

Is it really co-design? - Investigating collaborative research in the design and implementation of Aboriginal public health programs.

Author:

Pollard-Wharton, Nellie

Publication Date:

2024

DOI:

<https://doi.org/10.26190/unsworks/30711>

License:

<https://creativecommons.org/licenses/by/4.0/>

Link to license to see what you are allowed to do with this resource.

Downloaded from <http://hdl.handle.net/1959.4/103583> in <https://unsworks.unsw.edu.au> on 2024-12-04



Is it really co-design? - Investigating collaborative research in the design and implementation of Aboriginal public health programs.

Nellie Pollard-Wharton

A thesis in fulfillment of the requirements for the degree of Master of Research

School of Population Health

Faculty of Medicine

May 2024

Acknowledgements

I would like to acknowledge and thank my family and friends for everything you have done for me throughout this process. Thank you – to all those that have supported me over the years. You know who you are.

A special thank you to Patrick and my children, Jack, and Hazel-Rose and to my nieces Zaharlia and Madison. You have all enriched my life so much and make this pursuit worthwhile. You remind me what is important and keep me grounded.

To my supervisors, I appreciate you and thank you for helping me complete this body of work.

I want to acknowledge those that shaped me into who I am and continue to guide me.

Abstract

Background:

Aboriginal Australians are the most over-researched population globally; this research has focussed largely on discovery rather than research with tangible outcomes that are led by Aboriginal peoples in academia, in community and in Aboriginal organisations. To investigate this further I have sought to explore approaches to collaborative research, drawing on a real-world example in the context of unintentional child injury prevention.

Unintentional injuries are a major issue for children globally and are experienced inequitably by Aboriginal and Torres Strait Islander children. This inequity is largely attributed to a wide range of social determinants of health.

Aims:

This thesis aims to explore the nature of collaborative research with Aboriginal and Torres Strait Islander peoples in health research, with a specific focus on co-design as an approach that could yield positive results in prevention of unintentional injury.

Methods:

In undertaking this thesis, I have examined existing relevant literature and established the context for this work (chapter 1), conducted a systematic scoping review of collaborative and co-designed health research with Aboriginal and Torres Strait Islander peoples (chapter 2), conducted primary research as part of the co-design of an unintentional injury prevention program (chapter 3), and summarised my findings and the implications for future research within public health in the discussion.

Results:

Chapter 2 showed that there is a commitment amongst researchers to conduct quality research with Aboriginal and Torres Strait Islander peoples with 70% of the final selection reporting that there was community consultation and engagement. However, more complex details that are also key elements of collaborative research were under-reported in the studies, only 5% of the final selection reported on intellectual and cultural property. This demonstrates that engagement and collaboration are accepted as important elements amongst researchers and well-reported, but more complex components of collaboration were less likely to be reported on.

Chapter 3 showed that co-design was a successful approach to designing an unintentional child injury prevention program with an Aboriginal Community Controlled Health Organisation (ACCHO). The iterative nature of co-design, as well as the importance of equitable partnerships and shared leadership roles between researchers and community partners, yielded positive results, that enabled the creation of a tangible and sustainable research output.

Discussion:

This thesis has found that whilst there is a growing and demonstrated level of commitment to quality research with Aboriginal and Torres Strait Islander peoples, there remain gaps in how key aspects of collaboration are enacted. My work has uncovered a gap in research practice that could be filled with the development of further frameworks and/or toolkits specific to collaborative

approaches, such as co-design, that would extend the remit of existing tools and support researchers and participants involved in Aboriginal health research.

Originality statement, Copyright and Authenticity statements

ORIGINALITY STATEMENT

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

COPYRIGHT STATEMENT

☒ I hereby grant the University of New South Wales or its agents a non-exclusive licence to archive and to make available (including to members of the public) my thesis or dissertation in whole or part in the University libraries in all forms of media, now or here after known. I acknowledge that I retain all intellectual property rights which subsist in my thesis or dissertation, such as copyright and patent rights, subject to applicable law. I also retain the right to use all or part of my thesis or dissertation in future works (such as articles or books).

For any substantial portions of copyright material used in this thesis, written permission for use has been obtained, or the copyright material is removed from the final public version of the thesis.

AUTHENTICITY STATEMENT

☒ I certify that the Library deposit digital copy is a direct equivalent of the final officially approved version of my thesis.

Publications statement

Thesis submission for the degree of Master of Public Health (Research)

[Thesis Title and Abstract](#)[Declarations](#)[Inclusion of Publications
Statement](#)[Corrected Thesis and
Responses](#)

UNSW is supportive of candidates publishing their research results during their candidature as detailed in the UNSW Thesis Examination Procedure.

Publications can be used in the candidate's thesis in lieu of a Chapter provided:

- The candidate contributed **greater than 50%** of the content in the publication and are the "primary author", i.e. they were responsible primarily for the planning, execution and preparation of the work for publication.
- The candidate has obtained approval to include the publication in their thesis in lieu of a Chapter from their Supervisor and Postgraduate Coordinator.
- The publication is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in the thesis.

☒ The candidate has declared that their thesis has publications - either published or submitted for publication - incorporated into it in lieu of a Chapter/s. Details of these publications are provided below..

Publication Details #1

Full Title:	'Better Together': Co-design of an Aboriginal unintentional child injury prevention program
Authors:	Nellie Pollard-Wharton, Amy Townsend, Dr BJ Newton, Dr Melanie Andersen, Dr Rona Macniven, Christine Corby AM, Associate Professor Ruth McCausland, Peta MacGillivray, Wendy Spencer, Dr Kate Hunter, Professor Kathleen Clapham, Christine Erskine, Madeleine Powell, Prof Rebecca Ivers
Journal or Book Name:	Injury Prevention
Volume/Page Numbers:	n/a
Date Accepted/Published:	n/a
Status:	submitted
The Candidate's Contribution to the Work:	Candidate was lead author of the paper.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The paper is positioned within the thesis as a standalone chapter, to report on the methods (co-design process) of the CHIPP program that the HDR program was embedded in.

Publication Details #2

Full Title:	Collaborative approaches to program design in Aboriginal and Torres Strait Islander health research. A systematic scoping review
Authors:	Nellie Pollard-Wharton, Dr BJ Newton, Dr Melanie Andersen, Dr Rona Macniven, Dr Rona Macniven, Dr Peter Malouf, Dr Aryati Yashadhana, Madeleine Powell, Prof Rebecca Ivers
Journal or Book Name:	Australian and New Zealand Journal of Public Health
Volume/Page Numbers:	n/a
Date Accepted/Published:	n/a
Status:	submitted
The Candidate's Contribution to the Work:	Lead author.
Location of the work in the thesis and/or how the work is incorporated in the thesis:	The paper is positioned within the thesis as a standalone chapter, reporting on the results of a systematic scoping review conducted as a part of the body of work, of the thesis.

Candidate's Declaration



I confirm that where I have used a publication in lieu of a chapter, the listed publication(s) above meet(s) the requirements to be included in the thesis. I also declare that I have complied with the Thesis Examination Procedure.

Table of Contents

Acknowledgements.....	ii
Abstract.....	iii
Originality statement, Copyright and Authenticity statements	v
Publications statement	vi
Abbreviations.....	ix
List of Figures	x
List of Tables	xi
List of presentations and future publications.....	xii
Chapter One – Introduction	13
Standpoint.....	15
Theoretical Frameworks	17
Injury	22
Co-design	25
Thesis Aims.....	26
Chapter two: Systematic Review	28
Abstract.....	28
Introduction	30
Methods.....	32
Discussion.....	36
Strengths, Limitations and Future Directions	40
Conclusion.....	41
Acknowledgements.....	42
Funding	42
Competing interests.....	42
Figures and Tables.....	43
Chapter three - ‘Better Together’: Co-design of Aboriginal unintentional child injury prevention	52
Introduction	53
Methods.....	55
Results.....	59
Discussion.....	67
Conclusion.....	70
Chapter Four - Discussion	72
Aims of the thesis.....	72
Summary of research	74

Why collaborative research? Why should Aboriginal people/communities be research partners?	77
Recommendations – Implications for future research	79
Final Reflections - The lasting impact of research on Blak bodies.....	80
Conclusions	81
References	82

Abbreviations

ACCHO – Aboriginal Community Controlled Health Organisation

ACCO – Aboriginal Community Controlled Organisation

DEG – Dharriwaa Elders Group

NHMRC – NSW Aboriginal Health and Medical Research Council

NSW – New South Wales

NT – Northern Territory

SA – South Australia

WA – Western Australia

QLD – Queensland

ACT – Australian Capital Territory

TAS – Tasmania

QAT – Aboriginal and Torres Strait Islander Quality Appraisal Tool

YN – Yuwaya Ngarra-li

WAMS – Walgett Aboriginal Medical Service

List of Figures

Figure 1 – PRISMA flow chart of review process and sampling. Pg 43

Figure 2 – CHIPP Program Logic. Pg 62 to 63

List of Tables

Table 1 – Search strategy. Pg 44

Table 2 – Characteristics of included studies. Pg 44 to 49

Table 3 – QAT Scores. Pg 50

Table 4 – Key themes from formative family and caregiver interviews. Pg 65

List of presentations and future publications

Publications

Pollard-Wharton, N., Townsend, A., Newton, B.J., Andersen, M., Macniven, R., Corby, C., Ruth McCausland, R., MacGillivray, P., Spencer, W., Hunter, K., Clapham, K., Erskine, C., Powell, M., Ivers, R., 2024, *'Better Together': Co-design of an Aboriginal unintentional child injury prevention program*, Sydney, Australia

(Submitted for publication; May 2024)

Future Publications

Pollard-Wharton, N., Macniven, R., Powell, M., Andersen, M., Malouf, P., Yashadhana, A., Newton, B.J., Ivers, R., 2024, *Collaborative approaches to program design in Aboriginal and Torres Strait Islander health research: A systematic scoping review.*, Sydney, Australia.

Presentations

Chapter 3 presented by NPW at the Australia and New Zealand Injury Prevention Conference, 2024.

Chapter 3 presented by NPW at the Indigenous Allied Health Australia conference, 2022.

Chapter One – Introduction

Aboriginal Australians are the most over researched population group globally [1-3]. A focus on discovery and descriptive research, rather than research that enables tangible community-led solutions, has shaped the deficit narrative that dominates Aboriginal and Torres Strait Islander health [3]. As such, it is imperative that all current and future research conducted with Aboriginal and Torres Strait Islander peoples (hereafter Aboriginal) and communities is community-led and collaborative. Community-led research requires a shift, a shift from focus areas being dictated by Government priorities to the priority areas dictated by Aboriginal communities. Research must address the needs outlined by our communities and must be relevant and important. If research meets these requirements, then the way forward for better health outcomes, collaboration, Aboriginal leadership, and capacity building through research will be more widely achievable. Collaborative research is the involvement of participants and partners at all stages of the research process, often referred to as co-design. Authentic co-design should be the gold standard for research, seeking to collaboratively answer priorities for Aboriginal peoples, set by Aboriginal peoples.

This thesis has provided the space for me to investigate what constitutes collaborative health research specifically in relation to Aboriginal health and the design of initiatives and/or health programs. In doing so, I have been able to turn the gaze onto the academy to critically analyse what is being reported as collaborative research with Aboriginal peoples when designing programs. Prior to embarking upon the co-design of the unintentional child injury prevention project that my research has focussed on, I undertook a systematic review to answer the following research question: *‘Do public health programs that identify as being collaboratively designed with Aboriginal and Torres Strait Islanders communities and people meet the threshold of co-design?’* (Chapter 3).

From here, my thesis expands on the results of the systematic review through contributions to a research project, ‘Community led solutions to prevent Aboriginal child injury’, funded by The Australian Prevention Partnership Centre. This project is a collaboration between The School of

Population Health (SPH) at UNSW, Sydney, Walgett Aboriginal Medical Service (WAMS), Yuwaya Ngarra-Li (YN), Dharriwaa Elders Group [4], Kidsafe NSW and Wollongong University. It seeks to address the disproportionate rates of unintentional injury amongst Aboriginal children, through a partnership between SPH and Aboriginal community-controlled organisations in Walgett, north-western NSW. This project is known as the Child Injury Prevention Program (CHIPP). CHIPP is a collaboration between key stakeholders in Walgett and SPH that aims to design a program that weaves unintentional child injury prevention knowledges into early childhood education programs whilst privileging Aboriginal and Gammillaray ways of knowing, being and doing in educating families, their children and community.

The CHIPP project and my thesis walk side-by-side in synergy with one another to understand the approach of co-design not only in theory, but also first-hand, providing the primary data that can be discussed in depth in relation to existing literature. The significant gap in unintentional injury between Aboriginal and non-Aboriginal children is an important issue to focus on in this work as the gap is linked to the social determinants of health (SDH), the biopsychosocial factors, all of which are linked to the continued experiences of colonisation in Australia.

This chapter outlines the theoretical framework that informs my research and argues the significance of applying these theories to better understand the context of unintentional child injury for Aboriginal families and communities. The importance of approaching co-design in Aboriginal research through this theoretical lens is also discussed to support the privileging of community-led approaches to program design in preventing unintentional injury amongst Aboriginal children.

In this chapter, I will define injury, describe the burden of injury for different populations, with a focus on Aboriginal children, and examine similarities in injury prevalence patterns in Indigenous populations in Australia, New Zealand, Canada and the United States of America. I will then highlight the gaps in unintentional child injury prevention programs for Aboriginal communities, whilst exploring the application of codesign more broadly in public health and Aboriginal health. In doing so,

I will also discuss the theoretical frameworks and concepts that are driving the movement towards collaborative design and evaluation of health initiatives in the development of public health program design by using the CHIPP program as an example of this in the Aboriginal unintentional child injury field.

The CHIPP program is being collaboratively designed (with the aforementioned organisations) to raise awareness of the risks and rates of unintentional child injury amongst Aboriginal children, with families and the community to prevent injury through culturally appropriate, integrated health education and program design, implementation and evaluation. The CHIPP program aims to integrate cultural knowledges, early childhood education and injury prevention literature into the design and delivery of the codesigned unintentional injury prevention program. In doing so CHIPP will address high rates of injury amongst Aboriginal children through an engaging, supportive, culturally safe play and activity-based program for children and families that embeds discussion and knowledge sharing about child injury risks and prevention strategies. Thus, designing a strengths-based approach to unintentional injury prevention. The core CHIPP working group included: Amy Townsend (Manager of Goonimoo, WAMS); Tara Smith (Goonimoo Aboriginal Child Injury Prevention Educator, WAMS); Melanie Andersen (Research Fellow, UNSW); Madeline Powell (project manager, UNSW); Rebecca Ivers (lead investigator); and myself. My role in CHIPP as a research assistant required that I work with the CHIPP team to collaboratively design the CHIPP program, that was implemented by Goonimoo staff in 2021. This work included regular team meetings; co-design meetings; facilitating yarning circles; and the eventual analysis of data collected.

Standpoint

Embarking upon this research is not simply a thesis within a funded program seeking to collaboratively design an unintentional child injury prevention program for Aboriginal families in Walgett, north-western NSW. It is much more; it is the beginnings of an investigation into what steps need to be taken to move towards Blak community-led research within Aboriginal health. Being a Kooma woman

and existing in this space (white research institutions) means that there is an inherent connection to the issues you are researching, to the country and people you are conducting the research with. Being a part of research such as this can be conflicting, on the one hand you are a part of the institution and mechanism that perpetuates violence and control against your peoples, and on the other hand you are seeking to investigate ways in which to make a violent system less violent. You are absorbing the decades of deficit discourse, violent research practises and abuses in efforts to expose them with the goal of fixing a monster. As a Blak person engaging in Aboriginal health research, it is an exhausting and all-encompassing practise. There are very few other spaces where the evidence you must read and critically analyse and the data you collect and disseminate is so close to home. The numbers and the stories are your family, your community. We are so invested in breaking down the violent processes because we are committed beyond belief to the research outcomes, because it is our survival.

Establishing my positionality within my thesis is important as an emerging Aboriginal academic. I am accountable not only to my institution and the funders of the project, but to myself, my family, my community and to our partners in the Walgett community. When choosing to expand into the field of Aboriginal health research as a Blak woman I am acutely aware of the responsibility that rests on my shoulders, the power that is potentially in the words that I write. Not the power to hope to uplift or “empower” Aboriginal peoples that I work with, but the power and the weight of my words being misconstrued, twisted or falsely interpreted to potentially continue the oppression of Aboriginal peoples, specifically in health. Consequently, my standpoint must be central to my thesis, my identity as Kooma and my lived experiences as a Blak woman must be at the core of my HDR program. The way in which I exist in this world and experience the violence unleashed upon Aboriginal and peoples is not separate to the research I undertake or the words I write. To add value to the existing literature in Aboriginal health research and program design, my identity and positionality must not be ignored, research about Aboriginal people and communities should not carry on without us. Blak voices must be central to these research programs and associated projects in order to even comprehend closing

any sort of gap between Aboriginal and non-Aboriginal peoples in Australia. This gap is vast and covers many fields. Without Black voices being vocal within the academy the deficit rhetoric will remain unchangeable.

The intersecting factors that directly impact our roles as Aboriginal researchers is complex and cannot be respectfully or wholly addressed in this introductory piece of writing and are factors that are part of an ever-expanding wealth of literature [5-10]. However, the literature that underpins my positionality will be introduced in the following section to demonstrate relevance to my HDR program.

Theoretical Frameworks

The literature that supports the need for Aboriginal voices, or rather the literature that firmly argues for the privileging of critical Indigenist pedagogy [8, 11, 12], is key in establishing the gaps and thus the way forward for both Aboriginal health and Aboriginal health research. To move forward in positive and collaborative ways in Aboriginal health research we must commit to understanding the context in which Black bodies exist in society. I will discuss the historical and contemporary context of Aboriginality in Australia and introduce key concepts, theories and frameworks that establish the need for co-designed programs such as CHIPP. The theoretical framework informing this project is complex and will draw on several key theories. While beyond the scope of this review, the thesis will include Indigenous Feminist Standpoint and critical race theories.

Invasion, colonisation, dispossession and oppression

Australia was invaded in 1788 and subsequently colonised by the British under the doctrine of Terra Nullius ([5, 13] (this was ruled to be untrue in The High Court of Australia during iconic Mabo v Queensland case in 1992 [13])). This marked the beginning of the colonial acts of dispossession, dehumanisation and continued oppression and marginalisation of Aboriginal people. Massacres, frontier warfare, disease and cultural genocide [14, 15] were acts of colonisation, as were subsequent policies hoping to fix the so-called 'Aboriginal problem' [16]. The protection policies of the early 19th

and 20th centuries marked the beginning of systematically disfiguring Aboriginal peoples and communities, by severing ties to country, family and knowledge systems, through the introduction of western religion, removal of children and learnt dependency on highly refined foods. What followed was the Assimilation policies of the 20th century which saw the continuation of these acts of cultural genocide. This has continued into the 21st century through the creation of a culture of welfare control and dependency, continued removal of children at disproportionately high rates, currently 37.3% of the total out of home care population [17], racist and problematic interventions such as ‘The Northern Territory Intervention’ [18].

These acts of cultural genocide have led and significantly contributed to the physical, emotional and psychological wellbeing of Aboriginal peoples. Additionally, they are evidenced by the gaps between Aboriginal and non-Aboriginal peoples in health outcomes and experiences, housing situations, economic, employment, education, criminalisation and racism. Furthermore, through dispossession and government policies such as forced child removal, the kinship structures in many families were and continue to be irreparably disrupted resulting in lost cultural and parental knowledge. When familial structures are systematically destroyed, this interrupts the ability to pass parental knowledge onto children, grandchildren, nephews, nieces, and extended family. Acts and policies that directly contributed to this “interruption” of knowledge, not only stemmed the flow of knowledge and autonomy within families and communities, but also inflicted physical and emotional trauma upon generations, commonly referred to as intergenerational trauma [19].

This experience of violence is not unique to Aboriginal peoples in Australia; invasion and colonisation are systematic tools that have been used globally. There are clear parallels that can be drawn between the experiences of First Nations peoples in Aotearoa, Canada and the United States of America [20, 21]. The historical context in which first nations people have lived in these colonies are at the root of understanding the health disparities that exist. Warfare, genocide, infectious disease, and dispossession are just some of the notable reasons for existing inequity. I believe that when

systematic oppression is not a unique experience the urgency to decolonise and deconstruct oppressive systems amplified.

Shaping our understanding

Decolonising research methodologies [8], critical race theories [22], whiteness, intersectionality [23] and Indigenist feminist standpoint [7] are the key concepts that shape my positionality and approach to this HDR program and my future research endeavours. These are the concepts, frameworks, and theories I bring with me from my background as an Aboriginal woman and social worker. The critical reflexivity that we embrace as social workers is a key component in undertaking holistic approaches to research with Aboriginal peoples. It is key, as understanding one's layers of privilege is at the core of ethical practice and research. More broadly concepts and theories brought across again from social work and public health such as life stages and development (social work), behavioural change [24] and The Social Determinants of Health [25-27] will guide my HDR program.

It is not simply good enough to be guided by one or two key thinkers in this space, we must amplify the significant literature being produced by First Nations peoples in how we actively decolonise and engage with anti-racist approaches.

Decolonising and Indigenist Research

Indigenist research centres around Aboriginal ways of knowing, being and doing. Indigenist Research as a methodology has emerged to allow these knowledges to rightfully exist within western research, by weaving western research practices into Aboriginal ontology [5]. The key guiding principles are:

“recognition of our worldviews, our knowledges and our realities as distinctive and vital to our existence and survival; Honouring our social mores as essential processes through which we live, learn and situate ourselves as Aboriginal people in our own lands and when in the lands of other Aboriginal people; emphasis of social, historical and political contexts which shape

our experiences, lives, positions and futures; and privileging the voices, experiences and lives of Aboriginal people and Aboriginal lands” [5].

Indigenist research will continue to develop over time, but it is a methodology that can help Aboriginal peoples within research to “take control of our lives and protect ourselves, our lands, our past, our present, and particularly our futures” [5].

Decolonizing Methodologies [8] facilitate the active recognition of the intersecting forces [22, 23] that continue to affect individuals and communities surviving in settler-colonial societies. The literature highlights the need for research with First Nations peoples to be framed by decolonising concepts and to be led by First Nations peoples across the globe. Working within a decolonising framework and through an Indigenist lens is of the utmost importance for my HDR program and linked CHIPP program.

Social Determinants of Health:

The World Health Organisation [28] defines the Social Determinants of Health as “the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.” (World Health Organisation 2020). These determinants explain many of the health inequities that exist between countries with differing incomes and access to resources, and within countries, particularly for marginalised populations across the globe.

Whilst the Social Determinants of Health are not key drivers of all aspects of health care systems and health care provision, they can provide a potential framework that allows for critical approaches towards addressing ill health and inequity in public health. The WHO definition, when unpacked, clearly identifies the systematic issues that exist within colonised countries such as Australia, where it is the ongoing process of colonisation that has led to the stark disparities between Aboriginal and non-

Aboriginal peoples in Australia. As such, the Social Determinants of Health take the emphasis off a neoliberal focus on individual responsibility and accepts collective responsibility for changing inequitable systems, not people in order to achieve equitable health for all; “Inequalities in health arise from inequalities in society.” [26].

Without critically considering the reasons for inequitable health outcomes we cannot hope to address the significant gaps between classes and races that exist in health. To do this, we must engage with existing literature, theory and evidence from a variety/cross-section of disciplines to ensure our research and approaches are well positioned. As my thesis aims to explore the benefit of codesigned programs within public health, we must understand the context that has been provided in this section to best approach significant health issues that could potentially be addressed through codesigned programs, such as CHIPP.

When working in the field of Aboriginal health research it is important to be led by decolonising research methodologies and critical race theory to ensure that, as professionals, we can commit to fully understanding how the Social Determinants of Health impact Aboriginal communities and the barriers towards health equity. This theoretical underpinning is the backbone of this body of work. Ensuring that we conduct our research grounded in specific theoretical approaches and understandings is key to ensure that this work has integrity, depth and a genuine focus on the experiences of Aboriginal peoples.

Cultural Determinants of Health:

The cultural determinants of health (CDH) are another important framework that encourage one to have a more in-depth understanding of additional factors that strengthen or inhibit the of Aboriginal people. Cultural determinants include Indigenous language; connection to country; self-determination and leadership; Family, kinship and community; Indigenous beliefs and knowledge; and cultural expression and continuity [29-31]. They shape Aboriginal ways of knowing, being and doing, and help to explain the relationships between culture, health and lived experience. The cultural

determinants of health guide the perspectives that have shaped this thesis, especially as they operate alongside the SDH [29].

With all of this in mind, there are many health factors that could and should be explored from the perspectives of Bla(c)k researchers and community voices. However, as identified previously, my thesis has the benefit of being attached to the CHIPP program and as such a portion of my focus will be focusing on unintentional child injury.

Injury

Injury is defined as “the physical damage that results when a human body is suddenly subjected to energy in amounts that exceed the threshold of physiological tolerance – or else the result of a lack of one or more vital elements, such as oxygen” [32, 33]. Injury can result in temporary or permanent impairment and the impacts can be both physiological and psychological, temporary and lifelong [34-36]. The impacts of injury affect not only the individual, but their families, communities and broader social systems.

Injury can be classified as either intentional (deliberate) or unintentional (accidental). Intentional (deliberate) injury includes: interpersonal (homicide, sexual assault, violence, neglect and abandonment); self-harm (abuse of drugs and alcohol, self-mutilation, suicide); legal intervention (action by police or other law enforcement personnel); war, civil insurrection and disturbances (demonstrations and riots) [33]. Unintentional injuries are often described as ‘accidents’ although this term is no longer used in an injury prevention context, as it implies that nothing can be done to prevent them and it ignores the structural, behavioural and environmental factors that contribute to injuries occurring. Unintentional injuries can occur through a myriad of mechanisms, including: traffic injuries; drownings; burns; poisons; and falls [32, 37].

Unintentional injury is a significant public health issue worldwide, especially for children and young people over one year of age, as the risks that children and young people are exposed to increase with

age and developmental stage [38]. In addition, death and disability occurring from unintentional injury is higher as there are fewer deaths due to cancer and communicable diseases in children over one year of age.

Burden of Child Injury

Preventable child injury has far-reaching impacts, “an injured child may face ongoing limitations related to their physical abilities, experience chronic pain and psychological issues, such as post-traumatic stress disorder.” [34]. Unintentional injuries are responsible for 830 000 child deaths per year [37] and over 950 000 non-fatal hospitalisations worldwide [32, 34]. There are significant factors that expose children and young people to the risk of death or non-fatal injury resulting from unintentional injuries. These factors include developmental stages, geographic location, socioeconomic status, experiences of marginalisation, limited access to adequate health care and human rights.

Whilst unintentional injuries occur in all populations globally; children, families and communities from low-income countries and those that belong to marginalised populations in middle and high-income countries are disproportionately affected [32, 36-41]. Children in low-income countries are at greater risk of unintentional injury due to many factors, many of which can be linked to the Social Determinants of Health, as previously noted. These are also the same factors that impact marginalised populations within middle- and high-income countries.

Given the enormous burden, reducing child injury is a worldwide issue that must be addressed. Specifically, unintentional injuries must be addressed considering the trends in injuries have not been met with the same vigour as communicable diseases in children [38].

Australian Burden:

Child injury is a major cause of hospitalisation and leading cause of death in Australia [34, 42]. Rates of injury are influenced and impacted by age, stages of development, gender and Social Determinants

of Health. Injuries account for 33% of all child deaths in Australia, with children aged between 1-4 having the highest rates [42]. Injuries also account for life-long disabilities for children, potentially altering their life courses and impacting their families and communities. Beyond the initial stress and trauma of hospitalisation related to injury, chronic pain, ongoing limitations relating to physical abilities and psychological issues have significant impacts on children, their families and communities [34].

Unintentional injuries in Australia are generally described in terms of injury mechanism or rather what action or behaviour causes the injury to occur. The most common injury mechanisms for children in Australia are classified as: falls (injuries due to inanimate mechanical forces, such as being struck by/striking against objects); road transport-related incidents; drowning and submersion; burns; and collisions [34, 35, 43]. Whilst injuries can occur amongst all communities and populations within Australia, the geographical and cultural landscape does provide several challenges in terms of access to healthcare, increased risk and marginalisation that see the rates differ across the country.

Aboriginal Experience:

As the literature in previous sections has Aboriginal children are at greater risk of unintentional injury because of the impact of the social determinants of health. Whilst the injury mechanisms for unintentional injury remain largely the same for Aboriginal and non-Aboriginal children in Australia, the rates of injury are up to 5 times higher in Aboriginal children [37, 39, 40, 43-46]. The highest inequities between Aboriginal and non-Aboriginal children in NSW in relation to injury mechanisms were fire, flames, heat and hot substances; and transportation [37, 39]. Additionally, the children aged between 1 and 13 were at greater risk of hospitalisation or death of unintentional injury [35, 39, 40].

A significant factor for these higher rates are the impacts of the social determinants of health outlined previously. Therefore, unintentional child injury is an area that requires urgent attention especially within Aboriginal populations [35, 37, 39, 40]. Injury data in Australia had not been effectively

mapped until a 10-year review of child injury hospitalisations in 2017 [34], suggesting that a “monitoring and prevention strategy in Australia is long overdue” [141]. This review reported the need for the “development of multisectoral childhood injury preventions strategies” in order to effectively reduce hospitalisation as a result of unintentional injury [141]. Current guidelines for good practice suggest targeted injury prevention measures be adopted to reduce the rates of unintentional injury, as population wide measures may not be effective for all population groups [40, 41, 44, 47].

Effective injury prevention strategies for Aboriginal families have centred around culturally safe home visiting and parenting support programs that raise awareness of injuries and provide education and resources [41, 44]. A key document to note is the ‘Active & Safe: Aboriginal child injury prevention guidelines’ [41]. This document is a foundational piece of literature that brings together current data to provide the basis for effective ways in which to reduce unintentional Aboriginal child injury.

Aboriginal children and families have unequal access to unintentional child injury prevention programs and interventions, as such it is important to develop targeted evidence-based approaches in this field [41, 44]. A potential targeted solution for this is collaboratively designed prevention strategies with Aboriginal Community Controlled Organisations focusing on children aged 1-5 years of age, that are guided by cultural determinants of health [29, 31].

Co-design

Co-design is a term that is used to describe the collaborative process of design where professionals engage with service users and health practitioners to maximise success of a proposed idea, environment or program [48, 49]. Co-design is an approach to research rather than a clearly defined methodology.

Proponents argue that this collaborative approach of co-design is a way forward in supporting communities to have their voices heard and needs met on their terms respecting their autonomy and expertise, whilst weaving in the expertise of western health practices and theories. Co-design is

potentially a way forward in authentically embodying the notion of 'nothing about us, without us' a phrase and call to action that is leading research in Aboriginal health research shaped by Decolonising and Indigenist research [50, 51].

Aboriginal communities must be afforded the opportunity to decide what they need for their communities. The goals of researchers and health workers should be to walk beside community in an authentic way. It should not be up to community to navigate the complex systems of institutions or funding bodies. Researchers should be a tool and a resource that communities use for their benefit. If non-Aboriginal researchers choose to work in Aboriginal spaces, it is important that significant steps are taken to understand the experiences of each community they work. These steps could be achieved through codesign approaches to program design and implementation. Aboriginal people are not a homogenous group, we are diverse. We have complex systems of knowledge that have been underappreciated since colonisation.

Co-design is a core element of my HDR program and a focus that will be discussed in depth in a chapter of my thesis. My systematic review will seek to expand and explore definitions and understandings of the codesign approaches to program design and implementation specifically in relation to Aboriginal research within Australia. Additionally, the CHIPP program will be used as a case study to explore the effectiveness of co-design in relation to unintentional child injury prevention programs with Aboriginal peoples.

Thesis Aims

The overall aim of this thesis is to investigate the nature of collaborative research in Aboriginal health and document the collaborative co-design processes of the CHIPP program to address unintentional child injury in Aboriginal communities. Specifically, this research will address the following questions:

- What are the tenets of effective co-design when working in partnership with an Aboriginal Community Controlled Organisations (ACCHO)?

- How do Indigenous knowledges manifest and enhance community ownership of program and research design?

In undertaking this research, I have worked within the tenets of Aboriginal ways of knowing, being and doing; whilst integrating western research frameworks. Additionally, this thesis will discuss the complexities of the impacts of external factors on the emerging Blak early career researcher/academic. This will be explored through my experiences throughout and drawing on existing literature. I aim to provide insight into the importance of genuine collaborative research that privileges Aboriginal peoples as the experts of research conducted with and for their communities and provide insight into the experiences of Blak academics/early career researchers navigating the whiteness of the academy and institutions.

Chapter two: Systematic Review

Title: Collaborative approaches to program design in Aboriginal and Torres Strait Islander health research: A systematic scoping review.

Nellie Pollard-Wharton¹, Dr. Rona Macniven¹, Madeleine Powell¹, Dr. Melanie Andersen², Dr. Peter Malouf³, Dr. Aryati Yashadhana¹, Dr. BJ Newton^{4*}, Dr. Rebecca Ivers^{1*}.

1 School of Population Health, University of New South Wales, Sydney Australia

2. Ministry of Health, New South Wales, Sydney Australia

3. Faculty of Medicine and Health, University of New South Wales, Sydney Australia

4. School of Social Sciences, The University of New South Wales, Sydney Australia

*Joint senior authors

Correspondence to: Ms Nellie Pollard-Wharton, Level 3, Samuels Building, Kensington, NSW, Australia.

Submitted:

The authors have no conflicts of interest.

Abstract

Objective: Collaborative research approaches involving Aboriginal and Torres Strait Islander people have been widely applied across research, particularly in health service and population health contexts. However, the extent to which genuine involvement of Aboriginal and Torres Strait Islander people has occurred in such work is often unclear. This systematic scoping review identifies and appraises research self-described by authors as using collaborative methods or approaches involving Aboriginal and Torres Strait Islander populations.

Methods: Seven (7) bibliographic databases were searched for studies published from January 2000 to February 2021. Studies that utilised participatory action research (PAR) methods, co-design approaches, and other collaborative research methods that involved Aboriginal and Torres Strait Islander populations were eligible for inclusion. The Aboriginal and Torres Strait Islander Quality Appraisal Tool (QAT) was used to assess the extent to which the collaborative research methods were

applied, including Aboriginal and Torres Strait Islander leadership, adherence to ethical guidelines and research quality.

Results: A total of 1,601 titles and abstracts were screened, 209 full-text records were reviewed, and 37 research papers met the inclusion criteria. Of the final selection, 14 identified Participatory Action Research (PAR) as a methodology, and 9 stated they were using or guided by variations of participatory research processes (Action Research and CBPAR). No papers achieved the maximum QAT score.

Discussion: The research methods in papers in this review were often not aligned with the criteria in Aboriginal and Torres Strait Islander quality control tool and some were also not aligned with appropriate ethical guidelines. No papers met all criteria in the QAT, and many did not report that they were conducted in a manner consistent with key principles for researching Aboriginal and Torres Strait Islander people/s.

Conclusions: The concept of 'co-design' within public health research needs further development and a more explicit definition to ensure that it denotes genuine Aboriginal-led collaborative research when utilised in Aboriginal and Torres Strait Islander spaces. The development of a co-design tool is recommended to guide practice.

Keywords: Indigenous, co-design, program design. The term Aboriginal is used respectfully in this paper to refer to Aboriginal peoples who inhabit the mainland of Australia.

Introduction

Collaborative approaches and research methods have been identified as positive processes, especially with Aboriginal and Torres Strait Islander peoples [52, 53]. This is largely because of the growing acceptance that research about specific population groups should directly involve them in their conduct and methods. Research conducted with Aboriginal and Torres Strait Islander populations must endeavour to be strengths-based, privileging Indigenous ways of knowing and being on the path to decolonising practice, to make way for tangible self-determination [9, 54].

Co-design is recognised globally as an important element of behavioural science, particularly in the planning, designing, and implementing of health programmes and policies [55]. Co-design is described “as an active collaboration between stakeholders in designing solutions to a specified problem. It promotes citizen participation to formulate or improve specific concerns.” [56]. Co-design is associated with participatory research methods. It is an approach that focuses on teamwork and the participation of “untrained” groups or individuals in a design process [57, 58] and it privileges the voices of the participants through the research process [59, 60].

In recent years, the term ‘co-design’ has emerged in Aboriginal and Torres Strait Islander research environments as an approach involving individuals and communities in the research process in ways that promotes collaborative research practices. However, whilst co-design represents a positive step for equitable research, guidance on co-designed approaches is unclear, and practices that describe co-design approaches vary considerably. To date, there is no clear Indigenous-defined definition of co-design and how to practically apply the method within Aboriginal and Torres Strait Islander research [56, 58, 61, 62].

Research with Aboriginal and Torres Strait Islander peoples can yield positive and lasting results authentically and collaboratively with strong Aboriginal and Torres Strait Islander leadership [60, 63]. Aboriginal and Torres Strait Islander peoples have been subject to decades of over-researching, arguably with limited impacts on improved overall health outcomes [1, 2, 64]. Whilst much research

has been conducted on and with Aboriginal and Torres Strait Islander peoples, the large-scale impact of such research is yet to achieve its goal of closing the health gap between Aboriginal and non-Aboriginal Australians [9, 28, 65, 66].

While there are examples of researchers and institutions conducting research in partnership with Aboriginal and Torres Strait Islander peoples and communities, high-quality research needs Aboriginal and Torres Strait Islander leadership and collaboration to effect tangible change [9, 67]. Tangible research outcomes in designing preventative health programs are not always effective or sustainable unless the architects are also the consumers. The phrase ‘nothing about us, without us’, has never been more pertinent; health initiatives are more likely to be successful if their design and implementation involve the intended recipient/s [67]. Additionally, the importance of Aboriginal authors writing about Aboriginal health cannot be understated.

Co-design could be a profoundly collaborative and genuine approach to research with Aboriginal and Torres Strait Islander peoples and communities. Key principles for co-design can be drawn from existing ethical guidelines [52, 68] and decolonising research methods [8]. When used in partnership with Aboriginal-specific ethics guidelines, collaborative research methods can result in high-quality research with Aboriginal and Torres Strait Islander peoples and communities. These guidelines seek to empower and protect from the research fatigue experienced [69-72]. Within health research, some forms of ethical guidelines for research on Aboriginal and Torres Strait Islander peoples have existed for several decades [71]; however, Indigenous-led ethical guidelines have only been developed more recently [53, 71]. This sound development of Indigenous-led ethics for Indigenous research has opened the doors for further refinement and development of future uses and iterations of Indigenous-led frameworks.

In theory, research with Aboriginal peoples is governed by appropriate ethical guidelines that provide a governance framework for conducting such research [52, 68, 73]. However, not all states and territories have specific Aboriginal and Torres Strait Islander ethics processes, so the quality of

research may be impacted as specific Aboriginal and Torres Strait Islander ethics guidelines do not always need to be adhered to and, in some cases, are actively ignored [70]. Active ethical guidelines and companion documents include positive research methods with Aboriginal and Torres Strait Islander populations: recognition and respect, engagement and collaboration, informed consent, cultural capability and learning Indigenous leadership, strengths-based, impact, value, and sustainability [68, 73, 74].

This review aims to understand whether public health programs that identify as being collaboratively designed with Aboriginal and Torres Strait Islander communities and people are authentically conducted in a collaborative partnership to undertake appropriate research. It seeks to explore the extent to which researchers actively engage in collaborative research with Aboriginal and Torres Strait Islander peoples and communities and how collaboration is described, measured, and translated through co-design, participatory research methods, adherence to Indigenous ethics, informal processes, or a combination.

This review addressed the question: ‘Have public health programs for Aboriginal and Torres Strait Islander peoples and communities been collaboratively designed?’.

Methods

Search strategy

The search strategy and key terms were derived by running test searches in online databases in consultation with a health research librarian (table. 1). The following electronic databases were searched: Embase, CINAHL, Scopus, Web of Science, Pubmed (Medline), Proquest and Informit. The search was restricted by date and country (Australia). The search was limited to papers published between January 2000 and February 2021 and the country (Australia). Search results were imported into an Endnote library, where duplicates were removed, and imported into Covidence for title abstract and full-text screening. Backwards and forward searches of the articles that met inclusion criteria after full-text screening were also conducted to identify other relevant articles. NPW and MP

performed the screening to ensure the process was consistent. Conflicts were resolved through group discussion with RM, and a consensus was reached.

Study selection

Articles were included if they addressed Aboriginal and Torres Strait Islander health, were located within Australia, engaged with a participatory research methodology, or self-identified as using co-design as an approach or elements of co-design, identified as partnering with participants; and were focussed on the development, implementation, or evaluation of a program. For this review, a clear definition of 'program' was necessary to ensure that the appropriate data was gathered and reviewed. 'Program' was defined as a series of activities or events to be implemented in a community or healthcare setting or the production of health literature or health education resources distributed within healthcare services or community settings. These 'programs' should have a specific and intended result and aim to be sustainable.' [75]. The articles excluded were reviews, study protocols, conference presentations, grey literature, articles not focusing on Aboriginal and Torres Strait Islander population groups, articles not program-focused, and studies not based in Australia.

Data extraction tool and Quality appraisal

The Aboriginal and Torres Strait Islander Quality Appraisal Tool (QAT) (fig. 3) was utilised to investigate the extent of collaboration and Aboriginal and Torres Strait Islander participation in the final paper selection.

The QAT is an appraisal tool developed by a team of researchers from the Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE): six senior Aboriginal and Torres Strait Islander researchers and five non-Indigenous researchers [63]. It was developed to provide an Aboriginal and Torres Strait Islander perspective to improve how systematic reviews were reviewed [63].

Aboriginal Oversight: The research was led by an Aboriginal academic (NPW), with two other Aboriginal co-authors (PM and BJN) and non-Indigenous authors.

Results

Overview and descriptive results.

Figure 1 presents the review stages and associated sample numbers. The search of electronic databases returned 1601 potentially relevant records, with 1595 remaining for title and abstract screening once duplicates were removed. A total of 209 papers underwent full-text review using a dual author screening process; 37 papers met the eligibility criteria for inclusion in this review.

Demographics

Of the 37 included publications, seven reported on programs designed with or for Aboriginal and Torres Strait Islander populations in QLD; 11 in NT; 6 in NSW; 5 in WA; 1 in SA; 2 in VIC; 1 tri-state/territory (NT, SA & VIC); 2 dual-state/territory (VIC & NT; NSW & NT); and two nationals. Of the articles included, 20 were considered remote locations [76]. Six were in regional locations, three were in urban locations, and the remainder were national projects in multiple areas, as identified by the authors of the publications.

Co-design methods

The included papers described various methodologies that shaped the methods when designing, implementing, or evaluating public health programs with Aboriginal and Torres Strait Islander peoples. The 37 identified records are shown in Table 2, summarising the characteristics of the included publications. Of the 37 records, 14 identified Participatory Action Research as a methodology, and nine stated they were using or guided by variations of participatory research processes (Action Research and Community Based Participatory Action Research), whilst 13 used no explicit participatory research methods. Seven of those 13 papers reported using 'co-design approaches' or 'co-design workshops.' [77-83]; 1 used a case-study approach (*the term co-design was included in the*

title and mentioned once in the paper itself)[84]; 1 reported to be community-driven and co-developed[85]; 1 reported to be collaboration; 1 was a self-controlled cluster randomised trial with community consultation[86]; 1 reported using discovery education [87]. Of the 37 articles, 11 directly used the term co-design, and 4 used the term when referring to 'co-design' workshops held as part of the study [79, 81, 82, 88]; and 7 used the term to describe the overarching approach used [78, 80, 83, 85, 89-91].

Of the final paper selection, 14 scored nine or more [80, 87, 89, 90, 92, 93, 94-101]; 13 scored between 5 and 8 [78, 79, 83, 86, 91, 102-110]; 7 scored between 1 and 4 [81, 82, 85, 88, 111-113]. No papers reached a maximum score when assessed using the QAT. Papers were given a score of 1 for each QAT question where they met or partially met the question. Papers were given a score of 0 where they did not meet, or it was unclear whether they met the QAT question.

Table 2 shows the results of the quality appraisal using the QAT. The results showed that 58% (21 of 37) of the papers were identified as responding to a need or priority determined by the community. Of the included papers, 70% (26 of 37) reported sufficient consultation or engagement with the community, and 70% (26 of 37) reported Aboriginal and Torres Strait Islander research leadership. Only 62% (23 of 37) reported Aboriginal and Torres Strait Islander governance, whilst only 54% (20 of 37) reported that community protocols were followed. Whilst no papers reported that negotiations or agreements were made regarding rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property, 5% (2 out of 37) had made agreements regarding ownership of intellectual and cultural property created through the research. Only 30% (11 out of 37) reported that Aboriginal and Torres Strait Islander people and communities had control over collecting and managing research materials. Similarly, only 38% (14 out of 37) of the papers reported that an Indigenous research paradigm guided the research, but 62% (23 out of 37) took a strengths-based approach to their study. Of the included papers, 73% (27 of 37) reported that the research planned to or did translate into sustainable changes in policy and/or practice. Whilst 65% (24 of 37) benefitted

the participants and Aboriginal and Torres Strait Islander communities, only 38% (14 of 37) of the papers reported that their research demonstrated capacity strengthening for Aboriginal and Torres Strait Islander individuals. Finally, only 57% (21 of 37) of the papers noted that everyone involved in the research had an opportunity to learn from each other.

Discussion

This review has found a breadth of approaches being used to conduct collaborative research within public health program design and research evaluation. The level of collaboration reported in the included papers varied, in the design, implementation, and reporting of results. While there is a clear expectation within health research to ensure collaboration with Aboriginal and Torres Strait Islander populations, there is no universal framework outside of ethics guidelines and Indigenous research methodologies to provide guidance to ensure that collaboration is adequate and meaningful.

This review has identified some quality work being conducted with Aboriginal and Torres Strait Islander peoples to design, implement, and evaluate health programs. There was evidence of studies being undertaken with strengths-based approaches [77, 80, 90, 97], and being guided by Indigenous and decolonising research methodologies [77, 90, 97, 98]. Additionally, several papers reported on key partnerships that enabled the study to be undertaken with Aboriginal leadership, participation, and ownership [80, 100, 101, 113, 114].

Several elements of the QAT were consistently reported in included papers. These elements are representative of the basic tenets of collaboration with Aboriginal peoples in research that can be found in ethics guidelines, frameworks, and partner documents [73, 74, 115]. We found that 30% of papers scored 10 or more when assessed using the QAT. Of that group, all identified that the research took a strengths-based approach acknowledging the harm of experienced by Aboriginal peoples (Q10); and all identified a research benefit for the communities/participants of the research conducted (Q12). All but one identified that: research responded to a community need (Q1); there was community consultation (Q2); there was Aboriginal leadership (Q3); there was Aboriginal governance

(Q4); and community protocols were followed (Q5). In this group all papers, except 1, identified that there were opportunities for two-way learning (Q14). All papers, bar one, were able to demonstrate that the research had translated into sustainable changes in policy or practice (Q11). Of the high scoring group all except 2 papers were guided by an Indigenous research paradigm (Q9); all except 3 reported on elements of capacity strengthening for Aboriginal peoples involved in the studies (Q13).

What these findings indicate, as seen in the results, is that there is a commitment to engaging appropriately and conducting research appropriately with Aboriginal peoples, however there are clear gaps in areas that may be perceived as complex or difficult within research, or outside of the scope of research projects. Papers that scored lower on the QAT did so because of two factors; 1. what was not reported on, noting that greater involvement, Aboriginal leadership, and Indigenous knowledges could have been present in the research; 2. Reporting on details related to intellectual and cultural property; data collection and management of research materials was limited. This indicates that there are areas within research that the researchers themselves may struggle to understand how to integrate and implement into research projects, thus supporting the call for development of frameworks or a toolkit to provide a clear process. Even of the 30% of papers that scored 10 or more in the QAT, only 1 of those was able to report on intellectual and cultural property, whilst only 19% of all papers reviewed were able to report on Aboriginal control of the collection and management of research materials.

The review process also revealed a significant gap in the consistency in the way in which research with Aboriginal peoples is undertaken and reported on. Highlighting what is considered of value within research practice and what is not. As indicated in the results, less than 5% of the papers could report on matters related to intellectual and cultural property related to the research. Only 30% were able to report on Aboriginal control of collection and management of research materials; and less than 40% were able to report on demonstrated capacity building for Aboriginal community/individuals in which the research was conducted. What this demonstrates is that the current level of commitment to collaboration stops at a point which could be considered tokenistic and is representative of calls for

research to move away from being descriptive and towards having tangible positive impacts on individuals and communities [70].

For a larger percentage of papers to elicit a higher score, and thus demonstrate best practice in Aboriginal health research, in-depth reporting on the formative stages undertaken within research would be beneficial. Reporting on these elements would enable other communities and professionals to understand best practices and be guided by them. Furthermore, the inclusion of reporting on all elements, outlined in the QAT, would improve the quality of the research overall, and provide the opportunity for researchers to demonstrate where they are in fact including these important elements in their research practice and reflect on where they are not, and why they are not.

Research with Aboriginal and Torres Strait Islander people's needs to be driven by Aboriginal peoples and communities [116]. The proponents of collaborative and community-led research that may seem unimportant to non-Indigenous researchers are in fact tangible factors that must be met if research is conducted in this space. Additionally, these steps towards refining research practice do not negate the use of participatory research methods and the positive outcomes they achieve but rather seek to improve research practice to hold researchers accountable while providing guidelines and frameworks that can be followed. Quality research with Aboriginal peoples is more than relationship building, it is the genuine involvement and inclusion of Aboriginal peoples and communities in all aspects of research.

Research that seeks to address "problems" within Aboriginal and Torres Strait Islander communities should include involving the community and incorporating place-based knowledge to be considered collaborative with strong Aboriginal leadership. All research that has an impact on Aboriginal and Torres Strait Islander lives must have Aboriginal leadership with accountability measures and real power within any research project [70, 117]. Aboriginal leadership in this context means seeking to ensure that research is conducted through authentic partnerships with local Indigenous organisations such as Aboriginal Community Controlled Health Organisations (ACCHO) [118] and place-based key

stakeholders and responding to community priorities. Aboriginal leadership also refers to research projects led by Aboriginal and Torres Strait Islander academics and researchers, with Aboriginal and Torres Strait Islander community researchers and professional staff voices being heard and valued, within the context of upholding and respecting Aboriginal knowledge systems and recognition that Aboriginal peoples have the inherent ability to be engaged at all stages of research, especially that relates to Aboriginal peoples [62, 73].

This review has explored several elements of collaborative research practice with Aboriginal peoples reported in papers describing health research, program design and implementation. Further, this review sought to investigate the use of ‘co-design’ within Aboriginal health research. Co-design is a term that has been used to describe approaches to collaborative research with Aboriginal and Torres Strait Islander peoples with varying degrees of effectiveness [60]. Whilst literature has sought to ascribe definitions and meanings to the term co-design, there does not appear to be a consensus [58, 119]. It remains a term *“used interchangeably to refer to a participatory or collaborative process involving researchers, stakeholders, and end users involved in the development or evaluation of such interventions.”* [59].

Existing definitions speak to the underlying values and ‘principles’ of co-design [56, 61], or the elements that underpin it. These principles (*equal partnership, openness, respect, empathy, and design together* [56]) align with many of the core values outlined in the NHMRC, *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*: Responsibility; Reciprocity; respect; equity; and cultural continuity [68]. The commonalities in these values/principles demonstrate the potential suitability of co-design for research with Aboriginal and Torres Strait Islander Peoples and communities. While one singular definition of co-design may not be clear, nor how it can be applied, the principles underpin it can align with good research practises. The QAT, utilised within this review to examine the content and assess the quality of the papers, is also underpinned by these core values [63].

Co-design in this context privileges Aboriginal and Torres Strait Islander knowledge systems and our ways of knowing, being, and doing [120]. It calls for the research to be embedded in or at least be led by Indigenous research methodologies. Whilst ethical guidelines exist for Aboriginal research, they are not always adhered to in practices, and ethics committees are not resourced to monitor the extent to which what researchers say they will do ends up occurring. Butler 2022 put forward six overarching themes that are relevant to co-design with Aboriginal peoples and communities: *First Nations Australian Leadership, Culturally grounded approach, Respect, Benefit to First Nations communities, Inclusive partnerships, and Evidence-based decision-making* [62]. These elements are mirrored in existing ethical frameworks and guidelines and in the QAT. This shows that there is a general understanding of and access to ways of undertaking quality research with Aboriginal and Torres Strait Islander peoples and communities. So why does damaging research still occur, or rather, why aren't accepted processes utilised consistently by researchers?

For co-design to be effective and become more than a broad term that can be freely utilised at the whim of researchers, more research is needed to build on existing evidence: to develop clear guidelines and thresholds for co-design to be used in health as a research method, (ii) to develop and define co-design as a theoretical approach, a methodology, or (iii) to develop specific guidelines for the use of co-design as a tool within research.

Strengths, Limitations and Future Directions

The strength of this review is that it was conducted by an Aboriginal researcher with guidance from Aboriginal academics in the context of a thesis about co-design.

This systematic review was limited to peer-reviewed publications, so potentially relevant grey literature was not included. Co-designed programs occurring in fields outside of health research and program design, such as education or social services, were also not included in this review.

This review can only report information that is reported in included studies themselves [121]. That is, much detail has been omitted from some of the publications, which could speak to the collaborative nature of the research in more depth. Perhaps, then, it is less the research practice but rather the types of scientific knowledge valued within academia and journals. Does the basis of what qualifies as the science behind research need to shift to include the intricate details of ensuring research is collaborative and community-led rather than prioritising studies that report on the aspects of their research that privilege Western research methods? The academy must accept community-led and Aboriginal and Torres Strait Islander approaches to research as the gold standard for Aboriginal and Torres Strait Islander health research. Ensuring that there is space for studies that report on approaches that privilege Indigenous ways of knowing, being and doing to be published and included in high-profile journals is critical to shaping the future of Aboriginal research so that community leadership and collaboration (on community terms) is recognised as a necessary part of undertaking research within Aboriginal and Torres Strait Islander health.

It may be that more extensive collaborative efforts were undertaken in the final selection of studies analysed in this systematic review. However, these measures and efforts were not reported on in detail. This gap in what information is reported supports the lead author's suggestion that scientific knowledge deemed suitable for publication needs to be amended and updated, specifically regarding Aboriginal and Torres Strait Islander health. To replicate or build on successful methods and approaches, we first need to know how they occurred; it is not simply the use of collaborative research methods that achieves successful goals; there are more layers. In research implementation, the approach should be able to identify and report on these different layers to ensure best practices for future studies hoping to improve the health outcomes of Aboriginal and Torres Strait Islander peoples, “researchers have been good at describing these problems but still have a poor track record of conducting intervention that can show what works to produce change” [114].

Conclusion

Quality research can be undertaken with Aboriginal and Torres Strait Islander peoples and communities if methodologies and methods support genuine collaboration. However, the standard of this practice is dependent on the research team and their commitment to sound, genuinely collaborative practice.

For co-design to be effective as an approach within research or utilised as a research methodology, there needs to be a consensus on how it is defined, how it is used, and what the thresholds are for saying it has taken place. In this systematic review, the QAT was used to appraise the level at which included studies reported on various aspects of collaboration within their research practice.

Further work is needed to develop a co-design framework to outline transparent and tangible processes for researchers to ensure that they are engaging collaboratively with participants in a genuine and equitable way [62]. Such a co-design framework could be a companion document to existing quality appraisal tools and ethics guidelines, to ensure that they are adhered to and that high-quality collaborative research is undertaken with Aboriginal and Torres Strait Islander peoples. This will help ensure that there is no space for cutting corners in Aboriginal and Torres Strait Islander research.

Acknowledgements

I would like to thank and acknowledge the Goonimoo Mobile Children's Service and the Walgett Aboriginal Medical Service (WAMS); this research would not have been possible without them.

Funding

This project was funded through MRFF and secured through the TAPPC

Competing interests

None to declare

Figures and Tables

Figure 1: PRISMA flow chart of review process and sampling.

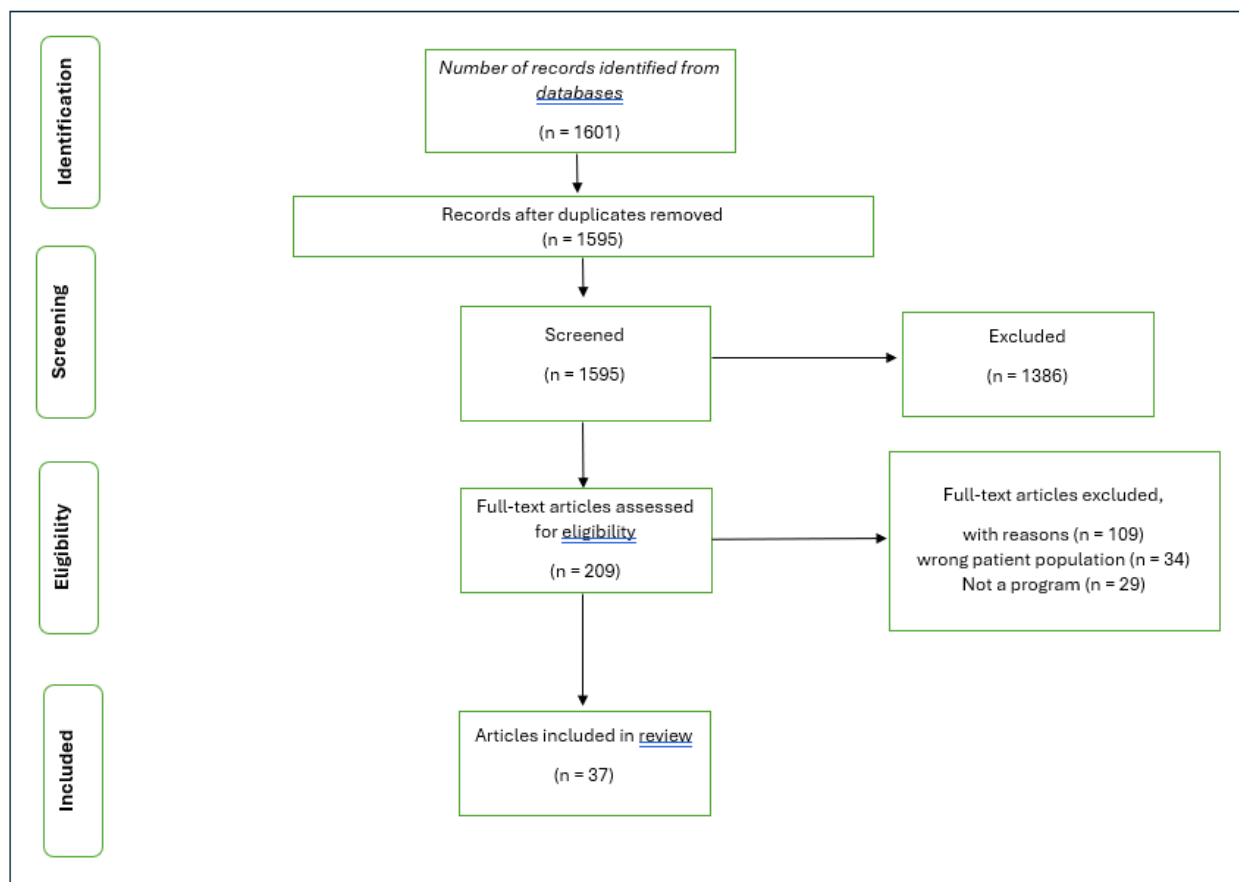


Table 1: Search strategy

Topic	Search terms
Population	(aborig* or indig* or first nation* or torres strait*).mp. OR Ancestry group/ OR exp indigenous people/ OR exp oceanic ancestry group/ OR exp indigenous people/ OR exp indigenous Australian/
Methodological approach	(co-design* or codesign* or co design* or action research).mp. OR exp action research/ or exp participatory action research/ OR exp participatory research/ OR exp community participation/
Health Area	(health educat* or health lit* or health promot* or health* or healthcare* or health care* or health prevent*).mp.OR exp health/ OR exp health literacy/ or exp health education/ OR exp health promotion/ or exp health education/ OR exp health care/ or exp health service/

* Each topic group was combined with the Boolean operator 'AND'

Table 2: Included studies

Authors (Year)	Location	Program Description/Focus of Paper	Study Type	Collaboration & Governance
Adams (2012)	VIC; Urban	Work collaboratively with urban Aboriginal community to understand meanings of food and food insecurity and strengthen response to this issue	Photo-Voice, Action-Research cycles	Research facilitated through Victorian Aboriginal Community Controlled Health Organisation (VACCHO); 5 services responded to an invitation to be involved.
Carr (2021)	NT; Top End; Groote Eylandt	Co-design of a physical activity and lifestyle program to keep individuals with Machado-Joseph disease (MJD) walking and moving around.	Experience-based co-design (EBCD) approach, Indigenous and Participatory methodologies	The knowledge of Aboriginal families living with MJD, combined with findings from worldwide MJD research, formed the foundation for the codesign. Aboriginal community research partners + Senior community members provided endorsement at end of each phase. Aboriginal families living in remote communities in the Top End of Australia invited researchers to collaborate with them.
Chamberlain (2020)	NT, SA & Vic	Reports on (an innovative combination of) Aboriginal leadership, participatory design and methods to elicit the perspectives of key stakeholders working with Aboriginal parents regarding complex trauma assessment in the perinatal period.	Participatory design and methods, Co-design workshops	Indigenous research methodologies underpin the conceptual framework. Aboriginal led research team.
Ching (2020)	NT; Katherine; Dagoman, Jawoyn, Wardaman: Santa Teresa: South-Western Sydney	Development and validation of the Hearing and Talking Scale (HATS) tool - for primary health and early childhood workers to screen for listening and communication skills in Aboriginal and Torres Strait Islander children	Co-design approach; Two Co-design workshops	Two co-design workshops undertaken with primary health and early childhood workers from urban, regional and remote Aboriginal and Torres Strait Islander communities. Feedback was also gained more informally from the parents/carers partaking in the study, as well as from Aboriginal research assistants and community engagement officer
Ching (2020)	(location not stated)	Development of an Aboriginal and Torres Strait Islander parent-report measure to assess listening behaviours of young Aboriginal and Torres Strait Islander children. Through two co-design workshops researchers sought to fine-tune the Parents' Evaluation of Listening and Understanding Measure (PLUM) questionnaire and make it more culturally appropriate.	Co-design approach; Two Co-design workshops and iterative design of resources	Participation from regional and remote Aboriginal communities
Clark (2015)	QLD; Urban	Aimed to develop and then assess feasibility and acceptability of a culturally safe electronic resource for Aboriginal Heart Failure patients.	Mixed Methods + Action research	Aboriginal researchers: consent gained through local elders and then patients; Aboriginal health workers

Cox (2014)	National; Narrogin, Perth, Northam/Toodyay; Cherbourg, Kuranda; Toomelah, Redfern; Mildura	Innovative Aboriginal-led community empowerment project that has worked with 8 Aboriginal and Torres Strait Islander communities across Australia	PAR	Community-co researchers enabled community engagement and empowerment process, conducting interviews. Formal relationship building with Aboriginal partner organisations at each site.
Crouch (2017)	Vic; Loddon Mallee	Descriptive paper reporting on the development of an antenatal yarning resource for parents.	Program development report. Action Research	Mallee District Aboriginal Service (MDAS), sought to develop a healing and culturally safe strategy for its antenatal services.
Davies (2015)	NT; Remote - Arnhem Land	Reports on the second phase of developing a culturally appropriate bilingual app about hepatitis B for Indigenous Australians in Arnhem land	PAR	Partnership with ACCHO, Miwatji Health Aboriginal Corporation Community Clinic;
Dimitropoulos (2020)	NSW; Central Northern NSW	Co-design of school fluoride varnish program with local Aboriginal Community	Co-Design	Community engagement process preceded study; Elders support and engagement.
Dimitropoulos (2020)	NSW; Central Northern NSW	Improve the oral health of Aboriginal children across three locations by co-designing an oral health promotion program with the local communities	Co-design approach + surveys	Research locations identified by local Aboriginal Elders. Co-design elements contributed to success and sustainability of program
Dudgeon (2017)	National	Reports on the application of a PAR approach by National Empowerment Project (NEP) Aboriginal community-based researchers	PAR - localised	Aboriginal researchers; Aboriginal led project; National Advisory Committee
Elsom (2020)	NT (specific location not stated)	Described client and staff perspectives of a model of clinical genetics services provided by the MJD Foundation (MJDF) in geographically and culturally complex contexts within the Northern Territory of Australia	Case Study	In addition to ethics permission was sought by Anindilyakwa ALC.
Fehring (2019)	QLD; Cape York (specific location not stated)	Evaluation of co-designed multi-strategy health promotion initiative. Create supportive environments to reduce sugary drink consumption and increase water consumption by partnering with Aboriginal and Torres Strait Islander communities	Mixed Methods; Evaluation	Engagement with local governments (Aboriginal Shire Councils), community leaders, organisations and community members to create supportive environments for health. Delivered alongside Apunipima Cape York Health Council (ACCHO that supports Cape York).
Gilbert (2021)	NT (specific location not stated)	Reports on ways to improve health literacy for young people in preconception health. Developing a culturally responsive preconception digital flip chart in collaboration with Aboriginal and Torres Strait Islander youth.	Mixed-Methods, Co-design process	Co-design workshops with Aboriginal and Torres Strait Islander youth.

Haynes (2019)	NT; North-East Arnhem Land	Implement and evaluate a community-based [122] PAR project on RHD prevention in a remote Aboriginal community in Australia's Northern Territory, where RHD prevalence is very high.	CBPAR & Co-design; strengths-based	Aboriginal community initiated a collaboration to work towards elimination of RHD; Aboriginal co-researchers, co-authors, co-facilitators and trainees. Aboriginal ways of knowing, being and doing. Two-way learning
Ireland (2020)	NT; Remote (specific location not specified)	Use of PAR to co-design a reproductive health literacy framework for Yolnu women.	Participatory Action Research (PAR)	Two-way learning; Indigenous leadership in research
Kildea (2009)	NT; Arnhem Land - Maningrida	Develop internet resource for health workers. Improve access by health professionals to Australian Aboriginal cultural knowledge specific to pregnancy and childbirth.	PAR combined with Aboriginal research process (Indigenous research methodology)	Aboriginal co-researchers and participants guided research process, leadership and guidance from retired AHW from location. Critical reference group with two Aboriginal members
King (2003)	SA; regional/remote (specific location not stated)	Conduct an eye program for Aboriginal health workers and develop eye health promotional resources for educational use in the Aboriginal community. Improve eye status of the Aboriginal population	Co-Operative Inquiry	Steering committee - Aboriginal health organisations, Aboriginal consumers, two Aboriginal communities, Aboriginal health division & Office of Aboriginal and Torres Strait Islander Health. Program design with Aboriginal health workers and Aboriginal health professionals
Lee (2012)	WA; Dampier Peninsula	address AOD use in five remote Aboriginal communities - Dampier Peninsula	Mixed Methods; Action Research project (community development approach); cycle planning, community action, evaluation and improvement.	Qualitative interviews with community members informed intervention. Inter-agency and inter-community co-ordination. Aboriginal leadership within study not reported.
McCalman (2009)	QLD; Yarrabah - Rural	Describes the efforts of an Aboriginal men's group to facilitate and support the empowerment of young people in their community. Reflection on the PAR process of related program within the broader project. Reduce suicide - strengthen community	Part of broader PAR project	Related to a PAR study of men's groups. Research initiated and led by Aboriginal men. Capability and capacity building of local community members
Miller (2018)	QLD; Woorabinda, remote	community-directed intervention to address strongyloidiasis. Implement a treatment program with whole of community to increase participation in strategies to prevent <i>S. stercoralis</i> and decrease environmental risk factors contributing to infection.	Community-driven Mass Drug Administration (MDA), co-designed	Community invitation following concerns raised about previous study and lack of involvement. Indigenous Health Workers from the community; Indigenous leadership

Munns (2017)	WA; Urban	Develop and evaluate the suitability, feasibility and effectiveness of an Aboriginal peer-led home visiting programme to support positive home environments and parental confidence	PAR - Action Learning sets (ALSs); focus groups	Aboriginal steering group (CREAHW); Aboriginal peer support workers, community support workers; PAR reported as an important methodology to create safe spaces where participants are able to work in equal partnership. ALSs are a PAR facilitating tool that provides a formal structure for participants to meet regularly in small learning groups to develop strategies for the program.
Munro (2017)	NSW; Fitzroy Valley	Articulate an Indigenous drug and alcohol rehabilitation service model of care - in collaboration with clients, service providers and researchers	Mixed Methods CBPR approach; co-design of Healing Model of Care (between researchers and service)	Aboriginal rehab service (Aboriginal Community Controlled Health Organisation) - Aboriginal leadership; CBPR is a collaborative methodology;
Nagel (2020)	NT; Alice Springs	Feasibility testing and adaptation of an existing culturally responsive brief wellbeing intervention, the Stay Strong App, and three commonly used wellbeing outcome measures, in preparation for a clinical trial testing effectiveness of the intervention.	Multi-method approach - Pilot sampling of purposive testing	Aboriginal research officers. Expert panel included a cultural consultant, Aboriginal Elder and a transplant recipient. Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) Aboriginal Corporation run Purple House facilitated recruitment
Payne (2013)	QLD; Nywaigi - Ingham FNQ, mouth of the Herbert River	Intervention for type 2 diabetes for young Indigenous people. Assist a group of Nywaigi female Elders in the development of a community-based support group which would strengthen participants capacity to manage diabetes in the context of their lives in a more effectual and enduring way. Designed to provide both informative content and the various strategies required to address barriers to effective self-management	Design and implementation of diabetes pre-intervention programme or community support group.	Indigenous holistic approach utilised. Mungalla Aboriginal Business Corporation approached programme team with an invitation to address the health issues of diabetes for their Elder women
Peake (2021)	NSW; Regional (specific location not stated)	Outlines processes used to engage Aboriginal communities in Northern NSW to develop culturally appropriate stroke health resources.	PAR - using yarning framework: community engagement & evaluation	Lead author Aboriginal Elder also led community engagement to propose the research study.
Povey (2020)	NT; Remote & Regional (specific location not stated)	Draft a new culturally responsive e-metal health resource in collaboration with Aboriginal and Torres Strait Islander youth.	Participatory design approach + Co-design workshops	Senior Indigenous co-researchers;
Seear (2020)	WA; Derby	Design a program for young Aboriginal people in the town of Derby, WA, to promote healthy living. Integrated previous international research to develop a program that was locally and culturally appropriate.	Formative participatory research; community-directed approach	Guidance from Derby Aboriginal Health Service

Shield (2018)	NT; remote (specific location not stated)	Improve education for health literacy of Australian Aboriginal people living remotely. Objective oral health literacy through community education about scabies and strongyloidiasis, including their transmission and control, preceding an ivermectin mass drug administration (MDA) for these diseases.	Discovery Education approach	two-way learning between Aboriginal and non-Aboriginal health workers and community; informal discussions with Elders to seek approval. Aboriginal and non-Aboriginal educators worked collaboratively to produce an in-depth flip-chart of relevant stories in local language to share with community.
Smith (2017)	VIC & NT (specific location not stated)	Reports on the intercultural processes underpinning the development of the KidsMatter Aboriginal Project, to design and develop resources to support the social and emotional wellbeing of Aboriginal children.	Case Study - Participatory Action Research (PAR), Narrative Therapy	Consultation, workshops, content approval, implementation feedback - Aboriginal leadership and participation.
Snijder (2020)	NSW; 3x rural Aboriginal communities (specific location not stated)	Investigates the participatory processes of three CBPR partnerships between university-based researchers and three rural Aboriginal communities - to develop, implement and evaluate community-based responses to alcohol-related harms.	Mixed-Methods Study. Community Based Participatory Research (CBPR)	Built on existing research partnership between two CI's and an Aboriginal Community Controlled Health Organisation (ACCHO). Aboriginal leadership roles within implementation
Tsey (2004)	QLD; Yarrabah - rural	Describe the first 12-months of the two-year implementation process of the Yarrabah men's group	PAR	Part of broader project with Yarrabah men's group
Tsey (2002)	QLD; Yarrabah	Part of the Yarrabah men's group project: Formative stages of PAR process to engage and support the members of the Yarrabah Men's Health Group plan, implement, and evaluate their activities.	PAR	Research partnership with Aboriginal men engaged in the design of the programs, involvement in design; co-author is Aboriginal and a founding member of the Yarrabah men's group
Vindigni (2009)	NSW; Kempsey	Development of a Chiropractic program for a large Indigenous community and introduction into the local Aboriginal Medical Service (AMS)	PAR	Research project overseen by Community Advisory Group (CAG) - Durri Aboriginal Medical Service, Booroongen Djugun Aboriginal Training College.
Wagner (2017)	WA; Fitzroy Valley	Describe the three-phase formative process to develop and pilot a culturally appropriate version of the Alert Program for school-based intervention for Australian Aboriginal children living in remote communities. Self-regulation for Aboriginal children in remote community schools - where some children have FASD diagnosis	Mixed methods; PAR; Pilot feasibility study	Community and stakeholder consultations - senior Aboriginal community researcher; Phase 1 'community engagement' privileged community voices, knowledges and participation in the study design and process.
Wagner (2020)	WA; Fitzroy Valley	Evaluation of the effect of an 8-week Alert Program intervention on children's executive functioning and self-regulation	Self-controlled cluster randomized trial	Community collaboration reported in depth in, "The development of a culturally appropriate school-based intervention for Australian Aboriginal children living in remote communities: A formative evaluation of the Alert Program intervention"

Table 3: Quality Appraisal of Included Studies (QAT Scores)

Author/Year	1. Did the research respond to a need or priority determined by the community?	2. Was community consultation and engagement appropriately inclusive?	3. Did the research have Aboriginal and Torres Strait Islander research leadership?	4. Did the research have Aboriginal and Torres Strait Islander governance?	5. Were local community protocols respected and followed?	6. Did the researchers negotiate agreements in regards to rights of access to Aboriginal and Torres Strait Islander peoples existing intellectual and cultural property?	7. Did the researchers negotiate agreements to protect Aboriginal and Torres Strait Islander peoples ownership of intellectual and cultural property created through the research?	8. Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?	9. Was the research guided by an Indigenous research paradigm?	10. Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?	11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?	12. Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?	13. Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?	14. Did everyone involved in the research have opportunities to learn from each other?	Score out of 14
Adams, 2012	1	1	1	1	1	0	0	0	1	1	1	1	0	1	10
Carr, 2021	1	1	1	1	1	0	0	1	1	1	1	1	1	1	12
Chamberlain, 2020	0	0	1	0	0	0	0	0	1	1	1	0	0	1	5
Ching, 2020	0	1	0	0	1	0	0	0	0	0	1	0	0	0	3
Ching, 2020	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
Clark, 2015	0	1	1	0	1	0	0	1	0	0	1	1	0	0	6
Cox, 2014	1	1	1	1	0	0	0	0	1	1	1	1	1	0	9
Crouch, 2017	0	0	0	0	0	0	0	0	0	1	0	1	0	0	2
Davies, 2015	1	1	1	1	1	0	0	0	0	0	1	1	0	0	7
Dimitropoulos, 2019	0	1	1	0	1	0	0	0	0	0	0	1	0	1	5
Dimitropoulos, 2020	1	1	1	1	1	0	0	1	1	1	1	1	1	1	12
Dudgeon, 2017	1	1	1	1	1	0	0	1	1	1	1	1	1	1	12
Elsum, 2020	1	1	1	1	1	0	0	0	1	1	1	1	1	1	11
Fehring, 2019	0	1	1	1	1	0	1	0	0	1	1	1	0	1	9
Gilbert, 2021	1	1	1	1	0	0	0	0	0	0	0	0	1	0	5
Haynes, 2019	1	1	1	1	1	0	0	0	1	1	1	1	1	1	11
Ireland, 2020	0	0	1	1	1	0	0	1	1	1	1	1	0	1	9
Kildea, 2009	1	1	1	1	1	0	1	0	1	1	0	1	0	1	10
King, 2003	0	0	1	1	0	0	0	0	0	0	1	1	1	0	5
Lee, 2012	1	1	0	0	1	0	0	0	0	1	0	1	1	1	7
McCalman, 2009	1	1	1	1	0	0	0	0	1	1	0	1	1	1	9
Miller, 2018	1	1	1	1	0	0	0	0	0	0	0	0	0	0	4
Munns, 2017	0	0	0	1	0	0	0	0	0	1	1	0	0	1	4
Munro, 2017	1	1	1	1	0	0	0	0	1	1	1	0	0	1	8
Nagel, 2020	0	0	1	1	1	0	0	0	0	1	1	1	0	1	7
Payne, 2013	1	1	0	1	0	0	0	0	0	1	0	1	0	0	5
Peake, 2021	1	1	1	0	1	0	0	1	1	1	1	1	1	1	11
Povey, 2020	0	0	1	0	0	0	0	1	0	0	1	0	1	0	4
Seear, 2020	1	1	1	1	1	0	0	1	1	1	1	1	0	0	10
Shield, 2018	1	1	0	0	1	0	0	1	1	1	1	1	0	1	9
Smith, 2017	0	1	0	0	0	0	0	0	1	1	1	0	0	1	5
Snijder, 2019	1	1	1	1	1	0	0	0	0	1	1	0	0	1	8
Tsey, 2002	0	0	1	1	0	0	0	1	0	0	0	0	1	0	4
Tsey, 2004	1	1	1	1	1	0	0	1	0	1	1	1	1	1	11
Vindigni, 2009	0	1	0	0	0	0	0	0	0	0	1	1	1	1	5
Wagner, 2017	1	1	1	1	1	0	0	0	0	1	1	1	1	1	10
Wagner, 2020	1	1	0	1	1	0	0	0	0	0	1	0	0	0	5

Chapter three - 'Better Together': Co-design of Aboriginal unintentional child injury prevention

Nellie Pollard-Wharton^{1*}, Amy Townsend², Dr BJ Newton³, Dr Melanie Andersen¹, Dr Rona Macniven¹, Christine Corby AM², Associate Professor Ruth McCausland⁴, Peta MacGillivray⁴, Wendy Spencer^{4,5}, Dr Kate Hunter^{1,6,7}, Professor Kathleen Clapham⁸, Christine Erskine¹⁰, Madeleine Powell^{1,9} Prof Rebecca Ivers^{1,6,7}

1. School of Population Health, University of New South Wales, Kensington, New South Wales, Australia
2. Walgett Aboriginal Medical Service, Walgett, New South Wales, Australia
3. Social Policy Research Centre, Faculty of Arts & Architecture, University of New South Wales, Kensington, New South Wales, Australia
4. Yuwaya Ngarra-li partnership, University of New South Wales, Kensington, New South Wales, Australia
5. Dharriwaa Elders Group, Walgett, New South Wales, Australia
6. The George Institute for Global Health, Sydney, New South Wales, Australia
7. College of Medicine and Public Health, Flinders University, South Australia, Australia
8. Ngarruwan Ngadju First Nations Health and Wellbeing Research Centre, Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, Australia
9. National Drug & Alcohol Research Centre, University of New South Wales, Kensington, Australia
10. Kidsafe NSW, New South Wales, Australia

Submitted: April 2024

Abstract:

Objective: To describe the co-design of an Aboriginal unintentional child injury prevention program in partnership with Walgett Aboriginal Medical Service (WAMS).

Methods: Informed by family and community priority setting, an unintentional child injury prevention program was designed and delivered through a locational supported playgroup in an Aboriginal community-controlled medical service. An iterative co-design process utilising Indigenous research methodology and development of a program logic model was employed with oversight from a panel of injury experts and key stakeholders. From its inception in 2019 through to its finalisation in 2022, this research project utilised yarning, stakeholder interviews and a co-design approach to program development, piloting and evaluation.

Results: Through an Aboriginal led co-design approach, a comprehensive injury prevention manual and program was developed by the community, for the community. Participants were able to guide researchers to ensure areas of child injury considered of high value within their community were addressed within the developed program. The key safety areas identified were water safety, road safety and safety around the home. Data collected throughout the iterative design process shaped the delivery of the program to ensure it met community needs. In addition to the creation of the manuals, the program included complementary initiatives to support the delivery. Water safety included mums and bubs swim lessons/water familiarisation. Road safety included car restraint fittings. Home Safety included a Goonimoo open day collaboration with KidSafe NSW with safety promotion information and resources.

Conclusions and public health implications: Co-designing an injury prevention program with staff at an Aboriginal Medical Service and injury experts provided a culturally tailored response to the needs of the community and partners. This process and approach has demonstrated feasibility of use of co-designed processes for development of community based injury prevention programs.

Keywords: Aboriginal, unintentional child injury prevention, co-design, Australia

***Correspondence to:** Nellie Pollard-Wharton, School of Population Health, level 3, Samuels Building, University of New South Wales, Kensington, New South Wales, Australia.; email: n.pollard-wharton@unsw.edu.au.

Introduction

Community led and collaboratively designed public health programs and approaches yield beneficial results for Aboriginal and Torres Strait Islander (hereafter Aboriginal) people. In fact, the success of public health interventions with Aboriginal communities depends on authentic partnerships and inclusion at all levels of pre-design, design and implementation [9, 123, 124]. Co-design is an approach within research that promotes authentically collaborative practice to ensure that key stakeholders impacted by the research can contribute meaningfully at all stages and at all levels. It is an approach that, if utilised effectively, can be beneficial in Aboriginal research [124]. A co-design approach, recognising and ensuring equal voice, built upon trust, respect and commitment to partnership, provides the structure for collaborative public health program design with Aboriginal communities [125, 126].

Unintentional injury amongst children is a significant global issue that requires urgent attention, causing almost 950,000 child deaths each year. Unintentional injuries can occur through a myriad of mechanisms, including traffic injuries, drownings, burns, poisons, and falls [32, 37]. They are a serious concern for Aboriginal children in Australia, with unintentional child injury accounting 47% of deaths for Aboriginal children aged 0-4 years [127]. There is evidence that preventative initiatives and programs grounded in behaviour change (individual and community) [24], environmental change, and systemic change reduce the risk of unintentional injuries, but such programs are scarce for Aboriginal children in Australia.

Due to ongoing impacts of invasion and colonisation of what is now called Australia, Aboriginal peoples and communities experience significant health inequities [128]. These are largely due to the complex intersection of the social and cultural determinants of health and their impact on access to primary care, health information and the involvement in the design and implementation of interventions, programs and solutions [129]. The complex nature of the social determinants of health on populations devastatingly impacted by ongoing colonisation means that a decolonising approach to health care must be prioritised [130], with Aboriginal groups at the fore. Explicitly this translates as Aboriginal communities controlling the resources, interventions and outcomes that impact the health and wellbeing of our communities.

The co-design process described took place in the context of an existing research partnership, called Yuwaya Ngarra-li (YN), between the Dharriwaa Elders Group [4] and the University of New South Wales (UNSW) that is built on community priorities identified through years of rigorous community-led collaboration and research. Yuwaya Ngarra-li provided the opportunity and access to place-based expertise that enabled the co-design for this unintentional child injury prevention project. Yuwaya Ngarra-li was established after invitation from the DEG to UNSW to work together on the Elders' vision for positive social change in their community of Walgett in north-western NSW, on Gamilaraay country, Australia [131]. This collaboration and work are guided by Gamilaraay and Yuwalaraay language and ways of knowing, being and doing [120, 132]. Through extensive community-led consultations, design and collaboration, YN has established and created clear research protocols and strategic goals for their partnership [131, 133] one of which is to improve the health and wellbeing of Aboriginal peoples in Walgett.

An important factor in this successful partnership is the leadership from well-established Aboriginal Community Controlled organisations within Walgett itself, namely the Walgett Aboriginal Medical Service (WAMS). WAMS is an Aboriginal Community Controlled Health Organisation (ACCHO) and opened its doors in 1986 following lobbying and organising by founding Aboriginal leaders from

Walgett. WAMS is committed to the health and wellbeing of the community and a leader in Indigenous health. ACCHOs are central to improving and maintaining the health and wellbeing of Aboriginal communities across this nation. WAMS has many innovative services available for the whole community in Walgett, both Indigenous and non-Indigenous, one of which is the Goonimoo Mobile Children's Service. Established in 1985, Goonimoo provides curated playgroup programs to support education and development of children aged 0-5 years and their families. The expertise and knowledge of the Goonimoo team were identified by WAMS and DEG as being a core element of improving the wellbeing of Aboriginal children and families in Walgett.

A group of UNSW injury researchers were made aware of funding available in Aboriginal child injury prevention, thus began discussions with Walgett Aboriginal Medical Service (WAMS) and Yuwaya Ngarra-li. During these exploratory discussions it was identified that this funding met the existing goals of the DEG, which led to YN extending an invitation for the researchers to collaboratively design a program, the Child Injury Prevention Program (CHIPP), developed on the foundation of this partnership. CHIPP, with the Goonimoo Mobile Children's Service, a successful playgroup program housed within WAMS aimed to meet the vision of the DEG Elders Council through its design, implementation, and evaluation to ensure that it is a holistic, community led, culturally connected and strengths focused program that will have a lasting contribution for positive social change in Walgett. This paper describes the process of co-designing an unintentional child injury prevention program (CHIPP) to develop a comprehensive manual and program created by community for community.

Methods

The qualitative research to develop and evaluate the program was guided by Indigenous research methodology [9, 123] and co-design principles through an iterative process across a period of 19 months, from June 2019 to January 2022. A decolonising research approach was taken, with research methods and questions collaboratively designed throughout the CHIPP partnership process.

Decolonising approaches paired specifically with Indigenist standpoint theories ensure that research with Aboriginal peoples is led by Aboriginal peoples [8, 120, 131, 133, 134]. The primary data used to co-design the CHIPP program was collected from yarning circles with participants and stakeholders, field notes, and expert injury knowledge. Research Yarning is a relaxed, conversational, semi-structured interview method developed by Aboriginal researchers [134, 135]. Yarning is a suitably flexible tool for data collection that ensures there is no burden for participants, which is of the utmost importance. From these data sources, a program logic and program content were created, iteratively developed, and implemented, all of which created the foundations for what became the CHIPP program.

Since its inception, this project has positioned all research and conduct within Indigenist research [8, 136, 137], privileging and centring the Aboriginal researchers, Aboriginal early childhood educators from Goonimoo/WAMS and Aboriginal participants involved in the project. The privilege of conducting research within an ACCHO such as WAMS with Aboriginal leadership and voices situates this research as Indigenist research. The lead researcher in this project is an Aboriginal woman, a Kooma woman. Her approach to research is centred in her identity as a Blak woman, which shapes her conduct and how she engages with communities and colleagues, strengthened by her expertise knowledge as a trained social worker. This approach ensures transparency and accountability to community and research collaborators. The necessity of Blak leadership within Indigenous Health research has been well identified and our presence is more vital than ever to ensure research meets community priorities [138, 139].

Data Collection

Yarning

Yarning circles were conducted in Walgett in October 2019. Guides for yarning were developed by the UNSW CHIPP team with input from Aboriginal staff members at WAMS and the Yuwaya Ngarra-li team to ensure appropriateness of questions and delivery method. These guides were used to

facilitate discussion at yarnning circles with families across two early childhood sites in Walgett, Goonimoo Mobile Children's (yarn 1) Service and MacKillop (yarn 2). MacKillop is a non-Indigenous service in Walgett that also facilitates playgroups for Aboriginal families. The second yarn was held at the MacKillop playgroup as it allowed more families to participate in the formative yarnning circles. These playgroups are held on different days. The deductive program topics as seen in table 1, were developed through formative research (literature review) conducted by the lead researcher and co-design meetings with two Aboriginal Goonimoo staff members. Participants were provided with verbal information on the yarnning process by one of the Goonimoo staff in the weeks preceding the group yarns to ensure they were comfortable and aware of the processes. The CHIPP team were able to gauge participants' depth of understanding around specific areas of injury and injury prevention. Topics were introduced into the yarns by facilitators to generate discussion and seek parent/carers insights about key child injury issues as identified in injury literature [140, 141].

Two yarnning sessions were held on consecutive days. The first was facilitated by the lead researcher, one of the Goonimoo Aboriginal early childhood educators, and supported by a non-Indigenous researcher, at WAMS Euragai Goondi community rooms in Walgett. The second was facilitated by one of the Aboriginal Goonimoo staff members, and supported by the non-Indigenous researcher, at MacKillop playgroup, Walgett. Participation in yarnning circles was open to families who ordinarily attended both Goonimoo and/or MacKillop playgroups. Both yarns were audio recorded. Inclusion criteria were being a parent/carers of children attending playgroups or a playgroup staff member. Both Aboriginal and non-Aboriginal families attend Goonimoo playgroup weekly, and all families were invited to participate in the yarns. Catering for participants during yarnning sessions and \$50 vouchers per participant were provided to compensate time spent and acknowledge the value of knowledges contributed by participants. All participants provided informed consent with assistance from the researchers and Goonimoo staff where necessary.

Co-design meetings between the CHIPP team, both from Walgett and UNSW, were held to collaboratively design and shape what the program would look like and how the content would be delivered between June 2019 and February 2021. The frequency of these meetings was fluid, dependant on staff capacity, but ranged from weekly to fortnightly. Most meetings were held online due to geographic location; however, some scheduled face-to-face sessions were interrupted by Covid-19. Clear ACCHO leadership ensured the safety of the Aboriginal community in Walgett, and as such face-to-face meetings were limited, or conducted in Dubbo, NSW or Sydney, NSW. With leadership from the Aboriginal early childhood educators, we were able to communicate in a flexible manner to ensure the co-design process was not a burden, but complimentary to their work and the impact of Covid-19. Written meeting field notes were taken to document the iterative process of co-design and were used to shape the design of the program and development of resources.

Expert Knowledge

Following formative yarns with playgroup participants and key stakeholders the CHIPP team facilitated an 'injury experts' workshop to ensure resources and knowledge provided to families was relevant and evidence based. In January 2020, an expert panel was invited to review content for delivery. The purpose of this expert panel was to ensure the program aligned with principles of injury prevention, was based on current evidence, and built on implementation science theories [142, 143, 144]. In addition to the workshop, specific injury experts with expertise in road safety, water safety and safety in the home were engaged at various stages in the development of CHIPP resources to review documents and ensure content was evidence based. These reviews were iterative, to ensure that as the program developed, key safety messages and injury prevention guidelines remained.

Data Analysis

Audio-recordings of yarning circles were transcribed by a professional transcription service and imported into NVivo. Data were analysed using inductive and deductive thematic analysis [134,

145]. Themes were identified that were used to determine both the existing knowledge about unintentional child injury among stakeholders in Walgett, and community priorities that could be addressed through CHIPP. Data analysis was conducted by the lead researcher.

Content of field notes and contributions made by the expert panel were incorporated into the program design in an iterative manner.

Program Logic Model

The process of designing the program logic model commenced in October 2019 and took several months of iterative discussion to revise and refine to reflect the emerging program design (see Fig. 2). It was developed with input from stakeholders in-line with the guiding principles of Indigenist research, privileging Blak leadership at all stages of design and development. The program logic was initially developed during the frequent co-design sessions between Goonimoo and UNSW CHIPP team. This process allowed for Goonimoo staff, who were also Walgett community members, to engage with working drafts to ensure the activities and outputs were feasible and met community priorities. During the injury expert review/workshop held in January 2020, injury experts were also invited to review the program logic and YN and DEG representatives also contributed to the logic model, ensuring it reflected identified community values and priorities.

Ethics Approval

The study follows the AH&MRC and UNSW guidelines for ethical conduct of Aboriginal and Torres Strait Islander research, and the project was approved by both committees [52, 146].

Whilst the specific CHIPP project did not have an Aboriginal Advisory Group, it came under the umbrella of the YN governance structure. In addition, the research team included two members of YN at UNSW (Aboriginal and non-Aboriginal), one representative from DEG and two WAMS Aboriginal staff members.

Results

Yarning

Each yarning session had between 10 and 15 participants. Yarning session 1 was attended by participants who ordinarily attended Goonimoo mobile children's playgroup. Yarning session 2 was held at Mackillop playgroup in Walgett, and the regular attendees in this playgroup participated, of whom all were Aboriginal.

Themes from the yarning provided important knowledge that shaped the way in which the CHIPP program was developed and implemented. Five initial overarching themes were constructed: community safety; making the delivery of CHIPP work for the community (delivery); We see injuries happen (injury), once we knew what to do, you were alright (knowledge), and safety. Each theme had between 0 and 6 subthemes (see Table 1).

Community Safety - Community safety was identified as a concern for participants. Within this theme participants identified negative police relationships and fear of the police from children and adults as a major issue for their community. For example, one participant commented, *'...our kids are frightened of the police'* another participant agreed, stating *'I've seen a little boy, he run when he see coppers. He don't like police.'* Participants also raised the concern that there is *'a lot of domestic violence going on'*, so a collective fear of police in the community in this context is a risk that victims may be too scared to report domestic violence.

Making the delivery of CHIPP work for the community - Participants identified interesting ways to get children and families involved and engaged in learning about injury prevention. When speaking together about how we get children engaged, one participant suggested, *'and maybe we can, like, give them all the head gear or design our own head gears'*. Other participants spoke about designing helmets, running interesting and engaging events and identified the importance of having playgroup run at different locations, *'like, maybe having playgroup at the pool...'*. Participants also discussed safety messaging and what they did and did not find receptive. Participants identified different modes of program delivery that were utilised in the CHIPP program.

Program Description: CHIPP is a Community-led Child Injury Prevention Program. CHIPP builds on the existing Goonimoo Mobile Children's Service, a holistic, supportive, responsive and strengths-based family playgroup service for Aboriginal and non-Aboriginal families with children aged 0-5 years. Goonimoo focuses on relationship building within families through engagement in activities that reflect positive parenting techniques and promote connected, healthy, active lives. CHIPP is a program being co-designed with input from parents, WAMS staff, local stakeholders and injury experts. CHIPP equips Goonimoo educators with injury prevention and positive parenting knowledge and resources, supporting them to create a local child safety hub that provides culturally safe activities, information, services and resources aimed at reducing injuries in children.

CONTEXT	INPUTS	ACTIVITIES	OUTPUTS	SHORT TERM IMPACTS	MEDIUM-TERM IMPACTS	LONG-TERM OUTCOMES
<u>Situation:</u> Aboriginal families are entitled to access to culturally appropriate child injury prevention information and services. Many Aboriginal families in remote communities do not currently have access to such services or information. Aboriginal children experience high rates of unintentional injury, especially in remote areas. <u>Guiding principles:</u> * Partnership model with community control	* TAPPC Funding: > Goonimoo staff wage contributions & operating costs > Training > Program resources > UNSW Project Officer * RMS community grant * Goonimoo playgroup: > skilled educators > existing relationships > established service > purpose-built centre * WAMS infrastructure * Indigenous knowledge systems about child safety, & ways of knowing, being & doing * WAMS, DEG & YN intellectual property	A1 Collate, adapt & create culturally appropriate injury prevention resources (songs, activities, videos, flyers, products) A2 Goonimoo staff* training: a) water safety b) swim instructor c) car restraint fitting d) Gamilaraay language & culture e) home safety f) positive parenting A3 Iterative co-design of CHIPP program, including: a) playgroups with CHIPP-enhanced activities** b) Safety displays regularly set up at Goonimoo (posters, displays, videos, slide shows) c) Goonimoo a drop-in centre for injury prevention advice & services (e.g. check child car seat)	Organisation (WAMS)			
			CHIPP pack produced with information & resources on injury prevention + positive parenting A1	A1.2 Goonimoo staff* have ongoing access to locally appropriate child injury prevention information & resources	A1.2.3.4 Goonimoo established as an ongoing, sustainable child safety resource centre for local families	A1.2.3.4.5 WAMS is a centre of excellence in Aboriginal child injury prevention, positioned to lead ongoing partnerships in this space
			Goonimoo staff* achieve qualifications (e.g. child restraint fitting & checking) A2	A1.2 Increased knowledge, skills & confidence of <u>Goonimoo staff*</u> in teaching child injury prevention, safety & positive parenting		A1.2.3.4 CHIPP contributes to evidence about program co-design & injury prevention A1.3 CHIPP a replicable, scalable program
			Families (Goonimoo)			
			A1.2.3.4 Culturally safe injury prevention services & resources are accessible in Walgett:	A1.2.3.4 Families attend and engage in CHIPP activities, receiving culturally safe injury prevention & positive parenting messages	A1.2.3 Families have increased knowledge, motivation, confidence & skills about child injury prevention & management	A1.2.3.4.5 Families adopt and disseminate child injury prevention strategies
			- playgroup activities			
			- drop-in centre	A1.2.3.4 Increased awareness of child injury	A2f. 3 Families have increased confidence in their parenting skills	A1.2.3.4.5 Improved safety, health & wellbeing of children & families
			- engaging displays			
			- event days	A1.3 Families reconnect with existing cultural knowledge about child safety &		

* Incorporates Indigenous knowledge systems & strengths-based approach * Responsive to changes in local priorities around child safety, not limited to particular injury topics * Builds on and adheres to WAMS goals, philosophies and ways of working	(e.g. local knowledge and ways of working) * In-kind contributions of UNSW Research Fellow & Investigators * Expert advice (child injury, culture & language) * Existing evidence about Aboriginal child injury prevention	d) CHIPP event days (car seat days, campfire lunches) A4 Local promotion of CHIPP A5 Injury advocacy & policy partnerships with organisations (council, local sporting organisations etc)	A1,2d,3 Families have increased opportunities to connect with local language & culture	parenting. Families have positive experiences with injury prevention messages		
			Community-level			
			A1,2,3d,4 CHIPP event days are held A1,2,3,4 Walgett families have access to injury prevention services A5 Policy goals discussed with stakeholders	A3d,4 Broad community participation in CHIPP event days A5 Stakeholders work together to improve policies or environments	A1,2,3,4 Increased community-wide awareness of injury prevention A5 Organisations adopt injury prevention measures A5 Safer policies & environments	A5 Improved community-wide safety standards and environments A1,2,3,4,5 Decrease in injury rates
Assumptions: providing opportunities for families to engage with injury prevention information and resources in a strengths-based way in a culturally safe space will make people more likely to be receptive to safety messages.			External Factors: COVID-19, group size and social distancing restrictions, weather			

Fig. 2. CHIPP Program Logic

We see injuries happen - Participants identified several areas in the community where injuries occurred, activities that children participated in where injuries could occur, and potential reasons why children weren't consistently wearing safety gear, i.e. helmets.

Once you knew what to do, you were all right – Participants identified the importance of having knowledge about injuries and passing it onto their own families and communities. There was discussion of fear around what to do when your child was injured and how speaking with professionals that had knowledge of what to do when injuries occur eased their fear, *'But once you knew what to do, you're all right. Yeah.'*, *'But once I knew what to do, I was right, you know?'*.

This part of the yarns provided participants with knowledge of injury and injury prevention to see what they already knew and what they were interested in.

The final overarching theme was safety and within this four injury topic themes were identified: Home Safety; Road Safety; Sun Safety; and Water Safety.

Home Safety – Participants identified the importance of safety in relation to first aid and preventative measures. In addition to concerns raised around bath safety, power points, stoves and hot beverages, participants also raised concerns about accessibility to safety equipment for the home and in some cases poor maintenance increasing the risk of injury for children. Participants also identified the importance of safety in relation to first aid and preventative measures.

Road Safety – During yarns participants discussed car seat safety, accessibility to car seats, and knowledge of car seat maintenance. Once participant said, *'... car seats go out of date...?'*.

Additionally, participants identified issues with footpath safety and the risks of children and families having to walk on the roads where there were no or poorly maintained footpaths.

Table 1: Key themes from formative family and caregiver interviews**Inductive themes**

Theme	Subtheme	Example quotes
Community Safety	Police; fines; attitudes	<i>"Just imagine a little kid doing it, when you see police you'd run."</i>
	Domestic and Family Violence	<i>"Yeah but some police talk down to our children"</i>
Delivery methods	Playgroup locations	<i>"Like, maybe having play group at the pool, where we have professionals actually teach us. Just some drills."</i>
	Events	<i>"I like that one. It was just watch me swim. So there's no, like, negativity or like parent blaming happening at all."</i>
Injury topics	Helmet design	
	Burn	
	Helmets	<i>"Because a lot of kids think that if it's a scooter, I don't need to wear a helmet."</i>
	Mouth guards	
Knowledge	Information for parents/carers	<i>"It would be good. Because there's a lot of misinformation and we don't really know"</i>

Deductive program topics

Theme	Subtheme	Example quotes
Safety topics	Home Safety	<i>"I never knew that" ... What, car seats? ... Car seats go out of date....No wonder they date them."</i>
	Road Safety	
	Sun Safety	<i>"And they, everyone walk around with no shoes on... I'm telling the kids, always put their shoes on."</i>
	Water Safety	

Sun Safety – Participants discussed sun safety in relation to the impact of heat and public spaces. For example, participants discussed the problematic nature of play equipment and the skate park being made from metal and not having covers to protect from the heat, resulting in children being burnt, or unable to use the equipment at all.

Water Safety – Participants strongly identified with this theme due to an incident that had occurred in the community preceding the yarns. Additionally, some participants were able to contribute personal stories linked to water safety. Discussions of structured playgroup sessions based at the pool were supported by participants for example, mums and bubs swimming classes. Participants

spoke positively about this idea, as there was limited if not no access to this style of program for Aboriginal families in Walgett.

The resulting CHIPP program is an unintentional child injury awareness and education program that allows Goonimoo staff to:

- educate families through raising awareness around the risks of unintentional injuries by participating in engaging activities in familiar settings, and
- holistically supporting parents/families/carers to adjust behaviours to reduce risks.

Informing the development and implementation of the CHIPP Program

A collaborative approach was taken to ensure the sustainability and reach of the CHIPP program. Through conversations with WAMS, Yuwaya Ngarra-li and UNSW, it was jointly decided that to improve suitability and sustainability, or continued implementation of the program beyond the research period, service delivery should be embedded in the existing services with prior relationships with families and to adopt a model of capability building for existing staff rather than bringing in outside people to deliver injury and prevention services. Additionally, the importance of Indigenous leadership from the community was integral to ensure best practise within Indigenous health research.

The early childhood expertise and valuing of cultural knowledges (Gamilaraay) specific to the location are a central tenet of the program. Goonimoo runs during school terms, as such each term focuses on a key theme to integrate knowledge: water safety; safety around the home; and road safety. Each term includes Gamilaraay knowledges incorporated into program outputs through language and song. Goonimoo staff and co-researchers AT and TS participated in language courses to ensure that correct language and knowledges were incorporated into the content of the CHIPP program. An additional key component of the program is to engage the broader community in this area through community safety events, promotion and publication.

Resources Developed

The collaboration found that to design a successful unintentional child injury prevention program, it was necessary to create resources that would be used to guide implementation in a concise and interesting way. As such, four documents (three instructional manuals and one delivery manual) were co-designed and produced by the CHIPP teams.

Field notes taken during co-design meetings from June 2019 to January 2020, and data collected and analysed from the October 2019 yarning groups highlighted the need for a structured approach to embedding injury prevention skills and knowledges into the Goonimoo playgroup based on expertise from Aboriginal early childhood educators on the effectiveness of play-based learning and methods to engage families in education. The structured approach agreed upon was the development of a program user manual, that would be used as a guide for Goonimoo staff to provide evidence-based injury prevention information to families in an engaging and appropriate manner for an early childhood setting.

As documented above, injury topics were discussed with stakeholders throughout the co-design process and the agreed injury focus topics were used to structure the program. These injury topics were then used to structure the main resource for CHIPP, which culminated in a program manual. Gali (Water Safety); Goondi (Home Safety); and Yurrun (Road Safety) were the final injury topics that were addressed in detail as a part of the CHIPP program. Each theme denoted the topic that would be covered in each term with instructions for early childhood educators on how to facilitate this program. Complementary initiatives aligned with the injury topics were also run throughout the course of CHIPP; child restraint fitting training for WAMS staff, and seat installation for community members at Goonimoo open day; swim instructor training for Goonimoo staff to run water safety sessions at the pool; and home safety education for Goonimoo staff at Kidsafe NSW shared with families and community at Goonimoo open day.

Discussion

This paper has documented the process of co-designing an unintentional child injury prevention program with an Aboriginal Community Controlled Health Organisation (ACCHO). It has highlighted the importance of flexibility when working with community in a collaborative way utilising a co-design approach. The iterative nature of co-designing programs such as CHIPP, has provided insight into the necessity of the flexible nature of this approach. The way in which the CHIPP program was guided by environmental factors (fires, floods and covid-19), participant feedback and team development demonstrated the ever-changing nature of co-design, the ability to pivot with changes as they occur.

Initial aims were to co-design a program with participants, namely Aboriginal parents and families attending the Goonimoo mobile children's playgroup. However, as the data showed, the true co-design at this formative stage occurred between the broader collaborating group, the Aboriginal early childhood educators employed through WAMS, and the UNSW research team, the lead researcher NPW and injury experts, while integrating feedback from participants gathered through initial yarns and program feedback. This demonstrated an interesting shift in applying a co-design approach to designing a preventative child injury program. This shift demonstrates that co-design methods are iterative and must be flexible to ensure that key stakeholders remain active throughout design processes [126]. The research skills were complementary to the knowledges and expertise of Goonimoo educators rather than overbearing and directive. This co-design process allowed the vision of Goonimoo educators to be at the forefront of design and delivery. The privilege of working closely with an ACCHO meant that the UNSW CHIPP team members were guided by place-based expertise and knowledges. Working in this way, through co-design meant that the work was led by the Aboriginal staff at the ACHHO rather than a university-led approach.

During the formative design and implementation stages of the CHIPP program, there were several environmental factors that also contributed to the changing dynamic of the team approach: COVID-

19, drought, fires and floods. The iterative nature of co-design allowed for CHIPP to pivot strategically to ensure that the voices of participants were still informing the design, whilst the co-design was occurring not directly between participants and UNSW, but with a broader team privileging the knowledges and leadership of Aboriginal women on the research project.

The resource manuals produced for CHIPP are further evidence of the co-design process between the UNSW and Goonimoo CHIPP teams. The iterative nature in which they were developed demonstrated the strength of WAMS and Goonimoo staff, specifically the way in which their service was able to pivot in times of crisis, Covid-19, floods, and fire. It also demonstrates the importance of active Indigenous leadership in community-based research projects. The development of the CHIPP program manuals is a testament to the way in which Indigenous knowledges and the experience and expertise within existing programs, held by Indigenous staff within ACCHO's can be utilised to embed preventative injury information into programs for the community.

This paper describes the process of co-designing a child injury prevention program within a research partnership group, specifically with an ACCHO. A genuine collaborative process privileges the knowledges of Aboriginal peoples throughout and at all levels. The first author is an Aboriginal (Kooma) woman and researcher at UNSW. Our co-design process highlights that community-led research and program design must have active Indigenous leadership throughout and at all levels. The CHIPP project sought to achieve this by utilising a co-design approach shaped by Indigenist and decolonising research methodologies and Indigenous methods of research [8, 147].

Taking these approaches within contemporary Aboriginal and Torres Strait Islander research settings is of the utmost importance: no longer can researchers or institutions defer to a lack of knowledge or awareness in relation to proper and authentic conduct when proposing or conducting research with Aboriginal and Torres Strait Islander communities or population groups. Ways to work with Aboriginal and Torres Strait Islander peoples has been clearly articulated over thirty years, by Aboriginal peoples from the community and within academia [120, 138, 147-149].

Australia is a colony that has developed through invasion and ongoing colonisation. Due to the lasting impacts of this, there are many complex issues faced by Aboriginal and Torres Strait Islander peoples [14, 128]. However, through decolonising processes, such as those described here, these issues can be overcome through Aboriginal and Torres Strait Islander led research, program design and control. Socioecological theory emphasises the contexts and systems within which child injuries occur and thus the different levels at which interventions may be targeted to prevent child injury: children, their family, peer group, community, institutions and organisations and the broader social, political and environmental factors that influence their lives, including culture, belief systems and social norms [150, 151].

The health of Indigenous peoples is intrinsically linked to the historical and contemporary context in which we, as lead Aboriginal author and research partners live, work and exist. Whilst chronic health conditions and acute health concerns impact Aboriginal and Torres Strait Islanders, and need to be addressed, at the individual and community levels, it is the systems level which presents the greatest challenges [152]. Systems shape the way in which care is provided but are often underlined by racist assumptions and practices that limit the autonomy, choice and self-determination in the health care delivered to Indigenous peoples [153-155]. Until we can control the health measures that are designed to “fix” our peoples and communities nothing will change. Without consistency in funding to support Indigenous led measures, our communities will continue to receive half measures that leave the pockets of people and institutions far removed from those they ‘aim to help’.

The social determinants of health underlying the gross health inequities between Aboriginal and non-Aboriginal children are well documented [156]. In relation to unintentional child injury, the social determinants help to explain the unequal division of access to services, safe and appropriate housing, and goods that impact the risk of unintentional injuries. However, the solutions for addressing these inequities are still out of reach for most Indigenous children. Preventative interventions in public health, for example, are often shaped by behaviour change models. But

changing behaviours also relies on having access to equipment and resources that enable children to be kept safe. The CHIPP program directly addresses this issue in a contextually tailored approach in partnership with an ACCHO embedded in a remote community, and in doing so has identified a need and a culturally safe avenue through which unintentional injury prevention can be made accessible for Aboriginal families.

Aboriginal community control is central to Aboriginal success. Aboriginal communities have the demonstrated capacity to identify areas of need and establish the priorities that will yield holistic success [157]. Until our communities have complete control over the priorities and funding that drive research, institutions and researchers must commit to community-led and authentically collaborative research projects. This process takes time which needs to be factored into the timeframes of grants.

Partnerships are essential for successful community-led public health interventions. When seeking to understand the importance and breadth of these partnerships it is often imperative that as a research team, institution or interested stakeholder, there is significant effort to understand what partnerships exist. Simply, it is important to explore existing partnerships and relationships within the community you hope to collaborate with. Fortunately for the CHIPP project, there were many years of partnership building that preceded our project, and we were invited to the community by the Dharriwaa Elders Group through its existing Yuwaya Ngarra-li partnership.

Conclusion

The process of co-designing the CHIPP project ensured that the intervention design, delivery and outputs were actively controlled by local Indigenous community leadership. The development of the CHIPP program provides useful insights into the way in which western safety and injury information can be successfully adapted to ensure that the messages are appropriate for the specific community. It has demonstrated that co-design can be an effective approach in responding to and meeting the

needs of community and partners. A one-size fits all approach does not work for Aboriginal and Torres Strait Islander communities; we are not homogenous.

Acknowledgements We pay our respects to elders past and present on whose lands this research was conducted – Gamilaraay, Yuwaalaraay, Wiradjuri, Bedegal, Tharawal, Gadigal and Wangal.

We would like to acknowledge and thank the people and community that allowed us to conduct this research and design this program with them.

The CHIPP program was developed in partnership with the Walgett Aboriginal Medical Service, Dharriiwa Elders Group, Yuwaya Ngarra-li, UNSW, Kidsafe NSW

Contributors Conceptualisation: NPW, AT, RI, MA; Methodology development: NPW, RM, RI, MA; Data collection & analysis, paper drafting: NPW, AT; Interpretation, review and editing: all authors.

Funding This research project was funded by The Australian Prevention Partnership Centre.

Competing interests None declared.

Patient and public involvement patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication yes.

Ethics approval Ethics approval was granted by the University of New South Wales Human Research Ethics Committee - 1580/19; and AH&MRCH Ethics Committee - 1494/19

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Not applicable.

ORCID iDs

Nellie Pollard-Wharton <https://orcid.org/0009-0007-7486-7773>

Rona Macniven <https://orcid.org/0000-0002-2967-7977>

Rebecca Ivers <https://orcid.org/0000-0003-3448-662X>

Kate Hunter <https://orcid.org/0000-0002-2757-1474>

Kathleen Clapham <https://orcid.org/0000-0001-9776-5496>

Madeleine Powell <https://orcid.org/0000-0002-2992-9900>

Chapter Four - Discussion

As a Blak woman and researcher I am guided by my understanding of the world and the way in which it functions, knowing that research is not exempt from the racism that this colony enacts on us, as Blak individuals and communities. The way in which I move through life shapes my interactions with academia, and my standpoint cannot be separated from my scholarship, and nor should it be [12]. Acknowledging this, in my final chapter I aim to provide a more in-depth insight into these factors whilst reporting and reflecting on the research I have undertaken in this thesis.

Aims of the thesis

This thesis has aimed to investigate and critically review collaborative research practices within Aboriginal health research. Collaboration is used generously throughout this thesis to attempt to capture the research practices conducted in the spirit of allyship. I have sought to gain a deeper understanding of what constitutes collaboration within Aboriginal health research, by taking a close look at the concept of co-design and how it has and can be applied to shape and improve the design of public health programs, research processes and outcomes for Aboriginal communities. To do this, I undertook a systematic scoping review (Chapter 2) of existing studies that reported to design health programs *with* Aboriginal participants and communities. I then conducted primary research by collaboratively co-designing an unintentional child injury prevention program with an Aboriginal community-controlled health organisation in north-west NSW (Chapter 3).

What is collaboration and how do we measure it?

Of particular interest to me throughout this research was: 1. the ways in which researchers were able to demonstrate and enact collaboration in their research with Aboriginal participants, communities, and organisations and 2. the ways in which my primary research was able to demonstrate collaboration with Aboriginal partners. I sought to understand whether researchers are genuinely “doing” co-design when they say they are using collaborative or co-design methods.

What emerged during the early stages of my research was a need to identify a mechanism to undertake health research with Aboriginal participants. I considered the Create Aboriginal and Torres Strait Islander Quality Appraisal Tool (QAT) [63] to be the most suitable tool for this purpose. This tool was developed “to assess the quality of health research from an Aboriginal and Torres Strait Islander perspective... that privileges Indigenous epistemologies, values and principles for ethical research.” [63] by a team of Aboriginal and non-Aboriginal researchers.

“The tool consists of 14 questions that assess the quality of health research from an Aboriginal and Torres Strait Islander perspective. The questions encompass setting appropriate research questions; community engagement and consultation; research leadership and governance; community protocols; intellectual and cultural property rights; the collection and management of research material; Indigenous research paradigms; a strength-based approach to research; the translation of findings into policy and practice; benefits to participants and communities involved; and capacity strengthening and two-way learning. Outcomes from the assessment of the tool’s validity, reliability, and feasibility were overall positive.” [63]

I identified that the 14 questions in the CREATE Tool encompassed the central tenants of the interpretation of co-design that I sought to include. In the formative stages of my research, I had planned to develop a co-design threshold to assess the ways in which the term was utilised in Aboriginal health research, however, I conceded that the QAT was an appropriate and validated tool that could be used to meet my research goals.

Upon choosing the mechanism through which I would assess existing studies, it was important however to define co-design (see Chapter 1) within the Aboriginal research health space.

Defining co-design

Co-design is defined as collaborative research that privileges Aboriginal participants and professionals in all aspects of the design, implementation and evaluation of a program sought to be

developed and reported in health research. As outlined in chapter 1 of this thesis (chapter 1), this definition has been extracted from existing literature that concedes that whilst there are many varying, yet similar, definitions of co-design within health, the core elements are equity, trust, transparency, partnership and shared power [56-58].

Co-design is an approach to research that can ensure accountability to community partners is maintained through all stages [56, 158]. Co-design theoretically supports equal voices within research, design, implementation and evaluation. Researchers that seek to work towards co-design are therefore also seeking to walk beside the communities in which they are conducting research, aiming to ensure that there is full and in-depth participation and ownership of the process. Co-design is an approach that could provide a model for communities to engage with researchers and research projects for their benefit, that meet their community needs.

Summary of research

Systematic scoping review

The systematic scoping review undertaken and documented in detail in Chapter Two found that whilst there was a general commitment to collaborative research within Aboriginal health there was a lack of consistency in both enacting, and reporting on collaborative research.

This review demonstrated that whilst various research methods can yield positive results, there was a lack of consistency amongst researchers in the way they conduct research with Aboriginal and Torres Strait Islander peoples. This lack of consistency, to me, represents a gap in the application of existing ethical guidelines and frameworks that are intended to be used when conducting research with Aboriginal and Torres Strait Islander peoples and communities, to ensure quality research [68, 70, 73]. Guidelines seek to promote the application of 'core values' to apply to research; reciprocity; respect; equality; responsibility; survival and protection; and spirit and integrity [115]. However, these guidelines are not always followed as intended [70]. It is my opinion that this gap, could

potentially be filled by ensuring that there is an over-arching co-design approach to guide research projects, meaning that different methods and methodologies could still be used, but with added protections for Aboriginal peoples and communities, that would enable community control of research. This may be the development of a more detailed checklist or process for researchers to complete that needs to be formally assessed before finalisation of the research. This is beyond the scope of this thesis but could be a useful next step.

An identifiable limitation of the scoping review was that key collaborative elements may not have been reported on in the published materials. What I have deduced is that this does not necessarily indicate that the studies were not undertaken in a collaborative manner, but rather that the criteria for publication may not allow for in depth reporting of collaborative research elements. Another potential limitation is the way in which I used the QAT, as it is not intended to be used as a stand-alone appraisal tool nor a data extraction tool [63]. However, for the purpose of my research and the information I was trying to uncover, I used the QAT to appraise collaboration, not overall quality of the papers in the final selection.

Co-designing an unintentional child injury prevention program

Following the systematic review, I was able to take a leadership role in the Child Injury Prevention Program (CHIPP) that was developed in partnership between the School of Population Health (UNSW Sydney) and the Walgett Aboriginal Medical Service (WAMS).

This project allowed me to test and implement co-design as an approach to discover which elements were central to ensuring genuine collaboration with the research project.

The CHIPP project discussed in Chapter Three provided the formative data and results that enabled us to better understand and evaluate the benefits of co-designing a public health program in partnership with an Aboriginal community-controlled health organisation (ACCHO). Over the course of the three years of the program, the co-design, implementation and evaluation process was rich

and provided valuable insight into the benefit of collaboration with stakeholders at all stages of research and program design. Whilst it was not a large-scale project, the evaluation data and results clearly indicated the successes of the co-design process [159].

CHIPP sought to collaboratively design an unintentional child injury prevention program with the Aboriginal community in Walgett, NSW. The CHIPP team comprised of researchers from UNSW and early childhood educators from Goonimoo Mobile Children's Service, a successful and enduring mobile preschool program run by the Walgett Aboriginal Medical Service (WAMS). As highlighted in Chapter Three, the co-design process was supported by existing partnerships between key stakeholders in Walgett and UNSW. Built on these foundations CHIPP was able to iteratively develop the methods through which the final product (the CHIPP Program) would be developed. A mixed-methods iterative co-design approach, informed by Indigenous and decolonising research methodologies [8, 11, 120, 134], was utilised to engage with participants at all stages of research.

The iterative way in which the CHIPP program developed was of keen interest, and what was proposed at the initial stages of design was not what eventuated. What did occur, was that expert knowledge from key community partners (at Goonimoo) was taken on board to re-shape the way in which the project would be approached. Initial aims (ideas/thoughts) of the program sought co-design a program with parents and families, with a focus on strengths-based parenting programs (AAA, circle of security) to enable behaviour change with a positive effect on reducing the risks of unintentional injury for children. However, the formative stages of collaboration with key partners and initial yarns (with participants), revealed that the co-design process and program development was best focussed on developing a program with Goonimoo staff, that the early childhood educators could integrate into their core business, to value add rather than burden them, by increasing the load.

This process and formative yarns were an important factor in the co-design of CHIPP. Co-design is an iterative process, it is dependent on the partners and community members, so that they are able

to shape what occurs. We as the external researchers were tasked with accommodating these changes. Our role was to use our expertise and knowledge to ensure that the community priorities, ideas, needs and knowledge could be combined with the expert injury knowledge and best practice guidelines.

The co-design process provided the space for Aboriginal leadership within the CHIPP team. Co-design, when undertaken with the correct intentions, sets out to remove power imbalances between participants and researchers and collaborators [56, 58]. Within the CHIPP project, local Aboriginal knowledges in early childhood expertise, place-based knowledges and organisational practices were positioned at the centre of the process. This meant that the iterative co-design held space to ensure that Aboriginal and non-Aboriginal researchers were simply able to integrate safety expertise and research knowledge into the vision of Aboriginal leads implementing the program. In this approach researchers must take a back step to ensure that what is being designed and delivered meets the needs of the participants. The iterative nature of the co-design process ensured that place-based Indigenous knowledge were always privileged and respected.

Why collaborative research? Why should Aboriginal people/communities be research partners?

To enable Aboriginal leadership in research, researchers must acknowledge the value and importance of partnering with Aboriginal people and communities [50]. Genuine collaborative research that is conducted with Aboriginal peoples and communities encompasses many core elements of Indigenous leadership, control and power of said research [50, 70].

“The decolonisation of research requires self-determination of Indigenous people and organisations in the entirety of a research project (from design to dissemination) and acknowledge in the ongoing colonial discourse and unequal power differentials that are unleashed through a Western research paradigm.”[70]

Research conducted on Aboriginal peoples and communities has a negative history that has perpetuated the violence of the colony, with results being used as evidence to control the lives of Aboriginal and Torres Strait Islander peoples. This has perpetuated a deficit narrative of ill health whilst diminishing concepts of Indigenous health and wellbeing [54]. In more recent years, this has been recognised as inherently problematic. Efforts made to rectify this issue or at the very least reduce harm moving forward has seen ethical guidelines, frameworks and partner documents created to guide researchers and institutions towards best practice [68, 73, 74, 115-117]. In addition to these there is a growing commitment to; Indigenous research methodologies; decolonising methodologies; strengths-based approaches; and participatory research methods [8, 11, 54, 123, 160]. However, these efforts have not yet yielded the positive outcomes they have sought to achieve to combat the failures of the health system for Aboriginal and Torres Strait Islander peoples.

It is imperative that Blak leadership within Aboriginal health and health research is prioritised within Australia. This thesis has allowed me to test the concept of co-design and how it can be used to develop an unintentional child injury prevention program with an Aboriginal Community Controlled Health Organisation (ACCHO). Showing that the success of such a program is dependent on Aboriginal leadership, from the community and within institutions, and an iterative and flexible mode of design and implementation of said program.

The strength of Aboriginal led design and delivery enabled the program to pivot where it needed to, based on the community's needs. This highlighted the importance of local Aboriginal leadership within this program's development (design and implementation). At times, the UNSW facing team would suggest solutions that we thought would or could be effective, but were often informed that, no, that wasn't the right way. Letting go of power (even as another Blak woman) is important, as supporting the development of a place-based program is dependent on the knowledge of that specific place, something that I (nor the rest of the UNSW team) did not have. When acknowledging and then relinquishing power to your community partners, it is imperative that this is done in an

authentic way. The CHIPP program was able to do this, complete autonomy of how the program was delivered was taken up by the Aboriginal women that ran Goonimoo. As such, we as the research team were able to be the support and fill in the gaps with specific injury knowledge as needed to help create the evidence-based program and manuals for CHIPP. This leadership is demonstrative of the expertise and agility of community-controlled services ability to pivot and meet needs.

Throughout the course of undertaking this thesis the community and the research team faced significant local, national and international issues – Covid-19 global pandemic, floods, fires and the Blak Lives Matter global movement. These factors created challenges for the overall project; data collection; implementation of program; and reporting.

Recommendations – Implications for future research

Unintentional child injury prevention

To further evaluate the effectiveness of the CHIPP program there is a need for implementation and co-design of the resources at additional sites in different playgroup settings. In doing this, we would be able to measure if culturally appropriate injury prevention manuals integrated into early childhood education settings were an effective way in which to reduce the risks of unintentional injuries in children. If found to be similarly effective in different settings, it would be important to consider the program and aligned research project for wider implementation at to scale. Scalability tools could be tested and refined in Aboriginal community settings, as evaluation measures would be different for scaled projects [161].

Scoping for appropriate future sites for CHIPP scalability would need to be explored through a formative process of building relationships, partnerships, and community yarns. Potential sites for a future CHIPP study could be in an Aboriginal community-controlled playgroup within an urban

environment. However, due to the place-based knowledges included in the manuals and program, researchers and program implementers would need to ensure that cultural protocols were followed.

Co-design

This thesis has exposed the need for further development of how co-design is used by researchers within implementation research, to develop a robust mechanism to ensure researchers are accountable to the standards found within ethical guidelines and frameworks that already exist.

The development of a substantive co-design framework or 'toolkit' would be a useful tool to ensure best practise in collaborative research with Aboriginal peoples and communities. The conclusions I have drawn, that is, that co-design is applied broadly, we need to synthesis the way in which it applied to ensure the best outcome for Aboriginal peoples and communities within health research, has also been reported [62].

Indigenous Data Sovereignty

Further research in this space must also be informed and guided by the increasing shift towards Indigenous Sovereignty within Indigenous Data. Much of the data that relates to the health of Indigenous people is collected, held, managed and owned by non-Indigenous groups, institutions and government [162-164]. This shift in data sovereignty is an area that must be engaged with closely for researchers seeking to undertake research with Aboriginal people, the inclusion of Inclusion of Indigenous Data Sovereignty is a key element identified within the collaborative approaches discussed in this thesis.

Final Reflections - The lasting impact of research on Blak bodies

Engaging in research as a Blak woman is not an easy task: you walk in two worlds, sometimes three, fulfilling many roles. Race and racism are embedded within our health systems and within the academy, and the violence experienced by Aboriginal peoples in this colony cannot be separated from our practice as researchers and academics.

Anti-blackness is one way some black scholars have articulated what it means to be marked as black in an anti-black world. It's more than just "racism against black people." That oversimplifies and defangs it. It's a theoretical framework that illuminates society's inability to recognize our humanity — the disdain, disregard and disgust for our existence. [165]

The impacts of racism on Aboriginal and Torres Strait Islander people's health and well-being are well documented [128, 153, 159, 166]. The social context in which I operate cannot be ignored or pushed to the side. As an Aboriginal academic I do not have the privilege of separating work from reality [167]. The "work" is literally our lives, it is an endeavour to integrate our acquired skills into pathways that will have a tangible impact for our families and our communities. The participants, the data, the results, and the outcomes *are* our people, the "work" is personal, and when research causes harm, it is a personal offence; especially when conducted by our "peers" and "colleagues". These statements are measured, they are not dramatic, and they are not radical.

Conclusions

This thesis is a stepping stone, it is an opportunity to document what comes from ensuring that Black voices and practices are elevated and privileged rather than sidelined in research. It has been a privilege to conduct primary research in partnership with an ACCHO to design and implement a program that could have a tangible impact on current and future generations. To enact co-design as an approach to public health research and reflect on the processes whilst undertaking my thesis has been a positive experience. I look forward to exploring the development of the ways in which co-design can be utilised to support community-led and equitable research with Aboriginal peoples and communities.

References

1. Matsumoto, A., Blackburn, K., Spicer, B., Seear, K., & Johnson, C., *A Mixed Methods Study of 15 Years of Aboriginal Health Research in the Kimberley: 'We've Been Researched, We Think, from Head to Toe, Inside and Outside, Upside Down'*. International journal of environmental research and public health, 2023. 20(6): p. 4823.
2. Bainbridge, R., Whiteside, M., & McCalman, J., *No one's discussing the elephant in the room: Contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research*. BMC Public Health, 2015. 15(1): p. 696-696.
3. Thomas, D.P., Bainbridge, R., & Tsey, K., *Changing discourses in Aboriginal and Torres Strait Islander health research, 1914-2014*. Med J Aust, 2014. 201(S1): p. S15-S18.
4. Azzopardi, P.S., Sawyer, S.M., Carlin, J.B., Degenhardt, L., Brown, N., Brown, A.D., & Patton, G.C., *Health and wellbeing of Indigenous adolescents in Australia: a systematic synthesis of population data*. Lancet (London, England), 2018. 391(10122): p. 766-782.
5. Martin, K. & Mirraabooa, B., *Ways of knowing, being and doing: A theoretical framework and methods for indigenous and indigenist re-search*. Journal of Australian Studies: Voicing Dissent, 2003. 27(76): p. 203-214.
6. Moreton-Robinson, A., *Introduction: Critical Indigenous Theory*. Cultural Studies Review, 2009. 15(2): p. 11-12.
7. Moreton-Robinson, A., *Talkin' up to the white woman: aboriginal women and feminism*. 2000, St Lucia, Qld.: St Lucia, Qld: University of Queensland Press.
8. Smith, L.T., *Decolonizing methodologies: research and indigenous peoples*. 2nd ed. ed. 2012, London, New York: London, Zed Books.
9. Askew, D.A., et al., *Closing the gap between rhetoric and practice in strengths-based approaches to Indigenous public health: a qualitative study*. Australian and New Zealand journal of public health, 2020.
10. Walter, M. & Walter, M. *Social research methods: an Australian perspective*. 2006, South Melbourne: OUP.
11. Tuck, E., *Commentary: Decolonizing methodologies 15 years later*. AlterNative: an international journal of indigenous peoples, 2013. 9(4): p. 365-372.
12. Moreton-Robinson, A., *Towards an Australian Indigenous Women's Standpoint Theory: A Methodological Tool*. Australian feminist studies, 2013. 28(78): p. 331-347.
13. Simpson, G.J., *Mabo, international law, terra nullius and the stories of settlement: an unresolved jurisprudence.(Australia)*. Melbourne University Law Review, 1993. 19(1): p. 210.
14. Bennett, B., *Our voices: Aboriginal and Torres Strait Islander social work*. Aboriginal and Torres Strait Islander social work, ed. S. Green, S. Gilbert, and D. Bessarab. 2013, South Yarra, Vic.: South Yarra, Vic. : Palgrave Macmillan.
15. Elder, B., *Blood on the wattle : massacres and maltreatment of Australian Aborigines since 1788*. 1988, Frenchs Forest, N.S.W: Frenchs Forest, N.S.W: Child & Associates.
16. Ellinghaus, K., *Absorbing the 'Aboriginal Problem': Controlling Interracial Marriage in Australia in the Late 19th And Early 20th Centuries*. Aboriginal History, 2003. 27: p. 183-207.
17. Davis, P.M., *Family is Culture review report 2019 Independant review of aboriginal children and young people in OOHC*. 2019.
18. Northern Territory Government, *Ampe Akelyernemane Meke Mekarle "Little Children are Sacred"*. 2007: Northern Territory.
19. Newton, B., *Understanding child neglect in Aboriginal families and communities in the context of trauma*. Child & Family Social Work, 2019. 24(2): p. 218-226.
20. Warne, D. & Lajimodiere, D., *American Indian health disparities: psychosocial influences*. Social and Personality Psychology Compass, 2015. 9(10): p. 567-579.
21. Warne, D. & Frizzell, L.B., *American Indian health policy: historical trends and contemporary issues*. American journal of public health, 2014. 104 Suppl 3: p. S263.
22. Hill Collins, P., *Intersectionality as critical social theory*. 2019, Durham: Duke University Press.

23. Crenshaw, K.W., *Mapping the margins: intersectionality, identity politics, and violence against women of color*. (Women of Color at the Center: Selections from the Third National Conference on Women of Color and the Law). Stanford Law Review, 1991. 43(6): p. 1299.
24. Michie, S., van Stralen, M.M., & West, R., *The behaviour change wheel: A new method for characterising and designing behaviour change interventions*. Implement Sci, 2011. 6(1): p. 42-42.
25. Marmot, M., *Social determinants of health inequalities*. Lancet (London, England), 2005. 365(9464): p. 1099.
26. Marmot, M., *Social determinants and the health of Indigenous Australians*. Medical Journal of Australia, 2011. 194(10): p. 512-513.
27. Marmot, M. & Allen, J.J., *Social determinants of health equity*. American journal of public health, 2014. 104(S4): p. S517.
28. Kennedy, M., Bennett, J., Maidment, S., Chamberlain, C., Booth, K., McGuffog, R., Hobden, B., Whop, L.J., & Bryant, J., *Interrogating the intentions for Aboriginal and Torres Strait Islander health: a narrative review of research outputs since the introduction of Closing the Gap*. Medical journal of Australia, 2022. 217.
29. Lowitja Institute, *Culture is Key: Towards cultural determinants-driven health policy - Final Report*. 2020: Melbourne.
30. Bourke, S.C., Chapman, J., Jones, R., Brinckley, M.M., Thurber, K.A., Calabria, B., Doery, K., Olsen, A., & Lovett, R., *Developing Aboriginal and Torres Strait Islander cultural indicators: an overview from Mayi Kuwayu, the National Study of Aboriginal and Torres Strait Islander Wellbeing*. International journal for equity in health, 2022. 21.
31. Lowitja Institute, *We nurture our culture for our future, and our culture nurtures us*. 2020: Melbourne.
32. Sminkey, L., *World report on child injury prevention*. Injury Prevention, 2008. 14(1): p. 69-69.
33. Holder, Y., Peden, M., Krug, E., et al (Eds), *Injury surveillance guidelines*. Geneva, World Health Organization, 2001
34. Mitchell, R.J., K. Curtis, and K. Foster, *A 10-year review of child injury hospitalisations, health outcomes and treatment costs in Australia*. Injury prevention : journal of the International Society for Child and Adolescent Injury Prevention, 2018. 24(5): p. 344.
35. Moller, H., Falster, K., Ivers, R., Clapham, K., Harvey, L., & Jorm, L., *High rates of hospitalised burn injury in Indigenous children living in remote areas: a population data linkage study*. Australian and New Zealand journal of public health, 2018. 42(1): p. 108-109.
36. Peden, M., *World report on child injury prevention appeals to "Keep Kids Safe"*. Injury Prevention, 2008. 14(6): p. 413-414.
37. Moller, H., Falster, K., Ivers, R., & Jorm, L., *Inequalities in unintentional injuries between indigenous and non-indigenous children: a systematic review*. Injury Prevention, 2015. 21(E1): p. E144-E152.
38. Meddings, D., *Child Injury Prevention: An Overlooked Challenge for Child Survival*. International Journal of Environmental Research and Public Health, 2013. 10(2): p. 568-70.
39. Moller, H., Falster, K., Ivers, R., Falster, M., Randall, D., Clapham, K., & Jorm, L., *Inequalities in Hospitalized Unintentional Injury Between Aboriginal and Non-Aboriginal Children in New South Wales, Australia*. American journal of public health, 2016. 106(5): p. 899-905.
40. Moller, H., Falster, K., Ivers, R., Falster, M.O., Clapham, K., & Jorm, L., *Closing the Aboriginal child injury gap: targets for injury prevention*. Australian and New Zealand journal of public health, 2017. 41(1): p. 8-14.
41. Clapham, K., Bennett-Brook, K., Hunter, K., Zwi, K., Ivers, R., *Active and Safe: Preventing unintentional injury to Aboriginal children and young people in NSW: Guidelines for Policy and Practice*, S.C.s.H. Network, Editor. 2019: Sydney.
42. Australian Institute of Health and Welfare, *Australia's children*. 2020, Australian Institute of Health and Welfare: Canberra.

43. Kreisfeld, R., Harrison, J.E., *Indigenous injury deaths: 2011–12 to 2015–16*, Injury research and statistics, 2020, Australian Institute of Health and Welfare: Canberra.
44. Clapham, K., Bennett-Brook, K., & Hunter, K., *The role of Aboriginal family workers in delivering a child safety-focused home visiting program for Aboriginal families in an urban region of New South Wales*. Health Promotion Journal of Australia, 2018. 29(2): p. 173-182.
45. Clapham, K., Ivers, R., Hunter, K., & Bennett-Brook, K., *Addressing Australian aboriginal child injury through policy and practice guidelines*. Injury Prevention, 2016. 22: p. A74-A74.
46. Moller, H., Ivers, R., Clapham, K., & Jorm, L., *Are we closing the Aboriginal child injury gap? A cohort study*. Australian and New Zealand journal of public health, 2019. 43(1): p. 15-17.
47. Elkington, J., Brown, J., MacKay, M. & Adams, S., *129 The child safety good practice guide: we don't need to reinvent the wheel*. Injury Prevention, 2016: London.
48. Durl, J., Trischler, J., & Dietrich, T., *Co-designing with young consumers - reflections, challenges and benefits*. Young Consumers, 2017. 18(4): p. 439-455.
49. Donetto, S., Pierri, P., Tsianakas, V., & Robert, G., *Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector*. The Design Journal, 2015. 18(2): p. 227-248.
50. Funnell, S., Tanuseputro, P., Letendre, A., Bearskin, L.B., & Walker, J., *'Nothing About Us, without Us.': How Community-Based Participatory Research Methods Were Adapted in an Indigenous End-of-Life Study Using Previously Collected Data*. Canadian journal on aging, 2020: p. 145-155.
51. Came, H., Gifford, H., & Wilson, D., *Indigenous public health: nothing about us without us*. Public Health, 2019. 176: p. 2-3.
52. Aboriginal Health & Medical Research Council of NSW, *AH&MRC Ethical Guidelines: Key Principles (2020) V2.0*, AH&MRC, Editor. 2020, Aboriginal Health & Medical Research Council of NSW: Surry Hills.
53. Australian Institute of Aboriginal and Torres Strait Islander Studies, *Guidelines for Ethical Research in Australian Indigenous Studies*. 2012, Australian Institute of Aboriginal and Torres Strait Islander Studies: Canberra.
54. Bryant, J., Bolt, R., Botfield, J.R., Martin, K., Doyle, M., Murphy, D., Graham, S., Newman, C. E., Bell, S., Treloar, C., Browne, A. J., & Aggleton, P., *Beyond deficit: 'strengths-based approaches' in Indigenous health research*. Sociology of health & illness, 2021. 43.
55. World Health Organization Department of Communications, *Technical note from the WHO Technical Advisory Group (TAG) on behavioural insights and science for health*. 2021, World Health Organization: Geneva.
56. Vargas, C., Whelan, J., Brimblecombe, J., & Allender, S., *Co-creation, co-design, co-production for public health - a perspective on definition and distinctions*. Public Health Research & Practice, 2022. 32(2).
57. Belko, S., Hutchinson, M., Hayden, G., & Pugliese, R., *Co-designing Diabetes Care With Patients*. Journal of diabetes science and technology, 2023: p. 19322968231213394-19322968231213394.
58. Masterson, D., Areskoug Josefsson, K., Robert, G., Nylander, E., & Kjellström, S., *Mapping definitions of co-production and co-design in health and social care: A systematic scoping review providing lessons for the future*. Health expectations : an international journal of public participation in health care and health policy, 2022. 25(3): p. 902-913.
59. McGill, B., Corbett, L., Grunseit, A. C., Irving, M., & O'Hara, B.J., *Co-Produce, Co-Design, Co-Create, or Co-Construct-Who Does It and How Is It Done in Chronic Disease Prevention? A Scoping Review*. Healthcare (Basel), 2022. 10(4).
60. Milroy, H., et al., *Co-designing research with Aboriginal and Torres Strait Islander consumers of mental health services, mental health workers, elders and cultural healers*. Aust J Rural Health, 2022.

61. Blomkamp, E., *The promise of co-design for public policy*. Australian journal of public administration, 2018. 77(4): p. 729-743.
62. Butler, T., Gall, A., Garvey, G., Ngampromwongse, K., Hector, D., Turnbull, S., Lucas, K., Nehill, C., Boltong, A., Keefe, D., & Anderson, K., *A Comprehensive Review of Optimal Approaches to Co-Design in Health with First Nations Australians*. International journal of environmental research and public health, 2022. 19.
63. Harfield, S., Pearson, O., Morey, K., Kite, E., Canuto, K., Glover, K., Gomersall, J. S., Carter, D., Davy, C., Aromataris, E., & Braunack-Mayer, A., *Assessing the quality of health research from an Indigenous perspective: The Aboriginal and Torres Strait Islander quality appraisal tool*. BMC medical research methodology, 2020. 20(1): p. 79-79.
64. Commonwealth of Australia, *Commonwealth Closing the Gap Annual Report 2022*. 2022, National Indigenous Australians Agency: Canberra.
65. Productivity Commission, *Closing the Gap Annual Data Compilation Report 2023*, Australian Government: Canberra.
66. Bond, C.J. & Singh, D., *More than a refresh required for closing the gap of Indigenous health inequality*. Med J Aust, 2020. 212(5): p. 198-199.e1.
67. Finlay, S.M., Cargo, M., Smith, J.A., Judd, J., Boulton, A., Foley, D., Roe, Y., & Fredericks, B., *The dichotomy of commissioning Indigenous health and wellbeing program evaluations: What the funder wants vs what the community needs*. Health promotion journal of Australia, 2021. 32(2): p. 149-151.
68. National Health and Medical Research Council, *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*. 2018, Commonwealth of Australia: Canberra.
69. George, L., Taori, J., & MacDonald, L.T.A.o.T., *Indigenous research ethics: claiming research sovereignty beyond deficit and the colonial legacy*. First edition. ed. Advances in research ethics and integrity, volume 6. 2020, United Kingdom: Emerald Publishing.
70. Sherwood, J. & Anthony, T., *Ethical Conduct in Indigenous Research: It's Just Good Manners*, in *Indigenous Research Ethics: Claiming Research Sovereignty Beyond Deficit and the Colonial Legacy*, L. George, J. Tauri, and L.T.A.o.T. MacDonald, Editors. 2020, Emerald Publishing Limited. p. 19-40.
71. Farnbach, S., Eades, A.-M. & Hackett, M.L., *Australian Aboriginal and Torres Strait Islander-focused primary healthcare social and emotional wellbeing research: A systematic review protocol*. Systematic reviews, 2015. 4(1): p. 189-189.
72. Mc Loughlin, F., Hadgraft, N.T., Atkinson, D., & Marley, J.V., *Aboriginal health research in the remote Kimberley: An exploration of perceptions, attitudes and concerns of stakeholders*. BMC health services research, 2014. 14(1): p. 517-517.
73. National Health and Medical Research Council, *Keeping research on track 2*. 2018, Commonwealth of Australia: Canberra.
74. Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*, AIATSIS, Editor. 2020, Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS): Canberra.
75. Australian Indigenous Health Info Net, *Closing the Gap: Indigenous Chronic Disease Package Healthy Lifestyle Worker TOOLKIT*, The Commonwealth Department of Healthy Ageing. 2012, Commonwealth Government: Canberra.
76. Australian Bureau of Statistics. *Remoteness Areas*. 2023; Available from: <https://www.abs.gov.au/statistics/standards/australian-statistical-geography-standard-asgs-edition-3/jul2021-jun2026/remoteness-structure/remoteness-areas>.
77. Ireland, S. & Maypilama, E.L., *"We are sacred": An intercultural and multilingual approach to understanding reproductive health literacy for Yolŋu girls and women in remote Northern Australia*. Health Promot J Austr, 2020.

78. Dimitropoulos, Y., Gwynne, K., Blinkhorn, A., & Holden, A., *A school fluoride varnish program for Aboriginal children in rural New South Wales, Australia*. Health Promot J Austr, 2020. 31(2): p. 172-176.
79. Chamberlain, C., Gee, G., Gartland, D., Mensah, F.K., Mares, S., Clark, Y., Ralph, N., Atkinson, C., Hirvonen, T., McLachlan, H., Edwards, T., Herrman, H., Brown, S. J., & Nicholson, A.J.M., *Community Perspectives of Complex Trauma Assessment for Aboriginal Parents: 'Its Important, but How These Discussions Are Held Is Critical'*. Front Psychol, 2020. 11: p. 2014.
80. Haynes, E., Marawili, M., Marika, B.M., Mitchell, A.G., Phillips, J., Bessarab, D., Walker, R., Cook, J., & Ralph, A.P., *Community-based participatory action research on rheumatic heart disease in an Australian Aboriginal homeland: Evaluation of the 'On track watch' project*. Eval Program Plann, 2019. 74: p. 38-53.
81. Povey, J., Sweet, M., Nagel, T., Mills, P., Stassi, C.P., Puruntatameri, A.M.A., Lowell, A., Shand, F., & Dingwall, K., *Drafting the Aboriginal and Islander Mental Health Initiative for Youth (AIMhi-Y) App: Results of a formative mixed methods study*. Internet Interv, 2020. 21: p. 100318.
82. Ching, T.Y.C., Hou, S., Seeto, M., Harkus, S., Ward, M., Marnane, V., & Kong, K., *The Parents' evaluation of Listening and Understanding Measure (PLUM): Development and normative data on Aboriginal and Torres Strait Islander children below 6 years of age*. Deafness & Education International, 2020. 22(4): p. 288-304.
83. Gilbert, E., Collins, R., Webster, V., Boyd, N., Maple-Brown, L., Boyle, J., & Smith-Vaughan, H., *Using co-design to develop a culturally responsive reproductive health learning resource for Aboriginal and Torres Strait Islander youth*. Health Promot J Austr, 2021. 32 Suppl 1: p. 179-185.
84. Elsum, I., Massey, L., McEwan, C., LaGrappe, D., Kowal, E., Savarirayan, R., Baynam, G., Jenkins, M., Garvey, G., & Kelaheer, M., *A community-based co-designed genetic health service model for Aboriginal Australians*. PLoS One, 2020. 15(10): p. e0239765.
85. Miller, A., Young, E., Tye, V., Cody, R., Muscat, M., Saunders, V., Smith, M., Judd, J., & Speare, R., *A Community-Directed Integrated Strongyloides Control Program in Queensland, Australia*. Tropical Medicine and Infectious Disease, 2018. 3: p. 48.
86. Wagner, B., Latimer, J., Adams, E., Carmichael Olson, H., Symons, M., Mazzucchelli, T.G., Jirikowic, T., Watkins, R., Cross, D., Carapetis, J., Boulton, J., Wright, E., McRae, T., Carter, M., & Fitzpatrick, J.P., *School-based intervention to address self-regulation and executive functioning in children attending primary schools in remote Australian Aboriginal communities*. PLoS one, 2020. 15(6): p. e0234895-e0234895.
87. Shield, J.M., Kearns, T.M., Garngulkpuy, J., Walpulay, L., Gundjirryirr, R., Bundhala, L., Djarpanbuluwuy, V., Andrews, R.M., & Judd, J., *Cross-Cultural, Aboriginal Language, Discovery Education for Health Literacy and Informed Consent in a Remote Aboriginal Community in the Northern Territory, Australia*. 2018. 3(1): p. 15.
88. Ching, T.Y.C., Saetre-Turner, M., Harkus, S., Martin, L., Ward, M., Marnane, V., Jones, C., Collyer, E., Khamchuang, C., & Kong, K., *The Hearing and Talking Scale (HATS): Development and validation with young Aboriginal and Torres Strait Islander children in urban and remote settings in Australia*. Deafness & Education International, 2020. 22(4): p. 305-324.
89. Dimitropoulos, Y., Holden, A., Gwynne, K., Do, L., Byun, R., & Sohn, W., *Outcomes of a co-designed, community-led oral health promotion program for Aboriginal children in rural and remote communities in New South Wales, Australia*. Community Dent Health, 2020. 37(2): p. 132-137.
90. Carr, J.J., Lalara, J., Lalara, G., Lalara, G., Daniels, B., Clough, A.R., Lowell, A., & Barker, R.N., *Staying Strong Toolbox: Co-design of a physical activity and lifestyle program for Aboriginal families with Machado-Joseph disease in the Top End of Australia*. PLoS One, 2021. 16(2): p. e0244311.

91. Munro, A., Shakeshaft, A., & Clifford, A., *The development of a healing model of care for an Indigenous drug and alcohol residential rehabilitation service: a community-based participatory research approach*. Health Justice, 2017. 5(1): p. 12.
92. Adams, K., Burns, C., Liebzeit, A., Ryschka, J., Thorpe, S., & Browne, J., *Use of participatory research and photo-voice to support urban Aboriginal healthy eating*. Health Soc Care Community, 2012. 20(5): p. 497-505.
93. Dudgeon, P., Scrine, C., Cox, A., & Walker, R., *Facilitating Empowerment and Self-Determination Through Participatory Action Research: Findings From the National Empowerment Project*. International Journal of Qualitative Methods, 2017. 16(1): p. 1609406917699515.
94. Cox, A., Dudgeon, P., Holland, C., Kelly, K., Scrine, C., & Walker, R., *Using participatory action research to prevent suicide in Aboriginal and Torres Strait Islander communities*. Aust J Prim Health, 2014. 20(4): p. 345-9.
95. Fehring, E., Ferguson, M., Brown, C., Murtha, K., Laws, C., Cuthbert, K., Thompson, K., Williams, T., Hammond, M., & Brimblecombe, J., *Supporting healthy drink choices in remote Aboriginal and Torres Strait Islander communities: a community-led supportive environment approach*. 2019. 43(6): p. 551-557.
96. Ireland, S. & Maypilama, E.L., *"We are sacred": An intercultural and multilingual approach to understanding reproductive health literacy for Yolŋu girls and women in remote Northern Australia*. 2021. 32(S1): p. 192-202.
97. Kildea, S., Barclay, L., Wardaguga, M., & Dawumal, M., *Participative research in a remote Australian Aboriginal setting*. Action Research, 2009. 7(2): p. 143-163.
98. Peake, R.M., Jackson, D., Lea, J., & Usher, K., *Meaningful Engagement With Aboriginal Communities Using Participatory Action Research to Develop Culturally Appropriate Health Resources*. Journal of Transcultural Nursing, 2020. 32(2): p. 129-136.
99. Seear, K.H., Atkinson, D.N., Henderson-Yates, L.M., Lelievre, M.P., & Marley, J.V., *Maboo wirriya, be healthy: Community-directed development of an evidence-based diabetes prevention program for young Aboriginal people in a remote Australian town*. Evaluation and Program Planning, 2020. 81: p. 101818.
100. Tsey, K., Patterson, D., Whiteside, M., Baird, L., Baird, B., & Tsey, K., *A microanalysis of a participatory action research process with a rural aboriginal men's health group*. Australian journal of primary health, 2004. 10(1): p. 64-71.
101. Wagner, B., Fitzpatrick, J., Symons, M., Jirikowic, T., Cross, D., & Latimer, J., *The development of a culturally appropriate school based intervention for Australian Aboriginal children living in remote communities: A formative evaluation of the Alert Program^(®) intervention*. Aust Occup Ther J, 2017. 64(3): p. 243-252.
102. Vindigni, D., Polus, B., Edgecombe, G., Rotterdam, J., Turner, N., Spencer, L., Irvine, G., & Walsh, M., *Bringing Chiropractic to Aboriginal communities: The Durri Model*. 2009. 39: p. 80.
103. Snijder, M., Wagemakers, A., Calabria, B., Byrne, B., O'Neill, J., Bamblett, R., Munro, A., & Shakeshaft, A., *'We walked side by side through the whole thing': A mixed-methods study of key elements of community-based participatory research partnerships between rural Aboriginal communities and researchers*. 2020. 28(4): p. 338-350.
104. Smith, S., O'Grady, L., Cubillo, C., & Cavanagh, S., *Using Culturally Appropriate Approaches to the Development of KidsMatter Resources to Support the Social and Emotional Wellbeing of Aboriginal Children*. Australian Psychologist, 2017. 52(4): p. 299-305.
105. Payne, C., *A diabetes support group for Nywaigi women to enhance their capacity for maintaining physical and mental wellbeing*. Contemp Nurse, 2013. 46(1): p. 41-45.
106. Nagel, T., Sweet, M., Dingwall, K.M., Puszka, S., Hughes, J.T., Kavanagh, D.J., Cass, A., Howard, K., & Majoni, S.W., *Adapting wellbeing research tools for Aboriginal and Torres Strait Islander people with chronic kidney disease*. BMC Nephrology, 2020. 21(1): p. 130.

107. Lee, L., Midford, R., & Malone, S., *The Dampier Peninsula Prevention Project: working with a group of remote Australian Aboriginal communities to address alcohol and drug use*. International Journal of Health Promotion and Education, 2012. 50(3): p. 111-124.
108. King, M. & Baxter, S., *Co-operative inquiry: The development of a visual impairment prevention program initiative for two Aboriginal communities in South Australia*. Contemporary Nurse, 2003. 15(3): p. 241-248.
109. Davies, J., Bukulatjpi, S., Sharma, S., Caldwell, L., Johnston, V., & Davis, J. S., *Development of a Culturally Appropriate Bilingual Electronic App About Hepatitis B for Indigenous Australians: Towards Shared Understandings*. JMIR research protocols, 2015. 4, e70 DOI: 10.2196/resprot.4216.
110. Clark, R. A., Fredericks, B., Buitendyk, N. J., Adams, M. J., Howie-Esquivel, J., Dracup, K. A., Berry, N. M., Atherton, J., & Johnson, S., *Development and Feasibility Testing of an Education Program to Improve Knowledge and Self-Care Among Aboriginal and Torres Strait Islander Patients with Heart Failure*. Rural Remote Health, 2015. 15(3): p. 1-13.
111. Crouch, K., *Wondering From the Womb: Antenatal Yarning In Rural Victoria*. Children Australia, 2017. 42(2): p. 75-78.
112. Munns, A., Toye, C., Hegney, D., Kickett, M., Marriott, R., & Walker, R., *Peer-led Aboriginal parent support: Program development for vulnerable populations with participatory action research*. Contemp Nurse, 2017. 53(5): p. 558-575.
113. Tsey, K., Patterson, D., Whiteside, M., Baird, L., & Baird, B., *Indigenous men taking their rightful place in society? A preliminary analysis of a participatory action research process with Yarrabah men's health group*. 2002. 10(6): p. 278-284.
114. McCalman, J., Tsey, K., Baird, B., Connolly, B., Baird, L., & Jackson, R., *'Bringing back respect': the role of participatory action research in transferring knowledge from an Aboriginal men's group to youth programs*. Australas Psychiatry, 2009. 17(s1): p. S59-S63.
115. National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research (2023)*. 2023, National Health and Medical Research Council: Canberra.
116. Laycock, A. & Laycock, A., *Researching indigenous health : a practical guide for researchers*. 2011, Carlton South, Vic: Lowitja Institute.
117. Arabena, K. & Moodie, D., *The Lowitja Institute: building a national strategic research agenda to improve the health of Aboriginal and Torres Strait Islander peoples*. Medical journal of Australia, 2011. 194(10): p. 532-534.
118. Laccos-Barrett, K., Brown, A. E., Saunders, V., Baldock, K. L., & West, R., *Are We Teaching Nurses to Be Racist towards Aboriginal and Torres Strait Islander Peoples? A Critical Race Document Analysis of Discrete Aboriginal and Torres Strait Islander Health Courses*. International Journal of Environmental Research and Public Health, 2022. 19.
119. King, M. & Baxter, S., *Co-operative inquiry: The development of a visual impairment prevention program initiative for two Aboriginal communities in South Australia*. Contemporary nurse: a journal for the Australian nursing profession, 2003: p. 241-248.
120. Martin, K. & Mirraoop, B., *Ways of knowing, being and doing: A theoretical framework and methods for indigenous and indigenist re-search*. Journal of Australian studies, 2003. 27(76): p. 203-214.
121. Williams, V., A.-M. Boylan, and D. Nunan, *Critical appraisal of qualitative research: necessity, partialities and the issue of bias*. BMJ evidence-based medicine, 2020. 25.
122. McBride, K., Franks, C., Wade, V., King, V., Rigney, J., Burton, N., Dowling, A., Mitchell, J.A., Van Kessel, G., Howard, N., Paquet, C., Hillier, S., Nicholls, S. J., & Brown, A., *Getting to the heart of the matter: a research partnership with Aboriginal women in South and Central Australia*. Critical Public Health, 2023. 33: p. 363-374.
123. Ryder, C., Mackean, T., Coombs, J., Williams, H., Hunter, K., Holland, A.J.A., & Ivers, R.Q., *Indigenous research methodology - weaving a research interface*. International journal of social research methodology, 2020. 23(3): p. 255-267.

124. Wright, M., Brown, A., Dudgeon, P., McPhee, R., Coffin, J., Pearson, G., Lin, A., Newnham, E., King Baguley, K., Webb, M., Sibosado, A., Crisp, N., & Flavell, H. L., *Our journey, our story: a study protocol for the evaluation of a co-design framework to improve services for Aboriginal youth mental health and well-being*. BMJ Open, 2021. 11(5): p. e042981-e042981.
125. Dreise, T., & Mazurski, E., *Weaving Knowledges: Knowledge exchange, co-design and community-based participatory research and evaluation in Aboriginal communities*, Aboriginal Affairs. 2018, NSW Government: NSW.
126. Tamwoy, N., Rosas, S., Davis, S., Farthing, A., Houghton, C., Johnston, H., Maloney, C., Samulkiewicz, N., Seaton, J., Tuxworth, G., & Bat, M., *Co-design with aboriginal and torres strait islander communities: A journey*. Aust J Rural Health, 2022. 30(6): p. 816-822.
127. Australian Government, *Infant and child mortality*, N.I.A. Agency, Editor. 2023, Australian Institute of Health and Welfare.
128. Sherwood, J., *Colonisation - It's bad for your health: The context of Aboriginal health*. Contemp Nurse, 2013. 46(1): p. 28-40.
129. Waterworth, P., Pescud, M., Braham, R., Dimmock, J., & Rosenberg, M., *Factors influencing the health behaviour of indigenous Australians: Perspectives from support people*. PLoS One, 2015. 10(11): p. e0142323-e0142323.
130. Haynes, E., Walker, R., Mitchell, A. G., Katzenellenbogen, J., D'Antoine, H., & Bessarab, D., *Decolonizing Indigenous health: Generating a productive dialogue to eliminate Rheumatic Heart Disease in Australia*. Soc Sci Med, 2021. 277: p. 113829-113829.
131. McCausland, R., Spencer, W., MacGillivray, P., Robinson, V., Hickey, V., Baldry, E., & McEntyre, E., *CommUNITY-Led development: A partnership to realize Aboriginal Elders' vision for change*. Community development (Columbus, Ohio), 2021. 52(5): p. 573-591.
132. Drummond, A., *Embodied Indigenous knowledges protecting and privileging Indigenous peoples' ways of knowing, being and doing in undergraduate nursing education*. The Australian journal of indigenous education, 2020. 49: p. 127-134.
133. Robinson, V., *Yuwaya Ngarra-li Research Brief Core Principles of our Partnership*. 2019.
134. Chilisa, B., *Indigenous research methodologies*. 2012, Thousand Oaks, Calif.: Thousand Oaks, Calif. : SAGE Publications.
135. Bessarab, D. & Ng'andu, B., *Yarning About Yarning as a Legitimate Method in Indigenous Research*. International Journal of Critical Indigenous Studies, 2010. 3(1): p. 37-50.
136. Rigney, L.I., *Internationalization of an Indigenous Anticolonial Cultural Critique of Research Methodologies: A Guide to Indigenist Research Methodology and Its Principles*. Wicazo sa review, 1999. 14(2): p. 109-121.
137. Vicki, S., Roianne, W., & Kim, U., *Applying Indigenist Research Methodologies in Health Research: Experiences in the Borderlands*. The Australian journal of indigenous education, 2010. 39(Supplementary): p. 1-7.
138. McKenzie, C. & Bandler, L.G., *Aboriginal and Torres Strait Islander health research leadership*. Med J Aust, 2023. 218(2): p. 75-76.
139. Harper, A. & Pratt, B., *Combating neo-Colonialism in Health Research: What can Aboriginal Health Research Ethics and Global Health Research Ethics Teach Each Other?* Journal of empirical research on human research ethics, 2022. 17(4): p. 431-454.
140. Australian Institute of Health and Welfare: Pointer S, *Hospitalised injury in Aboriginal and Torres Strait Islander children and young people: 2011–13*. 2016, Australian Institute of Health and Welfare: Canberra.
141. Mitchell, R.J., Curtis, K., & Foster, K., *A 10-year review of child injury hospitalisations, health outcomes and treatment costs in Australia*. Injury Prevention, 2018. 24(5): p. 344-350.
142. Brownson, R.C., Colditz, G.A. & Proctor, E.K., *Dissemination and implementation research in health: translating science to practice*, O.U. Press, Editor. 2017: New York, NY.
143. Della Bona, M., Crawford, G., Royce, B., Jancey, J., & Leavy, J.E., *Using ERIC to Assess Implementation Science in Drowning Prevention Interventions in High-Income Countries: A*

- Systematic Review*. International journal of environmental research and public health, 2023. 21(1).
144. Balis, L.E., Houghtaling, B., & Harden, S.M., *Using implementation strategies in community settings: an introduction to the Expert Recommendations for Implementing Change (ERIC) compilation and future directions*. Translational Behavioral Medicine, 2022. 12(10): p. 965-978.
 145. Cresswell, K., Williams, R., & Sheikh, A., *Developing and applying a formative evaluation framework for health information technology implementations: Qualitative investigation*. J Med Internet Res, 2020. 22(6): p. e15068-e15068.
 146. Aboriginal Health & Medical Research Council of NSW, *NSW Aboriginal Health Ethics Guidelines: Key Principles*. 2016.
 147. Bainbridge, R., Whiteside, M. & McCalman, J., *Being, Knowing, and Doing: A Phronetic Approach to Constructing Grounded Theory With Aboriginal Australian Partners*. Qual Health Res, 2013. 23(2): p. 275-288.
 148. Massi, L., Weatherall, L., Nielsen, C., Toombs, M., Fredericks, B., & Rae, K. M., *"It's research, our input can grow": identifying health research priorities with Aboriginal and Torres Strait Islander communities—study protocol*. Res Involv Engagem, 2023. 9(1): p. 59-59.
 149. West, R., Stewart, L., Foster, K., & Usher, K., *Through a Critical Lens: Indigenist Research and the Dadirri Method*. Qual Health Res, 2012. 22(11): p. 1582-1590.
 150. Cullen, P., Clapham, K., Hunter, K., Treacy, R., & Ivers, R., *Challenges to driver licensing participation for Aboriginal people in Australia: a systematic review of the literature*. Int J Equity Health, 2016. 15(1): p. 134.
 151. Funnell, S.C. & Rogers, P.J., *Purposeful program theory : effective use of theories of change and logic models*. 1st ed. ed. 2011, San Francisco, CA: Jossey-Bass.
 152. Markwick, A., Ansari, Z., Clinch, D., & McNeil, J., *Perceived racism may partially explain the gap in health between Aboriginal and non-Aboriginal Victorians: A cross-sectional population based study*. SSM Popul Health, 2019. 7: p. 010-010.
 153. Gatwiri, K., Rotumah, D., & Rix, E., *BlackLivesMatter in Healthcare: Racism and Implications for Health Inequity among Aboriginal and Torres Strait Islander Peoples in Australia*. Int J Environ Res Public Health, 2021. 18(9): p. 4399.
 154. Kairuz, C.A., Casanelia, L.M., Bennett-Brook, K., Coombes, J., & Yadav, U.N., *Impact of racism and discrimination on physical and mental health among Aboriginal and Torres Strait islander peoples living in Australia: a systematic scoping review*. BMC public health, 2021. 21(1): p. 1-1302.
 155. Hampton, R. & Toombs, M., *Indigenous Australians and health : the wombat in the room*. 2013, South Melbourne, Victoria: South Melbourne, Victoria : Oxford University Press.
 156. Bodkin-Andrews, G., Martin, K.L., & Walter, M., *Indigenous Children Growing Up Strong : A Longitudinal Study of Aboriginal and Torres Strait Islander Families*. 2017, London: London : Palgrave Macmillan UK.
 157. Pearson, O., Schwartzkopff, K., Dawson, A., Hagger, C., Karagi, A., Davy, C., Brown, A., & Braunack-Mayer, A., *Aboriginal community controlled health organisations address health equity through action on the social determinants of health of Aboriginal and Torres Strait Islander peoples in Australia*. BMC Public Health, 2020. 20(1): p. 1859-1859.
 158. Messiha, K., Chinapaw, M.J.M., Ket, H.C.F.F., An, Q., Anand-Kumar, V., Longworth, G.R., Chastin, S. & Altenburg, T.M., *Systematic Review of Contemporary Theories Used for Co-creation, Co-design and Co-production in Public Health*. Journal of public health (Oxford, England), 2023. 45(3): p. 723-737.
 159. Townsend, A., Macniven, R., Pollard-Wharton, N. Andersen, M., Powell, M., Cairnduff, S. McCausland, R., Corby, C., Clapham, K., Ivers, R., *"They have a really good way of getting it to the kids": evaluation of a child injury prevention program in Walgett, New South Wales, UNSW, Editor*. 2024.

160. Dudgeon, P., Bray, A., Darlaston-Jones, D., Walker, R., *Aboriginal Participatory Action Research: An Indigenous Research Methodology Strengthening Decolonisation and Social and Emotional Wellbeing*. Lowitja Institute Discussion Paper Series. 2020, Australia: The Lowitja Institute. 23.
161. Milat, A.J., et al., *A guide to scaling up population health interventions*. Public Health Research & Practice, 2016. 26.
162. Carroll, S.R., Garba, I., Figueroa-Rodríguez, O.L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J.D., Anderson, J., & Hudson, M., *The CARE principles for indigenous data governance*. Data science journal, 2020. 19.
163. Lovett, R., R. Jones, & B. Maher, *The intersection of Indigenous Data Sovereignty and Closing the Gap policy in Australia*. 2020, Routledge: United Kingdom. p. 36-50.
164. Walter, M., Lovett, R., Maher, B., Williamson, B., Prehn, J., Bodkin-Andrews, G., & Lee, V, *Indigenous Data Sovereignty in the Era of Big Data and Open Data*. The Australian journal of social issues, 2021. 56.
165. Bell, M.P., Berry, D., Leopold, J., & Nkomo, S., *Making Black Lives Matter in academia: A Black feminist call for collective action against anti-blackness in the academy*. Gender, work, and organization, 2021. 28.
166. Falls, T. & Anderson, J., *Attitudes towards Aboriginal and Torres Strait Islander peoples in Australia: a systematic review*. Australian journal of psychology, 2022. 74(1).
167. Povey, R., Trudgett, M., Page, S., & Locke, M.L., *Hidden in plain view: Indigenous early career researchers' experiences and perceptions of racism in Australian universities*. Critical studies in education, 2023. 64: p. 355-373.