br>Approval<br>Recruitment<br>Data analysis<br>Knowledge production<br>Reporting | Avoid protocols<br>Speed up research | Non-compliance with ethical approval<br>Not following ethical processes | Failure to fulfill ethical obligations<br>Ethical breaches<br>Potential harm to Indigenous participants |
| | Stretching ethical approval | After ethics approval | Through HRECs | Avoid *guidelines*<br>Exploit gap in review | Submit lengthy amendments | Unwarranted ethical approval |
| Manufacturing community approval | Constructing institutional mechanisms to streamline Indigenous community approval processes | Before research commences | Through institutions without appropriate authority | To speed up ethics applications<br>To conduct Indigenous health research | Shopping around for approval<br>Institutionally appointed Indigenous representatives | Disrupting community ***spirit and integrity**<br>Unethical Indigenous community approval |
| Manufacturing representation | Co-opting Indigenous representatives to approve research through institutional mechanisms | Before research commences | Through individuals without a mandate to represent Indigenous collectives | To secure Indigenous research funding | Ignoring Indigenous authorities<br>Manufacturing and exploiting Indigenous representation | Disrupting community ***spirit and integrity** |
| Brokering research | Guiding researchers through cultural and community protocols | Throughout the research | Through interactions with community elders and cultural authorities | Preparing researchers<br>To uphold and respect local community cultural protocols | Guiding researchers<br>Advising on protocols<br>Identifying appropriate cultural authorities and representative bodies | Understanding cultural protocols<br>Navigate community approval<br>Enabling relationships<br>Right research partners<br>Culturally safe research |

Appendix M Conditional relationships for theoretical concepts and other codes

| | | | | | | |
|---|---|---|---|---|---|---|
| Tuning researchers | Indigenous community 'testing' and 'tuning' researchers | Before research commences | Informal meetings, gatherings, research activities | Testing researchers' obligations and commitment<br>Evaluating alignment of values and ethics (shared understanding) | Community assessment of researchers fit with community | Researchers become trusted<br>Researchers get rejected |
| Becoming known | Researchers 'fronting up' and becoming known | Before research commences | Within the Indigenous community | Building community trust<br>Get research approval | Developing authentic ethical relationships with communities | Become trusted researchers<br>Become obligated |
| Preconceiving research | Research groups and researchers predetermining AHR priorities | Before Indigenous communities are engaged | Within research institutions and research departments | Lack of time, resources, and capacity to engage<br>To attract Indigenous research funding | Through institutional research planning and funding processes | Inappropriate / unwanted research<br>Overburdened Indigenous communities |
| Respecting cultural protocols | Respecting protocols determined by relevant cultural authorities | Throughout the research | On Country<br>Within the Indigenous community | To ensure research is culturally safe<br>To prevent harm<br>Uphold ***spirit and integrity** | Listening to Elders<br>Listening to cultural advisors | Create culturally safe research |
| Forcing research | Speeding up ethical review<br>Lack of thorough review | Ethical review | Through institutional HRECs | HREC lack of Indigenous health expertise<br>Institutional pressure<br>Funding pressure | Lack of Indigenous representation on HRECs<br>Uninformed HRECs | Inappropriate / unwanted research<br>Unethical Indigenous health research |
| Creating agreements | Research agreements with Indigenous community research partners | After research is conceived | Within Indigenous community settings | To establish agreed purpose, research design, deliverables, and outcomes | Through negotiations between Indigenous community partners and researchers (and institutions) | Established measures for accountability<br>Track research progress<br>Accountable researchers |
| Commodifying Indigenous data and knowledge | Using Indigenous knowledge<br>Exploiting community cultural capital | During the research<br>After research is completed | Data analysis<br>Data collection<br>Dissemination of findings<br>Academic publication | Strengthen understanding of Indigenous peoples and knowledges<br>Academic progression | Control Indigenous data<br>Control Indigenous knowledge contributed to research | Valuing of Indigenous knowledge<br>Exploitation of Indigenous knowledge |


Ngalinya – Djillay
1
Engaging Indigenous communities
Conceiving Indigenous health research
Getting Approval
Respecting Indigenous protocols
Protecting Indigenous communities
Best cultural practice
Becoming obligated
Community priorities
Community approval
Embedding protocols
Culturally strengthen
Satisfactory
Becoming known
Co-design
Institutional approval
Respecting protocols
Culturally safe research
Unethical
Overburdening communities
Preconceiving research
Manufacturing approval
Disregarding protocols
Harming participants


Ngalinya – Djillay
2
Interpreting ethics
Valuing Indigenous contribution
Reciprocal obligations
Best cultural practice
Privileging Indigenous worldview
Data sovereignty
Indigenous authorship
Community research impact and utility
Community benefits and outcomes
Satisfactory
Shared understanding
Sharing knowledge
Acknowledging Indigenous contribution
Further community knowledge
Indigenous partners benefit
Unethical
Institutional / researcher perspective
Taking and commodifying knowledge
No acknowledge ment
Limited research impact
Only researchers benefit