



# Victorian Aboriginal Research Accord

Literature Review

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Victorian Aboriginal Community  
Controlled Organisation

# Victorian Aboriginal Research Accord Project

## Literature Review

### *Acknowledgement of Country*

*We acknowledge the beautiful and unique Country, waterways, skies, plants, seasons, and animals of Victoria. We acknowledge Victorian Aboriginal communities, their Elders, and their Ancestors. We acknowledge their living cultures and their continuing worldviews, governance, ways of knowing, being and doing.*

Throughout this review the term Aboriginal refers to Aboriginal and Torres Strait Islander people. At times Aboriginal is used interchangeably with Indigenous and First Nations. This literature review was written 'author first', if authors used a term, this review did not edit for homogeneity throughout, but left the diversity of language used.

Elements of this review are written in first person, my own experience and standpoint as a researcher. I am a proud Yorta Yorta woman, from Dungala river area in Northern Victoria. From my Communities, Country and Ancestors, including my Celtic heritage I have been fortunate to position my research standpoint as relational. Meaning the philosophical worldview, I interpret my reality through includes scientific measurement, lived experience but also teachings or knowledges held by entities of Country, and my Ancestors.

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## List of Abbreviations and Terminology

**ACCHO** Aboriginal Community-Controlled Health Organisation

**AH&MRC** Aboriginal Health and Medical Research Council (NSW)

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

**AMSANT** Aboriginal Medical Services Alliance Northern Territory

**CRE-STRIDE** Centre for Research Excellence: Strengthening Systems for Indigenous Health Care Equity

**HREC** Human Research Ethics Committee

**Lowitja Institute** National Institute for Aboriginal & Torres Strait Islander Health Research

**NEAC** National Ethics Advisory Committee (Māori)

**NHMRC** National Health and Medical Research Council

**ONEMDA** Aboriginal Health Research, Policy and Service Delivery (University of Melbourne)

**SAHMRI** South Australian Health and Medical Research Institute

**TOG** Traditional Owner Group

**VARAP** Victorian Aboriginal Research Accord Project

## Introduction

First and foremost, the Victorian Aboriginal Research Accord project positions Victorian Aboriginal community's sovereignty, including sovereign knowledges, governance, worldviews and social systems thousands of years old. This position aligns with United Nations Declaration of Indigenous Rights, AIATSIS Code of Ethics, Advancing the Treaty Process with Aboriginal Victorians Act 2018, Victorian Aboriginal Affairs Framework 2018-2023, Victorian Closing the Gap Implementation Plan 2021-2023 (State of Victoria, 2021), Korin Korin Balit Djak: Aboriginal health, wellbeing and safety strategic plan 2017-2027 (State of Victoria, 2017) and Victorian Government Self-Determination Reform Framework (State of Victoria, 2019).

United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) describes self-determination as the ability for Indigenous people to freely determine their political status and pursue their economic, social and cultural development (State of Victoria, 2019).

The State of Victoria's (2019) Self-Determination Reform Framework supports many recommendations positioned throughout this literature review. As stated above Victorian Aboriginal communities since time immemorial have held scientific, experiential, and relational systems of knowledge for health, wellbeing and healing. However, the frameworks cited above now enables Victorian Aboriginal communities, Universities, Medical Research Institutes and the Victorian Government the opportunity to embed best practice through a statewide agreement outlining ethical research which impacts Aboriginal communities. The Self-Determination Reform Framework (State of Victoria, 2019) states.

- To improve outcomes for Aboriginal Victorians, Victorian government must enable self-determination through systemic and structural transformation.
- Self-determination acknowledges that Aboriginal Victorians hold the knowledge and expertise about what is best for themselves, their families and their communities.
- The structures and systems established during colonisation had the specific intent to exclude Aboriginal people and their laws, customs and traditions, resulting in entrenched systemic and structural racism. Government must transform its systems to address structural racism and unconscious bias and enable Aboriginal self-determination.
- Develop and implement a whole of government approach to improving the quality, accessibility and use of Aboriginal data and establish data sovereignty.
- Government will continue to work with Aboriginal Victorians to design policy and programs that achieve community-defined outcomes, and ensure investment is directed to responses that work.
- The need to reform funding arrangements for Aboriginal organisations, working towards pooled, outcomes-based funding, and support Aboriginal organisations through these changes.
- Strategies to increase regional engagement to ensure government-funded programs are responsive to local Aboriginal needs, priorities and aspirations.

The recent Victorian Closing the Gap Implementation Plan 2021-2023 (State of Victoria, 2021) also outlines actions Victoria will undertake to achieve objectives of self-determination and the new National Agreement on Closing the Gap (2020). Key priorities of this plan include formal partnerships and shared decision-making with Victorian Aboriginal communities; building Aboriginal community-

controlled sector; systemic transformation of government processes and systems, and shared access to data and information at regional Victorian Aboriginal community level.

The Korin Korin Balit Djak: Aboriginal health, wellbeing and safety strategic plan 2017-2027 (State of Victoria, 2017) positions many strategic directions which support transformation of the Victorian Aboriginal research sector including; increased Aboriginal involvement in leadership and government decision-making, use of Aboriginal research methods, establishment of new governance structures ensuring that Aboriginal communities lead research in Victoria, development of an Aboriginal-specific ethics committee, use of Aboriginal indicators and methods to measure success, and lastly employment of Aboriginal researchers.

The themes, terms, principles and processes explained in the following sections of this review are building blocks, constructed from Aboriginal intellectual sovereignty, supported by Victorian Governments frameworks described above, and will inform the Victorian Aboriginal Research Accord's, components and mechanisms.

A beautiful quote from Watson, et al., (2010, p. 3), 'Aboriginal research is an opportunity for us to create innovation and change for our people. If we develop an approach to research which is unique and reflects our values and beliefs, we will reflect the spirit of our Ancestors, the spirit of our people who are alive today, and the spirit of our Aboriginal children who are yet to be born'. From these words a statewide agreement framing ethical research which impacts Aboriginal communities recognises our worldviews, sovereignty, culture but also holds possibilities for an innovative future, shifting our communities from surviving to thriving.

### **Literature Review Methodology**

The methodology to locate literature was predominantly through the Aboriginal research method of relational mapping (McMahon, 2017). From Western dominance of the research sector Aboriginal authored texts may not necessarily be found through library data searches or in high impact journals, making relational mapping an important additional process for Indigenist research (Rigney, 1999). Relational mapping entails: checking the reference list of an article authored by an Aboriginal person to learn other key articles, talking to Aboriginal community members, and searching for articles on website resources of Aboriginal organisations. This method allows the researcher to map key Aboriginal texts in a particular field of research, overcoming historical systems of gate keeping in academic journals.

Through relational mapping articles were found from the reference lists of Onemda VicHealth Koori Health Unit, Lowitja Institute, AIATSIS, AH&MRC, AMSANT, Wardliparingga Aboriginal Research Unit, Cooperative Research Centre for Aboriginal and Tropical Health literature. Also, resources developed by Victorian Government, NHMRC national guidelines and we also learnt key articles to include through conversations with the VARAP Aboriginal Reference Group. A search via Monash University data bases was also completed. This search resulted in 40 articles being reviewed, mostly Australian, a couple international but almost all were authored or co-authored by Aboriginal or First Nations people.

This review entailed coding each article by extracting text into a themes grid. As the literature discussed aspects of ethical Aboriginal research these extracts built the themes grid. The themes, and the language used to position the themes changed throughout the analysis. This review constructed language through prevalence of phrases, and clarity of phrases. Prevalence meaning how many articles used a similar way of discussing a concept, and clarity referring to cultural



definition. At times different articles discussed an aspect of ethical Aboriginal research in different ways, and then a particular article would encapsulate these discussions, or clarify the concept through a poignant, culturally informed phrase. This methodology constructed the following ten themes, and sub themes.

## 1. **Aboriginal Community Control**

A central theme when reviewing the literature which is like a drumbeat becoming louder with time is the absolute necessity for Aboriginal governance systems for research which impacts Aboriginal communities. This central theme holds resonance for all the following principles to be discussed. It is the foundation stone. As Duke, et al., (2021, p.15) explains, the missing link in the current environment for research projects, especially in mainstream institutions, is a framework of empowerment for Indigenous voices and priorities, centred around elevating principles of Indigenous governance.

For this theme I use the term Aboriginal Community Control because it stipulates exactly what we are describing. However, for non-Aboriginal readers this term does not mean separatism, principles such as both ways practice, partnerships and two-way learning inform many items discussed in this review. Aboriginal Community Control creates space and opportunity for Aboriginal governance to strongly position our continuing ways of knowing, our processes and our culture from a localised perspective. Western universalism and racist ideologies socially constructed our humanity outside of what is normal, proper, acceptable or allowed. Aboriginal Community Control acts as a decolonist vehicle shifting us all to space where both Aboriginal and non-Aboriginal people, in the field of research work together, possibly different in ways, but as equals.

### **Aboriginal Leadership**

The literature discussed Aboriginal leadership as an initial learning related to Aboriginal governance. Leaders may be Aboriginal community members in lead positions or as explained in the AIATSIS Guide (2020, p.6) decolonising research includes recognising and honouring the role and status of Elders. Researchers need to secure approval from community leadership entrusted with the authority to confirm engagement in research (Lin, et al., 2020, p.9), a process which involves learning who is 'leadership' in each localised landscape as Jamieson et al. (2012, p.16) states, researchers need understanding of the local "lay of the land" in terms of governance. The CRE-STRIDE (2020, p.3) document stated communities also provide leadership through research agenda setting and guiding appropriate methodological approaches, and AIATSIS (2020, p.17) positions that Indigenous leadership should be evident both in the 'why' as well as the 'how' of research. The Central Australian Aboriginal Congress guidelines insist on Aboriginal control of research, the adoption of non-invasive and culturally sensitive methodologies, the pursuit of research of need and benefit to communities, and full Aboriginal control over the dissemination of findings (Humphery, 2001, p.198).

### **Localised Governance**

An important aspect of Aboriginal governance different to the Western concept of universalism defined as, a particular way of knowing which can be applied to multiple other groups, is the concept of localised. The term localised stems from the Aboriginal relational worldview or philosophy that each landscape contains knowledge holders that are both human and non-human. The spirit world or our Ancestors, landscape, animals, plants,

waterways, skies, the seasons are all equal stakeholders in creating knowledge's, cultures and languages (McMahon, 2017). From this relational worldview each landscape is a different epistemology or way of knowing, being and doing. This philosophy is very different to Western imagination that only humans are stakeholders in knowledge. However, this Aboriginal view of reality means that Aboriginal governance systems are predominantly localised, or land based.

As stipulated through AH&MRC (2016, p.6) and AMSANT (2013, p.1) documentation, researchers should seek the active involvement and support of local Aboriginal Community Controlled Health Services, and the Boards of these organisations are the appropriate authorities and decision-makers in relation to determining the priorities of health research. Henry, et. al. (2002, p.10) explained 20 years ago Aboriginal Community controlled organisations should have greater control over the research agenda because their role in providing health services at the local community level places them in a unique position to determine local health research needs, and to assist in the brokerage and conduct of subsequent research activity. An excellent example of localised Aboriginal governance is Inala Community Citizens' Jury, which enables 'lay' involvement in decision-making processes. An institutional HREC will not approve a project that has not already been approved by the Inala Community Jury (Bond, et al., 2016, p.90) or explained concisely, Aboriginal Community Controlled research is the most beneficial research that can be done, without community the research is going nowhere, and researchers are going to have poor research findings (VicHealth, 2000, p.20). The South Australian Accord states the balance of power in decision-making should reside with Aboriginal people, for whom the research is proposed to be of benefit, (SAHMRI, 2014, p.14).

### **Victorian Aboriginal Human Research Ethics Committee (HREC)**

A quote from Onemda VicHealth Koori Health Unit (2008, p.21), explains succinctly the next theme; 'there is no Koori ethics committee, we need one'. Aboriginal Communities in Victoria want Aboriginal people to have more control of how ethics is assessed when research affects their Communities (Stewart and Pyett, 2005, p.13). For Inala Jury members, Bond, et al. (2016, p.94) explain how the jury is a site of agency and activism that extended beyond reviewing health research within the service. At a Victorian Aboriginal workshop Salina Bernard is quoted saying (VicHealth, 2000, p.20) an Aboriginal Ethics Committee provides opportunity to say to Community 'Don't be scared of research, if it's in your hands and it's in your control'. Onemda (2008, p.43) states it's important that Koori people be empowered to take control of Koori health strategies, and research directions, methodologies and ethics. This can be achieved by having an Aboriginal head of NHMRC and/or ARC, an Aboriginal Ethics Committee in Victoria, and Aboriginal CEOs in all our Koori organisations.

However, the literature also discussed key areas which need to be addressed regarding a Victorian Aboriginal HREC; a Victorian Aboriginal HREC Committee could provide advice, but each Aboriginal community itself decides if it wishes to participate in a research project (AH&MRC, 2016, p.7), the greatest need for a Victorian Aboriginal Ethics Committee is administrative support (VicHealth, 2001, p.5), a point raised by Salina Bernard when Victoria had an Aboriginal HREC in the 1990's 'the VAHS Ethics Committee refers to the NHMRC Guidelines, but they are very broad, they don't give us specific guidance and Victorian communities are very diverse, it's very difficult coming to a conclusion whether a project is



ethical (VicHealth, 2001, p.4), and lastly appropriate funding is essential to support the administration costs of the Victorian Aboriginal Ethics Committee, (Stewart and Pyett, 2005, p.16).

### **Research Governance Structure**

Positioning Aboriginal leadership and governance systems, requires research in Victoria to adapt a new research governance structure. AIATSIS (2020, p.12) states strongly, in exercising self-determination, Indigenous peoples have the right to strengthen their institutions, practice, teach and protect cultural traditions and knowledge systems and develop and use their lands and waters. However currently mainstream research projects are undertaken using traditional “top-down” approaches to research governance (Duke, et al., 2021, p.1). There is a need to shift Aboriginal governance away from purely advisory or consultative roles to genuine decision-making capacity and authority within Indigenous health research (Duke, et al., 2021, p.11). Humphery, (2001, p.199) explains this requires guidelines to be more than a set of written procedures but to be concrete mechanisms for the Indigenous control, instigating a transformation of health research governance structures.

A governance structure was outlined by Aboriginal community leaders during a three-day 1987 workshop held in Camden, NSW. This workshop shifted Aboriginal research language from guidelines to ‘Principles, Standards and Rules’, articulating a governance structure where funds for research projects are controlled by Indigenous community-controlled organisations; a community needs-based approach to research be adopted; training of Indigenous researchers becomes a priority and development of administrative systems to ensure that the management of research is under Indigenous community control (Henry, et al., 2002, p.8 Links 1).

Aboriginal governance also includes Aboriginal community control over all aspects of research design, ownership of data, data interpretation and publication of research findings (AH&MRC, 2016, p.4) and Aboriginal leadership in the membership of the project team, governance arrangements and partnership agreements (Bond, et al., 2016, p.18). For the potential researcher, it is essential to understand that there will not be a single ‘correct’ way to approach Aboriginal governance, each Aboriginal community will provide guidance to prospective researchers on how to proceed within their own Governance structure (Assembly of First Nations, 2009, p.34)

### **Veto Control**

Duke, et al (2021, p.6) recently positioned that good governance requires Indigenous communities to have genuine decision-making powers in matters pertaining to their lives and realities. This means, as Jamieson et al. (2012, p.17) explains researchers must be ready for Aboriginal communities to say “no” at any point during a study. The fundamental principle that empowers Aboriginal communities is that they hold the final voice to approve research projects, and research results before they are disseminated (Lin, et al., 2020, p.10). These three statements describe veto control as an ongoing theme of Aboriginal research governance. Aboriginal community control holding veto power within the research sector can be daunting for the non-Aboriginal researchers. This power is vested in our own sovereignty as First Nations people, but it is also aligned with a relationship-based research

framework. When working with individuals, professionals within the health sector will establish client safety through conversations enabling the client to understand, at any time you are not comfortable you can stop the interview immediately. Veto control for Aboriginal communities is a similar relationship informed rule. Aboriginal communities since colonisation have endured racially informed scientific research such as eugenics, social Darwinism and continuing social policies which create generational trauma for individuals and communities, this trauma has become part of our cultural consciousness. Relationship based research considers this continuing context, and the non-negotiable safety requirement that Aboriginal communities hold veto control throughout the whole research process. Important points highlighted through the literature; guidelines need to be strong that only communities can approve what research is going on in their communities (AIATSIS et al., 2013, p.16) and research can be terminated by the Aboriginal communities when ethical principles are breached (AIATSIS, et al., 2013, p.33), dissemination of results can only occur if communities approve, and according to their terms and conditions (Lin, et al., 2020) and importantly, ethics approval is separate from Community approval, individual Community organisations have the right to approve or reject any research proposals involving their Communities (Stewart and Pyett, 2005, p.28).

### **Treaty**

Findings from New Zealand literature demonstrated the significant relationship between Treaty, and ethical research which impacts Aboriginal communities. New Zealand's Guidelines on Ethics in Health Research state that all researchers must respect and incorporate Treaty principles in research proposals (NEAC, 2012, p.7). Māori organisations and researchers use principles of sovereignty from the Treaty of Waitangi, to argue for ethical research for their communities. Māori view the Treaty of Waitangi as a vital component of Māori research ethics, and state that greater Māori involvement in health research ethics, as an important contribution to fulfilling the responsibilities of Treaty (NEAC, 2012, p.6). Māori terms and concepts are used in the ethical framework described in Te Ara Tika, these ways of talking are integrated with Western principles, and can be traced back to language used in the Treaty of Waitangi. This integration creates a research framework that resonates with both Māori and non-Māori researchers (AIATSIS, et al., 2013, p.24). From the foundation of Treaty, persistent and significant health inequalities between Māori and other New Zealanders have been described as an ongoing breach of the Treaty of Waitangi (NEAC, 2012, p.10). This relationship between Treaty and Māori health outcomes meant the New Zealand Government legislated through the New Zealand Public Health and Disability (NZPHD) Act 2000, recognition and respect of the principles of the Treaty of Waitangi with a view to improving Māori health (NEAC, 2012, p.29).

### **Data governance**

Walter & Suina (2019, p.236) positioned data governance within the broader theme of Aboriginal community control, stating Indigenous self-determination relies on data self-determination. They discussed the requirement for continuing application of data governance throughout the research process. Indigenous peoples in Australia have the right to exercise control of the whole Indigenous data ecosystem inclusive of data creation, development, stewardship, analysis, dissemination and infrastructure to ensure that data is: contextual and disaggregated; relevant and empowering of sustainable self-determination and effective self-governance; accountable to Indigenous peoples and

protective of Indigenous individual and collective interests (Indigenous Data Sovereignty Summit Communique, 2018) cited in Walter & Suina (2019, p.237).

## 2. Aboriginal Research

The theme of Aboriginal research stems from a context beyond human perception, Aboriginal communities for thousands of years, studying, learning and positioning knowledges through complex systems of knowledge holding. My culture has always been re-told to me by Western culture as simply an oral society. Less intelligent than societies which record knowledge through writing or print. Recently Kelly (2016) through her publication *The Memory Code* re-positioned Aboriginal systems of holding knowledges stating, Aboriginal Elders have encyclopaedic memories, they hold knowledges from animals, plants, the landscape, and the skies through sophisticated systems of memory. Aboriginal societies use song, landscape, ceremony, dance, symbolism and stories to hold and transmit vast amounts of factual information, for all aspects of living and surviving. A memory technique demonstrating intelligence beyond written words. However, considering colonisation, print media is the medium Aboriginal research needs to now use. This continuing cultural heritage means Aboriginal research into health and wellbeing will always straddle two cultures and two ways of holding knowledges. As Laycock, et al. (2011, p.9) explains Aboriginal people have always done research, measuring very precisely features of social, emotional, spiritual and physical wellbeing. It is critical that our research is conducted, and that Western research understands current research by Aboriginal communities into health and social issues is conducted with integrity and intellectual rigour, from our cultural heritage as researchers.

### Aboriginal Worldviews

Underpinning Aboriginal research is Aboriginal relational worldviews. A major reason for past failures has been the dominance of Western intellectual and moral epistemological and ontological approaches to health and medical research at the expense of Indigenous governance and knowledge systems (Duke, et al., 2021, p.8). Discussing worldviews Husserl (1970) explained that our worldviews are the 'taken for grantedness' of our embodied realities, the apparent fixedness of a groups beliefs of reality, are actually a reflection of the social and cultural experiences, they are not verifiable truths (Walter & Suina (2019, p.234). This statement shines a light on all worldviews, both Western and Aboriginal, explaining they are all socially constructed. However, over many generations, worldviews or what human groups believe is real or not real, is how we epistemologically develop our ways of knowing for health and wellbeing. The ontology of an invading group can subjugate through systems such as terra nullius, the ontological traditions of First Nations.

Aboriginal research methodologies are built upon worldviews that Aboriginal and Torres Strait Islander people have been practicing for tens of thousands of years. Our knowledge systems are holistic and relational, including Country, culture, spirituality, community and family as equal knowledge holders (CRE-STRIDE, 2020, p.2). When we think about health and wellbeing, it is not compartmentalised into separate systems (for example, education, legal, health); rather it is a fluid and organic process that connects all elements (both human and non-human), (CRE-STRIDE, 2020). From an Aboriginal relational worldview research must

engage with Aboriginal perspectives, ways of operating, engage with Aboriginal literature, both academic and community, and engage with Aboriginal methodologies (AIATSIS, 2020, p.18). Researchers need to approach health research in a holistic way because humans are interconnected with the environment and animals; spend time with participants; ensure mutual understanding; appropriate approaches; not rushing research, and not intrusive questions (AIATSIS, et al., 2013, p. 37).

Continuing to place Aboriginal ontology, epistemologies and knowledge in an external box as irrelevant and 'other', reinforces unethical research projects to be generated and inflicted on Aboriginal communities (Assembly of First Nations, 2009, p.7). Ten years later Duke, et al. (2021, p.9) states Indigenous ways of knowing, being and doing continue to be situated as marginal or peripheral to mainstream conventions, rather than fundamentally enmeshed in core ways of undertaking research. Considering all people groups develop worldviews from lived experience, Aboriginal peoples also have the right to create new knowledges based on our own cultural traditions (NEAC, 2012, p.62), and sit at a table of researchers, equal but different, designing innovative health initiatives. Formalising Aboriginal philosophies, and continuing knowledges as legitimate for our own communities and possibly others (Dudgeon, et al., 2010, p.83).

### **Aboriginal-led Analysis**

Laycock, et al. (2011, p.13) citing (Grieves 2003) explains a poignant relationship between ontology and methodology, stating that Western consciousness is often inadequate to interpret Aboriginal ways of being and doing. A research study maybe informed through a relational standpoint, meaning Aboriginal ways of knowing and doing construct the methodology, Aboriginal authored literature is used, and the study has an Aboriginal advisory group. However, if the analysis of the data is completed by a researcher whose own worldview is different, how does this researcher even see and understand nuanced understandings and use of language within the data, from an Aboriginal worldview. The research project at this point is at high risk of being assimilated back into the dominant Western ways of knowing.

This point was reiterated throughout the literature; Aboriginal researchers and peoples are best placed to lead analyses of the data (AIATSIS Guide, 2020, p.21), researchers should include community representatives in interpreting the data and reviewing research findings before they are published (AIATSIS, et al., 2013, p.29), the research can be fine but the interpretation of findings is not fine (VicHealth, 2001, p.8) and Aboriginal leadership needs to remain involved in the process of analysing and interpreting data, (Lin, et al., 2020, p.4). The National Ethics Advisory Committee (2012, p.38) explained that in New Zealand this has been described as 'equal analytical power' and necessitates Māori research workforce development. Aboriginal-led analysis as described through Māori experience in turn enhances the contribution Māori research makes to improving outcomes for Māori communities.

### **Aboriginal Authorship**

Closely related to Aboriginal-led analysis is Aboriginal authorship. As defined in 2001 through Victorian Health Koori Health Research & Community Development Unit (2001, p.11) publication, agreement is needed from the outset of the project, this must include process for Aboriginal community agreeing to and co-authoring all publications at end of research. Reiterated again, community co-authorship on all reports/publications, and co-

presentation of all conference presentations (Gwynn, et al., 2015) and finally within the South Australian Accord, individual and community contributions must be recognised in publications (SAHMRI, 2014, p.12).

However Aboriginal authorship holds challenges which must be discussed. Aboriginal communities and researchers need to agree how the collaboration of different parties will be recognised in the publications (AIATSIS, et al., 2013, p.29), how will Aboriginal knowledge that is learned from Elders, and is held by a collective group rather than an individual, be referenced? (Laycock, et al., 2011, p.13), and finally a challenge from our relational worldview; individual 'ownership' is contrary to Aboriginal governance structures and our requirement that traditional knowledges are 'authored' by our Ancestors, and geographic areas of Country (Assembly of First Nations, 2009, p.15).

### **Aboriginal Research Methodology**

In the area of research methodology, the historical application of 'colonial' research methodologies has significantly contributed to the marginalization of Aboriginal communities. Aboriginal people want research to contribute to self-determination, as defined and controlled by their communities. To do this Aboriginal people themselves must first analyse and critique Western epistemologies commonplace the research sector (Henry, 2002, p.3). This has required Aboriginal researchers to explain why elements of Western methodologies are not appropriate, while at the same time fighting for space in academia for their own methodologies. Walter & Suina (2019, p.234) state Indigenous methodologies are a separate methodological paradigm, not the opposite or a derivative of Western methodologies. Harfield et al. (2020, p.2) explains the risks associated to not implementing Aboriginal methodological processes saying that to conduct research that is both respectful and credible, researchers need to privilege Aboriginal epistemologies. Failure to tailor the research questions, design, analysis, dissemination and knowledge translation towards capturing understandings that are specific to Aboriginal peoples results in research of limited acceptability and benefit, and potentially harms Aboriginal peoples.

Further discussions from the literature included research must respect and include Indigenous methodologies, incorporating the strengths, knowledge, experiences, and culture of the community (AIATSIS, et al., 2013, p.41), researchers need to listen and respond to Aboriginal ways of working, research processes need to be embedded into accepted community lifestyles, rhythms and history (VicHealth, 2001, p.9). Then important to note, Aboriginal 'ways of doing' does not preclude 'rigour' and can be more rigorous due to community scrutiny of the Research (Gwynn, et al., 2015, p.237). The Assembly of First Nations (2009, p.5) report declared that Indigenous methodologies would play an important role in the process of mending the relationships between First Nations and Western ways of knowing.

Particular to quantitative research methodologies the South Australian Accord (SAHMRI, 2014, p.21) positioned that collection, handling, storage, use, destruction or repatriation of any biological samples taken during the course of research should form a critical part of the informed consent process, and transparent negotiations with Aboriginal communities. Institutions and researchers need to produce protocols relating to the use and storage of biological materials that are agreed to, with clear provisions regarding withdrawal of samples for communities. Lastly these protocols agreed to by the Aboriginal community also

states that use of samples for secondary purposes requires further community consent and approval, without exception (SAHMRI, 2014, p.21).

### **Culturally Restricted Knowledge and Research Integrity**

Cultural integrity acknowledges and protects Aboriginal traditional knowledges and intellectual property (NEAC, 2012, p.13). Maintaining cultural integrity is everyone's business; institutions or non-Aboriginal researchers who listen and respect, and also the Aboriginal researcher or community who are enabled to state which topics, content, data or processes are allowed. It is important for researchers to understand that some things cannot be researched (Assembly of First Nations, 2009, p.29), recognising there is culturally restricted knowledges within Aboriginal communities. The South Australian Accord explains strongly, communities can restrict or refuse use of sacred or traditional cultural knowledge (SAHMRI, 2014, p.19). the Community retains the right to censor research materials of a sensitive nature at any stage of the research process (Humphrey, 2003, p.17).

Culturally restricted knowledges are localised, meaning under each community's governance structure somethings may be restricted in one community, but not another. Researchers need be open to continuous learning. This area is also not limited to traditional knowledges, as communities develop contemporary perspectives from their continuing worldviews, these new ways of knowing will also fall under localised governance structures.

Concerning culturally restricted knowledges there are some areas of risk associated to research, the NEAC (2012) explained Māori knowledge is 'recorded' in memory as discussed earlier in this review, those who received knowledge were specially chosen. Research practices now rely almost exclusively on the written format, which makes it harder to protect cultural knowledge against misappropriation by others. The Victorian Health Koori Health Research & Community Development Unit (2001, p.11) report discussed how research needs to be mindful of women's business and men's business. Lin, et al. (2020, p.11) explained researchers must clearly define which data is to be collected and agree on the limits for data collection. An AMSANT (2013, p.2) resource clearly defines this theme, health research must be culturally intelligible to Aboriginal people and must not compromise or endanger their legitimate cultural rights and values.

### **Aboriginal Research Language**

Concerning language use there is multiple factors for researchers to consider. For this review 'language' may include Aboriginal languages, or Aboriginal communities use of English with their own meanings attached. During research both 'use of language' may occur. The South Australian Accord explains Aboriginal communication styles differ significantly from non-Aboriginal communication styles. Therefore, time needs to be allocated within project timelines to cater for Aboriginal decision-making processes (SAHMRI, 2014, p.15), during engagement, especially for non-Aboriginal researchers to have time to familiarise themselves with elements of Aboriginal communication and during analysis so there is enough time for careful review of Aboriginal use of language.

Researchers need to manage risk associated to language, such as studies focused on suicide, mental illness, loss, trauma or grief, terms which may clash with a community's strengths-based use of language when discussing these topics. Lin, et al. (2020, p.9) explains a



strength-based research lens is needed when developing research goals and objectives. There may also be risks when research language reinforces negative stereotypes or deficit profiling of Aboriginal people (AIATSIS Guide (2020, p.13).

Bond, et al. (2016, p.19) raise another concern related to language, researchers should not hide behind their shared understanding of research language and processes, and instead need to develop translational skills in health research terminology. Research needs to be careful of the use of research terminologies when communicating, avoiding terms that might be viewed as colonizing or simply research jargon which potentially reinforces negative power dynamics (Lin, et al., 2020, p.3). Communication and language used must be culturally and community relevant and involve a willingness of researchers to listen and learn (SAHMRI, 2014, p.9).

### **Aboriginal Researcher Identity**

An unexpected outcome from Aboriginal research is the strengthening of Aboriginal researcher identity. Bond, et al. (2016, p.91) tell the story how for the Indigenous researcher, the Community Jury provided a platform for their professional identity to be discernible within their own community. One Indigenous researcher explained 'What I like about the jury is it allows me to yarn with my own mob about the stuff that I love doing, I can 'out' myself as a researcher'. Previous experience in Victoria for the Aboriginal researcher was that academic qualifications of Koori people did not mean much in Koori community, qualifications were something Aboriginal researchers had to fight against for acceptance because Koori community were suspicious of qualified people (VicHealth, 2001, p.9). However, Tuhiwai Smith (1999) observed that when Indigenous peoples become researchers and not merely the researched, the activity of research is transformed; questions are framed differently; priorities are ranked differently; problems are defined differently; and people participate on different terms (Henry, et al., 2002, p.5).

## **3. Social & Historical Context**

A review of ethical research which impacts Aboriginal communities needs to also include evaluation of the social and historical context. It is well placed to begin with a Linda Tuhiwai Smith quote, "The word itself, 'research', is probably one of the dirtiest words in the Indigenous world's vocabulary." One Indigenous response to this 'dirtiness' has been to reject participation in, and the value of, research itself (Humphery, 2001, p.197). Henry, et al. (2002, p.3) defines the only option to change this context; research transformation in the underlying paradigm or approach required, that is research needs to shift away from only being non-Indigenous individualistic, investigator driven. However, in spite of the continuing social historical context, Victorian ACCHOs began to use research to influence and lobby for increased services in their communities from the 1970's. Activity from Aboriginal Community Controlled Health sector, joined international voices contesting the ways in which research and knowledge about Indigenous peoples was gathered. Documents produced in the 1990s demonstrated that Aboriginal people increasingly wanted to be actively engaged in determining who, what, where, when and how research would take place and the conditions under which it should happen (Watson, et al., 2010, p.4). In other words the transformation required began from the community level.

## Research and Colonisation

Laycock, (2011, p.5) paraphrasing (Smith 1999) explains through imperialism and colonisation, the West came to 'see', to 'name' and to 'know' Indigenous lands, peoples and resources. Classification systems were developed to cope with the mass of new knowledge and discoveries and to help the observers make sense of what they saw. These developments gave the colonial researchers authorship and ownership of knowledge. From this, the strong link between invasion, colonisation and research is demonstrated. Research, and theories derived from it, have been the pivotal instrument behind dispossession, terra nullius, assimilation, theft of Aboriginal remains, child removals and acts of genocide. This context is not hundreds of years ago, but within the living memories and grandparent's stories of current Aboriginal communities. This places research, as one of the de-colonising starting points. Bond, et al. (2016, p.89) further explains, research acted as an overt tool of colonial control espousing and enacting racial pseudoscientific theories. Then Bainbridge et al. (2015, p.2) the underlying mistrust of researchers and associated research activities persists in Indigenous populations today. Sovereignty, self-determination and research practices are linked, the three are fundamentally interconnected. Research has been used as an instrument of oppression, imperialism and colonialism (Assembly of First Nations, 2009, p.5). AH&MRC Ethics Committee (2016) document stipulates research must be conducted in a manner sensitive to the cultural principles of Aboriginal society and recognise the continuing impact of colonisation on Aboriginal people.

## Aboriginal Communities Experience of Research

The social and historical context of research informs Aboriginal communities current experience of research and how they feel about it. AIATSIS, et al. (2013, p.29) article states, researchers must ensure that their research does not accidentally re-traumatise these individuals. Ian Anderson explains how community commonly experience research, 'this is the usual experience of research, of having someone come into the community, pinch all this information and run away, and people never hearing about it again' (VicHealth, 2000, p.10). From this AIATSIS (2020, p.20) recently explained, given the history of exploitation of Indigenous peoples, their lands and resources through processes of colonisation that includes research, Indigenous peoples may perceive risks of engaging in research, through their own historical and cultural lens.

Another component of Aboriginal community's experience of research is research fatigue. Research involving Indigenous communities has been linked to research fatigue, through the misuse of genetic samples and research approaches rooted in community deficits rather than community strengths. It is for these reasons that many communities have developed a fear and fatigue towards the term 'research' (Lin, et al., 2020, p.4). During a survey completed by AIATSIS with Traditional Owner Groups (Burbidge, et al., 2021, p.44) members were asked what the research sector can do for them, and how it can do it? Fatigue from community towards 'research' was highlighted as a real issue, demonstrated by the fact that research was the least chosen option as 'further support' requested. In the context of research, Indigenous Australians' past experience of research needs to be understood, in order to foster support and trust (Jamieson et al., 2012, p.17).

## Dynamic Aboriginal Communities

A review of the current context also includes discussion within the literature regarding the dynamic, diverse nature of Aboriginal communities. Walter & Suina (2019, p.235) defined this well, Indigenous lifeworld, encompasses the relational positioning inherent in the social, political, historical, and cultural embodied realities of Indigenous lives framed through intersubjectivity; inclusive of traditional and ongoing culture, belief and systems, practices and identity but also intersubjectivity as colonized, dispossessed marginalized peoples whose everyday life is framed through and directly impacted by their historical and ongoing relationship and interactions with the colonizing nation state. Duke, et al. (2021) explained however, that Western intellectual approaches conceptualise Indigenous knowledge and culture as static and anchored in the past. Informed possibly by a past, incorrect, Western European anthropological understanding of Aboriginal communities. Continuing to limit the emancipatory potential of dynamic, complex, and ever-changing Indigenous knowledges and cultures across time and place. AIATSIS, et al. (2013, p.30 /37) further explained researchers need to acknowledge that Aboriginal people can be part of multiple communities and that community is a fluid concept and the need to respect the diversity between and within Aboriginal communities. A major challenge facing partnerships between Aboriginal communities and organisations is the enduring remnants of Australia's colonial imaginations (Gwynn, et al., 2015, p.236).

## Western Control of Research

Conscious or unconscious Western institutions still maintain an authoritative control of research in general, research priorities, research funding / timeframes, intellectual property and research translation as described throughout this review. The one area that has experienced a small shift in control is research methodologies, through the advocating by Aboriginal academics and community members. Regarding research ethics Duke, et al. (2021, p.3) states, the articulation of ethical guidelines within mainstream research continues to be an amalgam of Western standards regulating Indigenous knowledge and values. Bainbridge et al. (2015, p.2) strongly summarises that the key reasons for the poor translation of research findings into indicators of social change or benefits, has been because in large measure, research continues to be controlled by non-Indigenous people, and conducted 'on' Indigenous people; and is still strongly biased toward the incentives of the colonising society.

Interesting Watson, et al. (2010, p.3) says control from higher education institutions in Australia where ownership of Aboriginal communities' knowledge, ways of being and doing is assumed; can be compared to other sites such as museums, libraries and art galleries where theft of Aboriginal culture has also occurred. The ongoing colonisation agenda and Indigenous health research in Australia, is a point of tensions, as Western standards regulate Indigenous values and norms (Duke et al., 2021, p.10). I understand for many non-Aboriginal individuals their perspective may be that the colonist agenda is over, however from my perspective as an Aboriginal researcher we haven't stopped walking in one direction until we turn around and start walking in the opposite direction. Meaning the colonist agenda continues until there is a significant shift in power through all phases of the research process.

## 4. Aboriginal Knowledge Sovereignty

Aboriginal data refers to any information or knowledge (regardless of its format) that is about and may affect Aboriginal and Torres Strait Islander peoples, collectively and individually (AIATSIS Guide, 2020, p.25). Walter & Suina (2019, p.236) summarise Indigenous Data Sovereignty centres on Indigenous collective rights to data about our peoples, territories, lifeways and natural resources and is supported by Indigenous peoples' inherent rights of self-determination and governance over their peoples, country and resources as described in the United Nations Declaration on the Rights of Indigenous Peoples. The term Aboriginal knowledge sovereignty in this review also extends to, the right of Aboriginal peoples to determine the means of collection, access, analysis, interpretation, management, dissemination and reuse of data pertaining to the Indigenous peoples from whom the knowledges originate from (Walter & Suina, 2019, p.236). Within the umbrella term Aboriginal Knowledge Sovereignty many concepts, processes and principles are presented.

### Aboriginal Data Governance Framework

The initial theme to be presented is an overarching Aboriginal data governance framework. A framework which positions Aboriginal Community Control over data from the beginning of all research processes. Indigenous data sovereignty both recognises the rights of Indigenous peoples to control the use of their data, wherever it is held (governance of data), and the importance of access to data for Indigenous decision making and self-determination (data for governance (AIATSIS, 2020)). From Canada the First Nations Information Governance Centre (FNIGC, 2021) has structured four main principles to assert First Nations control over data: ownership, control, access and possession (OCAP). These principles have been developed as an accepted, standalone framework for researchers to follow with respect to data and information management prior to, during and after a research project has been completed (Assembly of First Nations, 2009, p.21). The CRE-STRIDE (2020, p.4) article states institutions need to acknowledge research data belongs to community; disrupt deficit discourses; give data back in accessible forms (as advised by community); and strengthen capacity of community and their health services to act as data custodians. A framework needs to stipulate that Aboriginal community's benefit from, hold ownership in, commercial development of scientific and biological research derived from their lands and waters (AIATSIS, 2020, p.22). Those working with Aboriginal data must clearly articulate how data collected is used to support and progress Aboriginal peoples' self-determination and collective benefit (AIATSIS Guide, 2020, p.26). The Onemda VicHealth Koori Health Unit (2008, p.17) publication explained that Koori research is a social, political, action of ownership of knowledge, informing systems of governing and administration, which strengthens community.

### Data Custodians

As Data Custodians community is empowered to use their data for their own planning, implementation and monitoring of health and wellbeing issues and for setting research agendas (CRE-STRIDE, 2020, p.4), this includes communities holding data for their own determined purposes, both now and for their future. Even when data is shared with institutions and researchers, the Aboriginal community retains ownership, rights over the

reporting and publication of the results, and the on-going responsibility of monitoring culturally appropriate implementation of research findings (AH&MRC, 2016, p.8). As data custodian's communities will always seek to protect private cultural knowledge (SAHMRI, 2014, p.14). AIATSIS Guide (2020, p.15) lastly explains data custodianship also extends to data translated into different multimedia including print, pictorial, audio, video and digital materials.

### **Collective Consent and Ownership**

Western research has only defined consent from their paradigm of individualism. However individual ownership rights within the western intellectual property rights regime does not address First Nations collective ownership worldview (Assembly of First Nations, 2009, p.15). Collective Aboriginal consent is different to individual rights, responsibilities and ownership. It is important that researchers learn how to discuss collective consent with communities, and how to evidence collective consent within research agreements. It is the researcher's responsibility for developing through engagement and maintaining the validity of both individual and collective consent throughout the life of the project (AIATSIS, 2020, p.13). Collective consent from a community for a research project derives from authentic, meaningful engagement with communities. This engagement is aligned to Aboriginal governance for each localised area, via community leaders who assess the benefits, risks, safety and usefulness of the study for their community (NEAC, 2012, p.36). However, community consent does not replace individual consent required for each participant of a research project (Anderson, et al., 2003, p.25). Collective consent includes a few more important elements. The AH&MRC Ethics Committee (2016, p.8) document explained communities can transfer the rights or grant a licence for the use of data or results, however this needs to be strictly within a written agreement. All media releases or articles from research which impacts Aboriginal communities should also obtain collective consent from Aboriginal communities (VicHealth, 2001, p.12). Lastly, secondary use of data for purposes other than its original intent must be re-negotiated with local communities (SAHMRI, 2014, p.20).

### **Aboriginal Knowledge Building**

Aboriginal people are, and have always been, highly numerate in understanding our worlds. Complex formulas and calculations underpin Aboriginal cropping, hunting and navigation to name just a few traditional daily activities (Walter & Suina, 2019, p.233). Both traditional knowledges and contemporary understandings from a continuing Aboriginal relational worldview, require space and opportunity to transition to print media in a colonised context. Indigenous knowledge comes from our collective memory in languages, social practices, events, and features of the land and animals (Laycock, et al., 2011, p.9). Aboriginal communities encoded every bit of knowledge into the plants, animals, skies, waterways not just of the present but of the past. That is one reason we have survived being colonised, not because we wrote things down but because we used sophisticated systems of embedding knowledge into everything around us. So now, the more stories we know, the more we become (Martin 2009:1) as cited in (Laycock, et al. (2011, p.10). Aboriginal researchers and community members need opportunity to build a textual construction of their knowledge

systems so that western academics and researchers can begin to understand and value these knowledges (Assembly of First Nations, 2009, p.7). As sectors and organisations include Aboriginal ways of knowing for practice and policy, both for Aboriginal and non-Aboriginal health and wellbeing, research frameworks will need to include incentives for Aboriginal knowledge building in print media.

### **Dysfunctional Data**

The South Australian Accord states that researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge (SAHMRI, 2014, p.9). Currently Government datasets only include data of interest to government, not data relating to the broader determinants and elements of Indigenous health and wellbeing, as determined by Aboriginal communities (Laycock, et al., 2011, p.21). Currently Indigenous data in mainstream institutions largely conform to what Maggie Walter describes as 5D data. That is, mainstream Indigenous statistics focuses almost exclusively on items related to Indigenous difference, disparity, disadvantage, dysfunction and deprivation. 5D data are produced within a set of research practices that tend to the aggregate, are decontextualised from their social and cultural context and simplistically analysed with the problematic Indigene compared pejoratively to the non-Indigenous norm. From this Indigenous deficit is entirely predictable (Walter & Suina, 2019, p.235). This detrimental face of current data sets, or how they are constructed demands a transformation within research, and how data is formalised.

### **Aboriginal Data Sets**

From the Victorian Health Koori Health Research & Community Development Unit (2001, p.11) report, twenty years ago, Victorian Aboriginal community stated, if non-Aboriginal researchers can't research with Aboriginal communities properly then your research will not be true research, you will not have true data. For all researchers, both quantitative and qualitative, valid research data or findings is desired. During research with Aboriginal communities' meaningful engagement, including respect of Aboriginal governance is not optional but directly linked to valid data sets. Without meaningful engagement community members may withhold information, withhold participation and reject implementation of research findings. Initially research must hold community agreement on the need for data sets, addressing Aboriginal localised needs and aspirations. These include data that disrupt deficit narratives, data that is disaggregated, data that reflect the embodied social, political, historical, and cultural realities of Indigenous people's lives, as Indigenous peoples, and data that address Indigenous nation re-building agendas (Walter & Suina, 2019, p.236).

Identifying as Aboriginal within research is also important. Health researchers set out on projects only to find that the background data they need does not exist. Incomplete and inconsistent Indigenous identification in datasets needs to be taken into account when planning and designing health research projects (Laycock, et al. 2011, p.21).

In Māori research, Equal Explanatory Power (EEP) refers to the power of research to generate data which offers meaningful explanations that are specific to Māori participants, and their communities. EEP requires over-sampling of Māori participants to achieve equal explanatory power for Māori, and therefore produce information to improve Māori health to at least the same depth and breadth as that obtained to improve non-Māori health (NEAC, 2012, p.35). EEP oversampling means a research project will include participants from a group not ratio to the groups population rate. So, the study is enabled to produce



data with depth and breadth of meaning, achieving useful findings for a community's health outcomes.

Aboriginal Age Standardisation is another important principle for Aboriginal data sets. New Zealand Māori population is predominantly young, particularly compared with non-Māori. When researchers standardise data by applying 'older' standard populations such as the commonly used Segi's or the WHO world standard, the analysis favours health events that occur in older ages. If a population includes a larger percentage of young people, then findings related to diseases may not be within acceptable numbers, whereas a random group of non-Māori participants the same data may be within an acceptable range (NEAC., 2012, p.36). Meaning, Aboriginal Age Standardisation is the only way to obtain accurate Aboriginal data sets.

## 5. Victorian Research Framework

*When we have power over our destiny our children will flourish. They will walk in two worlds and their culture will be a gift to their country (Uluru Statement from the Heart, 2017).*

Victorian Aboriginal communities attempts to transform research processes in Victoria has a long history. From this background key documents were developed in Victoria to reflect Aboriginal Communities vision of research, this included reports written by VicHealth Koori Health Research and Community Development Unit (2000 & 2001), and the Onemda VicHealth Koori Health Unit (Stewart and Pyett 2005, Onemda 2008) cited in (Watson, et al., 2010, p. 5). These various projects included significant participation from Victorian Aboriginal community members, and findings were written into reports. However, these reports were not actioned or reviewed by Victorian Government, Universities or Medical Research Institutes. As Henry, (2002, p.3) explained, an important focus of the Indigenous Research Reform Agenda is formalisation of Indigenist research philosophies, principles and practices. The following section outlines important elements for a research frameworks, guidelines, standards and protocols for Victorian implementation.

### Research Guidelines Discussion

The Camden, NSW (1987) workshop, attended by Aboriginal community members nationally to discuss ethical research, strongly and collectively stated that adhering to only ethical guidelines, was no guarantee for ethical research practice. As such, the term 'guidelines' was dropped in favour of the phrase 'Principles, Standards and Rules', and the formulation and enforcement of these was clearly seen as one step in a broader process of transforming research (Humphery, 2001, p.199). Humphery, (2001, p.200) further explains, reliance on only guidelines encourages procedural observance of rules rather than a more dynamic movement to-wards fully reconceptualising research practice. Practical application of the guidelines enables understanding of minimum standard, good practice and best practice relating to application of national guidelines, at the local level (AIATSIS, et al., 2013, p.25). In New Zealand there are different types of Māori health research within their research frameworks: Kaupapa Māori research (major Māori involvement, led by Māori); Māori-centred research (major Māori participation), and research where Māori are involved as participants (minor Māori participation) (AIATSIS, et al., 2013, p.22). Relying solely on national frameworks to generate ethical research can result in tokenistic gesturing by

researchers to appease human research ethics committees (Bond, et al., 2016). Currently fears remain that the guidelines did not, and still do not, go far enough towards empowering Indigenous self-determination (Duke, et al., 2021, p.15)

### **Ethics versus Ethical Research**

An Aboriginal research framework within any institution or as part of a state agreement will need to educate researchers the difference between an ethics proposal for research which impacts Aboriginal communities, and ethical Aboriginal research. It is possible for researchers to meet rule-based ethics requirements without embracing the values and principles that are relevant to ethical Aboriginal research (Laycock, et al., 2011, p.30). To establish the foundations for ethical research in Aboriginal and Torres Strait Islander health it is critical that national guidelines and state-wide research agreements provide explicit framework for incorporating the key values that, from an Indigenous perspective, are foundational to an ethical relationship with research practice (Anderson, et al., 2003, p.27). AIATSIS, et al. (2013, p.37) defined that there is an ethic's review, and an ethical Aboriginal research review. The ethical review looks at whether the research is ethical, the research review evaluates if the proposed research fits the community's research agenda and priorities, and whether it ensures that benefits are maximised for the community.

### **Aboriginal Research Documentation & Language**

A transformed research framework will require new documentation to be developed. New partnerships, processes and mechanisms require new templates, information sheets and applications, which address key principles of the new research framework. One article explained that Western ethical research perspectives focus on legal and institutional codes of ethics which commonly centre on ensuring benefits and fairness to individuals and protecting individual rights. From this Western perspective, researchers design documents such as information sheets for prospective participants with a focus on the individual rather than on the collective (NEAC., 2012, p.2). Stewart and Pyett, (2005, p.13) stated ethical Aboriginal research needs briefing papers, pro-formas to make reviewing simpler and a central register of research projects (past and present, approved and rejected). Re-development of documentation attached to research which impacts Aboriginal communities will enable more streamlined processes for non-Aboriginal researchers who may be hesitant to include Aboriginal populations in research studies because of fear of doing something wrong. Bond, et al. (2016, p.93) described how some researchers were uncertain about local protocols, appropriate language use, and/or were unfamiliar with learning through story. Humphery, (2001, p.201). we need to develop definitions for concepts such as 'ethical practice', 'appropriate methodology' and 'community control' for researchers unfamiliar with these terms. In Canada, Indigenous organisations challenged deficit-based re-search, which focusses on problems, and demanded instead that research use strengths-based language (Harfield et al., 2020, p.2).

### **Training Non-Aboriginal Researchers**

The AIATSIS (2020, p.16) established non-Aboriginal researchers are responsible for their own professional development, ongoing cultural learning and must be able to demonstrate

cultural competency, including self-awareness, knowledge and understanding of relevant Indigenous culture, laws and protocols, and an ability to engage and communicate respectfully. Watson, et al. (2010, p.13) described three training areas: Aboriginal community engagement, reciprocal relationships and Aboriginal research design. An earlier Victorian community-based study stated, non-Aboriginal researchers lack knowledge regarding the right protocols to follow (VicHealth, 2000, p.25). Through the Inala Community Jury, jury members assessed the spirit and integrity, not of the research, but of the researchers, much to the researchers' surprise (Bond, et al., 2016, p.94). The Nga Ara Tohutohu Rangahua, Guidelines for Research with Māori, gives a list of characteristics that a research team member should own to be able to engage in culturally appropriate and effective consultation with Māori (AIATSIS, et al., 2013, p.26). Non-Aboriginal researchers need to be open to and commit to navigating complex inter-cultural values and priorities (Ewen, et al., 2019, p.12). This training requirement extends to non-Aboriginal members on ethics committees who still do not understand cultural and community protocols in research. Ethics training should involve how to do research in a culturally appropriate way (Onemda, 2008, p.21).

### **Aboriginal Research Funding**

Ian Anderson argues in (Humphery, 2001, p.201) that through the distribution of federal and state research funds, very little go to Aboriginal community-controlled organisations. He explained how this actively undermines attempts to link research with community development and social change. In the same article Humphery (2001, p.200) insists on Aboriginal control of research funds, and on related principles such as the ability of those researched to censor and veto publication of research results. In a later article stating there needs to be Indigenous community control over research priorities, the methodological approach, the 'selection' of research projects, and importantly the allocation and on-going supervision of research funds (Humphery, 2003, p.17). Recently community-controlled funding was reiterated, Lin, et al. (2020, p.11) explained, initial awarding of funds should be on demonstration of appropriate Indigenous community engagement, as vetted by Indigenous researchers and community representatives. A transfer of power relating to fundings will address the history of colonial control of research, and to activate the notion of 'guidelines' as not just a set of written procedures but facilitate concrete mechanisms for Aboriginal community control, and transformation of Aboriginal health research to Aboriginal organisations (Humphery, 2003, p.17).

## **6. Aboriginal Research Agenda**

### **Community Driven Research Priorities**

Research in the health and social sciences still fail to partner with Indigenous peoples and organisations and thereby fail to meet Indigenous people's real needs (Harfield et al., 2020, p.2). Colonial research priorities in Victoria have been like a river, which flows in a direction, from a particular source. The source has always been state and national Western institutions. These bodies decide and articulate the research agenda for Victorian Aboriginal communities. This is completed with Aboriginal 'advice' at times, however predominantly

from no Aboriginal input. The theme Aboriginal Research Agenda is altering the direction of current; it's altering the source of the river. A community-driven research agenda means research priorities are developed from the research needs of localised Aboriginal communities. Positioning research to 'Close the Gap' rhetoric in an authentic, sustainable and meaningful way. Multiple articles reiterated this message; research needs to address health issue as determined by the community (AIATSIS, et al., 2013, p.13), research should be initiated by Community (VicHealth, 2000, p.24), research should respond to priorities determined by Aboriginal community (AIATSIS, 2020, p.18), Aboriginal leadership should determine health agenda (Lin, et al., 2020, p.9) and research must address needs identified as priorities by Indigenous people (Laycock, et al. 2011, p.18).

The AIATSIS Guide to Applying the Code (2020, p.5) states that mainstream organisations need to align their research agendas with community driven priorities, rather than asking Aboriginal communities to contribute Western institutions interests. Interesting in New Zealand the NEAC (2012, p.23) article it discusses the term initiate, in relation to research. Research initiation is the very first phase overlooked, it asks who initiates the research. Beginning from initiate, an Aboriginal community driven research agenda river is the only possibility for improving health outcomes for Aboriginal communities. Koori organisations, such as VACCHO, should set their own research agenda, and have capacity to conduct their own research, as part of a Koori health research strategy (Onemda, 2008, p.42).

### **Transformative - Developing Needs Driven Research**

The Inala Community Jury for Aboriginal and Torres Strait Islander Health Research ensures that research undertaken is in the community's interests, and that the assessment of 'community interest and benefit' is determined by the local Indigenous community (Bond, et al., 2016, p.90). As Lin, et al. (2020, p.11) quantifies, research can only be considered if it originates from community needs. Needs-driven research is an alternative process to the status quo, and will require new processes, principles and structures. This transformation includes researchers hearing community research needs and working with community knowledge-holders, so they are enabled to build upon their existing knowledge (Assembly of First Nations, 2009, p.8), meaning that researchers work in close partnership with the community however constantly self-evaluating if their own objectives and ideas are masking the community's own priority areas (Jamieson et al., 2012, p.16). Research practices must transform from 'investigator-driven', to re-assertion of control by Indigenous community-controlled organisations, and adoption of the needs-based approach to research (Dudgeon, et al., 2010, p.83). Is it not common sense and fiscal, that research priorities are set by the people most likely to use the research (Laycock, et al. 2011, p.57)?

### **Sustainable, Economic Research**

If the research project is a community priority, then risk is already minimized (Gwynn, et al. 2015, p.238). This strong statement illustrates the relationship between community driven research and addressing research risks. As detailed; research responding to priorities arising from and endorsed by the Aboriginal community affected by the research, ensures the research is relevant and thus improves acceptability of the study by the Aboriginal community (Harfield et al., 2020, p.9). This relationship positions community driven research as sustainable research. Whenever acceptability of a research project is increased, engagement with the project also increases, improving chances of research validity within community. Research findings resonating with an Aboriginal community, improves

successful implementation of programs and policies informed by the same research data. Signifying sustainable research.

Aboriginal members living in communities are the most valuable resource for research, they live the information as experts, their able to access information needed for sustainable, fiscal research outcomes (VicHealth, 2001, p.9). Use of the term fiscal highlights that an Aboriginal research agenda has potential to reduce long term research expenditure. Currently from the status quo outlined at the beginning of this theme Universities, research institutes and Governments have wasted copious amounts of money through research agendas established by Western Institutions. The process for sustainable, economic processes is explained; once there is acceptance of the researcher through meaningful engagement with the community and its governance structure, then discussions to learn about community needs is prioritised, rather than the researcher determining the topic or a pre-set research agenda from their institution (Lin, et al., 2020, p.4).

### **Cultural Integrity**

Agency must be given to Indigenous communities to propose alternative hypotheses and questions that better reflect Indigenous worldviews, methodologies, and priorities (Duke et al., 2021, p.11). Sustainable, economic research for studies which impact Aboriginal communities begins with localised agency, standpoints and needs. As an Aboriginal woman I hypothesise this principle could be equally true for research impacting non-Aboriginal communities. An Aboriginal research agenda also holds improved chances of observing cultural integrity. This is a significant risk to be addressed and could potentially impact the sustainable impact of the study, if not properly addressed. Through Inala Community Jury members valued the jury process as an opportunity to express and affirm cultural protocols in terms of observing rules regarding acknowledging country, telling one's own identity story, attending to women's/men's and sorry business, managing shame or shameful issues, attending to Elders, and inclusion of young people's voices (Bond, et al., 2016, p.93). This jury model facilitated better research and cultural integrity, by enhancing individual researcher skills and knowledge, community accountability and more respectful engagement with Indigenous knowledge and perspectives, within the local community cultural context (Bond, et al., 2016, p.94).

## **7. Aboriginal Research Capacity Building**

### **Research Capacity Building**

The development of research capacity within Indigenous communities is proposed as central component to research reform within Indigenous research (Henry, 2002, p.5). It involves Aboriginal communities developing research skills to co-lead and lead research in their own communities. Ewen, et al. (2019, p.12) explains broadly, characteristics of effective research capacity building are action-focused, oriented to relationship building, provision of opportunities for learning and co-construction of research agendas, sustained funding and enduring embracement by the wider organisation. Also stated, research must provide opportunities for the involvement of community researchers. Meaningful community capacity-building must be incorporated into all stages of the research process (AIATSIS, et al., 2013, p.42) and, increasing the capacity of communities to engage in research, but also to identify their own knowledge requirements (Brands, 2014, p.14).

Research Capacity Building should be a non-negotiable benefit of research partnership with external institutions and government. It needs to occur at all levels (individual Aboriginal person, Aboriginal community and Aboriginal organisation) (Gwynn, et al., 2015, p.240). Research capacity strengthening for Aboriginal communities is to be provided through training and employment opportunities, throughout the research project. At the end of each project, Aboriginal communities should have additional skills, experience and knowledge to negotiate, assist with, implement and lead future research (Harfield et al., 2020, p.7). An important factor of research capacity building is funding. Institutions need to consider the cost of facilitating participation in research and hiring community members to do different research activities (Lin, et al., 2020, p.4). The South Australian Accord states, researchers should formally employ Aboriginal community members, and factor this cost into research budgets (SAHMRI, 2014, p.12).

### **Benefits of Aboriginal Research Capacity**

A Victorian Aboriginal community workshop explained the risk if research capacity is not achieved. Research must be a mechanism to build capacity within the Koori community. Until the capacity within Aboriginal organisations is developed and we have full ownership and control, the research being developed will have reduced outcomes potential or fail; completely (Onemda, 2008). Addressing this risk shifts the research projects to holding potential benefits. Building capacity of Aboriginal health researcher workforce creates a stronger working environment in Indigenous health and disrupts research foci that have, historically not been on Indigenous-led health priorities (Ewen, et al., 2019, p.2). Other benefits: Aboriginal people should be employed in research projects. This will improve the quality of communication and the researchers understanding of the community (AIATSIS, et al. (2013, p.11), employing Aboriginal people at all phases and management levels of the research. Developing their skills and knowledge has a ripple effect into the wider community (Gwynn, et al., 2015, p.237) and employment of local people builds legitimacy and community connectivity of the study (Gwynn, et al., 2015, p.238). Lastly, research capacity building enhances service evaluation, skills of health care staff and program assessment capacity of health organisations (Ewen, et al., 2019, p.3).

In New Zealand it was positioned that gains in Māori research are achieved through developing the Māori research workforce (NEAC, 2012, p.41). Fostering technical research skills leads to the development and validation of tribal driven health surveys. Such skills allow tribes to develop instruments that are built on their own Indigenous lifeworld's definitions and explanations of health, generating Indigenous data sets (Walter & Suina, 2019, p.239). As explained through (Stewart and Pyett., 2005, p.18) Victorian ethical review, Aboriginal Research Managers located at Victorian ACCHO's would include checking and monitoring Community consultation and informed consent processes, culturally appropriate methods, data ownership, and the relevance and benefits of the research to the Aboriginal Community in Victoria. Significant benefits derived from research capacity building in Aboriginal communities.

### **Aboriginal Community Research Skills Development**

Research capacity building has been stated as an important research sector attribute, for a long time. In 2001 it was discussed there should be a research course for Kooris to skill up. Victorian Aboriginal community strongly stated, if research doesn't advance the process of empowerment and self-determination, then were not interested (VicHealth, 2001, p.8).



Later at another Victorian Aboriginal community workshop attendees explained, a skills base is required for Aboriginal communities to conduct research appropriately, but research is not a skill taught in Koori communities, and Kooris do not have easy access to training in research skills (Onemda, 2008, p.21). Research projects should build the capacity in the community through enhancement of research skills, through collaboration with and participation of community members as researchers (AIATSIS, et al., 2013, p.29). Internationally literature explained, Mi'kmaq people of Canada and United States should not be treated as mere participants, research should impart new skills into the community (AIATSIS, et al., 2013, p.33). Importantly research skill development in communities in turn, helps communities to identify which areas require research as a next priority (Assembly of First Nations, 2009, p.32). Looking into the future Ewen, et al. (2019, p.12) states we need to deliver excellence-based research training, and secure Aboriginal research trainee access to experienced supervisors and mentors.

### **Identified Research Skill Sets**

From the AIATSIS survey with Traditional Owner Groups (TOG), results demonstrated that it's important to broker a wide array of scientific, technical, and research skills for TOG through a 'TOG first' and 'Country-first' framework (Burbidge, et al., 2021, p.45). Delivering research training needs to be across the spectrum of research skill sets (e.g., writing, research plans, conference presentations, grant applications, project management), (Ewen, et al., 2019, p.12). Also identified are skills related to survey development, data collection, analysis, and reporting and build understanding regarding research methodologies (Walter & Suina, 2019, p.239). Another area specified related to ethics training for Aboriginal Community members (Stewart and Pyett., 2005, p.13). To summarise Victorian community stated, we need to build the capacity of our communities, and organisations, to do more community-initiated research, through on-the-job training and by placing researchers in ACCHOs for a time. (Onemda, 2008, p.19).

### **Employing Aboriginal People**

Employing Aboriginal people is a component of research capacity building, including both employment on the project and/or research training (AIATSIS, 2020, p.20). The AH&MRC Ethics Committee (2016, p.9) resource requires that Aboriginal people (and especially local community members) are employed in research projects, including as co-investigators. There should be arrangements for the training and development of Indigenous research workers. Ensuring Indigenous employment as part of any research project is essential. Research employment in First Nations communities should privilege community members who are dedicated to their language, culture and Elders (Assembly of First Nations, 2009, p.32). Similar to other themes Victorian community also discussed Aboriginal employment during research saying, employing Aboriginal community members as Research Assistants so their involved in the whole research process is essential (VicHealth, 2000, p.20).

## **8. Research Benefits**

Justin Mohamed explained, 'I think that the way to get positive research is when you get outcomes at the end of it and the research doesn't stay on the shelf and get left to collect dust (VicHealth, 2000, p.9). Research benefits for Aboriginal communities in past and current research studies has been questionable, as the below discussion illustrates. One factor

contributing to this is Western methodology. Research responsibilities in Western methodology finish after findings are collated, with reference to possible conference presentation or journal articles for research translation. Ethical Aboriginal research moves into a final phase, at the same time Western research may end.

### **Aboriginal Research Translation Phase**

This phase is the translation of research findings into tangible benefits for the Aboriginal communities who were partners in the project. This final phase is non-negotiable, it is agreed to by all stakeholders during the initial engagement phase. Within each project, methodology must address implementation for the transfer of knowledge to Aboriginal communities (AMSANT, 2013, p.1). Again, reiterating the importance of research design; the likelihood of favourable research impact and thus benefits, is related to the ethical implementation of Indigenous health research processes (Kinchin et al., 2017, p.2). However, as Duke et al. (2021, p.8) explains this pivotal phase of ethical Aboriginal research does not occur, much research with Indigenous people to date has not resulted in tangible benefits for the communities involved. Western research takes knowledge back to their universities and uses it to acquire degrees and advance their careers. Very rarely, would researchers ensure communities have benefited from the research in some way (Laycock, et al. 2011, p.7). As the South Australian Accord states, research benefits universities, institutions and individual researchers in many ways, benefits should also be identified for local communities (SAHMRI, 2014, p.17). Methodology and process are very important, an attendee at a community workshop explained, we have a dilemma, what a researcher put's down on paper, may be very different to what occurs during, and from the research (VicHealth, 2001, p.8).

### **Tangible Benefits**

The AIATSIS Code of Ethics states, benefit for communities from a research project must be specific, tangible and agreed (AIATSIS, 2020, p.20). Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves (SAHMRI, 2014p, p.9). Research benefits should be meaningful for the communities who were partners during the project. Society can reap the benefits of successful research studies only if the results are converted into marketable and consumable products (e.g., medicaments, diagnostic tools, machines, and devices) or services (Bainbridge et al., 2015, p.3). Agreement between researchers and communities regarding the forms research benefits take may include, arts-based, exhibition driven, web-based and/or other creative and/or collaborative community driven outcomes (AIATSIS Guide, 2020, p.22). Mainstream institutions need to also be transparent regarding any commercialisation resulting from Indigenous data (Lin, et al., 2020, p.11).

Research must demonstrate overall Net Benefit, for Aboriginal communities' health outcomes. Historical Western research has not improved health outcomes for Aboriginal communities, so now expectation of 'Net Benefit' for Aboriginal communities needs to be demonstrated (AH&MRC, 2016, p.4). A community should be strengthened by any research project with which it is affiliated (Assembly of First Nations, 2009, p.24). From meaningful, tangible benefits for the communities who partner in a research project, translation of knowledge generated must extend to and impact policy and practice (SAHMRI, 2014, p.9).

We need to shift away from peer-reviewed journal publications being evidence of meaningful implementation (Dudgeon, et al., 2010, p.84). Using only journals is not fiscal, it has not resulted in improved health outcomes for Aboriginal communities.

### **Research Evaluation**

Within the NHMRC guidelines there is little mechanisms to ensure ongoing surveillance of research projects, the guidelines themselves established a type of gateway process of obtaining ethical approval, with little stated means of following research projects once inside the perimeter (Humphery, 2001, p.200). This context was twenty years ago, however a recent article explains the absence of formal mechanisms for Indigenous oversight of research projects once they fall within the parameters of mainstream conventions also speaks to a lack of attention given to conceptualising what comes 'after the guidelines' (Duke, et al., 2021, p.3). Project scrutiny should be ongoing, rather than simply 'once-off', and that such scrutiny should be performed by local community-controlled agencies (Humphery, 2003, p.17). Explained concisely, most research institutions require evidence of consultation with Aboriginal groups prior to granting ethics approval, there is concern that once a research project has received ethics approval, there are no mechanisms in place to monitor, evaluate or report on research outcomes (Dudgeon, et al., 2010, p.84). The same article also suggested development of an instrument for measuring social impact as a way of evaluating the quality of research undertaken in partnership with Aboriginal communities (Dudgeon, et al., 2010, p.5).

### **Aboriginal-led Dissemination**

Research results must be presented to the community before being disseminated in the public domain (AIATSIS, et al., p.42). The South Australian Accord says, research results must be presented back and formally signed off at the community level prior to any public discussion, presentation or publication of the findings (SAHMRI, 2014, p.20). Aboriginal-led dissemination respects Aboriginal governance, it ensures the data is described through language, or the use of English, which resonate with Aboriginal communities, and it also enables the research to be sustainable. Sustainability means ensuring that the knowledge and data collected during research is available for use by current and future generations, for example through the return of materials to communities and through appropriate archiving (AIATSIS, 2020, p.21).

## **9. Relationship Based Research**

The worldview informing positivist, quantitative research is realism; the view that objects hold knowledge separate to the knower, there is a discoverable reality independent of the researcher. Positivist researchers go into the world impartially, discovering absolute knowledge about a reality separate to themselves (McMahon, 2017, p. 89). This belief of reality constructs how Western research is completed, the scientist is removed, discovery truth without attachment, and without belief that what their researching could be connected to them or connected to other entities in the Lifeworld. This is very different to Aboriginal relational worldviews explained earlier. First Nations groups scientifically study the world; however, through the understanding that everything of the Lifeworld is connected, and in relationship.

### **Relationship Based Research**

Relationship based research as a research term may scare non-Aboriginal researchers. They may be concerned immediately about bias and validity. However, these terms are equally important for research informed by Aboriginal worldviews, and in fact addressed transparently, as Aboriginal researchers be open with communities regarding who they are, aspects of themselves and the project, and their motives for being involved in the study. Relational worldview is the cultural consciousness that everything is connected, like a web. Humans included. Bond, et al. (2016, p.94) explains this succinctly; researchers had to learn how to communicate their relatedness to the proposed research. Jury members examined less the researcher's methodology, and more the researcher's identity, passion and relationship to the work they were doing. Communities are more likely to embrace working with researchers with whom they have an established rapport, than with someone unfamiliar, regardless of the eminence of the researchers, sophistication of the study design or amount of funding available (Jamieson et al., 2012, p.16). Then as Duke, et al. (2021, p.12) discusses, meaningful connections are developed incrementally and over extended periods of time and achieved through both formal and informal modes of collaboration. Indigenous health research is an approach that is relational and not transactional (Duke, et al., 2021, p.13). Through the Inala Community Jury, respectful talk is important to jury members and was witnessed when researchers acknowledged country, showed signs of nervousness, and spoke to jury members in a way that they could understand (Bond, et al., 2016, p.92). The ripple effects of relationship-based research in Aboriginal communities extends from positive engagement, through to increased participation and ownership of the study, validity of research data and successful implementation of research findings.

### **Relationship Based Research Framework**

Mistrust exists around what happens to the information collected and how it will impact community (Onemda, 2008, p.22). Mistrust is the foundation most research projects with Aboriginal communities begin from. A framework is required to transition to relationship-based research. Firstly, outsider researchers understand their research must fit into the localised Indigenous knowledge paradigm, or perspectives. This means starting from a place of respect and being open to an entire overhaul of the research project during the community approval process (Assembly of First Nations, 2009, p.29). This includes respecting the need to 'settle-in' with each other, the researcher and community members, before engaging in research discussions (NEAC, 2012, p.57). Understanding a genuine relationship spans the entire research process including post-project completion (AIATSIS Guide, 2020, p.11). From this point a trust basis is hopefully developed towards the research, from the community (AIATSIS, et al., 2013, p.37). Continuing dialogues remain necessary to facilitate knowledge exchange between Indigenous communities and researchers leading to a common understanding of what resources (knowledge, personnel, infrastructure, funding), and if changes to research decision making structures are needed, to address existing community governance (Duke, et al., 2021, p.11).

### **Transformative Research**

The processes of Inala Jury inspired transformative research practice because it transformed relationships of power between Indigenous people and researchers and research institutions and privileged Indigenous voices, experiences and perspectives in health care research (Bond, et al., 2016, p.94). This transpired to Jury members feeling empowered as a result of respectful engagement with researchers, the health service and the respect given to the jury's decisions (Bond, et al., 2016, p.93). Transformative research, which includes transferring power between stakeholders but also research which transforms the lived experience of the communities involved in the study. Every stage of the research project included potential to increase Indigenous communities' capacity to address their own health issues, strengthen the relationships between community and researchers, and to equilibrate power and knowledge between these community and researchers (Lin, et al., 2020, p.10). Transformative research also requires restructuring the methodology to focus on relationship building during the research process, rather than the usual emphasis solely on research outcomes (Henry et al., 2002, p.84). This relationship building also included Aboriginal Medical Services, local community-controlled agencies and national peak bodies of community-controlled health services (Humphery, 2003, p.17).

### **Non-Aboriginal Assumptions**

As research relationships are formed, assumptions from non-Aboriginal researchers are addressed through meaningful relationships. Reflections from Inala Community Jury members are a great example. The Jury reconfigured the researcher's pre-existing imaginings of the community. Most researchers spoke of their surprise at appearing before a jury of community members who each appeared strong physically and culturally, individually and collectively (Bond, et al., 2016, p.92). This transformation of researcher perceptions, extended to their ideas regarding the local Indigenous community, who researchers had previously assumed were passive, ill and subjects of research, only to learn community was active, engaged and healthy citizens (Bond, et al., 2016, p.92). Assumptions regarding Aboriginal communities and Aboriginal researchers' ability to conduct research requires addressing. An attendee at a community workshop stated, you shouldn't have to have a Masters to be recognised to do research. There is a lack of mainstream appreciation of the additional skills that Aboriginal researchers have (Onemda, 2008, p.21).

### **Research Agreements**

A major sub-theme is research agreements. For research conducted with a particular community, group or organisation, a written agreement (a protocol, MOU or contract), should be entered into to clarify the relationship (AIATSIS, 2020, p.14). AMSANT in Northern Territory clarifies what a research agreement includes. A research contract includes obligations of each of the parties, including communication, participation, consent, methodology, monetary and in-kind costs, and necessary employment and training of Aboriginal researchers. An agreement will also address data ownership and management, intellectual property, publications, including conference presentations, cultural security and research transfer (AMSANT, 2013, p.3). In South Australia the Accord states formal research agreements need to be developed based on equivalent intercultural partnership (SAHMRI, 2014, p.11). Research agreements ensure that the research process is transparent, that interests are appropriately balanced, and that all parties understand and agree on a range of issues (Assembly of First Nations, 2009, p.25).

### Intercultural Learning

Equivalent intercultural partnership as discussed above requires learning and unlearning, for non-Aboriginal researchers, and their organisations. Intercultural is defined as practice informed by local and socially contextualised perspectives, it recognises there may be different but equal ways of knowing. Positioning that each geographic space holds its own understandings and processes to resolve local challenges. Intercultural learning requires empathetic learning, discourages belief rigidity, and encourages personal flexibility as local perspectives lead solutions (Townsend & McMahon, 2021, p.5). An alternative to Western concept of universal. Intercultural practice during Aboriginal research in localised contexts meant appreciating silence, appreciate wisdom of Elders and children and appreciate someone's humor (AIATSIS, et al, 2013, p.37), Indigenous "ways of knowing, being and doing" were made visible to health researchers (Bond, et al., 2016, p.94).

Without intercultural learning meaningful partnerships are hard to achieve when Indigenous communities and non-Indigenous researchers differ on what constitutes knowledge, how it is acquired and how it is used (Harfield et al., 2020, p.2). This space also includes both parties to learning how to work together to manage potentially conflicting agendas, including differences in priority perceptions, community politics and interpretation of findings (Jamieson et al., 2012, p.16). Working in intercultural partnerships increases the ability of non-Aboriginal researcher to understand and learn from Aboriginal knowledge systems (SAHMRI, 2014, p.12). Learning also includes self-exploration, recognition of diversity and power relationships, recognition and respect for differences in world views, values and knowledge between different groups (NEAC, 2012, p.10).

### Required Research Timeline

Relationship based research with Aboriginal communities changes the project timeline. The literature discussed; researchers need to add time at the beginning of all new research with Aboriginal communities to support the establishment and maintenance of governance structures and procedures (Gwynn, et al., 2015, p.240), this includes extensive development at the beginning of the project, and extensive dissemination of results at the end of the project (Gwynn, et al., 2015, p.238). Research within Indigenous communities involves establishing personal relationships and committing to involvement over a long period of time (Assembly of First Nations, 2009, p.31). These relationships should be entered with a longitudinal commitment (Lin, et al., 2020, p.3). Genuine collaborative research requires time, commitment and hard work, and a long-term approach to Indigenous health research, including the development of strategic alliances (Henry et al., 2002, p.84). However, the myriad of demands placed on Indigenous communities and their members, require research to "wait its turn" (Jamieson et al., 2012, p.17). From an Aboriginal way of being, priorities may not be triaged the same as non-Aboriginal researchers.

## 10. Western Institutional Reform

*Our crisis tells plainly the structural nature of our problem. This is the torment of our powerlessness (ULURU STATEMENT FROM THE HEART, 2017).*

Transformation of Aboriginal health research, the principles which inform it, the ethics which act as boundaries and the mechanisms which enable new processes, necessitate great change within mainstream institutions. The motive, the intent for this transformation needs clarifying. Is it rights based? Change from status quo is the right thing to do, in line with human rights frameworks. Is it fiscal? Aboriginal-led research will address research priorities

established by Aboriginal communities and be conducted through research processes which resonate with communities, so its research practice moving closer to, doing it once and doing it right. Is it de-colonial? Identifying that current research power structures in Aboriginal research were birthed from British colonisation. Is it humanity? Recognising that Aboriginal perspectives for health and wellbeing are from tried and tested corpus of knowledge thousands of years old, with benefits for all Australians. This literature review positions its all of them, the next theme presents mainstream responsibilities as we transition Aboriginal health research into a new space.

### **Institutional Accountability**

Who is the non-Aboriginal researcher accountable to? (NEAC, 2012, p. 23). To address continuing mistrust in Aboriginal communities towards research, this question needs to be clearly answered through future research frameworks. Researchers, research organisations, the academy, funding bodies and higher education institutions are being called upon to justify their involvement in Indigenous health research by showing how research activity impact positively on the achievement of improved health outcomes for Indigenous peoples (Henry et al., 2002, p.4). This statement was written twenty years ago, but still disgustingly accurate for now. Any research project into Aboriginal health must evidence net benefit for communities, and actually improve Aboriginal health. Accountability includes honesty and transparency; mainstream organisations historically hold funds for Aboriginal health, and research into Aboriginal health has not been Aboriginal led. The track record for Western institutions continuing to lead Aboriginal research is poor. Questioning the way researchers do business is being challenged by Indigenous people, who continue to voice concerns about being over-researched without corresponding improvements in their health (Kinchin et al., 2017, p.1).

Accountability also extends to Indigenous communities holding the right to request information and ask questions about the qualifications and experience of the researchers who partner with their communities (AIATSIS, 2020, p.16). Researchers undertaking Aboriginal research must demonstrate they have experience, knowledge and understanding of the cultural context in which they are working. No research is purely objective, and no researcher is without bias. Before undertaking Indigenous research, it is important to reflect on your own worldview and how that might affect the research (AIATSIS Guide, 2020, p.5). Aboriginal communities report there are gaps occurring, regarding researchers responding to community guidance in relation to research protocols, capacity building, data management, dissemination of results, and authorship of papers (Gwynn, et al., 2015, p.239).

### **Institutional Professional Development**

It is institutions responsibility to develop their researchers' cultural capabilities (AIATSIS, 2020, p.16). Professional development for non-Aboriginal researchers is continuing. Education content within undergraduate and postgraduate, within resources easily available within medical research institutes and Universities, training opportunities at organisations and localised listening, learning and respecting when researchers engage with Aboriginal communities. Throughout this continuing learning non-Aboriginal researchers need to examine their own realities and attitudes, that they bring to each research participant and demonstrate flexibility in their relationships (NEAC., 2012, p.39). This will be a continuous

process of self-reflection throughout all research stages, to recognise individual preconceptions and worldviews, and transcend these to collaborate with community members to produce knowledge that can be shared and accepted by all (Lin, et al., 2020, p.10). Failure of researchers to understand difference in values and culture could jeopardise both the ethics and quality of research (Dudgeon, et al., 2010, p.82).

Other elements of institutional training include institutions reviewing Aboriginal literature relevant to their area of research, and review of research projects which have already been completed with the Aboriginal community they hope to engage. Research guidelines: Nga Ara Tohutohu Rangahau Māori, highlights the importance of thorough desk research, to prevent Aboriginal communities from being over-researched (AIATSIS, et al., 2013, p.25). Universities and research sponsors should be open to changing and developing their research practices and institutional templates to respond to and accommodate Indigenous protocols (AIATSIS, 2020, p.14). Research trauma is another area institutions need to recognise, researchers need to make effort to deal with and address the perception held by many Aboriginal communities that research is always an exploitative exercise (Dudgeon, et al., 2010, p.82). However, the act of meeting face-to-face with community to explain research maybe new and daunting for most researchers (Bond, et al., 2016), without training researchers may be ill-prepared to engage effectively with Indigenous people and communities (Bond, et al., 2016, p.94).

### **Aboriginal Health Policy Development**

Aboriginal research needs to translate into Aboriginal-led policy development. An Aboriginal research framework includes a process for seamless transition where research findings build good policy. Aboriginal community has had policies placed upon us that have resulted from bad research, or bad interpretation of research (VicHealth, 2001, p.7). An Indigenous absence from the analysis of Indigenous data, risks the absence of Indigenous participation in the framing of policy directions, that flows data (Walter & Suina, 2019, p.234). Literature also indicated conflict, institutions involved in research activity are expected to conform to funding and policy imperatives, that are potentially at odds with Aboriginal-led health reform initiatives (Henry et al., 2002, p.5). Another area of conflict within the relationship between research and policy is the Western tradition of siloing. Siloing is not seeing humans as interconnected and interdependent with the whole lifeworld. Aboriginal-led health policy needs to navigate Western siloing, enabling Aboriginal health policy to be designed through a more holistic understanding (Burbidge, et al., 2021, p.44).

### **Institutional Resource & Time Allocation**

As discussed in other sections of this review, resource and time allocation is also a key area to be addressed in Aboriginal research. Institutions need to provide time and resources for appropriate engagement with Aboriginal communities and ethics committees have responsibility to build the cultural competency of their systems and membership (AIATSIS, 2020, p.17). There should be no imposition upon the Aboriginal community-controlled health sector to be involved in processes that are not adequately funded or resourced (AIATSIS, et al., 2013, p.11). Institutions need to pay community members contributing to research in recognition of their expertise (AIATSIS Guide, 2020, p.13). For researchers attempting to conduct themselves in an ethical fashion, it will be necessary to withstand



pressure to complete projects according to rigid funding timelines and external expectations for publication (Assembly of First Nations, 2009, p.31). Timelines require non-Indigenous researchers to allow sufficient time to develop trust, relationships and respect from the outset, and a fundamental commitment to open, honest and accountable research (Gwynn, et al., 2015, p.236). Extended timeframes are required for multiple reasons already discussed but also for the collective nature of Aboriginal governance decision making (VicHealth, 2001, p.1). Currently the length of time and dollars allocated for Indigenous health research is underestimated (Onemda, 2008, p.20). Each research plan needs to reflect community strengths, be realistic, feasible and transparent, especially relating to actual costs and project timelines of the project (Lin, et al., 2020, p.11).

### **Aboriginal Health Funding Governance**

Mechanisms, cycles and processes for funding Aboriginal health research will need to be re-constructed if components of this review are to be addressed. It is essential that research monies earmarked for Aboriginal health, actually sit with regional Aboriginal organizations, who understand local needs, protocols and are familiar with existing local directions for improving Aboriginal health (Assembly of First Nations, 2009, p.8). In Australia, the central task of the Camden workshop (1987) was to formulate mechanisms, tying research funding to the fulfilment of improved Aboriginal health outcomes, the workshop put forward a key proposal in which funds for research projects were to be channelled through and controlled by Aboriginal community-controlled organisations as a way of guaranteeing Aboriginal-led health research (Humphery, 2001, p.199), significantly increasing the possibility and opportunity that research improves Aboriginal health outcomes. This sentiment is reiterated; we need to transfer funds to the community or Community organisation to support the research process (Lin, et al., 2020), give community organisations involved in research partnerships more recognition and power over funding arrangements (Onemda, 2008, p.44), research funds should be available for VACCHO members' research needs (Watson, et al., 2010, p.13).

The research sector needs to identify the mechanisms necessary to establish a nexus between national guidelines and the funding of research into Aboriginal health. So, funds are channelled to Aboriginal Medical Services or other community-controlled organisations (Humphery, 2003, p.17). Humphery (2003) also questions if there was a connection between instilling ethical national guidelines for Aboriginal health research, instead of the language the Camden Workshop (1987) proposed which was 'principles, standards and rules', and the control mainstream institutional hold over research funds. Attendees at a Victorian community workshop also explained how community health organisations miss out on funding, because of the high level of technical demands by mainstream research funding bodies, when allocating Indigenous health research funds. Attendees explained, places like the NHMRC just don't seem to fund many projects in the community-controlled sector, to get funding, we must go through a partner (Onemda, 2008, p.19). Funding for projects is competitive and successful grants come with market-style forces that are transactional and time sensitive, threatening to undermine partnerships with community stakeholders that rely heavily on investments of time to develop genuine relationships built around trust (Duke, et al., 2021, p.5). Funding governance for research addressing Aboriginal health, requires a major re-structure.

### **Aboriginal Health Research Transformation**

Twenty years ago, an Aboriginal community member pinpointed a dilemma which stems directly from imported terra nullius beliefs; Aboriginal research conducted from an Aboriginal community-controlled organisation, is not seen as credible (VicHealth, 2000, p.25). This hangover from colonial thought is a difficult Western mindset to dismantle. It is a challenge which links Aboriginal health to institutional reform (Henry et al., 2002, p.3). It requires an Aboriginal health research transformation. Radical changes are required in how Indigenous health research is positioned and funded generally, and how each institution actualises, processes and monitor their own Aboriginal health research (Dudgeon, et al., 2010, p.83). Research which impacts Aboriginal communities requires a shift from colonial power, from Western institutions to the Aboriginal communities, to prioritise community-driven needs (Lin, et al., 2020, p.2), and reinstate Aboriginal knowledges, processes and governance for Aboriginal health.

### **Conclusion**

This journey covered multiple themes; some were repeated throughout. As the reviewer I didn't summarise multiplicities, so the repetitive strength of the messages could be felt. As a Yorta Yorta researcher the content at times resonated strongly with my own experience. This was possibly evident in the style of writing used. This review began with Aboriginal Governance, everything beneath holds relationship to this core theme. I understand this theme may hold uncertainty for institutions, and some non-Aboriginal researchers. However, I request individuals to critique where that feeling of uncertainty stems from. Is it holding everyone, Aboriginal and non-Aboriginal people, back from a research sector which is decolonised, innovative, fiscal, sustainable and built upon strong intercultural professional relationships? Radical change is hard work, as this review demonstrates its multi layered, and significantly impacted by social and historical context. However, from the Camden NSW workshop (1987), the multiple Victorian Aboriginal-led community workshops, diverse voices of First Nations authors informing this review, and Victorian Government's multiple plans, we do have a road map forward.

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