Co-creating a Health Navigator model of care to address social determinants of ear health among Aboriginal and Torres Strait Islander children: addressing upstream drivers rather than downstream symptoms

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BCT (AudEng), MClinAud, MPH

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Author Attribution Statement

I am the first author of the published systematic content review featured in Chapter 2.4. The preliminary research activity for this publication was completed by me with the support of two research supervisors during the completion of my Master of Public Health Degree. However, the writing of this manuscript and its subsequent publication occurred during my PhD candidature. This paper formed the basis for my PhD and contributed to the development of the Aboriginal Community Controlled Ear-health Support System (ACCESS). My PhD was embedded in the Aboriginal Community Controlled Ear-health Support System (ACCESS) project and the Study of Environment on Aboriginal Resilience and Child Health (SEARCH). Moreover, the research activities presented throughout this thesis were co-created with ACCESS and SEARCH Aboriginal and Torres Strait Islander community and research partners. Co-created research is considered best practice when working with Aboriginal and Torres Strait Islander communities, with relevant methodologies and supporting evidence described throughout. Lastly, I am the one and only author of this thesis and I am the first author on all papers and publications featured from Chapter 1 to Chapter 5. These publications had co-authors who were ACCESS and SEARCH collaborators. Details about author contributions for each paper can be found within the published manuscripts, if not otherwise stated in each chapter. All publications were supported by community partners and the Aboriginal Health and Medical Research Council of New South Wales.

Jack Alexander DeLacy | **Date:** 30/09/2024

As primary supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Hasantha Gunasekera | **Date:** 01/10/2024

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Abstract

Background: Social determinants contribute to inequities in ear health for Aboriginal and Torres Strait Islander children. Despite this, no evaluated programs identified by this review target these underlying determinants of ear health and hearing. Key determinants of ear health and hearing for Aboriginal and Torres Strait Islander children include living in crowded and poor-quality houses, living in out-of-home care, attending childcare, exposure to tobacco smoke, and access to culturally safe and appropriate care. To date, research has been non-participatory, which has failed to produce meaningful improvements in ear health and hearing for Aboriginal and Torres Strait Islander children. This has prompted calls for strengthening co-created and community-led research. This thesis explores social determinants of ear health and hearing among Aboriginal and Torres Strait Islander children aged six months to 18 years living in metropolitan and regional communities in New South Wales and embeds relevant findings into the co-design and co-implementation of the community-led Aboriginal Community Controlled Ear-health Support System (ACCESS) Child Health Navigator model of care.

Methods: Research activities included ***Chapter 2)*** a literature review and systematic content review exploring the social determinants of otitis media, and Aboriginal and Torres Strait Islander research methodologies to underpin this work, ***Chapter 3)*** Community Yarning circles (i.e., qualitative focus groups), ***Chapter 4)*** quantitative data on otitis media and hearing loss prevalence, and analyses of relationships between otitis media, hearing loss and associated child, family and social factors, and ***Chapter 5)*** a systematic review of Health Navigators supporting Indigenous child and adolescent populations. These studies informed the co-creation of ACCESS and were consolidated into a ***Chapter 6)*** research protocol.

Results: ***Chapter 2)*** The literature and systematic content review revealed key gaps within the literature. Namely, there is overwhelming consensus within the literature that social determinants of health play a key role in driving high prevalence and incidence of otitis media among Aboriginal and Torres Strait Islander children. However, there are no known evaluations published within the literature employing rigorous methodological approaches that target these underlying determinants of health. ***Chapter 3)*** Yarning circles revealed care provided by Aboriginal Community Controlled Health Services were perceived as culturally safe, holistic and well-integrated, whilst mainstream services were largely associated with negative experiences linked to racism, cultural safety, transport and cost barriers, waitlists,

continuity challenges, and poor housing. ***Chapter 4)*** Quantitative data showed ~50% of children younger than 3 years had otitis media, ~30% of the whole cohort had otitis media, and ~25% had hearing loss, with otitis media linked to younger age, childcare, foster care, previous infection, and overcrowding. ***Chapter 5)*** The systematic review provides important recommendations that Health Navigators provide a promising model of culturally safe care, with Health Navigators reported to possess important local knowledge and cultural understanding to effectively address social determinants through holistic approaches, and proactively removing barriers. Furthermore, this review identified key gaps within the literature, namely a lack of data on Indigenous Health Navigators supporting child and adolescent populations, and the need for impact evaluations of Indigenous Health Navigator programs. Importantly, the co-creation activities of ACCESS, as detailed in ***Chapter 6),*** have highlighted the importance of building strong relationships with Aboriginal and Torres Strait Islander communities to ensure community priorities are embedded into programs and therefore, are relevant and sustainable.

Conclusion: Findings underscore the critical importance of ear health and hearing for childhood development, with profound implications for long-term outcomes into adulthood for Aboriginal and Torres Strait Islander children. This work provides a deeper understanding of the social determinants of ear health, particularly the impact of ongoing colonisation, housing and access to care. Importantly, this thesis highlights the pervasive social and cultural barriers faced by Aboriginal and Torres Strait Islander children in accessing healthcare and achieving optimal health outcomes. Therefore, there is an urgent need to address structural racism and discrimination and uphold principles of Aboriginal and Torres Strait Islander self-determination. Using a co-creation framework, with ACCESS as a real-world example, this thesis advocates for Aboriginal and Torres Strait Islander -led research and health approaches that harnesses community voices and values. Furthermore, this work emphasises the potential benefits of Health Navigators in optimising access to local health systems to ensure the provision of culturally safe and relevant care for ear health and overall wellbeing, that addresses unmet social determinants of health for Aboriginal and Torres Strait Islander children and adolescents at risk of ear disease.

Thesis Publications

Papers published in peer-reviewed journals

Chapter 2.3.4: DeLacy J, Dune T, Macdonald JJ. The social determinants of otitis media in Aboriginal children in Australia: are we addressing the primary causes? A systematic content review. BMC Public Health. 2020;20(492):1-9.

This paper was initiated prior to my PhD enrolment (i.e. search and data analysis were completed). However, the reporting of results, completion of the manuscript and publication occurred during my PhD candidature. This work was the foundation for this thesis and contributed to the co-created ACCESS Child Health Navigator model of care.

Chapter 4: DeLacy J, Burgess L, Cutmore M, Sherriff S, Woolfenden S, Falster K, et al. Ear health and hearing in urban Aboriginal children. Aust N Z J Public Health. 2023;47(4):1-11.

Papers submitted for publication or ready for submission

Chapter 3: DeLacy J, Dickson M, Woolfenden S, Rattos S, Hay E, Sperring A, et al. (2024). Hearing what Community has to say: informing a co-created approach to improve ear health and hearing among Aboriginal and Torres Strait Islander children. *Ready for submission to BMC Public Health*

Chapter 5: DeLacy J, Cutmore M, Dickson M, Woolfenden S, Rattos S, Rowley C, et al. (2024). Health Navigators supporting Indigenous children and adolescents: a systematic review. *Submitted to PLOSONE*

Chapter 6: DeLacy J, Woolfenden S, Sherwood J, Wright D, Newman J, Bailey S, et al. (2024). Aboriginal Community Controlled Ear-health Support System (ACCESS): Study protocol for a co-created model of care. *Ready for submission to BMJ Open*

Papers, Reviews, Grants, Presentations and Awards arising during candidature

Published Papers

Chando S, Tong A, Howell M, Dickson M, Craig J, **DeLacy J,** Eades S, Howard K. (2021). Stakeholder perspectives on the implementation and impact of Indigenous health interventions: A systematic review of qualitative studies. Health Expect. 2021;24:731-743.

Submitted Papers

James R, Machell A, **DeLacy J,** Stephens J. (2024). Longitudinal outcomes of otitis media and hearing loss in childhood: a systematic review. *Submitted to BMJ Open*

Machell A, Callahan L, Northcott C, Poirier BF, **DeLacy J,** Stephens JH. (2024) The accuracy of otoacoustic emissions to diagnose otitis media in children: A systematic review of diagnostic test accuracy. *Submitted to the International Journal of Audiology*

Peer Reviews

April 2024: Risk factors for parent-reported otitis media in 12-month-old infants. International Journal of Audiology.

October 2023: Identifying barriers and facilitators for the effective diagnosis and provision of primary health care for otitis media from the perspective of carers of Aboriginal children. Journal of Paediatrics and Child Health.

October 2022: Assessing housing exposures and interventions that impact health cities: A systematic overview of reviews. Perspectives in Public Health.

May 2022: Environmental factors for hearing loss and middle ear disease in Alaska Native children and adolescents: A cross-sectional analysis from a cluster randomised trial. Ear and Hearing.

July 2021: Early detection of Hearing Loss for Infants in Western Australia: Comparison to International Benchmarks. Journal of Paediatrics and Child Health.

Grants

Associate Investigator (2022): Pathways for Aboriginal & Torres Strait Islander Hearing Health: The Pathway Project. National Health and Medical Research Council, Targeted Call into Hearing Health 2021. (NHMRC #2015793; $1,150,000)

Associate Investigator (2020): Aboriginal Community Controlled Ear-health Support System (ACCESS). National Health and Medical Research Council, Medical Research Future Fund Indigenous Health Research Grant Opportunity. (MRFF #1211077; $887,186)

Presentations

August 2024: "The social determinants of ear health in Aboriginal and Torres Strait Islander children: addressing upstream drivers rather than downstream symptoms" (PhD project) - Abstract presentation at the Australian Otitis Media Conference (OMOZ)

September 2023: "The social determinants of ear health in Aboriginal and Torres Strait Islander children: addressing upstream drivers rather than downstream symptoms" (PhD project) - presented to the Poche Centre for Indigenous Health (the University of Sydney) Advisory Committee

April 2023: "Early Childhood Group projects connected with the Study of Aboriginal Resilience and Child Health" - presented to ACI Paediatric Network Clinical Nurse Consultant Expert Advisory Group (Co-presented with Professor Hasantha Gunasekera)

April 2022: "Ear health and hearing in urban Aboriginal children" - Abstract presentation for the Academy of Child & Adolescent Health Conference 2022 (**Higher Degree Research Presentation Prize winner - $500 AUD**)

September 2021: "The social determinants of otitis media in Aboriginal and Torres Strait Islander children: are we addressing the primary causes?" - Abstract presentation for the Australian National Otitis Media Conference (OMOZ)

September 2021: "Yarning and Aboriginal and Torres Strait Islander research methods for ear health in Australia" - presented to the International Association of Communication Sciences and Disorders for the International Day of the World's Indigenous People (Invited speaker)

May 2020: "The social determinants of health within the context of Aboriginal and Torres Strait Islander Children" (Guest Lecture) - presented for the Graduate Diploma of Indigenous Health Promotion, The University of Sydney.

May 2019: "The social determinants of ear health in Aboriginal and Torres Strait Islander children: addressing upstream drivers rather than downstream symptoms" (PhD project) - presented to the Centre for Kidney Research, Aboriginal Health Research Group at Westmead Children's Hospital.

June 2019: "Access to ear, nose and throat services for Aboriginal children" - presented to the Centre for Kidney Research at Westmead Children's Hospital.

October 2019: "Aboriginal community perspectives about ear health project overview" - presented to the Centre for Kidney Research, Aboriginal Health Research Group at Westmead Children's Hospital.

October 2019: "The social determinants of ear health in Aboriginal children: addressing upstream drivers rather than downstream symptoms" - presented to the Centre for Kidney Research at Westmead Children's Hospital.

December 2019: Study of Environment on Aboriginal Resilience and Child Health progress 2019" - presented to Centre for Kidney Research at Westmead Children's Hospital.

December 2019: "The social determinants of ear health in Aboriginal children: addressing upstream drivers rather than downstream symptoms" - presented to Master of Public Health & Indigenous Health students from the University of Toronto.

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Terminology

Aboriginal	Refers to the first inhabitants of Australia, encompassing diverse groups with distinct cultures, languages, and histories. Aboriginal peoples are recognised as the original custodians of the land, with unique social and spiritual connections to their traditional territories. *Partnering communities directing this research have a general preference for the term "Aboriginal". However, we recognise that this may not capture all groups and people from across Australia, including those that may identify as Torres Strait Islander or other group, who are living or receiving care in the partnering communities involved in this work.*
Aboriginal and Torres Strait Islander	Aboriginal and Torres Strait Islander peoples are the original inhabitants of Australia, with distinct cultures, languages, and traditions, representing diverse communities across the continent and its islands. *Aboriginal and Torres Strait Islander is primarily used throughout this thesis in the context of Australia, with the use of this term following advice of cultural advisors to be more inclusive and respectful of the various people, communities, and cultures, some of whom may not identify specifically with the terms "First Nations", "Aboriginal", "Torres Strait Islander", "Indigenous" or other terms for First peoples in Australia.*
Auditory Processing	Auditory processing refers to how the brain interprets and makes sense of sounds that are heard.
Colonisation	Colonisation is a process where one group of people establishes control over another group or territory, often

	involving economic, political, social, and cultural disruption and oppression.
Co-creation	Co-creation is a collaborative process where stakeholders work together to design, implement, evaluate and translate, whilst integrating their diverse perspectives, expertise, and experiences.
Co-design	Co-creation is a collaborative process where stakeholders work together to plan work to be carried out. In the context of research, this involves stakeholders working together to plan future research activities.
Co-production	Co-production is a collaborative process of making or creating something. In the context of research, this typically refers to research implementation or carrying out the research activities decided in the co-design phase.
Ear Disease	Ear disease refers to any disease or disorder that affect the human ear and hearing.
Indigenous or Indigenous Peoples	Indigenous Peoples are custodians and practitioners of unique cultures and ways of relating to people and the environment. They possess social, cultural, economic, and political characteristics that are distinct from those of the dominant societies in which they live. *The above definition is from the World Health Organisation and is used throughout this thesis as an all-encompassing term to refer to Indigenous and First Nations groups internationally. We recognise that there is no generally accepted term that captures the strength and diversity of all groups, with the use of the term "Indigenous" utilised with respect for the disparate, distinct and unique cultures and communities discussed.*

Health Navigator	A health navigator is a professional who assists individuals or communities in navigating the complexities of the healthcare system, providing guidance, advocacy, and support to access appropriate healthcare services and resources.
Hearing Impairment	Hearing impairment defined as bilateral hearing loss and categorised by the audiometric result in the better ear as ≤ 20dB. *Defined by the 2020 Otitis Media Guidelines for Aboriginal and Torres Strait Islander children.*
Hearing Loss	Hearing loss defined as three frequency average (3FAHL 0.5, 1 & 2kHz) ≤ 20dB. *Defined by the 2020 Otitis Media Guidelines for Aboriginal and Torres Strait Islander children.*
Holistic Care	Holistic care is healthcare that considers the whole person, including the physical, mental, emotional, social, and spiritual aspects to promote overall wellbeing and address health issues by integrating various complementary and alternative therapies alongside conventional medical treatments.
Integrated Models of Care	Integrated models of care involve coordinated collaboration among healthcare providers from different disciplines and settings to deliver comprehensive and seamless healthcare services that address the diverse needs of patients across the continuum of care.
Mainstream Health Service	Mainstream health services refer to standard medical and healthcare services provided by hospitals, clinics, and healthcare professionals that follow conventional practices and exist outside of Aboriginal Community Controlled Health settings.

Mob	A group of people with a shared connection to place or country, and can refer to a family group, clan group or wider community group.
Non-remote	Refers to urban and regional areas in Australia that are not classified as remote or very remote. These areas typically have greater access to healthcare services, infrastructure, and resources compared to remote regions.
Otitis Media	Otitis media is an inflammation or infection of the middle ear, commonly characterised by symptoms such as ear pain, fluid buildup behind the eardrum, and associated hearing loss.
Social Determinants of Health	The social determinants of health are the economic, social, cultural, historical, political and environmental factors that influence health outcomes and access to health services.
Speech-Language	Speech-language refers to both speech and language. Speech refers to the verbal expression of language through the production of sounds using the vocal apparatus, while language encompasses a system of symbols and rules used for communication, including speech, writing, and gestures.
Stolen Generations	The Stolen Generation refers to the policies and practices in Australia that forcibly removed Aboriginal and Torres Strait Islander children from their families and communities, aiming to assimilate them into non-Aboriginal and Torres Strait Islander cultures and society.
Urban	Pertains to cities and large towns in Australia, characterised by higher population density, developed infrastructure, and greater access to services and amenities compared to rural or remote areas.
Yarn and Yarning	Yarning is an Aboriginal and Torres Strait Islander term that refers to a culturally sensitive and informal process of

	storytelling, sharing knowledge, and engaging in meaningful conversation, often involving deep listening and mutual respect.

List of Tables and Figures

List of Abbreviations

ABS	Australian Bureau of Statistics
ACCESS	Aboriginal Community Controlled Ear-health Support System
ACCHS	Aboriginal Community Controlled Health Service
AHMRC	Aboriginal Health and Medical Research Council
AIHW	Australian Institute of Health and Welfare
AOM	Acute Otitis Media
AOMwiP	Acute Otitis Media with Perforation
AOMwoP	Acute Otitis Media without Perforation
CFIR	Consolidated Framework for Implementation Research
CONSIDER	CONSolIDated critERia for strengthening reporting of health research involving Indigenous peoples: CONSIDER Statement
CRIAH	Coalition for Research to Improve Aboriginal Health
CSOM	Chronic Suppurative Otitis Media
DP	Dry Perforation
ED	Ear Disease
ENT	Ear, Nose and Throat
HAPEE	The Hearing Assessment Program Early Ears
HATS	Hearing and Talking Scale
HEALS	Hearing EAr-health Language and Speech services
HEAR	Hearing Education Application Research
HfLI	The Hearing for Learning Initiative
HI	Hearing Impairment

HL	Hearing Loss
MMAT	Mixed Methods Appraisal Tool
NACCHO	National Aboriginal Community Controlled Health Organisation
NHMRC	National Health and Medical Research Council
OM	Otitis Media
OME	Otitis Media with Effusion
PedsQL	Paediatric Quality of Life Inventory
pOME	Persistent Otitis Media with Effusion
PLUM	Parent-evaluated Listening and Understanding Measure
rAOM	Recurrent Acute Otitis Media
SEARCH	Study of Environment on Aboriginal Resilience and Child Health
TTO	Tympanostomy Tube Otorrhoea

Ethics

All chapters of this thesis featuring published papers and data collection have received ethics approval from the Aboriginal Health and Medical Research Council, the peak ethics body for Aboriginal and Torres Strait Islander research in New South Wales. The relevant chapters include detailed information regarding specific ethical approvals obtained.

Aboriginal and Torres Strait Islander, and Indigenous Terminology

Terminology used to describe Aboriginal and Torres Strait Islander, and Indigenous populations varies throughout this thesis. When referring to populations and people within the context of Australia, *"Aboriginal and Torres Strait Islander is used"*. This was determined as most appropriate upon advice from senior Aboriginal and Torres Strait Islander research supervisors and cultural advisors involved in this work. However, a broader term is required when referring to populations globally. Within the global context, the term *"Indigenous"* is used to capture the diverse groups from around the world. We recognise that there is generally no accepted term for all populations, and these terms have been used within this thesis with careful consideration and respect, whilst acknowledging the diversity of population groups across Australian and global settings.

CHAPTER 1: INTRODUCTION

1.1 Chapter 1 overview

This chapter will:

1. Present a real account of the potentially tragic consequences of life-long experiences of ear disease within inequitable and broken systems that are underpinned by ongoing colonisation which were the motivation for this work;
2. Provide an overview of this thesis including a description of the primary research aims;
3. Describe studies that underpin this thesis; and
4. Provide an overview of the thesis structure.

1.2 Mootijah's story

This thesis is dedicated to Douglas 'Mootijah' Shillingsworth, a Budjiti and Murrawarri man. Mootijah means "strong one" or "warrior" in Murrawarri language. Murrawarri are Aboriginal and Torres Strait Islanders people who, for millennia, have cared for lands that stretch from Northern New South Wales to South-Eastern Queensland. Mootijah died on 15th February 2018 at the age of 44 years from a Left Temporal Lobe Abscess. The origin of this abscess was an ear infection in Mootijah's left ear that was untreated while he was in the custody of Corrective Services New South Wales.[1]

The following family impact statements were retrieved from the State Coroner's Court of New South Wales inquest into Mootijah's death[1]:

"Although there will be no justice, we sincerely hope that his death in custody will bring about change. His death has left his family devastated to the core in all forms of incapacity." - *Aunty Ruby Dykes (Mootijah's cousin)*

"More so from the disbelief and awe-inspiring questions that haunt us when we think of Mootijah. when we see his totem, his moiety, when we listen to, or tell Mootijah's stories, and hear his song breeze, we will look at his photo and not get any answers but a great sense of numbness, shock and loss. Mootijah was a son, he was a brother, he was a father, he was a nephew and a cousin." - *Aunty Ruby Dykes*

Sadly, Mootijah reportedly experienced recurrent middle ear infections throughout his life resulting in hearing impairment. However, he did not receive adequate care[1] and this likely impacted his education, social and emotional wellbeing and limited his opportunity to thrive

into adulthood.[2, 3] Importantly, there are known links between ear disease and contact with the justice system.[4] Moreover, Aboriginal and Torres Strait Islander children in Australia experience ear disease at an earlier age and more often, with data showing ear disease as early as the first month of life.[5] Left untreated, ear disease and associated hearing loss can have devastating consequences across the life-course.[3, 4] Despite this, it is important to highlight that it was not ear disease alone that led to Mootijah's death. Rather, Mootijah's death is underpinned by inequitable and broken systems that are reinforced by ongoing colonisation.[6-8] This work is in memory of Mootijah and aims to advocate for all children, Aboriginal and Torres Strait Islander or otherwise, to receive the care they need to live a healthy life, and to thrive.

This section was reviewed and endorsed by Aunty Ruby Dykes, Mootijahs cousin who provided the family impact statements cited above.

1.3 Research aims and rationale

1.3.1 Thesis

Aim 1: To **a)** identify social determinants of ear health and hearing among Aboriginal and Torres Strait Islander children aged six months to 18 years living in metropolitan and regional communities in New South Wales and **b)** embed relevant findings into the co-design and co-implementation of a community-led model of care that targets the underlying determinants of ear health.

Overview: This thesis reports the methods and findings of qualitative and quantitative studies focussed on ear health, hearing and associated social determinants of health. Furthermore, existing literature was systematically searched, collated, analysed and reported to support findings from these qualitative and quantitative studies. These findings have been embedded into a community-led model of care called the Aboriginal Community Controlled Ear-health Support System (ACCESS) focussed on supporting families with children experiencing or at risk of ear disease.

Rationale: Social determinants of health contribute to the existing inequities in ear health and hearing among Aboriginal and Torres Strait Islande children. However, little is known about how to effectively address these factors, with most evaluated models of care are targeted toward biomedical factors. There is a need to better understand the relationship between ear health and social determinants and to develop improved culturally safe and holistic models of

care that target underlying determinants of ear health and hearing.

1.3.2 Hearing what Community has to say: informing a co-created approach to ear health and hearing among Aboriginal and Torres Strait Islander children (Chapter 3)

Aim 2: To capture and report community perspectives about ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales.

Overview: This chapter reports perspectives of community members living in three communities in non-remote New South Wales about ear health and hearing among children living in their communities. Perspectives were captured via Yarning circles (i.e., semi-structured focus groups using Aboriginal and Torres Strait Islander research methodologies) that were conducted at two metropolitan and one large regional Aboriginal Community Controlled Health Services in New South Wales. Participants included mostly Aboriginal and Torres Strait Islander and some non-Aboriginal people with connections to the participating services. Participants included Elders, parents, educators, early childhood workers, executive staff, and health workers. The Yarning circles were recorded, transcribed verbatim and analysed using thematic analysis. A framework methodology was used to map themes onto a social and cultural determinants of health framework.

Rationale: Co-creation is essential for effective Aboriginal and Torres Strait Islander research, ensuring the voices, knowledge, and experiences of the community are central to the research process. By engaging directly with Aboriginal and Torres Strait Islander communities through Yarning circles, this project aims to gather valuable insights and foster genuine partnerships. This approach will enhance the cultural relevance and appropriateness of ACCESS and empower the collaborating communities by involving them as active contributors in the co-design and co-implementation of healthcare solutions that directly affect them.

1.3.3 Ear health and hearing in urban Aboriginal children (Chapter 4)

Aim 3: To **a)** report ear health and hearing outcomes among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales, and **b)** to identify associations between otitis media, hearing loss, and child, family and social factors.

Overview: Data analysis was undertaken using baseline questionnaire data and ear health

examinations. Data were collected from 1,430 children aged six months to 18 years with otitis media diagnoses attending Aboriginal Community Controlled Health Services, and who were enrolled in the Study of Environment on Aboriginal Resilience and Child Health (SEARCH) (See ***Chapter 1.4***). Ear health outcomes were otitis media and hearing loss. Prevalence of otitis media and hearing loss, and relationships between otitis media, hearing loss, and associated child family and social factors are presented in this chapter.

Rationale: By identifying and reporting these associations, this paper provides a detailed understanding of the extent and impact of ear health issues within these communities and the associated risk factors. This quantitative approach compliments the community perspectives from the Yarning circles reported in ***Chapter 3*** and offers a comprehensive overview of the factors influencing ear health and areas for targeted intervention to be embedded into ACCESS.

1.3.4 A systematic review of Health Navigators supporting Indigenous children and adolescents: a meta-narrative synthesis (Chapter 5)

Aim 4: Systematically search and synthesise peer reviewed literature to identify key considerations for implementation of Health Navigators supporting Indigenous children and adolescents. This review will report the role and scope of Health Navigators on health outcomes and service use. Furthermore, this review aims to build upon existing recommendations to guide the design, implementation and evaluation of Health Navigation-focussed models of care supporting Indigenous children and adolescents.

Overview: This chapter provides a detailed synthesis of literature describing peer-reviewed studies evaluating models of care involving a health navigator or equivalent role supporting Indigenous young people. Data were from Australia, Canada and the United States of America. This paper reports key findings, recommendations, and research gaps, and informs an adapted model of Indigenous health navigation and care integration to guide the co-creation of navigation models of care within Indigenous populations. This adapted model will be used to support the ongoing co-creation of ACCESS, and findings could be extrapolated to other settings with Indigenous populations.

Rationale: There is recognition that modes of care like health navigators are potentially beneficial in addressing underlying social determinants of health. Given the overarching focus of this thesis is to explore the social determinants of ear health, this is an important avenue of

inquiry. By synthesising evidence on the effectiveness of health navigators, this work aims to inform the co-design and co-implementation of the ACCESS Child Health Navigator model, ensuring that it is grounded in best practices and tailored to the specific needs of Indigenous communities.

1.3.5 Aboriginal Community Controlled Ear-health Support System (ACCESS): study protocol for a co-created model of care (Chapter 6)

Aim 5: To accurately and systematically describe the research activities involved in the co-creation of ACCESS, with particular focus on the development and implementation of the Child Health Navigator model of care.

Overview: This chapter consists of a published protocol that includes the research activities for this PhD project. This chapter reports the methodological approach for the co-creation of the ACCESS project, including the Yarning circles detailed in ***Chapter 3***. This thesis focusses on 'Stream 1 Co-design' and 'Stream 2 Co-implementation', with Streams 3 (Co-evaluation and Stream 4 (Population-level surveillance) auxiliary to this work, and yet to occur as of the date of thesis submission (September 2024).

Rationale: The purpose of publishing the research protocol for ACCESS is to provide a comprehensive framework and detailed methodology for the project, ensuring transparency, reproducibility, and rigor in the research approach. The protocol outlines the collaborative and community-led strategies employed in the project, highlighting the significance of cultural safety and community engagement in enhancing ear health outcomes for Aboriginal and Torres Strait Islander children.

1.4 Studies underpinning thesis

1.4.1 Study of Environment on Aboriginal Resilience and Child Health - SEARCH

The Study of Environment on Aboriginal Resilience and Child Health (SEARCH) was a cohort study of Aboriginal and Torres Strait Islander children, living in urban and large regional communities in New South Wales, Australia.[9] SEARCH focused on Aboriginal and Torres Strait Islander community identified health priorities, with ear health and hearing an identified priority for all community partner sites.[9] This PhD project was initiated in collaboration with SEARCH researchers and community partners to build upon pre-existing and ongoing work in ear health and hearing.

1.4.1.1 Overview

For decades, health research within Aboriginal and Torres Strait Islander populations in Australia has been problematic, non-participatory and exploitative.[9-13] Importantly, Aboriginal and Torres Strait Islander Elders, communities and researchers have identified participatory and co-created research as necessary approaches to achieve meaningful improvements to existing health and social inequities.[9-13] Co-creation and participatory research approaches are collaborative methods of working that involve collectively planning, implementing, evaluating and translating research activities (a detailed explanation of co-creation and participatory action research is provided in Chapter 2.5).[10-13]

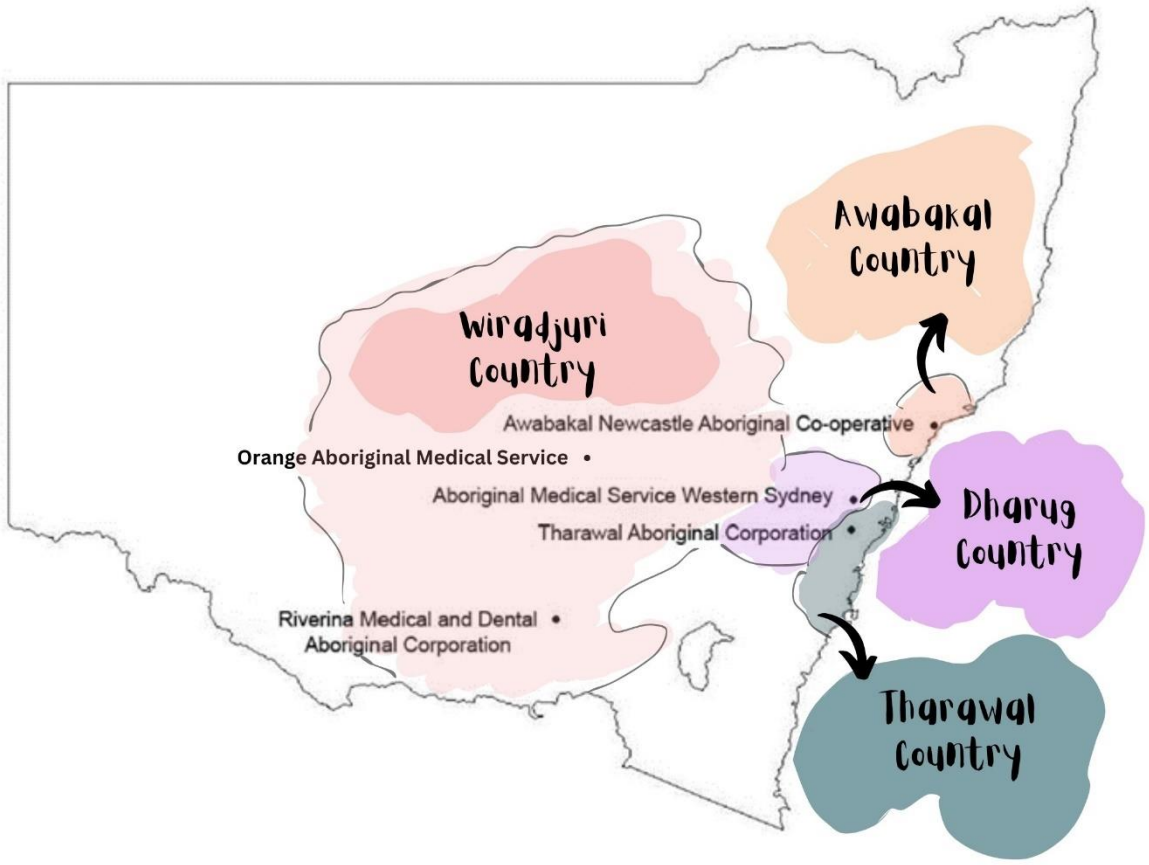
In response to calls for better research approaches within Aboriginal and Torres Strait Islander communities, the Coalition for Research to Improve Aboriginal Health (CRIAH) was established in 2004 in partnership with the Aboriginal Health and Medical Research Council (AHMRC) and the Sax Insitute.[9] CRIAH identified the need to develop longitudinal research centred on Aboriginal and Torres Strait Islander holistic perspectives of health and wellbeing, and research that focuses on children and families. Furthermore, the Coalition identified the need to account for social determinants of health and their impact on social and emotional wellbeing.[9] Lastly, priority health areas that were noted as crucial, were ear health and housing.[9] Consequently, SEARCH was the first major research program established by CRIAH, which was founded upon these underlying principles. SEARCH built on the partnerships established between Aboriginal Community Controlled Health Services, the Aboriginal Health and Medical Research Council of New South Wales (AHMRC), tertiary institutions, researchers and the Sax Institute.[14]

1.4.1.2 Setting

SEARCH community partners are located in urban and large regional centres in New South Wales: Aboriginal Medical Service Western Sydney located in Mount Druitt; Tharawal Aboriginal Corporation, located in Campbelltown; Riverina Medical and Dental Aboriginal Corporation, located in Wagga Wagga; and Awabakal Newcastle Aboriginal Cooperative, located in Newcastle (see Figure 1.1).[9] The focus on non-remote populations was largely driven by the scant health information about urban Aboriginal and Torres Strait Islander populations, with health research in recent decades largely focussed on rural and remote populations where health disparities between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander people are largest.[9, 14-19] Despite the importance of

improving health outcomes within remote populations, most (roughly 76%) Aboriginal and Torres Strait Islander people in Australia live in non-remote areas[14-19], with burden of disease in non-remote populations accounting for the majority[19] of the health gap between Aboriginal and Torres Strait Islander and non-Aboriginal people in Australia.[20, 21] The scant evidence among non-remote populations has serious implications for the provision of health services and is a major barrier for addressing gaps in health outcomes and life-expectancy between Aboriginal and Torres Strait Islander and non-Aboriginal people in Australia.[9, 20]

Figure 1.1: Study of Environment on Aboriginal and Child Health (SEARCH) Community partner locations[9]



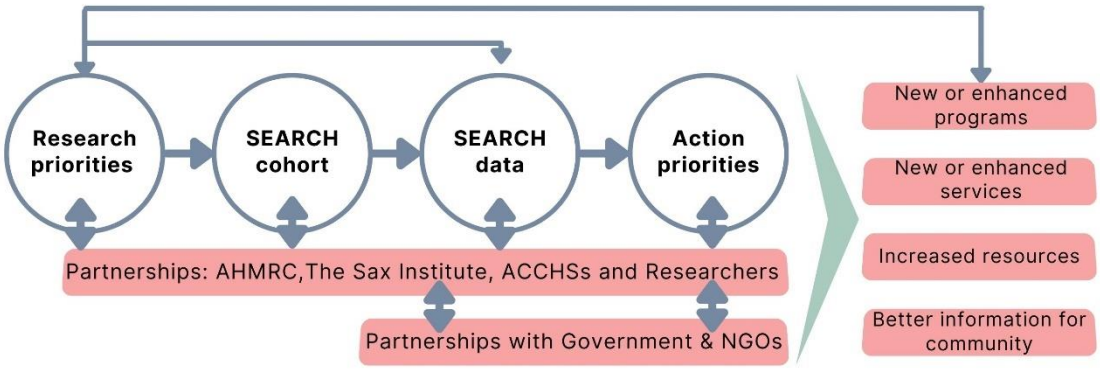
It has been reported that the limited evidence base in non-remote Aboriginal and Torres Strait Islander populations in Australia is due to the lack of clear geographical borders to identify non-remote Aboriginal and Torres Strait Islander communities, making it difficult to target and access non-remote populations for research. However, Aboriginal Community Controlled Health Services are recognised as effectively engaging with non-remote Aboriginal and Torres Strait Islander communities, with this 'invisibility' stemming from a mainstream racism that ignores key elements required to engage with Aboriginal and Torres Strait Islander

communities.[22] Namely, a lack of Aboriginal and Torres Strait Islander involvement in outreach and the perception that diversity is a barrier to engagement.[22] Furthermore, lack of emphasis on addressing the health gap of non-remote populations may be due to the perception that they are less vulnerable than remote populations.[22] This is despite the fact that most of the overall health gap between Aboriginal and Torres Strait Islander and non-Aboriginal Australians stems from non-remote populations.[20] Lastly, many studies that include non-remote Aboriginal and Torres Strait Islander populations in Australia do not specify or distinguish between non-remote and remote areas, making it difficult to apply research findings to policy development, service provision and future research design targeted at non-remote populations.[16, 19, 20]

1.4.1.3 Success and longevity

Importantly, SEARCH has demonstrated the importance of strong continued relationships between researchers and communities to enable meaningful improvements in health outcomes, and to enhance community-led research for partnering communities.[14] Robust governance and formal memorandums of understandings established at the beginning of SEARCH helped to facilitate these relationships and are, in part, credited to SEARCH's success and longevity.[14] Moreover, since it's initiation, the SEARCH model has iteratively improved it's approaches to research and community engagement to what we see today (Figure 1.2)[14]

Figure 1.2: Study of Environment on Aboriginal and Child Health Action Model[14]



1.4.1.4 SEARCH Data

Baseline questionnaire: a baseline questionnaire informed by the Western Australian Aboriginal Child Health Survey[23] was implemented to collect information from participating families and collected data on demographic, social, lifestyle and health-related factors.[11] Separate baseline questionnaires used for children aged zero to three years and four to 17 years. Additionally, there was a self-completed questionnaire for participants aged between 12 and 17 years.[9] ***Clinical measures:*** clinical measures collected included weight, height, waist circumference and blood pressure. ***Audiology measures:*** audiological measures included age-appropriate audiometry, tympanometry and video otoscopy/pneumatic otoscopy.[9] ***Speech, language and development measures:*** speech and language assessment included age-standardised speech pathology and language tests.[9] Screening for childhood developmental delay (for participants younger than eight years) was through the Parent Evaluated Developmental Status (PEDS) Questionnaire.[9] ***Data linkage:*** linked data collection will include information on emergency presentations, emergency presentations, deaths and other health and health service use data.[9]

Importantly, ear health was a research priority from the inception of SEARCH, as Aboriginal and Torres Strait Islander communities understood its importance and impact on education and life-course trajectories. The SEARCH community partnerships worked to prevent and address the adverse outcomes of ear disease through a program of translational research resulting in innovative service models that met the need of their communities. Early support is critical for a comprehensive strategy for healthy life-course trajectories. Aboriginal Community Controlled Health Service are essential in providing this support, given their connection to community and strong integrated services that are underpinned by Aboriginal and Torres Strait Islander concepts of health and wellbeing. As a result, SEARCH enabled the development of two key programs aimed at supporting ear health and hearing for children in partnering communities: the Hearing, EAr health Language and Speech services (HEALS) service delivery program and the Aboriginal Community Controlled Ear-health Support System (ACCESS) research program.

1.4.2 Hearing EAr health Language and Speech services - HEALS

HEALS was established in 2013 as a community-initiated project funded by New South Wales Health as a direct result of the initial ear health research findings from SEARCH. HEALS is a model of care focussed on improving access to culturally safe and community-

led clinical services for ear health, speech and language.[24] HEALS operates/has operated in the same partnering communities as SEARCH and ACCESS as well as Illawarra and the Aboriginal Health Service at La Perouse. HEALS is focussed on augmented clinical care, while ACCESS operates adjacent to HEALS and focusses on supporting families navigate the health system and address related social determinants of ear health.

1.4.2.1 Overview

HEALS is an ongoing clinical service delivery program operating since 2013. HEALS arose from ongoing community consultation through SEARCH, and preliminary data that showed a high burden of ear disease within the SEARCH cohort.[24] The community-identified objectives of HEALS were to provide free-to-patient/family Ear, Nose and Throat, Audiology, and Speech-Language services to Aboriginal and Torres Strait Islander children in New South Wales, whether or not they were enrolled in SEARCH. HEALS was run in partnership with SEARCH Aboriginal Community Controlled Health Services as this was logistically easier in the short time frames but additional non-SEARCH participating services were added when funding was available for this in subsequent years. [24] In 2013, in response to SEARCH data and community priorities, New South Wales Health Ministry of Health pledged funding ($950,000) for HEALS. Between 2013 and 2017, HEALS was funded by the New South Wales Ministry of Health through non-recurrent annual funding ($3.1 million). Between 2017 and 2025, HEALS was funded by a private donor ($1.4 million).

1.4.2.2 Setting

HEALS partner sites included Awabakal Newcastle Aboriginal Cooperative, Tharawal Aboriginal Corporation, Riverina Medical and Dental Corporation, Aboriginal Medical Service Western Sydney, Illawarra Aboriginal Medical Service, Orange Aboriginal Medical Service, and La Perouse Health Service. Memorandums of Understanding were initiated between the Sydney Children's Hospitals Network and the community partner sites. These Memorandums of Understanding were established to identify service needs and priorities. Funding was used to employ local Aboriginal and Torres Strait Islander Project officers who helped to identify lists of children who required HEALS support and arranged appointments and surgeries with local Ear, Nose and Throat surgeons and hospitals. In 2021 the Memorandums of Understanding were converted to Service Level Agreements.

1.4.2.3 Service delivery and outputs

To date, HEALS has delivered the following:

- ~8000 speech-language pathology sessions
- ~364 Ear, Nose and Throat operations
- Shortened waitlists for Ear, Nose and Throat surgery (i.e. children removed from public waitlists)
- Provision of Ear, Nose and Throat, audiology and speech-language resources for all Aboriginal Community Controlled Health Services
- Provision of sound-proof rooms to three Aboriginal Community Controlled Health Services (Tharawal Aboriginal Corporation, Riverina Medical and Dental Aboriginal Corporation and Orange Aboriginal Medical Service)
- Funding of HEALS project officers (at all participating sites annually other than La Perouse, which was managed through Sydney Children's Hospitals Network)
- Improved partnerships between Local Health Districts, local service providers and Aboriginal Community Controlled Health Services
- Improved awareness of ear health and hearing, speech and language and associated early childhood development.

1.4.2.4 Success and longevity

HEALS has illustrated that health services can become more accessible to Aboriginal and Torres Strait Islander families and improve clinical care by leveraging existing research relationships. This initiative serves as an exemplar of how strong partnerships between service providers, researchers, and Aboriginal and Torres Strait Islander communities can facilitate delivery of best-practice health services for Aboriginal and Torres Strait Islander families and children. HEALS reinforced and expanded clinical networks, creating avenues for introducing novel health services through new and established partnerships. HEALS improved access by offering timely, culturally sensitive healthcare without cost, promoted health awareness, and provided flexible and strategic services. This work contributed to New South Wales Health including Aboriginal Ear, Nose and Throat surgery numbers as one of the new Key Performance Indicators for Local Health District funding contracts and was continued through a donation to 2025.

1.4.3 Aboriginal Community Controlled Ear-health Support System – ACCESS

The Aboriginal Community Controlled Ear-health Support System (ACCESS) emerged from community consultations with SEARCH partnering communities over two decades and builds upon the ongoing work of SEARCH and HEALS. ACCESS and the Child Health Navigator model of care was identified as necessary to improve support for families, address underlying social determinants of ear health, better navigate referral pathways, and address systematic inequities in access to mainstream health services. The co-creation of ACCESS is the central focus of this thesis and is described in detail in the ACCESS research protocol ***(Chapter 6)***. Furthermore, all other chapters describe relevant research activities that have informed the continuing co-creation of the ACCESS project. In this section, we provide an introduction and overview of ACCESS.

1.4.3.1 Overview

ACCESS was established to identify key knowledge and service gaps and to address how to enhance access to ear health and hearing services by supporting Aboriginal and Torres Strait Islander families navigate the complex, fragmented and often culturally unsafe health system.[25, 26] Access to care has been shown to improve when children and their families are supported by navigators to facilitate culturally safe and holistic care, communication, support appointments, and address family priorities.[27] Internationally, Health Navigators have been shown to support children presenting to routine health care by improving access and addressing underlying social determinants of health. Health navigators have been shown to increase parental satisfaction, reduced avoidable hospitalisations, lower associated healthcare costs and improved child health.[27-31] However, data on navigation for Aboriginal and Torres Strait Islander and Indigenous children are lacking.

ACCESS is a National Health and Medical Research Council (AHMRC) Medical Research Future Fund (MRFF) funded project that commenced in early 2022 with three partnering Aboriginal Community Controlled Health Services with pre-existing relationships with HEALS and SEARCH. The three sites are located in New South Wales and included Orange Aboriginal Medical Service, Tharawal Aboriginal Corporation and Riverina Medical and Dental Corporation. The primary focus of ACCESS was the co-design, co-implementation and co-evaluation of a Child Health Navigator model of care. The Child Health Navigator is a local Aboriginal and Torres Strait Islander community member supporting families to navigate health pathways, translate knowledge, provide cultural support and improve

connections between local services.

In addition to the Child Health Navigator model, ACCESS consists of four ongoing research streams underpinned by Aboriginal and Torres Strait Islander concepts of co-created research, in part informed by ongoing SEARCH research collaborations. The four streams of ACCESS are 'Stream 1 Co-Design', Stream 2 'Co-Implementation', Stream 3 'Co-Evaluation' and Stream 4 'Population-level Surveillance' and are described below.

1.4.3.2 Stream 1 Co-design

This stream is centred on ongoing community consultation to ensure ACCESS is participatory and community led. This stream harnessed community perspectives around ear health and hearing and identified opportunities for the Child Health Navigator to provide support to families attending partnering Aboriginal Community Controlled Health Services. To capture community perspectives, a series of Yarning circles were held at the partnering sites. Participants included health workers, parents, caregivers, teachers, educators and Elders. Themes identified from these Yarning circles were used to help inform priorities and opportunities for the Child Health Navigators. This community engagement and consultation will continue across the life of ACCESS and ensures that all research activities are community-directed. The research activities for this stream are described in the ACCESS research protocol ***Chapter 6***, and in greater detail in the Yarning study described in ***Chapter 3***.

1.4.3.3 Stream 2 Co-implementation

The ACCESS team and Aboriginal Community Controlled Health Service partners will use key findings from Stream 1 Co-design to refine key components of the Child Health Navigator Model of care using a theory of change framework (shown in ***Chapter 6***). The adapted theory of change model and final ACCESS model of care will then be reviewed with the Aboriginal Community Controlled Health Services, community members, children, and their families before being adopted. The Consolidated Framework for Implementation Research (CFIR)[32] will be used as the initial framework in this stream, but the final implementation evaluation will be through co-creation with Aboriginal and Torres Strait Islander researchers and community to ensure community-driven outcomes are assessed. CFIR is a framework for assessing context in terms of existing or potential barriers and facilitators to successful implementation. Lastly, individual and service-level data will be captured by the Child Health

Navigators and Research Officers to assess those with and without access to the Child Health Navigator, educational outcomes, environmental and social factors, and access to prevention services.

1.4.3.4 Stream 3 Co-evaluation

This stream will involve an economic evaluation to compare costs and health service outcomes between the 12-month period of Child Health Navigator support and a 12-month pseudo control period prior to the Child Health Navigator support. Data will be pooled from all partner sites. Furthermore, we will evaluate changes in child and caregiver outcomes using the Pedatric Quality of Life Survey (PedsQL)[33] Quality of Life measure and the Kessler5.[34] These measures will be captured at various stages throughout the Child Health Navigator period, from before the navigation period commences for comparison.

1.4.3.5 Stream 4 Population-level Surveillance

ACCESS will produce an exemplar population-level ear health surveillance model that will help to inform and. Monitor ear health service delivery and policy provision for ear health outcomes in Aboriginal and Torres Strait Islander children living in New South Wales. The population surveillance activities include quantifying the extent and patterns of ear health outcomes for Aboriginal and Torres Strait Islander children, including identifying associated social factors for Aboriginal and Torres Strait Islander children experiencing ear disease. Further details of all streams are described in ***Chapter 6***.

1.5 Thesis structure

1.5.1 Chapter 2. Literature review

The literature review provides a comprehensive exploration of key themes and concepts that are crucial in understand the social determinants of ear health in Aboriginal and Torres Strait Islander children. The literature review explores topics including the historical context of colonisation in Australia, global and Australian perspectives of ear health and hearing amongst Indigenous populations, care coordination and navigation strategies, integrated models of care and the importance of co-creation in Aboriginal and Torres Strait Islander research. The topics explored in this review provides insights into systemic factors that influence access to services, relevant determinants of health, and associated health and social outcomes. Furthermore, this section provides the supporting evidence for exploring key

approaches to addressing these systematic inequities. By synthesising the literature, this review lays the groundwork for this thesis, provides relevant theoretical frameworks, identifies gaps in knowledge and guides the development of culturally appropriate co-created approaches to support Aboriginal and Torres Strait Islander children at risk of ear disease.

*1.5.2 Chapter 3. Hearing what Community has to say: informing a co-created approach to improve ear health and hearing for Aboriginal and Torres Strait Islander children^*

Chapter 3 describes the research activities conducted to gather community perspectives on ear health and hearing among Aboriginal and Torres Strait Islander children living in communities in urban and regional New South Wales. This chapter focusses on how the ACCESS Child Health Navigator could effectively support families with children at risk of ear disease living in participating communities. The methods for this work involved community Yarning circles that were recorded and transcribed. Key themes were derived from these transcripts and used to inform the ACCESS Child Health Navigator model of care. This Chapter showcases the importance of community engagement, cultural responsiveness and participatory methodologies in developing effective and sustainable health initiatives within Aboriginal and Torres Strait Islander communities.

*1.5.3 Chapter 4. Ear health and hearing in urban Aboriginal children**

Chapter 4 is a published paper from this thesis and provides a description of quantitative data on otitis media and hearing loss and its relationship with child, family and social factors from partnering Aboriginal and Torres Strait Islander communities, providing insights into the social determinants of ear health. Moreover, this paper reports the prevalence of otitis media and hearing loss within this cohort. Findings from these analyses were key in understanding the scope of ear health issues within urban Aboriginal and Torres Strait Islander children in New South Wales, and associated determinants of ear health. This paper serves as a critical component of my thesis, offering empirical evidence and statistical analyses that complement the qualitative research findings. Consequently, enhancing the depth and breadth of knowledge on ear health within Aboriginal and Torres Strait Islander children living in urban and regional communities.

*1.5.4 Chapter 5. A systematic review of Health Navigators supporting Indigenous children and adolescents: a meta-narrative synthesis^*

The systematic review detailed in ***Chapter 5*** provides a comprehensive exploration of peer-reviewed literature focussing on Health Navigators, or equivalent models of care, providing support for Indigenous children and adolescents aged zero to 18. This section describes the methods involved in gathering, critically appraising and synthesising existing evidence. Furthermore, this section helps to identify knowledge gaps, guide policy and practice, and approaches to research. Importantly, this review captured existing knowledge and insights to facilitate the evidence-based development and implementation of the ACCESS Child Health Navigator model of care.

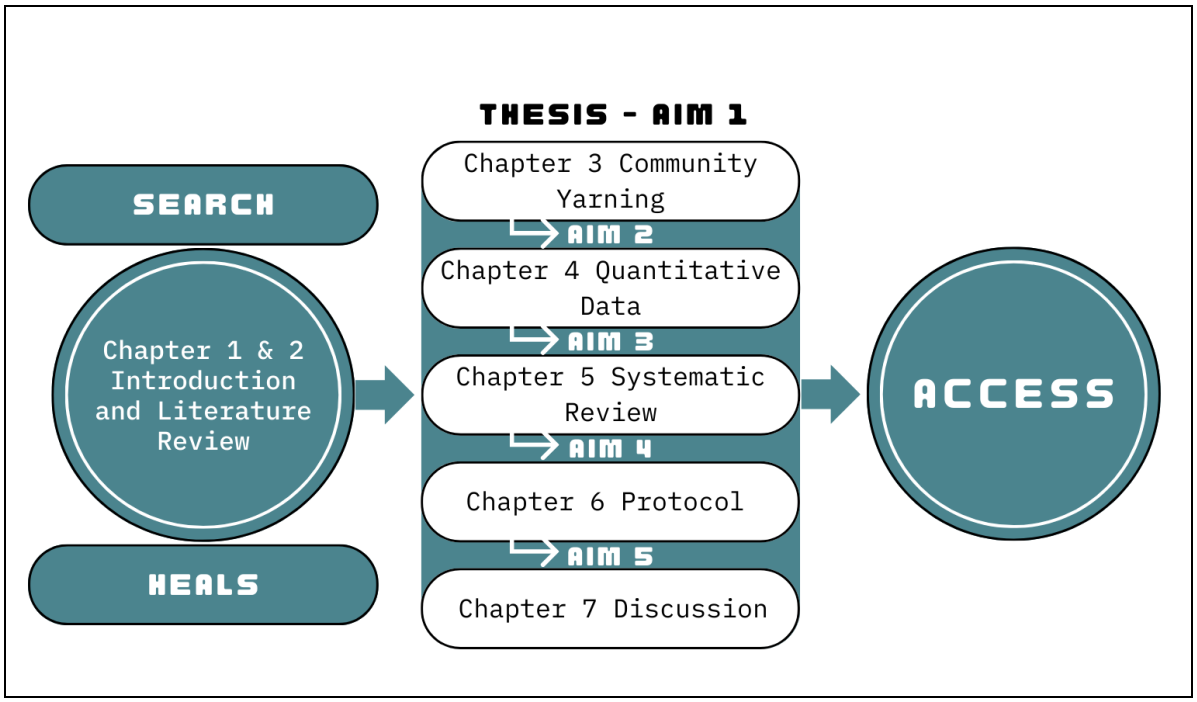
*1.5.5 Chapter 6. Aboriginal Community-Controlled Ear-health Support System (ACCESS): study protocol for a co-created model of care^*

The submitted protocol paper for the ACCESS project serves as the foundation for the Methods chapter of this thesis. This protocol outlines the comprehensive approaches taken in developing and implementing a co-created and community-led model of care aimed at improving ear health and hearing in Aboriginal and Torres Strait Islander children. The ACCESS project is a collaborative effort that integrates the expertise of healthcare providers, researchers and community stakeholders. A Child Health Navigator supporting families to navigate the healthcare system, access support services and address underlying social determinants of ear health is the central focus of ACCESS. Findings from the research activities detailed in ***Chapter 3***, ***Chapter 4*** and ***Chapter 5*** helped to inform the co-design and co-implementation of the Child Health Navigator. By describing key elements of the ACCESS research protocol in ***Chapter 6***, I aim to provide a transparent and rigorous account of the research, design, implementation and evaluation methods employed throughout this ongoing community-driven initiative. This section will contribute to advancing knowledge in Aboriginal and Torres Strait Islander health research methodologies and community-led models of care.

**Published papers*

^Papers submitted or ready for publication

Figure 1.3: Co-creating a Health Navigator model of care to address social determinants of ear health among Aboriginal and Torres Strait Islander children: addressing upstream drivers rather than downstream systems - Thesis map



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CHAPTER 2: LITERATURE REVIEW

2.1 Chapter 2 overview

This chapter will:

1. Summarise the role of colonisation and social determinants of health in creating and perpetuating existing inequities for Aboriginal and Torres Strait Islander people ***(Section 2.2)***,
2. Describe the pathophysiology of otitis media and hearing loss, clinical management of otitis media, and the importance of hearing for early childhood development and life-long wellbeing ***(Section 2.3)***,
3. Present a systematic content review on the social determinants of ear health and hearing among Aboriginal and Torres Strait Islander children in Australia ***(Section 2.4)***,
4. Describe ear health and hearing among Aboriginal and Torres Strait Islander and Indigenous populations ***(Section 2.5)***,
5. Provide an overview of the potential for Health Navigator models of care to address unmet social determinants of health ***(Section 2.6)***, and
6. Describe strengths-based and co-creation approaches and methodologies that underpin this thesis ***(Section 2.7)***.

2.2 Aboriginal and Torres Strait Islander Health and History in Australia

2.2.1 History of colonisation for Aboriginal and Torres Strait Islander health and wellbeing

2.2.1.1 *Aboriginal and Torres Strait Islander history of health*

The health landscape in Australia is complex and ever-changing. Health inequities between Aboriginal and Torres Strait Islander and other people in Australia present many challenges for Aboriginal and Torres Strait Islander communities, policy makers, health workers and health researchers. To understand the differences in health outcomes and the presence of social and economic inequities, it is important to understand Aboriginal and Torres Strait Islander and colonial history in Australia. Previous European reports of Aboriginal and Torres Strait Islander populations erroneously suggested that Aboriginal and Torres Strait Islander

life pre-colonisation was primitive, and the health of Aboriginal and Torres Strait Islander people was inferior to Europeans during the 18th-20th centuries.[1] However, these accounts are not supported by robust empirical or statistical evidence.[1] Contrary to these suggestions and despite the limited information on Aboriginal and Torres Strait Islander health pre-colonisation, historical accounts indicate that Aboriginal and Torres Strait Islander people lived productive lives, experienced an overall high standard of health and wellbeing, and had sophisticated health systems that acknowledged health within a social context.[1, 2] Good health within Aboriginal and Torres Strait Islander populations is supported by observations shortly after colonisation, which placed life-expectancy of Aboriginal and Torres Strait Islander people well above 60 years of age. This is 20 years more than early life-expectancy estimates reported throughout the 19th and 20th centuries.[1] Overall, early indicators of Aboriginal and Torres Strait Islander health were largely positive, with accounts of elderly Aboriginal and Torres Strait Islander individuals having notably good oral health and capable of undertaking manual labour and demanding physical tasks such as hunting.[1]

2.2.1.2 Colonisation's destruction of health and wellbeing

Despite indicators of good health pre-colonisation, the gap in health outcomes between Aboriginal and Torres Strait Islander and non-Aboriginal people in Australia has been growing ever since the arrival of the British in the late 1700s.[3] The invasion of Australia by the Britian marks a significant junction in Aboriginal and Torres Strait Islander history, and it must be emphasised that this has largely been to the detriment of Aboriginal and Torres Strait Islander health and wellbeing over the past two centuries. Estimates from the last two decades of the 18th century place the total Aboriginal and Torres Strait Islander population close to 500 000.[2, 3] It is believed that this number dramatically declined over the following decades, including a reported drop of 95% in Aboriginal and Torres Strait Islander communities in the Northern Territory by 1950.[2, 3] In the early parts of the 20th century the spread of communicable diseases, such as outbreaks of measles and influenza, caused the deaths of many Aboriginal and Torres Strait Islander people, with some communities dying out completely due to the newly introduced diseases.[3]

The impact of European settlement on Aboriginal and Torres Strait Islander populations in Australia extends beyond the passive biological spread of disease.[4] It is important to recognise the systematic abuse of Aboriginal and Torres Strait Islander populations at the hands of the Federal and State Governments in Australia, with the trauma from this abuse still evident

today.[5, 6] The emergence of 'White Australia' policies contributed to this abuse and countless atrocities throughout Aboriginal and Torres Strait Islander communities have been well-documented.[5-7] 'White Australia' policies placed the lives of Aboriginal and Torres Strait Islander people under control of the state; dictating where they could live, what jobs they could have and who they could marry.[7-11] This approach to immigration and control over Aboriginal and Torres Strait Islander people was founded on the belief that any non-white populations were inferior to the dominant white European populations in Australia.[7] This ideology would eventually lead to the forcible removal of Aboriginal and Torres Strait Islander children from their families, known as 'The Stolen Generations'.[8-11] These policies have caused ongoing damage and there are growing calls for this history to be acknowledged.[5, 8-11]

2.2.1.3 Aboriginal and Torres Strait Islander resilience

Despite historical and current discrimination, land dispossession and oppression,[5-7] Aboriginal and Torres Strait Islander populations have exhibited incredible strength and resilience for approximately 60 000 years.[12, 13] This strength and resilience is emphasised by the fact that Aboriginal and Torres Strait Islander populations have persevered through extreme climate change events, surviving in arid desserts and *"glacier-filled gorges"* reaching back thousands of generations.[14(p10)] These climate change events include sea level rises of up to 125 meters, volcano eruptions and mass extinction events.[14] It can be argued that the threat to Aboriginal and Torres Strait Islander health and wellbeing post-colonisation pales in comparison to the many challenges experienced and overcome by Aboriginal and Torres Strait Islander populations over millennia. Being the oldest continuing culture on the planet should not be understated, with the ongoing survival highlighting the fortitude of Aboriginal and Torres Strait Islander communities, cultures and knowledge systems.[12, 13] Consistent with historical examples of Aboriginal and Torres Strait Islander resilience, research has highlighted that Aboriginal and Torres Strait Islander populations often experience a lower burden of ill-health than that expected when considering the disadvantages faced by Aboriginal and Torres Strait Islander populations.[15]

2.2.2 Inequities and burden of disease

2.2.2.1 Inequities in burden of disease

Despite the strengths and resilience of Aboriginal and Torres Strait Islander people, communities have been fighting for existing health inequities to be addressed. Examples of these inequities include the disparity in life expectancy between Aboriginal and Torres Strait Islander and the general Australian population. Aboriginal and Torres Strait Islander people have a life expectancy almost nine years less than non-Aboriginal Australians.[16] The Aboriginal and Torres Strait Islander Health Survey, a National survey of Aboriginal and Torres Strait Islander health and wellbeing, shows that 47% of Aboriginal and Torres Strait Islander people report having some form of chronic health condition posing significant health issues, 38% report having a disability or restrictive condition, and 31% report experiencing significant psychological distress.[17] Further, 23.9% of Aboriginal and Torres Strait Islander people rated their health as fair or poor and were less likely (40% compared to 58%) than non-Aboriginal Australians to rate their health as very good or excellent.[18] Sadly, recent estimates highlight burden of disease contributes to around 400 years of healthy life lost per 1000 Aboriginal and Torres Strait Islander people, compared to 100 years of healthy life lost for per 1000 non-Aboriginal people.[18] Chronic disease among Aboriginal and Torres Strait Islander people on average results in a loss of 29.1 years of life per person, with those who have cardiovascular disease on average losing 31.5 potential years of life.[19] Moreover, a 2024 report by the Australian Institute of Health and Welfare states that approximately 49% of the total disease burden among Aboriginal and Torres Strait Islander populations can be attributed to modifiable risk factors, with factors such as smoking, alcohol consumption and diet playing a major role in driving the high rates of disease.[18]

The link between smoking and colonisation has been previously purported and it is important to reiterate that risk factors such as smoking are not merely lifestyle choices, but often consequences of ongoing colonisation and systemic inequities that disproportionately impact Aboriginal and Torres Strait Islander and other Indigenous peoples.[20, 21] High rates of smoking among Indigenous populations globally are reported in a 2016 systematic review, highlighting the common experiences among marginalised groups who have been historically impacted by colonisation.[22] Moreover, the relationship between negative lived experiences and health outcomes is supported by a Center for Disease Control and Prevention report published in 2019[23]. This report utilised data from 144,017 adults aged 18 and older from 25 different

regions of the United States of America and demonstrated a dose-response relationship between adverse childhood experiences and increased health-risk behaviours, such as current smoking and heavy drinking.[23, 24] The causal mechanisms for health and social outcomes are complicated and nuanced. However, there is growing consensus that colonisation underpins many health and social inequities among Aboriginal and Torres Strait Islander and other Indigenous peoples, with colonisation contributing to intergenerational trauma, including adverse childhood experiences, which have been shown to contribute to health risk behaviours driving health inequities.[3-6, 23, 24]

2.2.2.2 Inequities in early life

Aboriginal and Torres Strait Islander people experience health inequities from an early age, reflecting the intergenerational impact of colonisation, despite strong families and strong communities. A recent government report from the Australian Institute of Health and Welfare reported that infant and congenital conditions contribute to approximately 33% of the health gap between Aboriginal and Torres Strait Islander and non-Aboriginal youth aged zero to 14 years.[25] Similarly, this gap is presumed evident from birth, with cross-sectional data from a cohort study of Aboriginal and Torres Strait Islander and non-Aboriginal children showing that Aboriginal and Torres Strait Islander infants within the cohort were 1.57 times more likely to be born pre-term (< 37 weeks), 1.71 times more likely to be born with a low birth weight (< 2.5kg) and 1.85 times more likely for their parents to express concern about developmental risk.[26] In 2017, Aboriginal and Torres Strait Islander infant mortality data from the Australian Institute of Health and Welfare revealed mortality rates 2.4 times higher than non-Aboriginal children in Australia.[27] Health inequities appear to continue across later stages of the life-course, with cross-sectional population data from Aboriginal and Torres Strait Islander children aged up to 14 years indicating higher rates of ear disease, acute rheumatic fever and respiratory diseases.[18, 25, 27] While these data highlight the early onset of chronic disease that continue into adolescence, Aboriginal Controlled Health Services are actively addressing these inequities via the provision of community-centred, culturally safe, holistic and responsive services.[28]

A recent study[29] of Aboriginal and Torres Strait Islander children living in non-remote communities in Australia found that while 40% of caregivers had no significant concerns about their child's development, two thirds had significant concerns requiring further action. This is twice the estimated global prevalence.[30] Stable housing, no ear disease, parental

wellbeing and not being in out of home care were all associated with less developmental concerns. Furthermore, a recent study reporting National Assessment Program - Literacy and Numeracy (NAPLAN) data for Year 3 students, showed that while 45.1% of Aboriginal and Torres Strait Islander children met the National Minimum Standard results for reading and 48.9% for numeracy, 54.9% of Aboriginal and Torres Strait Islander children did not meet reading standards compared to 12.5% for non-Aboriginal Children,[31] and 51.1% of Aboriginal and Torres Strait Islander children scored lower than the National Minimum Standard for numeracy compared to 8.5% for non-Aboriginal children.[31] Importantly, this study[31] revealed risk factors associated with low literacy and numeracy were shared between Aboriginal and Torres Strait Islander and non-Aboriginal children, highlighting that differences are linked to socioeconomic conditions rather than Aboriginal and Torres Strait Islander status. This underscores the significance of the continuing legacy of colonisation and the social determinants of health that continue to contribute to health inequities across the life-course for Aboriginal and Torres Strait Islander people.

2.2.2.3 Inequities in access to care

Access to healthcare for Aboriginal and Torres Strait Islander populations is marked by significant inequities, which are deeply rooted in historical and ongoing systemic racism, geographical barriers, and socio-economic disparities.[32] These social determinants of health continue to contribute to intergenerational inequities[3] that create challenges for health services to deliver improved health outcomes.[21, 32, 33] Sadly, health systems often contribute to these ongoing inequities.[4-6, 21, 28, 32, 34, 35] Access to healthcare is considered a human right.[36] Importantly, access requires services to be physically, financially, and, for Aboriginal and Torres Strait Islander populations, culturally accessible.[37] Despite this, health systems are often poorly integrated and fragmented, impacting access to care.[38] Furthermore, this is compounded by experiences of racism, culturally unsafe or inappropriate care, and cost for Aboriginal and Torres Strait Islander people.[4, 32] Consequently, Aboriginal and Torres Strait Islander people experience a disproportionate burden of disease, as described previously in this chapter.

Furthermore, limited resourcing of Aboriginal Community Controlled Services and culturally safe care within mainstream services exacerbates these barriers, leading to poorer health outcomes.[28] Focusing on the underlying systems and determinants that lead to access barriers is important, as it acknowledges that deficits do not emerge from Aboriginal and Torres Strait

Islander people but from the systems and determinants that Aboriginal and Torres Strait Islander people endure[5, 6], consequently shifting the focus from blaming those impacted, to addressing the underlying systemic barriers. Crucially, addressing these inequities requires a concerted effort to implement policies and practices that prioritise the voices and needs of Aboriginal and Torres Strait Islander communities, ensuring that healthcare services are accessible, affordable, and culturally respectful.[39] This includes strengthening the role of Aboriginal Community Controlled Health Services, which have been shown to provide more effective and culturally appropriate care.[28] Consequently, care through Community Controlled Services should be prioritised, while the mainstream health system continues to catch up and improve workforce capacity, cultural competence, and address systemic issues such as racism.

2.2.2.4 Inequities in health funding

Aboriginal and Torres Strait Islander people experience better health than expected when accounting for health expenditure, further highlighting the resilience and fortitude of Aboriginal and Torres Strait Islander communities. Specifically, better than expected health is demonstrated by the relationship between health expenditure and disease burden among Aboriginal and Torres Strait Islander populations. A 2022 report[40] by the national leadership body for Aboriginal and Torres Strait Islander health, National Aboriginal Community Controlled Organisation (NACCHO), highlights health funding shortfalls. This report explains that health expenditure in Australia equates to approximately $7,365 spent per capita for non-Aboriginal people and $9,925 per capita for Aboriginal and Torres Strait Islander people in Australia. However, the current estimated burden of disease for Aboriginal and Torres Strait Islander populations is approximately 2.3 times the rate of non-Aboriginal Australians, which translates into 2.03 times the cost-of-service delivery, indicating that there is a significant funding inequity compounding existing health inequities. Sufficient health expenditure to account for this gap in burden of disease should be $14,967 per capita (i.e. 2.03 x $7,365).[40] The estimated required **additional** total health expenditure to support the 863,576 Aboriginal and Torres Strait Islander people in Australia is $4.4 billion per annum (($14,967 - $9,925 = $5,042) $5,042 x 863,576 = $4.4 billion) and this additional spending is only what would be needed to maintain the current gap in burden of disease and not what would be required to 'close the gap'.[40] Despite this clear deficiency in health expenditure, we still see some, although few, health gaps closing, such as improvements in healthy birthweight and more children meeting developmental milestones.[41] Hence, to make progress in closing existing health gaps, a greater commitment to health funding is required.

2.2.2.5 Aboriginal and Torres Strait Islander strengths in the face of adversity

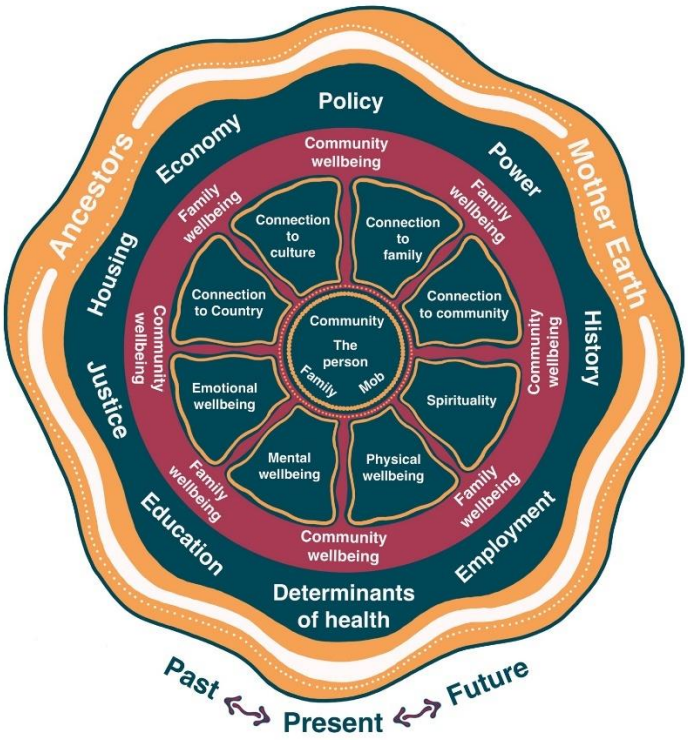
Notwithstanding existing inequities, Aboriginal and Torres Strait Islander peoples and communities have demonstrated remarkable resilience in the face of persistent inequities and subjugation stemming from ongoing colonisation. Despite centuries of dispossession, cultural suppression, and systemic discrimination, these communities have maintained and revitalised their cultural identities, knowledge systems, and ways of life.[28, 42, 43] A key aspect of this resilience is the strength drawn from community, kinship, and cultural practices that continue to sustain and empower individuals and families.[33, 44] Aboriginal Community Controlled Health Services play a crucial role in this resilience by providing culturally safe, holistic care that addresses not only physical health but the social, emotional, and cultural wellbeing of their communities.[28] These services are a testament to the self-determination and agency of Aboriginal and Torres Strait Islander communities in Australia, standing as vital institutions in the ongoing struggle for health equity and justice.

2.2.3 Social determinants of Aboriginal and Torres Strait Islander health

2.2.3.1 Aboriginal and Torres Strait Islander holistic view of health and wellbeing

It is important to recognise that measures of health outcomes and associated inequities stem from Western perspectives that often neglect crucial aspects of Aboriginal and Torres Strait Islander health and wellbeing. Aboriginal and Torres Strait Islander populations have long-standing holistic views of health that encompasses the physical wellbeing of an individual and their social, emotional and cultural wellbeing.[45] This perspective recognises the interconnectedness of health with family, community, land, and spirituality.[33] This holistic approach aligns closely with the concept of social determinants of health, which includes factors such as housing, education, employment, access to healthcare, and social support networks.[34, 46] For Aboriginal and Torres Strait Islander peoples, these determinants are deeply embedded in cultural identity and community connections, influencing their overall health and wellbeing. This holistic view of health is reiterated by Williams et al who state *"The individual person and mob are surrounded by eight elements of health and wellbeing that Aboriginal and Torres Strait Islander people often talk about: emotional wellbeing, mental wellbeing, physical wellbeing, spirituality and connections to Country, culture, family and community"* (see Figure 2.1).[45p2] Addressing these determinants is essential for improving health outcomes within Aboriginal and Torres Strait Islander communities.

Figure 2.1: Aboriginal and Torres Strait Islander view of health (taken from Williams et al 2020[45] - Aboriginal people's holistic view of health)



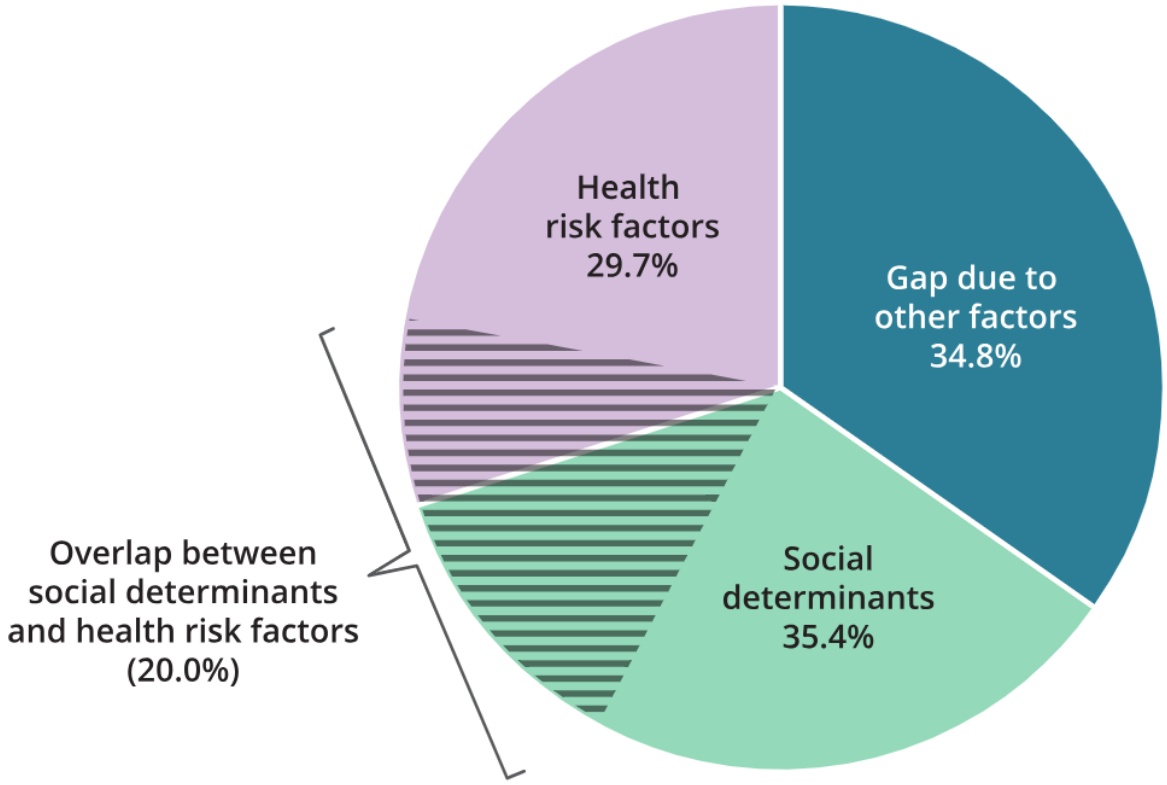
Copyright Williams, Ragg & Bulman, 2022. Artwork by Jessie Waratah

2.2.3.2 Social determinants

Existing health inequities are evident, and the underlying conditions driving these health gaps often begin in early life and continue across the life-course. Disease, injury and pathogenic environments at a young age adversely impact health trajectories for Aboriginal and Torres Strait Islander people.[18] To make progress in addressing these inequities, it is important to understand the context in which health inequities arise by exploring the cause of the causes of disease.[46] The cause of causes can be described as the social inequalities that exist within society and impact the way in which people are *"born, grow, live, work and age"*[46(p512)], also referred to as 'the social determinants of health'.[18] A recent report from the Australian Institute of Health and Welfare on the size and sources of the health gap for Aboriginal and Torres Strait Islander people suggests that at least 35.4% of the gap in health outcomes are attributable to social determinants, with almost 39.7% attributable to health risk factors.[47] Furthermore, 20% of factors were considered overlapping between social determinants and health risk factors, with the remaining 34.8% unexplained by the available data (see Figure 2.2).[47] Possible contributions to this unaccounted data are racism and discrimination, which

is not adequately captured within this dataset. Moreover, a recent study found that everyday discrimination significantly contributes to psychological distress among Aboriginal and Torres Strait Islander adults, with nearly half of the distress burden attributable to discrimination due to Indigeneity.[48] This paper also highlights that addressing both interpersonal and structural racism is crucial for improving mental health outcomes and reducing health inequities for Aboriginal and Torres Strait Islander populations.[48]

Figure 2.2: Proportion of the adjusted health gap explained by differences in social determinants and health risk factors[47]



The social gradient

The 'social gradient' is a broad measure of the relationship between socioeconomic status, and health and social outcomes. It provides a robust framework to understand the disparity in health outcomes between different groups within society and how social determinants impact health. The higher up the social gradient, the more likely you are to have better health outcomes than those lower down on the socioeconomic ladder.[34] The link between income and health outcomes are a prime example of how the social gradient impacts health.[34] Therefore, it is important to note that the Aboriginal and Torres Strait Islander Health Performance Framework Report (2024)[18] showed that between 2011-2021 Aboriginal and

Torres Strait Islander adults earned a median gross household weekly income of $619 to $825 compared to $998 to $1,141 for non-Aboriginal Australian adults. This clearly places Aboriginal and Torres Strait Islander populations at higher comparable risk of poorer health, but also emphasises the need to address the underlying social factors that influence health within Aboriginal and Torres Strait Islander populations. In addition to the social and economic determinants of health, cultural, historical and political determinants significantly impact Aboriginal and Torres Strait Islander health and wellbeing.[21, 33]

2.2.3.3 Housing

The social gradient of health highlights that socioeconomic status is a strong predictor of exposure to salutogenic (origins of health) or pathogenic environments, e.g., healthy or unhealthy housing. Importantly, housing and health are closely intertwined, with housing an important determinant of health for Aboriginal and Torres Strait Islander communities.[49, 50] Many Aboriginal and Torres Strait Islander communities face housing challenges such as overcrowding, poor quality housing, and housing instability, which contribute to adverse health outcomes.[51, 52] Overcrowding increases risk of infectious disease, including respiratory infections and otitis media, particularly among children.[53] Poor quality housing, includes issues like dampness and inadequate sanitation that exacerbates chronic health issues and creates environments that negatively impact physical and mental wellbeing.[51, 52, 54, 55] Housing instability further compounds these issues, leading to disrupted access to healthcare, education and social services critical for maintaining health and wellbeing.[51, 52, 54, 55] Addressing housing-related issues is essential for improving health outcomes. Efforts to improve housing conditions must be culturally sensitive and involve communities in decision-making processes to ensure that interventions are effective and sustainable.[49, 50, 55] The intersection of housing and health disparities underscores the pervasive impact of systemic inequities, leading to a critical examination of how racism shapes health outcomes for Aboriginal and Torres Strait Islander communities.

2.2.3.4 Racism

Racism and discrimination are key social determinants of health that profoundly impact Aboriginal and Torres Strait Islander people.[35, 56] Systemic racism, characterised by unequal access to resources, opportunities, and services based on race, continues to perpetuate health inequities.[56] Furthermore, discrimination in healthcare, education and employment settings contribute to higher rates of chronic illness, social and emotional wellbeing and reduced life

expectancy for Aboriginal and Torres Strait Islander people.[35, 37] Paradies et al (2016)[4] highlight the pervasive nature of racism and the detrimental effects it has on health outcomes, and emphasises the need to implement anti-racist policies. Moreover, there are calls to recognise the importance of addressing racism within a social justice framework to improve Aboriginal and Torres Strait Islander health and wellbeing. A social justice framework for Aboriginal and Torres Strait Islander people is grounded in principles of human rights, equity and respect for Aboriginal and Torres Strait Islander knowledges and perspectives.[4]

Racism has a direct impact on access to health services for Aboriginal and Torres Strait Islander people.[37, 56] Experiences of racism and discrimination lead to mistrust, avoidance of healthcare services and delays in seeking medical care.[37, 57] Importantly, there are numerous instances of deaths in healthcare and justice settings in Australia that have been linked to racism and barriers in accessing culturally safe care. High profile cases such as the death of Naomi Williams, a young Wiradjuri woman, who in 2016 was pregnant and sought medical help several times for severe abdominal pain. However, she was repeatedly dismissed by healthcare professionals. Sadly, Naomi passed away from meningococcal septicaemia caused by a ruptured ectopic pregnancy that was left untreated.[32, 58] As described in Chapter 1.1, the death in custody of Mootijah Shilingsworth, similarly to the death of Naomi Williams, occurred from an ear infection that was left untreated and resulted in a fatal temporal lobe abscess.[59] These examples highlight the tragic consequences of institutional racism and discriminatory practices within health and justice systems in Australia.

Examples of racism are not limited to health and justice settings. For example, streets labelled 'Boundary Street' can be seen in countless suburbs in Australia. These streets were historically used to signal areas where Aboriginal and Torres Strait Islander people were forbidden.[60] Having visible reminders of the destruction of Aboriginal and Torres Strait Islander culture, and continuing oppression and land dispossession is no doubt detrimental to the wellbeing of Aboriginal and Torres Strait Islander individuals and communities. Therefore, it is important to challenge existing and historical racism, and oppression.[60] Brand et al (2016)[60(p9)] highlight the ongoing impact of history and racism on Aboriginal and Torres Strait Islander health by stating *"the poor health status of Aboriginal and Torres Strait Islander people is embedded in enduring colonial legacies of dispossession and disruption".*

2.2.3.5 The loss of language in oral cultures as a cultural determinant of health

In addition to land dispossession, the loss of language and cultural practice is considered a

significant social determinant of health for Aboriginal and Torres Strait Islander people.[44, 61-65] For many Aboriginal and Torres Strait Islander people, this has led to a sense of identity loss and spiritual distress.[44] Storytelling holds deep significance within Aboriginal and Torres Strait Islander epistemology and knowledge systems, rooted in oral traditions that have been passed down for thousands of years.[66-68] The use of metaphors, animal stories, sound and visual aids in storytelling differs significantly from Western educational approaches.[66-69] Notably, storytelling is integral to learning, memory, self-awareness, empathy, and comprehending the world.[70] Disconnection from cultural roots and ancestral knowledge impacts mental and emotional wellbeing, contributing to higher rates of depression, anxiety, and suicide among Aboriginal and Torres Strait Islander populations.[44, 61-65] Importantly, there are protective effects of cultural continuity, and connection to land, language, and community for Aboriginal and Torres Strait Islander health outcomes.[44, 61, 62] Addressing cultural disconnection requires strategies that support cultural practices, strengthen cultural identity and promote the transmission of traditional knowledge across generations. This has been shown to foster holistic wellbeing and self-determination for Aboriginal and Torres Strait Islander people.[44, 61-65]

2.2.3.6 Colonisation and political determinants of health

Aligned with the importance of reclaiming culture is the growing push to support Aboriginal and Torres Strait Islander control over healthcare provision, health research and health policy,[28] to help eliminate the underlying foundations of racism that preserve inequities between Aboriginal and Torres Strait Islander and non-Aboriginal populations in Australia. Fundamental to the process of reaffirming Aboriginal and Torres Strait Islander self-determination is improving the understanding of non-Aboriginal people about the differing views of health that Aboriginal and Torres Strait Islander and non-Aboriginal people hold. Greater acknowledgement of the detrimental impact colonisation has had on Aboriginal and Torres Strait Islander populations is vital to shift the colonial forces that Aboriginal and Torres Strait Islander populations have had to persevere for generations.[5] This includes addressing historical trauma, intergenerational trauma, and ongoing systemic issues underpinned by colonisation. Additionally, efforts to decolonise healthcare systems, policies and practices are essential for promoting health equity and empowering Aboriginal and Torres Strait Islander communities in reclaiming sovereignty over their health.

The legacy of colonisation profoundly influences the health and wellbeing of Aboriginal and

Torres Strait Islander people.[4-6] Political factors such as discriminatory policies, lack of representation in decision-making processes, and limited access to resources and services, contribute to the health disparities experienced by Aboriginal and Torres Strait Islander communities.[4, 6, 71-74] Addressing these political determinants requires a multifaceted approach that includes advocating for policy changes that prioritise Aboriginal and Torres Strait Islander rights, promote meaningful engagement with Aboriginal and Torres Strait Islander communities in health governance and equitably allocate resources for Aboriginal and Torres Strait Islander-led initiatives.[73, 75, 76] Addressing the political determinants of health are necessary to move towards more equitable health and political systems.

2.2.4 Section 2.2 summary

A shift in public health approach is needed to address health inequities experienced by Aboriginal and Torres Strait Islander people. Greater emphasis on the social determinants of health, recognition of Aboriginal and Torres Strait Islander history, culture and resilience, and elimination of social, economic and structural inequities are essential to improve health outcomes for Aboriginal and Torres Strait Islander populations. Furthermore, we must actively work toward reconciliation, advocate for Aboriginal and Torres Strait Islander rights and sovereignty, address systemic injustices and foster genuine partnerships based on mutual respect, understanding and collaboration. Changing the narrative from injustice to justice is a difficult, yet important aspiration.

2.3 Ear health and hearing

The previous sections help to provide the underlying context for existing health inequities in ear health experienced by Aboriginal and Torres Strait Islander children, which is the focus of this thesis. This section provides an overview of ear health and hearing, including the pathophysiology of otitis media and otitis media clinical management. Additionally, otitis media-associated hearing loss, speech-language development and auditory processing is described throughout this section.

2.3.1 Otitis media overview

Otitis media is one of the leading causes of disease in Aboriginal and Torres Strait Islander children and is the largest cause of preventable hearing loss across all populations globally.[77, 78] Otitis media refers to infection or inflammation of the middle ear and is commonly referred to as 'middle ear infection' or 'ear disease'.[79-81] Otitis media is the most common diagnosis in pre-school aged children (two to five years) and the biggest factor for outpatient antibiotic prescription in the world.[80, 81] Otitis media occurs primarily in children and commonly leads to temporary or intermittent hearing loss. However, recurrent otitis media or chronic otitis media can lead to permanent hearing loss,[82] with otitis media-associated hearing loss linked to poor speech, language and cognitive development, which may impact social and emotional wellbeing, education and employment, and increase the risk of contact with the justice system.[77, 80, 83-86]

2.3.2 ***Otitis media classifications***

The following classifications are defined according to the 2020 Otitis Media Guidelines for Aboriginal and Torres Strait Islander children.[80]

Otitis media: Refers to all forms of inflammation and infection of the middle ear. Active inflammation or infection is nearly always associated with middle ear effusion (fluid in the middle ear space).[80(p8)]

Otitis media with effusion (OME): Presence of fluid behind the tympanic membrane without any acute symptoms. Other terms have also been used to describe OME (including 'glue ear', 'serous otitis media' and 'secretory otitis media'). OME may be episodic or persistent. A Type B tympanogram or reduced mobility of the tympanic membrane on pneumatic otoscopy are considered reliable indicators of OME.[80(p8)]

Episodic OME: Otitis media (as defined above) with duration less than three months.[80(p8)]

Persistent (Chronic) OME (pOME): Presence of fluid in the middle ear for more than three months without any acute symptoms or signs of inflammation.[80(p8)]

Acute otitis media (AOM): General term for both acute otitis media without perforation and acute otitis media with perforation. It is defined as the presence of fluid behind the tympanic membrane in addition to at least one of the following: bulging tympanic membrane, red tympanic membrane, recent discharge of pus, fever, ear pain or irritability. A bulging

tympanic membrane, recent discharge of pus, and ear pain are reliable indicators of AOM.[80(p8)]

Acute Otitis Media without Perforation (AOMwoP): The presence of fluid behind the tympanic membrane with at least one of the following: bulging tympanic membrane, red tympanic membrane, fever, ear pain or irritability. A bulging tympanic membrane and/or ear pain are the most reliable indicators of AOMwoP.[80(p8)]

Recurrent Acute Otitis Media (rAOM): The occurrence of three or more episodes of AOM in a six-month period, or occurrence of four or more episodes in the last 12 months.[80(p8)]

Acute Otitis Media with Perforation (AOMwiP): Discharge of pus through perforation (hole) in the tympanic membrane within the last two weeks. The perforation is usually very small (a pinhole) when the tympanic membrane first ruptures. The perforation can heal and reperforate after the initial onset of AOMwiP. The size of the perforation should be recorded, as this directs management, and duration of discharge is often difficult to establish.[80(p9)]

Chronic suppurative otitis media (CSOM): Persistent ear discharge through perforation in the tympanic membrane lasting two weeks or more and tympanic membrane perforation large enough to allow penetration of topical antibiotics into the middle ear space (generally > 2% of the pars tensa). The size of the perforation should be determined and recorded, as described with AOMwiP.[80(p9)]

Tympanostomy Tube Otorrhoea (TTO): Middle ear discharge (otorrhoea) through tympanostomy tubes (also known as ‘grommets’) in situ. TTO may be further classified as: early post-operative - occurring within four weeks of tympanostomy tube insertion, delayed-occurring after four weeks of tympanostomy tube insertion, chronic- persisting three months or longer, recurrent - three or more discrete episodes.[80(p9)]

Dry Perforation (DP): Presence of a perforation in the tympanic membrane without any signs of discharge or fluid behind the tympanic membrane. Some people also refer to this as inactive CSOM.[80(p9)]

Attic Perforation: This is a perforation in the superior part of the tympanic membrane. A perforation in this location may be associated with a deep retraction pocket or cholesteatoma.[80(p9)]

Cholesteatoma: Abnormal growth of skin cells in the middle ear, which continues to grow

eventually causing erosion of surrounding structures (middle ear ossicles, facial nerve, base of skull), resulting in hearing loss, facial paralysis or intracranial complications.[80(p9)]

2.3.3 Pathophysiology

The pathophysiology of otitis media involves a complex interplay of infection, inflammation, effusion, and eustachian tube dysfunction with varying degrees of severity and complications. Otitis media typically occurs following upper respiratory tract infection or congestion of the nasopharynx and eustachian tube, which may affect middle ear pressure, leading to effusion or bacterial infection within the middle ear.[79-81] Although there is some debate, there is general consensus within the literature that young children are at highest risk of congestion of the eustachian tube, due to underdeveloped immune maturity and eustachian tube anatomy.[79, 87] At a young age, the eustachian tube is smaller and sits more horizontally, potentially resulting in impaired aeration of the middle ear.[87] Aeration allows for the equalisation of air pressure within the middle ear, and the drainage of fluid from the nasopharyngeal and middle ear cavities.[79, 87] Following congestion within the nasopharynx and eustachian tube, fluid from the nasopharyngeal cavity can migrate to the middle ear causing effusion of the middle ear (see Figure 2.3). In addition to this process, negative middle ear pressure is associated with increased vascular permeability, also resulting in effusion.[81] Effusion may contain microorganisms that multiply in the middle ear leading to symptoms such as inflammation, pain and discolouration of the tympanic membrane. The most common microorganisms associated with otitis media include:

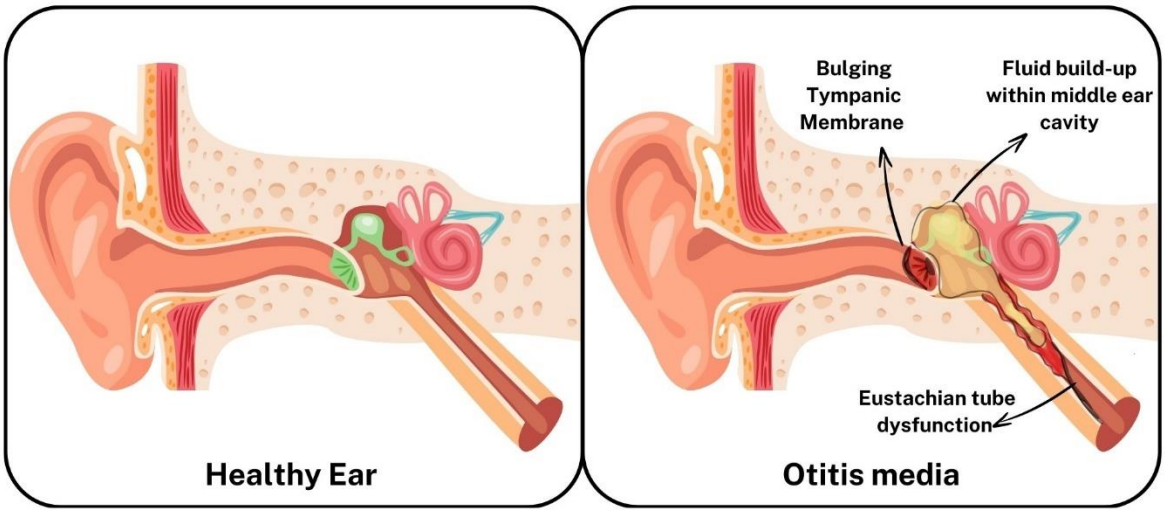
Streptococcus Pneumoniae: This bacterium is one of the leading causes of acute otitis media.

Haemophilus Influenzae: Haemophilus Influenzae and Type B Haemophilus Influenzae can cause otitis media, with Haemophilus influenzae particularly common in cases of chronic and recurrent otitis media.

Moraxella Catarrhalis: This bacterium is another common pathogen associated with acute and chronic otitis media in children.

Staphylococcus Aureus: This bacterium is less common than the other pathogens. However, still contributes to otitis media, especially chronic and recurrent otitis media.

Figure 2.3: Healthy middle ear versus otitis media[88]



2.3.4 Hearing loss

Within the middle ear, there are three small bones called the ossicles (incus, malleus and stapes). The ossicles help to transmit sound from the tympanic membrane, through the middle ear passage to the oval window of the cochlea (inner ear). Effusion and inflammation may obstruct the movement of the ossicles, hindering the conduction of sound from the outer ear to the inner ear, resulting in hearing impairment. This type of hearing impairment is known as conductive hearing loss.[82] Mild to moderate conductive hearing loss between 15dB to 40dB is most commonly associated with otitis media (see Table 2.1).[89, 90] However, permanent sensorineural hearing loss (hearing loss resulting from damage to the cochlea) can occur due to persistent or chronic otitis media.[82] Therefore, otitis media may impact hearing and communication into adulthood, compounding the potentially life-long consequences of delayed speech-language and cognitive development related to otitis media experienced earlier in life.[77, 80, 83-86]

Table 2.1: Grades of hearing loss defined by 2020 Otitis Media Guidelines for Aboriginal and Torres Strait Islander children[80(p12)]

Grade	Level in Decibels (dB)	Performance
Normal	≤ 20 dB	No or very slight problems. Able to hear whispers
Mild*	21-30 dB	Unable to hear and repeat words spoken in normal voice at greater than one meter
Moderate*^	31-60 dB	Unable to hear and repeat words spoken in raised voice at greater than one meter
Severe	61-80 dB	Unable to hear most words when shouted into ear
Profound	≥ 81 dB	Unable to hear or understand a shouted voice

**Grades typically associated with an otitis media-related conductive hearing loss*

^Moderate hearing loss: hearing loss greater than 40dB in the better ear in adults and greater than 30dB in the better ear in children

2.3.5.1 Speech-language

Otitis media has a comprehensive impact on the development and long-term trajectories for children. Importantly, otitis media is associated with hearing loss, with temporary, recurrent or persistent hearing loss having the potential to inhibit speech-language development.[91] Speech-language development is crucial for children, as it forms the basis of effective communication, supports cognitive growth and academic success, fosters social interaction and relationship building, enables self-expression and creativity, aids in problem-solving and decision-making, facilitates emotional regulation and resilience, and provides essential skills to thrive into adulthood.[92] Although there have been long-standing associations reported between hearing loss and speech-language development, study design limitations have meant the link between early childhood otitis media and later speech-language deficits are not well established.[93, 94] However, a recent study exploring this relationship employed strict controls

for confounding factors and reported an association between otitis media and later language acquisition, including limited access to ambient language and delayed auditory development.[94] Conversely, a 2020 study[93] exploring early otitis media and later language ability found no significant relationship between bilateral otitis media and language ability. Despite the lack of significant association between otitis media and later language acquisition, this study reported lower rates of receptive vocabulary growth for children aged 10 years who had otitis media at age six years.[93] Given the known links between otitis media and hearing loss, and hearing loss and speech-language, the lack of demonstrated association likely stems from research and clinical limitations, including the complexity of otitis media diagnosis, and difficulty in measuring the breadth of otitis media risk factors and associated confounding factors.[93] Given the uncertainty of research findings, there is a need to better understand the relationship between otitis media and speech-language acquisition given the well-established associations between otitis media and hearing loss, and hearing loss and speech-language deficits.

2.3.5.2 Auditory processing

In addition to speech-language development, auditory processing is fundamental to our ability to perceive and interpret sound, communicate effectively, and navigate our environment. Auditory development begins in the womb and continues to develop into adulthood, with critical periods of development occurring between birth and adolescence.[95] ***Auditory localisation*** is one of the most important auditory functions for communicating and learning. Auditory localisation is the process of identifying the direction and location of a sound source, with this function crucial for spatial awareness and safety.[96] Binaural hearing is key in auditory localisation, and involves detecting ***Interaural Time Differences*** and ***Interaural Level Differences***.[95-98] Furthermore, ***Head-Related Transfer Functions*** are unique filters created by the shape of ears, head and torso.[96-98] These filters impact sound prior to reaching the ear, providing spatial cues that help to identify the direction and elevation of a sound source.[96-98] Pinna (i.e. the outer ear) cues play an important role in localisation by capturing and amplifying certain frequencies based on the angle and trajectory of the sound source.[96] Furthermore, the pinna contributes to monaural cues which are important for vertical sound localisation.[96-98] Importantly, these cues are processed in the brain, particularly the olivary complex and auditory cortex, and integrate binaural and monaural cues to create a spatial map of sound locations. Neural computations combine timing, intensity, spectral, and localisation cues to determine the perceived direction and distance of sound sources.[96-98]

Other important auditory functions include auditory discrimination, pitch perception, auditory attention, auditory memory, auditory feedback and auditory integration. ***Auditory discrimination*** involves distinguishing between different sounds, such as recognising phonemes, musical notes and environmental sounds.[95] ***Pitch perception*** is our ability to perceive pitch and allows us to distinguish between high and low frequencies. This function is vital for recognising musical melodies, understanding tone variations in speech, and identifying subtle differences in sound quality.[99, 100] ***Temporal processing*** refers to how we perceive the timing and duration of sounds. It enables us to discriminate between rapid and slow-paced sounds, recognise rhythm and tempo, and comprehend timing of speech patterns.[99] ***Auditory attention*** involves focussing on specific sounds while filtering out background noise. This function is crucial for maintaining concentration during conversations or listening in an education setting.[101] ***Auditory memory*** is our ability to remember and recall auditory information, and is essential for learning, communication, and problem solving. Auditory memory allows us to retain spoken instructions, recall familiar sounds, and process sequential auditory information.[102] ***Auditory feedback*** is the process of hearing and evaluating our own speech or vocalisations. It helps us to monitor and adjust our speech production, maintain fluency, and detect errors in pronunciation or articulation.[103] ***Auditory integration*** is the process of combining auditory information with other sensory inputs, such as visual and tactile cues to form a comprehensive perception of the environment. This integration contributes to our overall sensory awareness and multi-sensory experiences.[104] These functions work together seamlessly to support communication, learning and interaction with the auditory world around us. A healthy and well-functioning auditory system is essential for optimal auditory experiences and overall wellbeing.

2.3.5.3 Hearing and wellbeing

Otitis media and associated hearing, speech-language and auditory deficits can manifest as challenges in academic performance, literacy skills, and overall educational engagement.[86, 105-108] A 2020 retrospective cohort study of Aboriginal and Torres Strait Islander children living in the Northern Territory using linked National Assessment Program Literacy And Numeracy (NAPLAN) data highlighted the association between otitis-media-related hearing impairment and poorer academic achievement.[109] A more recent 2021 cohort study of children living in Western Australia, also using linked NAPLAN data, demonstrated that all children within the cohort with reported otitis media episodes had an increased risk of low literacy and numeracy.[105] This study further states that Aboriginal and Torres Strait Islander children

experienced highest risk of low literacy and numeracy in association with otitis media episodes. Importantly , the impact of otitis media has been reported to extend beyond the classroom, potentially influencing later educational pathways and limiting future opportunities within higher education and employment.[110-112] Furthermore, otitis media can have profound implications for the social and emotional wellbeing of children. Communication difficulties arising from otitis media may contribute to feelings of social isolation, frustration, and reduced self-esteem.[113-116] These emotional challenges can impact peer interactions, social integration and overall mental health outcomes.[113-115] The psychosocial impact of ear disease is supported by data from the Longitudinal Study of Australian Children (LSAC), with a 2014 paper reporting that children who had experienced ongoing ear disease at four and five years of age, were more likely to experience abnormal or borderline psychosocial outcomes (measured using the Strengths and Difficulties Questionnaire, a screening tool for measuring psychological change following a health condition in children) at 10 and 11 years of age.[117] Although this study is not specific to Aboriginal and Torres Strait Islander children, this highlights the potential for otitis media to impact upon a child's social and emotional wellbeing across the life-course.

2.3.5 Section 2.3 summary

Otitis media is a complex condition, with each otitis media sub-type requiring specific diagnosis, prevention and management. Furthermore, the sub-types of otitis media impact children in vastly different ways and require nuance in understanding the ongoing consequences, particularly for more severe forms of otitis media that are left untreated. Otitis media is associated with inflammation, pain and irritation for children. However, it is otitis media-related hearing loss that has a significant impact on early childhood development and later-life health and social outcomes. Recognising the complex interplay of otitis media and hearing loss, speech-language development, auditory processing, education, social and emotional wellbeing and culture is crucial in designing effective approaches to best support children and their families.

2.4 The social determinants of otitis media in Aboriginal children in Australia: are we addressing the primary causes? A systematic content review

2.4.1 Overview

Otitis media disproportionately impacts Aboriginal and Torres Strait Islander children, leading to significant health and social disparities. Social determinants such as housing, access to healthcare, socioeconomic status, and environmental factors have been cited as playing a pivotal role in driving these health gaps. By systematically examining the literature, this review provides essential insights into the underlying drivers of existing disparities, identifies gaps within the literature and provides key recommendations to support the development of effective, culturally sensitive approaches and policies that target the social determinants of ear health.

2.4.2 Published paper

DeLacy J, Dune T, Macdonald JJ. The social determinants of otitis media in Aboriginal children in Australia: are we addressing the primary causes? A systematic content review. BMC Public Health. 2020;20(492):1-9.

DeLacy et al. BMC Public Health (2020) 20:492
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RESEARCH ARTICLE Open Access

The social determinants of otitis media in Aboriginal children in Australia: are we addressing the primary causes? A systematic content review

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Abstract

Background: Aboriginal and Torres Strait Islander children experience some of the highest rates of otitis media in the world. Key risk factors for otitis media in Aboriginal children in Australia are largely social and environmental factors such as overcrowded housing, poverty and limited access to services. Despite this, little is known about how to address these risk factors. A scoping content review was performed to determine the relationship between social determinants of health and otitis media in Aboriginal and Torres Strait Islander children as described by peer-reviewed and grey literature.

Method: Search terms were established for location, population and health condition. The search terms were used to conduct a literature search using six health research databases. Following the exclusion process, articles were scoped, analysed and categorised using scoping parameters and a social determinants of health framework.

Results: Housing-related issues were the most frequently reported determinants for otitis media (56%). Two articles (4%) directly investigated the impact of social determinants of health on rates of otitis media within Aboriginal and Torres Strait Islander children. The majority of the literature (68%) highlights social determinants as playing a key role in the high rates of otitis media seen in Aboriginal populations in Australia. There were no intervention studies targeting social determinants as a means to reduce otitis media rates among Aboriginal and Torres Strait Islander children.

(Continued on next page)

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(Continued from previous page)
Conclusions: This review identifies a disconnect between otitis media drivers and the focus of public health interventions within Aboriginal and Torres Strait Islander populations. Despite consensus that social determinants play a key role in the high rates of otitis media in Aboriginal and Torres Strait Islander children, the majority of intervention studies within the literature are focussed on biomedical approaches such as research on vaccines and antibiotics. This review highlights the need for otitis media intervention studies to shift away from a purely biomedical model and toward investigating the underlying social determinants of health. By shifting interventions upstream, otitis media rates may decrease within Aboriginal and Torres Strait Islander children, as focus is shifted away from a treatment-focussed model and toward a more preventative model.

Keywords: Otitis media, Ear disease, Hearing, Social determinants of health, Aboriginal and Torres Strait islander, Aboriginal, Indigenous, Children, Australia

Background

Otitis media (OM) is one of the leading causes of disease among Aboriginal and Torres Strait Islander (hereafter referred to as Aboriginal) children [1, 2]. OM refers to inflammation and infection of the middle ear and is classified as acute OM, OM with effusion or chronic suppurative OM [1, 3]. There are currently inadequate services to deal with ear and hearing health within Aboriginal communities and high demand for services is expected to continue in coming years [4]. The World Health Organisation have identified OM in its various forms as a major health issue for Aboriginal children, despite the fact that OM is preventable and treatable, and is far less common for non-Aboriginal children in Australia [1]. The gap in prevalence of OM between Aboriginal and non-Aboriginal children has consistently been associated with social determinants, particularly housing-related issues [2–8]. OM can impact upon educational outcomes and employability for Aboriginal people who are more likely to be socially and economically disadvantaged than non-Aboriginal Australians [5].

Key risk factors for OM in Aboriginal children include overcrowded housing, poor housing conditions, exposure to tobacco smoke, malnutrition, socioeconomic disadvantage and limited access to services [2–8]. Aboriginal children experience OM at similar rates, frequency and severity as children living in developing nations, despite the overall high standard of living in Australia [9, 10]. The prevalence of OM in some Aboriginal communities is close to 10 times higher than the 4% identified by The World Health Organisation as being a serious public health problem requiring urgent attention [2]. This puts Aboriginal children as one of the most at risk populations for OM in the world [3, 11].

Significant health gaps have persisted in Aboriginal populations since the British invaded Australia in 1788 [6, 10]. These health gaps are highlighted by the gap in life-expectancy between Aboriginal and non-Aboriginal Australians, with Aboriginal children born between 2010 and 2012 expected to live 10.05 years younger than non-Aboriginal children [12]. Furthermore, social and economic disadvantage have been underscored as significant contributing factors to these poor health outcomes [7]. Therefore, social determinants of OM in Aboriginal children need to be better understood in light of evidence supporting the impact of poor housing, exposure to tobacco smoke and socioeconomic disadvantage on the prevalence and persistence of OM in Aboriginal children.

This review aims to identify how social determinants are addressed in grey and peer-reviewed literature, regarding drivers of OM and proposed interventions aimed at minimising the health burden of OM among Aboriginal children. This review aims to identify gaps in the literature and guide further research, policy development and service provision.

Methods

Given the broad nature of the research objective, a scoping content review was conducted to explore available research, to evaluate the need for further investigation, to describe key themes and to identify gaps in the literature. The framework proposed by Arksey and O'Malley [13] for conducting a scoping content review was adapted for this study and is detailed below.

Research question and search strategy

Initially, the research objective was established through preliminary review of the literature and discussion between the research team. Following the establishment of the research objective, the search strategy was developed by implementing inclusion and exclusion criteria, and keywords (see Table 1). The location was limited to Australia, the included literature was limited to English only and no time constraints were placed on the date of publication. The population of focus was established by two criteria: individuals of Australian Aboriginal identity and children aged 12 years old or younger. Health condition terms related to OM and ear disease. Literature type included peer-reviewed and grey literature.

The literature search was conducted in April 2017. Keywords were established and agreed upon by the research

Table 1 Search Strategy and Keywords

Parameters	Inclusion	Exclusion	Keywords
Location	Australia	Outside Australia	(Abstract) Australia OR "New South Wales" OR NSW OR Queensland OR QLD OR Victoria OR VIC OR Tasmania OR TAS OR Adelaide OR "Northern Territory" OR NT OR "Western Australia" OR WA
Language	English	Not written in English	Select for English only
Time	Any	None	N/A
Population	Aboriginal and Torres Strait Islander Children/Aboriginal Children 0–12 years old in Australia.	Non-Aboriginal Australians of any age or Aboriginal individuals older than 12 years old.	(Title) Aborigin[a] OR "Torres Strait Islander" OR "Indigenous Australian" OR "Native Australian" AND Child[a] OR Infant[a] OR Infancy OR Kid[a] OR Neonate[a] OR Toddler[a] OR Baby OR Babies OR Pediatric OR Paediatric
Health condition	Otitis media and ear disease-related pathology	Not concerned with otitis media or ear-disease-related pathology	(Title) "Otitis media" OR "Middle ear" OR "glue ear" OR "ear infection" OR Ear OR Hearing OR "bulging eardrum"
Literature type	Published primary research and grey literature (including qualitative, quantitative and mixed method design) included in databases indicated[a].	Published literature not included in the databases indicated.	N/A

Google Scholar Modified Search

1. Australia AND Aborigin[a] OR "Torres Strait Islander" OR "Indigenous Australian" OR "Native Australian" AND Child[a] OR Infant[a] OR Infancy OR Kid[a] OR Neonate[a] OR Toddler[a] OR Baby OR Babies OR Pediatric OR Paediatric AND "bulging eardrum"

2. Australia AND Aborigin[a] OR "Torres Strait Islander" OR "Indigenous Australian" OR "Native Australian" AND Child[a] OR Infant[a] OR Infancy OR Kid[a] OR Neonate[a] OR Toddler[a] OR Baby OR Babies OR Pediatric OR Paediatric AND "Otitis media"

3. Australia AND Aborigin[a] OR "Torres Strait Islander" OR "Indigenous Australian" OR "Native Australian" AND Child[a] OR Infant[a] OR Infancy OR Kid[a] OR Neonate[a] OR Toddler[a] OR Baby OR Babies OR Pediatric OR Paediatric AND "Middle ear"

4. Australia AND Aborigin[a] OR "Torres Strait Islander" OR "Indigenous Australian" OR "Native Australian" AND Child[a] OR Infant[a] OR Infancy OR Kid[a] OR Neonate[a] OR Toddler[a] OR Baby OR Babies OR Pediatric OR Paediatric AND "ear infection"

5. Australia AND Aborigin[a] OR "Torres Strait Islander" OR "Indigenous Australian" OR "Native Australian" AND Child[a] OR Infant[a] OR Infancy OR Kid[a] OR Neonate[a] OR Toddler[a] OR Baby OR Babies OR Pediatric OR Paediatric AND "glue ear"

[a]**Databases**: PubMed, ProQuest, Scopus, Informit, Medline and Google Scholar

team with the assistance of university library staff for the parameters: location, population and health condition. The selected databases were chosen upon consensus and the search was conducted independently by each research team member and the assisting librarian to limit bias. Boolean operators were applied in the literature search within PubMed, ProQuest, Scopus, Informit, Medline and Google Scholar. For the Google Scholar literature search, multiple searches were conducted due to search box restrictions (see Table 1). Location keywords were substituted by selecting results from Australia only and each of the OM-related terms were searched for separately. The population keywords were searched with Boolean operators consistent with other database searches and is detailed in Table 1.

Selecting literature

The first step in selecting the literature was to exclude any duplicate papers. This was done using EndNote (electronic referencing software). Google Scholar results were limited to the first two pages, given the large number of results yielded and time constraints for conducting the literature search. An Excel spreadsheet was created to categorise the literature based on the following parameters: author, title, year, within Australia, 'Aboriginal-related term', 'OM-related term' and full text available. The literature was then systematically evaluated based on these criteria and included or excluded accordingly. Where there was any uncertainty regarding the suitability of an article, consensus on whether to include the article(s) was reached by the research team.

Collating, Analysing and reporting results

Following selection of the included literature, two separate Excel spreadsheets were created to analyse and report the results. One spreadsheet contained the peer-reviewed

literature and the other contained the grey literature. The articles were systematically analysed based on the following parameters: 'are social determinants mentioned?', 'what section are social determinants mentioned?', 'what social determinants are mentioned?', 'are social determinants mentioned as drivers of OM?', 'are social determinants discussed in regards to interventions for OM?', 'what is discussed in regards to future directions?', 'are interventions related to social determinants or mentioned but not fundamental to the discussion or conclusion?', and 'are social determinants related to one of three key areas of the Aboriginal and Torres Strait Islander social determinants of health framework?'- adapted from Department of Health and Ageing (Health*Info*Net) [14], as shown in Fig. 1.

Results

The literature search was conducted using six specified databases and the exclusion process is detailed in Fig. 2. The search yielded 186 results, 69 duplicates were excluded and a further 19 articles were excluded based on location of the studies. 98 articles were screened by title and article type, with 47 excluded based on irrelevance of the title and one article was excluded due to the article type (unpublished thesis). Following the screening process, 50 articles were included in the study. Of the 50 included articles, 40 were peer-reviewed and 10 were grey literature articles.

Drivers and intervention

Following the exclusion process, the included literature was evaluated by how OM related social determinants were addressed. 34 (68%) peer-reviewed and grey articles were identified as discussing social determinants, with 17 (34%) discussing social determinants as a significant factor for driving the high rates of OM and 17 (34%) articles identifying the need to address social determinants to reduce the high rates of OM in Aboriginal children. Of the 17 articles that discuss social determinants as important for OM management, 11 articles did not discuss this in detail - these articles did not provide specific recommendation or evidence for further research and policy development. For example, Sparrow et al. [15] (p14) state "the key to improving chronic middle ear disease must be by addressing living standards and general health". Although this type of statement is true and does acknowledge an important issue, the article does not pursue this theme further.

Further evaluation of the literature revealed that 16 (32%) articles did not mention social determinants at all, with four articles (8%) providing analysis of social determinants of OM. These four articles presented social determinants as key priority areas for future intervention and provided supported recommendations to help address social determinants linked to OM. For example, Jacoby et al. [16] (p602) state "there is a need for more input by Indigenous Australians in developing programs, increased funding and improved access to nicotine replacement therapy". Lastly, the most significant finding was that despite the majority (68%) of the literature discussing social determinants as impacting the presence of OM in Aboriginal children, there were no studies within the literature that proposed or investigated a social determinants-focussed intervention.

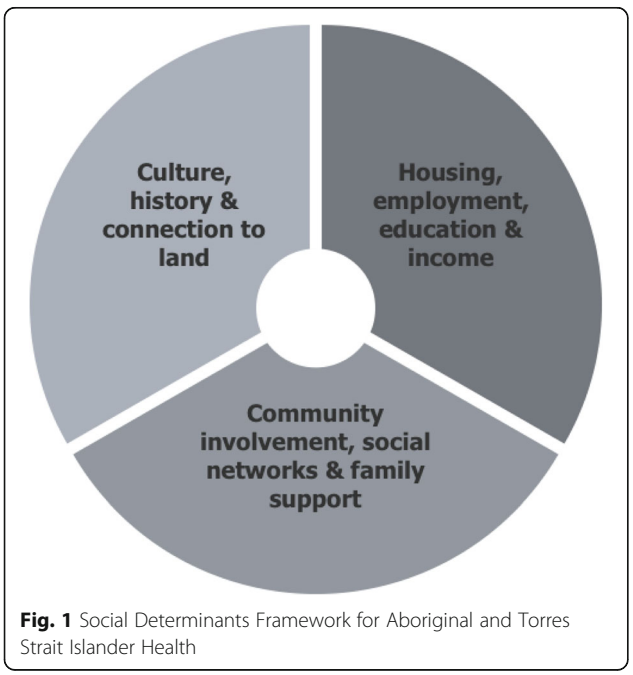

Fig. 1 Social Determinants Framework for Aboriginal and Torres Strait Islander Health

Aboriginal and Torres Strait islander social determinants of health framework

In addition to the social determinants-related scoping criteria, the literature was comprehensively assessed using the 'Social determinants framework for Aboriginal and Torres Strait Islander health'. [14] The social determinants of health framework identifies three key areas of health for Aboriginal populations, with the literature addressing 'housing, employment, education and income' most frequently (32%) in relation to high rates of OM in Aboriginal children. 'Community involvement, social networks and family support' were discussed by few articles (16%) and even fewer mentioned 'culture, history and connection to land' (8%). Moreover, over 50% of the peer-reviewed articles ($n = 22$) did not address any of the three key areas of the social determinants of health framework.

Social determinants

Housing-related social determinants were reported most frequently within the literature, with 28 (56%) reports of housing related risk factors for OM (18 specifically related to overcrowded housing). The next most frequently discussed social determinant was exposure to tobacco

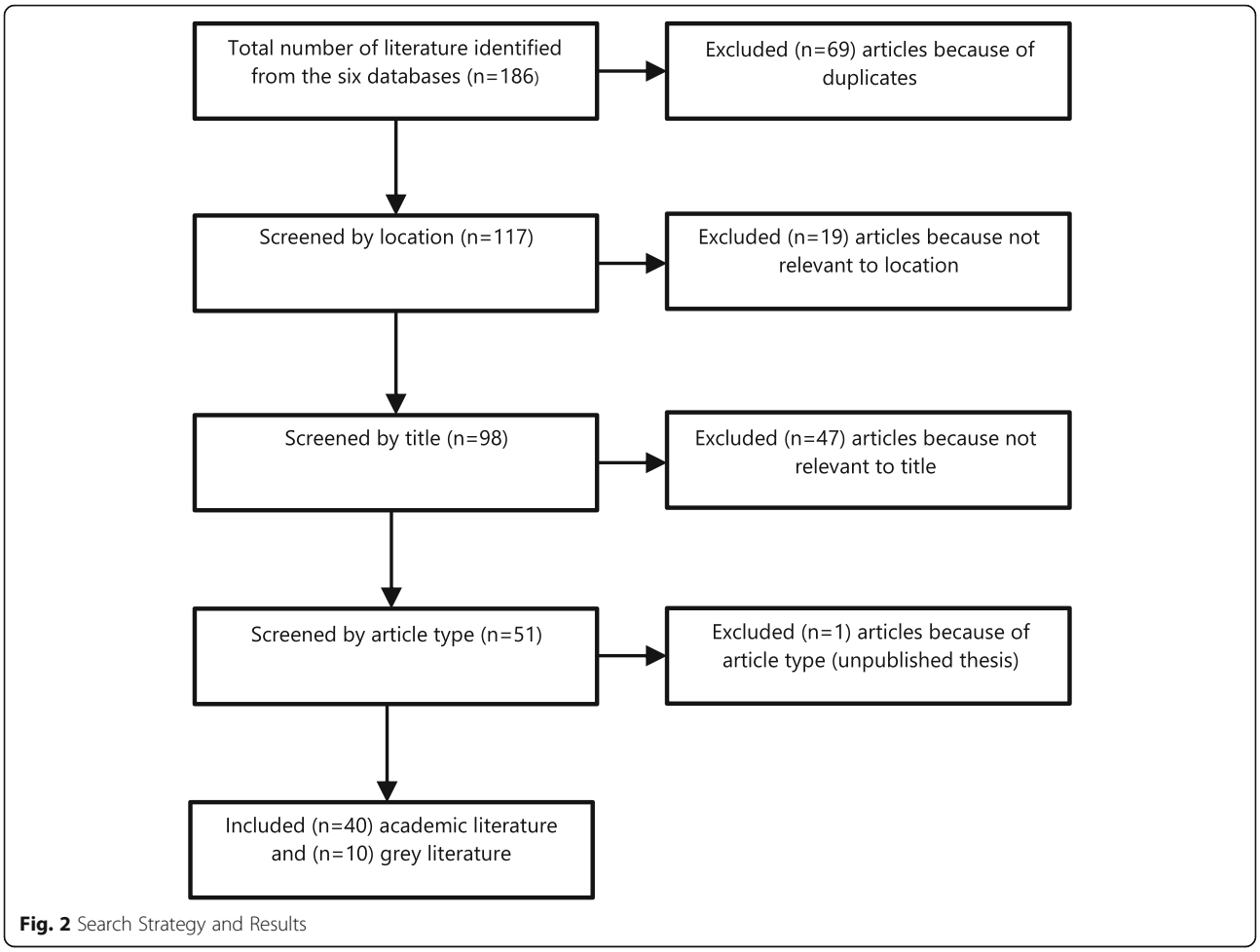

Fig. 2 Search Strategy and Results

smoke, with 11 articles (22%) discussing this as a significant determinant for OM. Low socioeconomic status, low income and poverty (20%), access to services (18%), hygiene (16%), and education of the primary caregiver (14%) were among the most frequently mentioned determinants. Other reported determinants for OM were employment status and employment opportunities (12%), nutrition (12%), community involvement in service provision and planning (6%), and cultural and language differences ($n = 4$). Sun et al. [17] (p8) explain that improved housing for Aboriginal populations is desperately needed, as "overcrowding is the single most important and most consistent risk factor for upper respiratory tract carriage (presence of bacteria), and consequently, the development of OM in Indigenous children". It is therefore important to note, that of the 40 peer-reviewed articles, only Jacoby et al. [18] examined overcrowded housing and its impact on OM associated bacterial carriage. Jacoby et al. [18] provide thorough analysis on aspects of overcrowding, such as the number of adults, children and rooms within a household and its impact on OM occurrence. More specifically, the greater the number of people, the greater the number of children and the fewer rooms within a house, the greater the risk of developing OM [18]. Unfortunately, this article did not identify any means to address these issues and only highlights the seriousness of the housing problems faced by many Aboriginal communities.

Future directions

A detailed analysis was performed on what recommendations were made in the literature (i.e. review of the recommended approaches to the management of OM in Aboriginal children). 31 (62%) of the peer-reviewed and grey articles did not discuss social determinants in future directions at all. 23 articles (46%) primarily recommended further research into antibiotic treatment and vaccine development, and the need for greater understanding of OM associated bacterial carriage. Five (10%) articles presented detailed recommendations for future research and policy development intended to address social determinants to reduce the high rates of OM in Aboriginal children.

Discussion

OM is one of the leading causes of preventable disease amongst Aboriginal children, and has been determined by The World Health Organisation to be a serious public health issue requiring urgent attention [1–3, 11]. OM primarily occurs during developmental years and can drastically impact upon speech and language development, which is likely to influence educational outcomes and prospective employability- precursors to potentially life-long socioeconomic disadvantage and poverty [5].

This study identifies how social determinants are addressed within grey and peer-reviewed literature, and summarises the primary determinants reported to be associated with OM and management recommendations within the literature. This study highlights gaps between factors reported to be associated with OM and recommended interventions within the literature. Given the significance of this gap, further research aimed at understanding social determinants associated with OM and identifying more effective management of the social determinants of OM within Aboriginal children is warranted. Furthermore, the inter-related nature of the social determinants of health is emphasised throughout this paper and helps to underline the challenge that an exclusively biomedical model poses in addressing specific aetiology [19].(p73–74)

Notably, a shift in approaches to manage OM is desperately needed, in conjunction with further research to better understand the relationship between the social determinants of health and risk of OM in Aboriginal populations. This review demonstrates that there is an imbalanced research focus towards biomedical approaches in contrast to improving our understanding about how to address key social determinants contributing to high rates of OM in Aboriginal children. Using the social determinants of health framework, this review has identified significant shortcomings within the literature and the current public health management of OM in Aboriginal children. The social determinants of health framework used within this study identifies three key areas of Aboriginal health that are largely neglected by the available grey and peer-reviewed literature in relation to OM management. Although the literature mentions various social determinants that are consistent with the framework (e.g. housing, education, employment, community engagement, culture and history), none of the included articles evaluated these key areas of Aboriginal health with the objective to establish effective social, environmental, political or cultural-focussed interventions for OM. Further, the key social determinants of OM can be argued to stem from the persistent social, economic and cultural discrimination experienced by Aboriginal populations. Through evaluation using the social determinants of health framework, this review highlights the need to preserve Aboriginal culture, strengthen Aboriginal self-determination, respect and support Aboriginal connection to land, empower Aboriginal communities, improve education and employment opportunities for Aboriginal people, and address poor housing conditions and overcrowding within Aboriginal communities. Importantly, one of the most significant and achievable goals should be to ensure the adoption of co-creation and a decolonised approach to ear health research, and health research more broadly, in Aboriginal populations. Aboriginal self-determination and services that are embedded within community are key to improving the management of OM within Aboriginal populations [20]. Such an approach is needed to help ensure success of public health programmes and services aimed at reducing the risk of OM in early life, and consequently helping to eliminate the cycle of disadvantage that contributes to social determinants driving ill-health across the life-course. Measurement of such targets should be done through formal and informal consultation with community at each step of the research process. There is growing acknowledgement within the literature that the current empirical research paradigm should adopt co-creation and qualitative research methods, in conjunction with quantitative methodology, to ensure successful research and research translation within Aboriginal communities [20]. Furthermore, recognising Aboriginal people as experts of their communities is vital to ensure successful planning, development, implementation and evaluation of health research and health approaches within Aboriginal contexts.

The most evident theme arising from this review was the importance of the home environment, with housing-related determinants reported almost three times more than the next most frequently reported risk factor. Despite acknowledgement of the association between housing and the prevalence of OM in Aboriginal children, there were no intervention studies within the reviewed literature that investigated how to effectively address the issue of housing in Aboriginal populations. Exposure to cigarette smoke and poor hygiene were not directly acknowledged as relating to housing within this review. However, these risk factors are likely to be influenced to some degree by the home environment, given the relatively high rates of smoking within the home in Aboriginal populations [15, 16]. It is therefore evident, that addressing the home environment is fundamental to adequately manage OM in Aboriginal populations. Moreover, further research into housing as a determinant of OM and as a means for intervention is desperately needed, given the lack of information available to adequately deal with this area of Aboriginal health. Addressing housing issues in Aboriginal communities is a complex issue, particularly when considering the importance of connection to land in contrast with the importance of the physical structure itself. It can be said that

the efforts of government housing programmes have been heavily focussed on the logistics. For example, funding and physical infrastructure, with little acknowledgement of the need to develop culturally appropriate housing policies and pathways [21]. (p207) Carson et al. [21] (p219) stress the lack of intervention studies that link housing to Aboriginal health outcomes and the ability to develop policy is limited as a result. The lack of intervention studies is also highlighted by this review, as no intervention studies looking at social determinants and Aboriginal health outcomes were identified within the literature. Intervention studies are crucial for policy development and although remoteness, and political and social barriers exist for improving housing and infrastructure in Aboriginal communities [21], a shift in focus towards more culturally appropriate housing policy and provision is urgently needed.

Exposure to tobacco smoke is consistently reported as a key contributing factor for Aboriginal children developing OM. Aboriginal children who are exposed to tobacco smoke in the home and who do not attend day-care have been suggested to be at greatest risk of developing OM [18]. This is not to say that home-care by parents and family is problematic. However, given the relatively high rates of smoking within the home environment [18], it is an important issue for consideration. Jacoby et al. [18] suggest that children who are exposed to tobacco smoke in the home who also attend day-care may be at lower risk of developing OM, presumably because the time spent at day-care means less time exposed to tobacco smoke in the home. However, day-care attendance has previously been associated with a greater risk of OM, and further research may help to explain this relationship. Moreover, this inconsistent research helps to highlight the evident gaps within the literature resulting from the long-standing narrow lens of the biomedical focus of the existing research. Furthermore, this supports calls for further investigation into the relationship of the social determinants of health and environmental factors with OM risk in Aboriginal children.

Education and employment of the primary caregiver is cited frequently as an important determinant for Aboriginal children developing OM. However, no paper within the reviewed literature discussed this any further than listing it as a significant contributing factor. It is important to highlight that low-level education and lack of employment opportunities consign many Aboriginal people to levels of poverty [22]. (p108) Furthermore, education that excludes culture and native language has been demonstrated to adversely impact individuals by disempowering Aboriginal communities and harming the cultural identity of these communities [21]. Moreover, hearing loss associated with OM is likely to further disengage children within the classroom, and this is compounded by lack of engagement due to hearing loss being misconstrued as misbehaviour. It is therefore clear, that Aboriginal children face significant barriers within the classroom and highlights the need for culturally appropriate schooling, accompanied by approaches to reduce rates of OM and hearing loss. Notably, there were no papers identified within this review that comprehensively evaluated the impact of OM across the life-course, including the impact of OM on speech, language and early childhood development, which may impact educational outcomes and long-term social and emotional wellbeing.

Aboriginal community involvement is an area that requires greater emphasis and encouragement from public health promoters, policy makers and service providers. Programmes such as the 'Healthy Ears, Happy Kids', [9] 'Aboriginal Otitis Media Project' [23], 'Hearing, Ear Health and Language Services' ('HEALS') [24] and 'Deadly Kids, Deadly Futures' [25] help to draw attention from government and non-government organisations towards the seriousness of the burden of OM in Aboriginal communities. 'HEALS' and 'Deadly Kids, Deadly Futures' have helped to demonstrate priority areas for the public health management of OM in Aboriginal communities, in addition to recommendations about key research considerations when working with Aboriginal communities. Priorities include working towards improved coordination, access and delivery of services, enhancing capacity building within communities, and Aboriginal control of research activities and translation [24, 25]. Furthermore, these programmes have helped to educate and empower Aboriginal communities and health workers to manage OM more effectively in a culturally safe way [9, 23, 24]. Given the historical marginalisation, neglect and subjugation of Aboriginal populations, empowering Aboriginal communities to manage health services, develop and implement research, and provide recommendations is essential to overcome issues of mistrust, and consequently, improve cultural access to essential services. Importantly, 'Deadly Kids, Deadly Futures', which was not identified by the systematic literature search, provides a 'social determinants model of ear and hearing health' that highlights relevant social determinants of ear health for Aboriginal children [25]. This model may be useful to guide future research, policy development and the development of services. However, research focussing on how to best target these social determinants is lacking. Therefore, further work is needed to advance these programmes and identify how to effectively target the underlying social determinants of OM in Aboriginal children.

Despite the lack of research about how to effectively target the social determinants of OM, there is a growing body of research regarding diversifying health approaches to better address social determinants of health more broadly. The term 'Integrated models of care' has emerged within the literature, which describes the integration of biomedical

services with non-medical community services (e.g. housing, employment and food insecurity services) to provide a more comprehensive approach to target underlying risk factors for ill-health [26]. Using a similar approach, it is recommended that tools to screen for social determinants associated with OM are developed. This will assist health workers to identify and target important social, environmental and cultural risk factors associated with OM [27, 28]. Information obtained through this type of screening may provide health workers with relevant information to refer at-risk children to community services, in conjunction with traditional medical management, to help alleviate factors placing a child at heightened risk. This process has been referred to as 'social prescribing' and aims to broaden the often-narrow focus of biomedical intervention alone [28]. Therefore, it is recommended that future research looks at 'integrated models of care' and 'social prescribing', and how they can be incorporated into primary care management of OM and ear disease. Additionally, service coordination is key for successful navigation of healthcare systems and referral pathways, which are often complex. By integrating a wider variety of services in the primary care of OM, such as housing or employment services, the need for coordination is particularly important to support the implementation of such models [24, 28].

While this review presented a comprehensive analysis of both peer-reviewed and grey literature, this study excluded unpublished masters and doctoral theses. Despite this, findings by Vickers and Smith [29] following review of the Cochrane Library, found only one of 878 systematic reviews included data from theses that could have significantly altered the conclusions of the 878 reviews. Moreover, there is limited benefit of including theses in systematic reviews, as they rarely influence the conclusions, and retrieving and analysing unpublished dissertations involves considerable time and effort [29]. The timeframe of this project also limited the number of selected databases and consequently the number of papers that were included within the study. However, 50 articles still provides comprehensive scope of the literature to enable thorough analysis, detailed explanation and well supported recommendations. Using Google Scholar presented limitations in search function, as search box options within the database meant that a modified search was needed to fulfil the specified search strategy and to remain consistent with searches performed on the other selected databases.

Conclusion

There is overwhelming consensus within the reviewed literature that Aboriginal children experience disproportionately high rates of OM when compared to non-Aboriginal children. The high rates of OM are linked to poor housing conditions, overcrowded housing, exposure to tobacco smoke, education, and overall social and economic disadvantage. Furthermore, there is disparity between reported risk factors of OM and current interventions aimed at reducing the burden of OM in Aboriginal populations. Current interventions are primary focussed on biomedical approaches such as investigating vaccines and antibiotics. Although vaccines and antibiotics are essential to the provision of high-quality clinical care for OM, a broader public health lens is required to address the underlying social factors reported to be driving the gap in OM rates between Aboriginal and non-Aboriginal children. It is important to mention that the Aboriginal understanding of health includes "body, mind, spirit, land, environment, custom, socioeconomic status, family and community" [10]. (p417) This understanding of health significantly differs from mainstream models of health, which typically involves the pursuit to merely limit ill-health within individuals without considering the context of their lives [10]. Therefore, policy and services founded upon this restricted understanding of health is likely to be restrictive in its ability to address the much more holistic Aboriginal understanding of health, which includes how people live, work and interact with their environment, and the importance of community for the individual. In accordance with this notion, engaging communities in research design and implementation is fundamental to shift the current research paradigm. Understanding the context of Aboriginal lives is key for successful research and meaningful translation of research. Further research into how social determinants contribute to OM and what interventions may be beneficial to address OM associated social determinants in Aboriginal children is needed. Intervention studies to evaluate the benefit of culturally suitable, accessible and safe housing on rates of OM in Aboriginal communities is vital. Lastly, development of an Aboriginal ear health framework is recommended. Development of a comprehensive ear health framework requires further research, although should include information about social determinants of health screening, social prescribing, and coordinating the complex network of health and community services that may help to address underlying social determinants of OM.

Recommendations and Future Directions

Research evaluating the association between social determinants of health and risk of OM in Aboriginal children

Research evaluating the consequences of OM across the life course

Development of a co-created social determinants of ear health framework including:
- The development of social determinants of health screening tools
- The development of a social prescribing model
- The development of a service navigation and coordination model

Evaluate if approaches targeting the social determinants of ear health reduce rates of OM in Aboriginal children

Abbreviations
OM: Otitis Media; Aboriginal and Torres Strait Islander: Aboriginal

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All authors have read and approved the final manuscript. **JD:** protocol development, literature search, data collection, data collation, data analysis, interpretation of results and was the major contributor to writing the manuscript. **TD:** protocol development, literature search, interpretation of results, reporting of results and contributed to writing the manuscript. **JM:** literature search, interpretations of results, reporting of results and contributed to writing the manuscript.

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Publisher's Note

2.4.3 Summary of paper and its significance to thesis

Key research, service provision and policy gaps were identified from this review. Namely, there was an overwhelming consensus that social determinants are critical in creating existing ear health inequities for Aboriginal and Torres Strait Islander children in Australia. However, this review identified that at the time there were no evaluated approaches to ear health published within the literature targeting social determinants of health. These findings highlighted the need to explore the relationship between social determinants and ear health within Aboriginal and Torres Strait Islander children and identify best practice models of care that address these underlying determinants of ear health. These findings provide the context, rationale and foundation for this thesis.

2.5 Aboriginal and Torres Strait Islander ear health and hearing

Globally, ear health for Indigenous children is a public health priority due to the high prevalence of otitis media and associated hearing loss. Otitis media, particularly chronic suppurative otitis media, disproportionately impacts Indigenous children and can lead to long-term consequences for educational outcomes, social and emotional wellbeing and health and wellness into adulthood.[118-120] This section describes ear health and hearing among Indigenous populations, including epidemiological data that highlights disparities in ear health outcomes. Furthermore, this section focusses on ear health and hearing within Aboriginal and Torres Strait Islander populations in Australia, including relevant underlying determinants of otitis media and Australia-wide ear health research projects and models of care.

2.5.1 Ear health and hearing within Indigenous populations

2.5.1.1 International summary

Otitis media is a prevalent health issue among Indigenous children globally, with otitis media having significant impacts on health and wellbeing.[118-120] Epidemiological data highlights a substantially higher burden of otitis media within Indigenous versus other communities, emphasising the need for targeted approaches and healthcare strategies.[120] Colonisation and its detrimental impact on the health and wellbeing of Indigenous populations is not unique to Australia. Countries such as the United States of America, Canada and New Zealand experience similar disparities in ear health outcomes.[121] Importantly, the cultural context is

important to understand when considering the impact of otitis media for Indigenous populations. Hearing is deeply intertwined with cultural practices, language preservation and storytelling traditions within Indigenous communities who are disproportionately impacted by otitis media.[67, 69, 78, 80, 122] Therefore, addressing otitis media and its consequences requires consideration for culture and tradition, acknowledging the importance of hearing and communication in preserving cultural identity and fostering wellbeing.

2.5.1.2 Australian overview

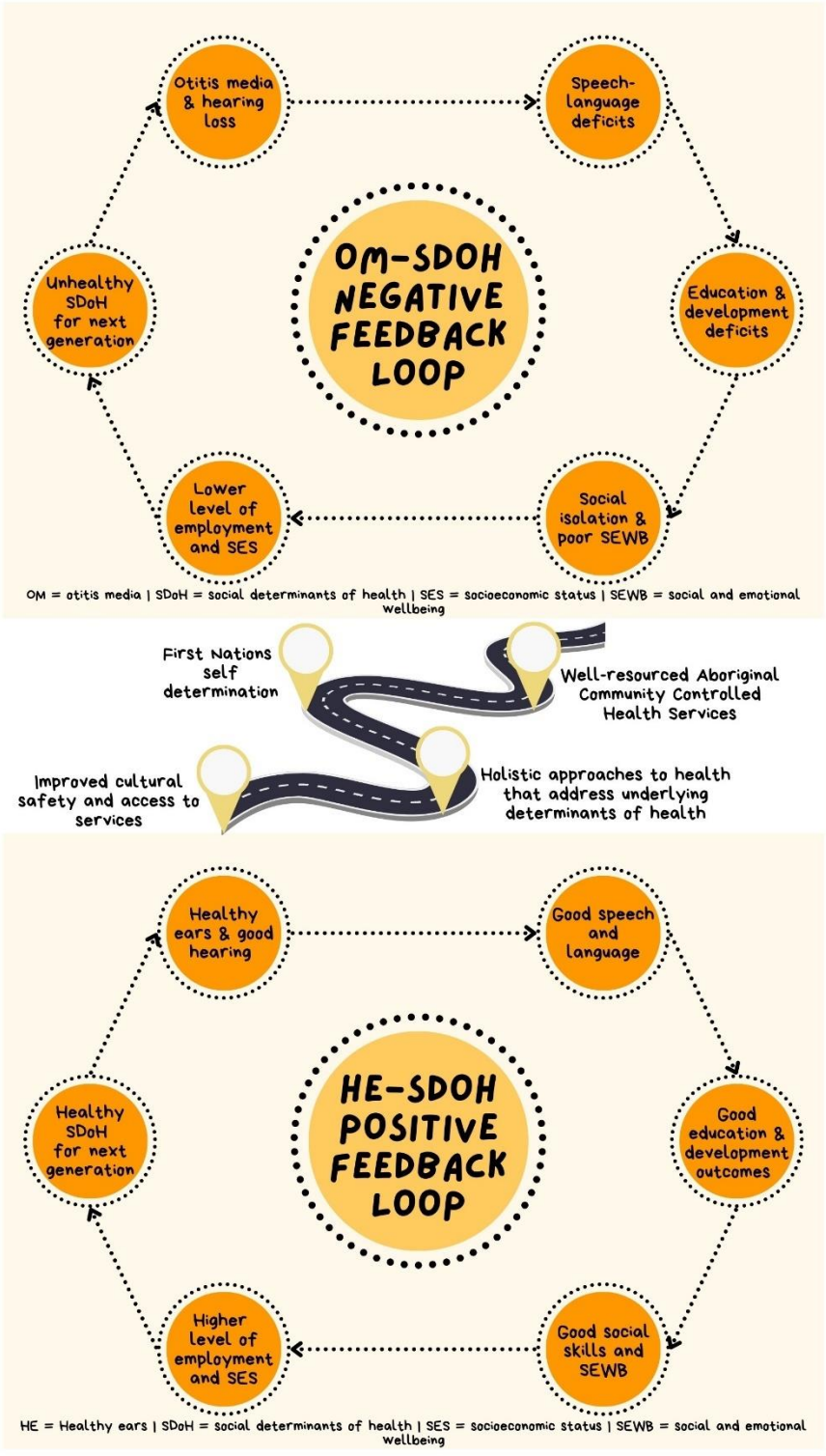
Aboriginal and Torres Strait Islander children experience the highest rates of otitis media globally, and experience otitis media that is generally more severe, more frequent and longer lasting than any other population in the world.[123] Prevalence in Aboriginal and Torres Strait Islander children in Australia varies between communities, with reported rates varying between approximately 20% and 90%.[124, 125] Furthermore, chronic suppurative otitis media rates in the Northern Territory and Central Australia have been reported to be approximately 15%.[126] These rates are of particular importance when we consider the World Health Organisation warn that rates of chronic suppurative otitis media higher than 4% within a population indicate a major public health problem requiring urgent attention.[127] Furthermore, Aboriginal and Torres Strait Islander children are around five times more likely to be diagnosed with severe otitis media (i.e. chronic and/or suppurative and/or perforation) than non-Aboriginal children in Australia.[128] Alarmingly, this is likely an underrepresentation of the inequality in otitis media prevalence, as Aboriginal and Torres Strait Islander children, regardless of remoteness, have been shown to have poorer access to otitis media-related services, meaning less access to otitis media diagnosis.[129-132]

2.5.1.3 Why is this important?

As discussed in Section 2.3.5, early years and months of life are critical for cognitive, auditory processing, and speech-language development.[92] The peak prevalence of otitis media and associated hearing loss within Aboriginal and Torres Strait Islander populations occurs during these key developmental years and months (five to nine months of age in Aboriginal and Torres Strait Islander children in Australia), with early exposure often occurring only weeks after birth.[133] Such exposure early in life can significantly hinder developmental trajectories and can be a precursor to lifelong disadvantage.[83, 84, 86, 105, 108, 110, 112] Moreover, otitis media and hearing loss in Aboriginal and Torres Strait Islander populations has been shown to negatively impact social and emotional wellbeing, and increase the risk of behavioural

problems, social isolation and problems in school.[113-116] Auditory processing and developmental delays are often hidden problems that can have serious consequences across the life-course.[95, 96] Aboriginal and Torres Strait Islander people who experience otitis media, associated hearing loss and developmental delay at a young age are more likely to have lower levels of employment, lower income and increased contact with the justice system.[84, 134] This highlights the negative feedback loop that can occur, with otitis media in childhood contributing to poorer health and social conditions in adulthood, that may ultimately contribute to poorer social determinant of health for the next generation. Without adequate approaches to address these underlying determinants, this cycle will continue. Conversely, positive feedback loops can also occur, where healthy environments and positive social determinants of health ensure healthy ears for children to thrive into adulthood, and consequently, contribute to healthy environments and positive social determinants for the next generation. Our goal must therefore be, to reorient these negative feedback loops to positive ones (see Figure 2.6)

Figure 2.4: Moving from a negative to positive social determinants of ear health feedback loop



2.5.2 Aboriginal and Torres Strait Islander ear health projects in Australia

Given the public health importance of otitis media and ear health for Firs Nations children in Australia, there are a growing number of ear health programs, in addition to Hearing EAr-health speech and Language Services ***(Chapter 1.4.2)*** and Aboriginal Community Controlled Ear-health Support System ***(Chapter 1.4.3)***, aimed at improving access to services and addressing underlying risk factors. Importantly, these programs are increasingly community-led and provide useful insights into how to better support Aboriginal and Torres Strait Islander communities to manage childhood otitis media and hearing loss. However, none of these programs have reported an impact evaluation, limiting our understanding of their effectiveness. Given the complexity of otitis media and diversity of Aboriginal and Torres Strait Islander communities, insights from these approaches are important for the development of wide-scale and adaptable ear health initiatives (i.e. upscaling approaches from the local level to state and national levels) to ensure universal access for all Aboriginal and Torres Strait Islander children.

2.5.2.1 Deadly Ears

The Deadly Ears project is an initiative based in Queensland, that focuses on addressing otitis media among Aboriginal and Torres Strait Islander children. It aims to improve ear health outcomes through various strategies such as early detection, comprehensive management, community education, and capacity building among healthcare providers and communities. The project involves collaboration with local communities, health services, and educational institutions to implement culturally appropriate interventions and support systems for children affected by otitis media.[135]

2.5.2.2 Hear our Heart Ear Bus

The Hear Our Heart Ear Bus is a mobile healthcare initiative in Australia that provides ear health services to remote and underserved communities, particularly focusing on Aboriginal and Torres Strait Islander populations. The bus is equipped with medical facilities and staffed by healthcare professionals, including audiologists and nurses, who conduct ear examinations, screenings for hearing loss and otitis media, and provide education on ear health and prevention strategies. The aim is to improve access to ear health services and reduce the impact of hearing-related issues in these communities.[136]

2.5.2.3 PLUM & HATS

The Parent-evaluated Listening and Understanding Measure (PLUM)[137] and Hearing And Talking Scale (HATS)[138] are questionnaires that assist healthcare and early childhood professionals in discussing and assessing a child's listening and communication skills with parents or caregivers. The PLUM, with 10 questions, identifies listening difficulties, while the HATS, with 5 questions, detects communication challenges. These tools are user-friendly for individuals without specialised training in hearing or language assessments, such as primary health workers and early educators. They employ a picture format to engage parents or carers in conversations about their child's daily listening and talking activities. Validated for use with Aboriginal and Torres Strait Islander children under 6 years old across different community settings, including urban, rural, and remote areas, the checklists can also be used with families speaking any language, utilising interpreters when necessary. Both checklists have a high accuracy rate (>80%) in identifying children who may require further professional assessment for hearing or communication issues.[137, 138]

2.5.2.4 HAPEE

The Hearing Assessment Program Early Ears (HAPEE)[139], administered by the Commonwealth Department of Health, targets Aboriginal and Torres Strait Islander children between zero and six years old who are not yet attending full-time school. This program offers free services, including age-appropriate hearing tests and assessments of middle ear function. HAPEE[139] employs Aboriginal and Torres Strait Islander Community Engagement Officers to foster meaningful local engagement by partnering with Aboriginal Community Controlled Health System, primary health clinics, early education providers, and key stakeholders. They support the establishment of hearing assessment clinics in collaboration with Hearing Australia and conduct awareness-raising activities within the community to promote the significance of ear and hearing health.[139]

2.5.2.5 Hearing for Learning Initiative

The Hearing for Learning Initiative (HfLI)[140] is a program aimed at improving services for Aboriginal and Torres Strait Islander children with ear and hearing issues. It seeks to integrate local Ear Health Facilitators into existing services across 20 communities, employing up to 40 part-time facilitators and screening 5,000 children aged zero to 16 years over five years. The reported goal of the project is to establish reliable, culturally appropriate services to

ensure optimal ear health for participating children. Furthermore, the initiative will evaluate the impact of enhanced ear health services on children's health and education outcomes.[140]

2.5.2.6 HEAR Improving pathways for otitis media project

Hearing Education Application Research (HEAR) is a Macquarie University based research group. HEAR employs multidisciplinary and community-engaged strategies to address significant hearing health issues. In collaboration with three Aboriginal Community Controlled Health System across urban, rural, and remote regions, HEAR researchers are undertaking a project called *"Improving care pathways for treating otitis media in Aboriginal children (aged zero to 12 years): A case study approach".* This project plans to utilise the World Health Organisation framework for health systems performance to analyse the current healthcare system addressing otitis media in Aboriginal and Torres Strait Islander children. Subsequently, in collaboration with these communities, they will co-create, implement, and evaluate a novel strategy for early and efficient detection and treatment of hearing loss.[141]

2.5.2.7 Djaalinj Waakinj

Djaalinj Waakinj is a cohort study of young urban Aboriginal and Torres Strait Islander children collecting data on otitis media prevalence, risk factors and consequences. Djaalinj Waakinj is tracking Aboriginal and Torres Strait Islander children residing in the South Metropolitan area of Perth from birth until 12 months old, investigating the prevalence of ear disease and the factors contributing to why certain children are more prone to developing otitis media compared to others.[142-145]

2.5.2.8 WATCH

The WATCH[146, 147] trial is a non-inferiority randomised controlled trial to identify whether watchful waiting is an acceptable alternative to immediate antibiotic prescription for acute otitis media without perforation among Aboriginal and Torres Strait Islander children 2-16 years living in urban settings. WATCH will also evaluate the cost effectiveness of the Watchful Waiting approach. The project will be conducted in collaboration with five Aboriginal Community Controlled Health Services and one Aboriginal and Torres Strait Islander health service and will employ a randomised control trial to compare Watchful Waiting with immediate antibiotic prescription within Aboriginal and Torres Strait Islander children aged two to 16 years with acute otitis media and considered low risk for complications.[146, 147]

2.5.2.9 INFLATE

The use of nasal balloon Autoinflation device has been found to be beneficial, non-invasive and low-cost.[148] INFLATE[148] aims to determine if nasal balloon Autoinflation is an effective therapy for Aboriginal and Torres Strait Islander children with otitis media with effusion. This initiative will contribute valuable evidence on safe, affordable, and accessible therapies for otitis media with effusion and help to bridge existing knowledge gaps in this area.[148]

2.5.2.10 Literature recommendations for ear health programs

Importantly, this list of programs is not exhaustive but provides an overview of well-established and promising ear health projects. A recent scoping review of ear health and hearing care programs for Aboriginal and Torres Strait Islander children identified twenty-one ear and hearing care programs.[149] Findings highlighted the challenge of sustainability, with funding being the major barrier to long-term success.[149] Furthermore, community involvement was identified as essential for most programs. However, involvement was reported to typically occur during implementation and not during other stages of program development.[149] Recommendations highlight the need for more robust co-creation throughout the life of future projects, including co-design, co-implementation, co-evaluation and co-translation.[149] Lastly, these projects are primarily focussed on clinical service delivery, with access the key social determinant of health addressed. However, as stated in the published systematic content review in ***Chapter 2.4***, there is a strong need to develop programs that target underlying social determinants of ear health and hearing.

2.5.3 Section 2.5 summary

The public and primary health approaches for otitis media among Aboriginal and Torres Strait Islander populations in Australia are diverse. There are a growing number of programs targeting ear health and hearing, with a strong focus on access to clinical services such as Audiology, Speech-Language and Ear, Nose and Throat surgery. However, there is a need to broaden these approaches to address other key social determinants of ear health, in addition to developing a better understanding of the complexity of service access for Aboriginal and Torres Strait Islander people. Notably, many projects had community involvement, with involvement primarily occurring during implementation. A stronger emphasis on co-creation throughout the life of these projects is recommended.

2.6 Health Navigators: addressing access barriers and social determinants of health

2.6.1 Overview

The social determinants of otitis media play a significant role in driving the high prevalence within Aboriginal and Torres Strait Islander communities in Australia. However, there are few known published and evaluated models of care that specifically target these underlying determinants. This section explores literature focussed on holistic approaches to primary care that target underlying determinants of health. Findings from the literature will inform the co-creation of the Aboriginal Community Controlled Ear-health Support System (ACCESS) project and importantly, guide the development of the Child Health Navigator model of care.

2.6.2 Aboriginal and Torres Strait Islander communities at the centre of care

Despite existing access barriers and underlying determinants of health, there is increasing awareness about how to more effectively support Aboriginal and Torres Strait Islander communities. Improving access is key.[150-152] Increasing access to services for Aboriginal and Torres Strait Islander communities should prioritise community and cultural awareness, education and involvement, with community guidance and collaboration playing a major role in advancing the cultural safety of health and community services.[151] These factors have been a central focus of Aboriginal Community Controlled Health Services, with Aboriginal Community Controlled Health Services playing a fundamental role in improving uptake of health services by Aboriginal and Torres Strait Islander people in recent years.[151] However, in 2012-13 around 45% of Aboriginal and Torres Strait Islander-focussed primary healthcare organisations were found in remote areas, despite 79% of Aboriginal and Torres Strait Islander populations in Australia residing in non-remote areas.[153] Furthermore, Lau et al[150] showed that there is a significant lack of information within the literature about how Mainstream Services in Australia can provide more culturally suitable and safe health services for Aboriginal and Torres Strait Islander populations. Notably, there is an apparent 'Inverse Care Law' in action across many Aboriginal and Torres Strait Islander communities. An 'Inverse Care Law' is when a population with greatest healthcare needs within society concurrently experiences the poorest access to healthcare.[150]

2.6.3 Focussing on the 'upstream'

Limited access for Aboriginal and Torres Strait Islander people can be seen throughout many domains of life, including limited access to ancestral lands, culture, education, employment opportunities, safe communities and healthy housing.[21] Simply put, Aboriginal and Torres Strait Islander people have had limited opportunity to fully participate in society in a way that supports their identity and overall wellbeing. It is from this perspective that understanding the notion of 'upstream' versus 'downstream' becomes an important distinction. The 'upstream' and 'downstream' analogy refers to looking at health as a continuum, with 'downstream' referring to addressing the symptoms and consequences of ill-health. Conversely, 'upstream' is where ill-health can be prevented, and good health can be promoted.[154] Importantly, 'upstream' factors include underlying social, environmental, historical and political determinants, and are key in preventing illness and promoting wellness for Aboriginal and Torres Strait Islander people.[21] There are many underlying determinants of health that contribute to the resilience and health of Aboriginal and Torres Strait Islander communities. Studies have identified that positive life circumstances, family and community wellbeing, kinship, identity and safe neighbourhoods are mediating factors for health and wellbeing in Aboriginal and Torres Strait Islander populations.[155, 156] Similarly, Brand et al[60] state that family and kinship, identity systems, community organisation, structural connections, activism networks and living in communities with many Aboriginal and Torres Strait Islander people play important roles in promoting health and wellbeing for Aboriginal and Torres Strait Islander people in urban communities. It is clear that social factors and support systems are fundamentally important for the health of Aboriginal and Torres Strait Islander people and therefore, the community and individual should not be viewed as innately separate.

2.6.4 Health Navigators and Indigenous Health Workers

Aboriginal Community Controlled Health Services provide promising examples of how to better integrate services, improve access to care and address social determinants of health.[28] Additionally, immerging evidence highlighting the effectiveness of Health Navigators and Aboriginal Health Workers to overcome social and systematic barriers, resulting in improved health and wellbeing.[28, 158-163] Heath Navigators, also known as Patient Navigators, Community Health Workers, Care Coordinators and Link Workers, have been acknowledged as helpful in overcoming barriers to service access and supporting the prevention of ill-health.[28, 158-163] Health Navigators can be described as individuals who support families and

patients to navigate health services, translate knowledge, and provide social, cultural and emotional support.[28, 158-163] McBrien et al[164p2] define Patient Navigators as non-clinically oriented personnel who help patients overcome modifiable barriers to service access. Health Navigators are reported to augment support for families by improving communication, providing culturally safe care, increasing appointment attendance and addressing family priorities.[161] Support from Health Navigators has been shown to save money, reduce unplanned hospital visits and missed school days, and improve accessibility of services.[158, 159, 162] A recent scoping review of Health Navigators supporting Indigenous people, not specific to child and adolescent populations, reported a significant absence of published literature within Australia and New Zealand when compared to countries with similar histories of colonisation.[161] Additionally, this review highlighted key roles for Health Navigators, which includes social service navigation, holistic support for Indigenous patients, advocacy and capacity building, health assessment, administrative navigation and community outreach.[161] However, despite existing literature on Health Navigators across general and certain targeted populations, there is scant evidence, including no known reviews, focussed on Health Navigators supporting Indigenous children and adolescents.

2.6.5 Section summary

Access barriers in addition to other social determinants of health contribute to ongoing health inequities within Indigenous populations globally. Health Navigators and similar health models have been shown to help families to overcome access barriers and address complex determinants of health. Therefore, the use and effectiveness of similar models of care within Indigenous health settings are immerging within the literature. However, data on navigation for Indigenous children, and specifically in relation to ear health are lacking. The ACCESS project, which is a major focus of this PhD thesis, is centred around a Child Health Navigator supporting Aboriginal and Torres Strait Islander children at risk of otitis media. This section provides an overview of the literature and helps to identify evidence gaps and opportunities for the co-creation and development of the ACCESS Child Health Navigator.

2.7 Theoretical and methodological approaches underpinning this thesis

Aboriginal and Torres Strait Islander research has historically been problematic and non-participatory. There is an immerging shift away from Western research paradigms, where research has been ‘done on’ communities rather than ‘done with’ communities.[39, 165-170] Co-

creation has been acknowledged as best-practice to support community members and service users to be active participants rather than passive end-users.[39, 165-170] This sections provides an overview of the broad methodological approach employed throughout this PhD project, ensuring research activities are culturally safe, community directed and participatory throughout every stage of research.

2.7.1 Decolonisation

2.7.1.1 Decolonising truth and history

There is general acceptance within public discourse in Australia that Western histories, politics, experience and academic norms are based on truth, despite failure to acknowledge conflicting historical and present realities.[171] Failure to acknowledge true history is closely tied to the dispossession and disempowerment of Aboriginal and Torres Strait Islander people, and colonisation.[5, 32, 172] Colonisation in Australia can be said to be underpinned by denial and false legalities that have excluded and oppressed Aboriginal and Torres Strait Islander people since the arrival of the British in the 1700's. 'Terra nullius', meaning unoccupied or uninhabited land, upon its declaration in 1788 meant that any claims or connection to land by Aboriginal and Torres Strait Islander people, despite occupying the land for tens of thousands of years, were deemed illegitimate by the colonising state. In an instant, Aboriginal and Torres Strait Islander people were left 'placeless' and traditional laws were disregarded by colonisers.[173] Havemann (2005)[173] highlights that colonial denial includes the unwillingness to accept, or to disregard present racism and historical atrocities, despite overwhelming evidence detailing such events. It should not be understated that these atrocities include the genocide of Aboriginal and Torres Strait Islander people.[173] The ongoing consequences that the genocide of Aboriginal and Torres Strait Islander people has had, includes high rates of suicide, incarceration, poor health and reduced life-expectancy.[4, 5, 21, 32, 173, 174] Moreover, Western ideologies and systems of knowledge have been used to justify the forcible removal of Aboriginal and Torres Strait Islander children from their families, legislation that undermines basic human rights for Aboriginal and Torres Strait Islander people and the ongoing subjugation of Aboriginal and Torres Strait Islander culture in Australia.[5, 174] Historical and ongoing oppression has occurred under the guise of liberal ideologies and the pursuit to 'modernise' society. In this pursuit, Aboriginal and Torres Strait Islander place, connection to land and knowledge has been disregarded and Aboriginal and Torres Strait Islander people and communities have suffered as a result.[173]

2.7.1.2 Decolonising knowledge systems

Differences between what is considered true knowledge from an Aboriginal and Torres Strait Islander and non-Aboriginal perspective have contributed to social exclusion and lack of self-determination within Aboriginal and Torres Strait Islander and Indigenous communities. Traditionally, those in the West have believed that Western knowledge is best.[154] However, there is a need to shift our understanding of what legitimate knowledge is, as knowledge and its legitimacy are highly dependent on its domain of applicability.[6, 171] Western knowledges have been clearly demonstrated as illegitimate, irrelevant or inappropriate in many Aboriginal and Torres Strait Islander and Indigenous contexts.[171] A recent paper by Yadav et al[175] explains that the concept of 'social prescribing', often credited to recent developments in the United Kingdom, has long been practiced by Aboriginal Community Controlled Health Services in Australia. The authors emphasise the need to recognise and support these Aboriginal and Torres Strait Islander models of holistic care, which address socioeconomic and cultural determinants of health through a comprehensive, community-based approach.[175] Moreover, when traditional Aboriginal and Torres Strait Islander knowledge is appropriated and rebranded, it may lead to the removal of the original cultural context and contributions. This reframing can diminish the recognition and value of Aboriginal and Torres Strait Islander practices, making it seem as though these ideas are novel or originated from non-Aboriginal sources. This perpetuates a colonial mindset where Aboriginal and Torres Strait Islander contributions are overlooked and undervalued.[5, 175]

Similarly, education of history within schools in Australia is often inaccurate or incomplete, neglecting the long-standing Aboriginal and Torres Strait Islander history. The curriculum for history taught in Australian schools has been imprecise and this serves to perpetuate a collective ignorance for many Australian's about Aboriginal and Torres Strait Islander culture and history.[171] Additionally, the Western understanding of health is relatively narrow in reference to the broader and more holistic Aboriginal and Torres Strait Islander understandings of health.[6, 154] It can be argued that the absence of a more holistic understanding of health has contributed to the lack of progress made within Aboriginal and Torres Strait Islander health and health research when approached from a non-Aboriginal perspective. This is consistent with calls to address the social determinants of health to better support health in Aboriginal and Torres Strait Islander populations, shifting away from a solely biomedical approach to health and healthcare.[21] Therefore, working towards a better understanding of Aboriginal and Torres Strait Islander knowledge systems and supporting

Aboriginal and Torres Strait Islander control and guidance over future research, policy development and service delivery will help to reinforce positive health outcomes for Aboriginal and Torres Strait Islander people and communities.

It is necessary to acknowledge that these colonial roots have negatively impacted Aboriginal and Torres Strait Islander health and wellbeing today. These detrimental aspects of colonisation must first be recognised by the broader Australian population. In addition, the ongoing oppressive remnants of colonisation should be rejected and eliminated from Australian society to ensure improvements in Aboriginal and Torres Strait Islander health can be achieved.[6] It is this shift away from colonisation and its persistent influence that has been referred to as 'decolonisation'.

2.7.1.3 Political decolonisation

At its core, decolonisation can be described as the process of re-establishing the self-determination of a population by removing the oppressive constraints underpinned by colonisation. Likewise, decolonisation is central in the pursuit to restore cultural identity, practices and way of life for those oppressed by colonising forces. Post-World War II and following the formation of the United Nations there were growing efforts to decolonise many parts of the world. However, following the global decolonisation process that occurred over proceeding decades, self-determination remained largely unchanged in populations historically impacted by colonisation.[176] Notably, global decolonisation had not translated into greater freedoms, self-determination or recognition for Aboriginal and Torres Strait Islander people in Australia, and as a result, efforts to decolonise Australia are ongoing. Australia is the only Commonwealth country without a treaty with its First Nation's people, highlighting the lack of progress toward decolonisation.[177]

The Australian Liberal Federal Government's initial response to 'The Uluru Statement', which details constitutional changes including a voice to parliament, legal reconciliation and the power to negotiate treaties, is an example of the challenge that exists in overcoming resistance to decolonise. The response of the then Turnbull Government was to reject calls for a referendum, despite the 'Uluru Statement' seeking what many consider relatively minor reforms afforded by treaties between other First Nation's populations and Commonwealth states.[177] The referendum, commonly referred to as *"the Voice"*, aimed to provide a formal mechanism enshrined in the Australian constitution, for Aboriginal and Torres Strait Islander people to have a say in matters that affect them directly, such as policies, laws and programs

that impact upon Aboriginal and Torres Strait Islander rights and wellbeing.[178, 179] When the Australian Labor party won the 2022 Federal Election, they announced they would hold a referendum on establishing the Voice to Parliament, signalling a commitment to addressing Aboriginal and Torres Strait Islander representation and rights.[178, 179] However, the result of the referendum held in October 2023, rejected the proposal for an Aboriginal and Torres Strait Islander Voice to Parliament. It can therefore be argued that this unwillingness to support Aboriginal and Torres Strait Islander identity and uphold basic rights for Aboriginal and Torres Strait Islander people in Australia provides the foundation for a wide range of cultural, social, environmental and political challenges driving ongoing inequities.[178, 179]

To achieve decolonisation, there needs to be a reclaiming of cultural identity, language, connection to land, removal of discriminatory policies and practices, and support for Aboriginal and Torres Strait Islander rights and representation in decision making. Decolonisation requires the recognition of historical and ongoing injustices, such as dispossession of land, forced removal of children and cultural suppression. Moreover, fostering reconciliation, healing and empowerment within Aboriginal and Torres Strait Islander communities is crucial in achieving this goal.[6, 21, 32, 172, 178]

2.7.2 Co-creation and participatory action research

2.7.2.1 Moving away from research 'done on'

Aboriginal and Torres Strait Islander health research in Australia has often been non-participatory, misrepresentative, exploitative and invasive.[39] Consequently, it is becoming increasingly clear that co-creation is key to ensuring Aboriginal and Torres Strait Islander control over healthcare and health research in Australia.[6] Co-creation includes cross-sector communication and collaboration that is driven by the needs of the community, as voiced by the community. The benefits of the Aboriginal and Torres Strait Islander voices in Aboriginal and Torres Strait Islander health research are clearly expressed in a qualitative study of community perspectives about co-creation conducted within a non-remote Aboriginal and Torres Strait Islander community in New South Wales, with a study participant stating, *"you might have a PhD but I'm an Aboriginal person from [this] community"*[39p384]. Consistent with the importance of the social context for health and wellbeing, is health research acknowledging the unique context of Aboriginal and Torres Strait Islander people's lives, by endorsing Aboriginal and Torres Strait Islander knowledge and experience, and welcoming guidance from Aboriginal and Torres Strait Islander people.[6]

2.7.2.2 Participatory action research

Participatory action research, or co-created research are research activities embedded within communities that act to strengthen participation and self-determination of community members.[180] Historically, non-participatory research has consistently failed to achieve improvements in health outcomes for Aboriginal and Torres Strait Islander and Indigenous people.[166] Furthermore, given the long-standing history and importance for oral storytelling or Yarning in Aboriginal and Torres Strait Islander cultures, participatory action research plays an important role in facilitating storytelling as a key tool to explore lived experiences of Aboriginal and Torres Strait Islander people.[180, 181] Fellner[182p283] further highlights the importance of *"Indigenous counter narratives"* in seeking historical truths, decolonising non-Aboriginal research paradigms and progressing western knowledge systems. Importantly, participatory action research helps to strengthen cultural safety and suitability of research activities and redresses the power imbalance in Aboriginal and Torres Strait Islander and Indigenous research.[166, 180] The benefits of greater community participation in Aboriginal and Torres Strait Islander research are clear. Similarly, the shortcomings of non-participatory Aboriginal and Torres Strait Islander research are well-known, with Geia et al.[181p13] emphasising that *"researchers cannot afford to allow [the health gaps] to grow wider",* with the incorporation of Yarning and Aboriginal and Torres Strait Islander storytelling into non-Aboriginal health research methodology an evident path away from a widening gap.

2.7.2.3 Co-creation

Other concepts related to strengthening community participation in research activities within Aboriginal and Torres Strait Islander communities include 'co-design', 'co-production' and 'co-creation'.[183] Co-design refers to the planning or development of methods to conduct research activities. Co-production is the implementation or execution of those research activities. Lastly, co-creation is the combination of co-design and co-production.[183] As with participatory action research, co-creation is important to overcome issues of mistrust by Aboriginal and Torres Strait Islander people and communities. Furthermore, for co-creation to be meaningful and ensure research activities translate into improved health outcomes, trust needs to be built, traditional power dynamics need to shift, and local Aboriginal and Torres Strait Islander knowledge must be valued.[39] Notably, Aboriginal Community Controlled Health Services are community-based primary health organisations that provide essential primary services for local Aboriginal and Torres Strait Islander community members.[28]

Aboriginal Community Controlled Health Services have been instrumental in advancing the Aboriginal and Torres Strait Islander voice in research over recent years. Likewise, Aboriginal Community Controlled Health Services provide culturally relevant, safe and supportive environments for research co-creation.[39] It is therefore important for researchers to embed their research activities within Aboriginal and Torres Strait Islander communities, and utilise the resources, expertise and guidance provided by Aboriginal Community Controlled Health Services.

The Aboriginal Health and Medical Research Council, New South Wales Aboriginal Health Ethics Guidelines outline five key principles that guide ethical research: Net Benefits for Aboriginal people and communities, ensuring that research outcomes provide clear advantages to the community; Aboriginal Community Control of Research, which emphasises the importance of community involvement and decision-making power throughout the research process; Cultural Sensitivity, requiring that research practices respect and incorporate the cultural values and protocols of the community; Reimbursement of Costs, ensuring that any expenses incurred by community members as part of the research are fairly compensated; and Enhancing Aboriginal Skills and Knowledge, focusing on building capacity and empowering communities through the research process.[184] Following the Aboriginal Health and Medical Research Council guiding principles will help to ensure the work presented throughout this thesis is culturally respectful, community-driven, and beneficial to partnering communities, leading to outcomes that are meaningful and sustainable. Undoubtedly, Aboriginal and Torres Strait Islander people have suffered due to colonisation in Australia, with the ongoing consequences still evident by the inequitable health gaps between Aboriginal and Torres Strait Islander and non-Aboriginal people. Despite the push for decolonisation and the evidence supporting the benefits of transitioning away from the negative aspects of Australia's colonial roots, there is ongoing resistance to appeal to these calls for change. However, progress is being made, with Aboriginal and Torres Strait Islander communities driving this progress through improved research methodology, strengthened community support, and advancing long-standing local knowledge systems.

2.7.3 Strengths-based approaches

2.7.3.1 Deficit discourse

Deficit discourse in Aboriginal and Torres Strait Islander health refers to a narrative that frames Aboriginal and Torres Strait Islander peoples primarily through a lens of disadvantage,

pathology, and failure.[185, 186] This perspective often emphasises negative statistics, such as higher rates of disease and lower life expectancy, without acknowledging the strengths, resilience, and cultural richness of these communities. Such discourse can reinforce stereotypes, perpetuate victimisation, and overlook the impact of historical and systemic factors like colonisation, racism, and social inequities.[155-157, 185, 186] By focusing solely on deficits, these narratives fail to recognise the importance of culturally informed solutions, community strengths, and the need for empowering approaches that support self-determination and holistic wellbeing in Aboriginal and Torres Strait Islander health.[155-157, 185, 186]

2.7.3.2 Strengths-based frameworks

Aboriginal and Torres Strait Islander strengths and resilience are often understated, and it is becoming increasingly recognised that public health policy and research must shift toward strength-based approaches.[42, 43, 187] Strength-based approaches differ from deficit-based approaches, as they emphasise community strengths, cultural values and traditional knowledge to address health disparities and promote holistic wellbeing. Furthermore, these approaches foster self-determination and facilitate collaborative partnerships between communities, health services and researchers.[42, 43, 187] Strengths-based approaches and frameworks are crucial for promoting the health and wellbeing of Aboriginal and Torres Strait Islander communities. By highlighting and leveraging existing strengths, strengths-based approaches empower communities to take control of their health and social outcomes, fostering a sense of agency, self-determination and cultural continuity.[186]

Strengths-based approaches promote positive identity and connection to culture.[186] By recognising and celebrating cultural strengths, languages, traditions, and knowledge systems, these approaches help to counteract negative impacts of historical trauma and colonisation.[185] Furthermore, they contribute to development of culturally relevant and effective initiatives that harness community values and beliefs, leading to greater engagement and participation.[155, 156, 185, 186] Strengths-based frameworks foster collaboration, partnerships and co-creation between communities, researchers, policymakers, and healthcare providers.[155, 156, 185, 186] This collaborative approach ensures that initiatives and policies are developed in a culturally safe, respectful, and meaningful way.[155, 156, 185, 186] By centring Aboriginal and Torres Strait Islander voices and perspectives, strengths-based approaches contribute to the creation of more equitable, inclusive, and holistic healthcare systems that address the social

determinants of health and promote overall wellbeing.[155, 156, 185, 186]

2.7.3.3 Strengths-based key principles

Strengths-based guiding principles for Aboriginal and Torres Strait Islander health focus on empowering communities, honouring cultural practices, and promoting holistic wellbeing.[188] Key strengths-based principles include:

Self-determination: Recognising and respecting the right of Aboriginal and Torres Strait Islander peoples to make decisions about their health and wellbeing, ensuring that health initiatives are community-led and culturally relevant.[188]

Cultural Safety: Ensuring that health services are culturally safe and responsive, acknowledging the importance of cultural identity, practices, and knowledge systems in promoting health and healing.[188]

Holistic Approach: Viewing health as encompassing physical, social, emotional, and spiritual wellbeing, and recognising the interconnectedness of individuals, families, communities, and the land.[188]

Strengths and Resilience: Focusing on the inherent strengths, resilience, and capabilities of Aboriginal and Torres Strait Islander communities, rather than on deficits or problems.[188]

Partnership and Collaboration: Building respectful and equitable partnerships between Aboriginal and Torres Strait Islander communities and health professionals, with a commitment to co-design and shared decision-making.[188]

Community Ownership: Empowering communities to take ownership of health initiatives, ensuring that programs are designed, implemented, and evaluated by the communities they serve.[188]

These principles guide the development of health research, policies and practice that support the wellbeing of Aboriginal and Torres Strait Islander peoples by building on their strengths and addressing the social determinants of health in culturally appropriate ways.

2.7.4 Section summary

This section highlights the importance for Aboriginal and Torres Strait Islander voice and lived experience as crucial in translating research into improved health outcomes. Co-creation

and participatory action research provide models to guide research activities in a meaningful and culturally safe way. Decolonisation is an important way forward to achieve social justice and improved health outcomes for Aboriginal and Torres Strait Islander people. This thesis is underpinned by these principles, and the co-creation methods employed throughout will be reflected on and discussed as relevant research outcomes.

2.8 Chapter 2 conclusions

2.8.1 Why the social determinants of ear health?

Why is this a problem? Ongoing colonisation continues to contribute to significant inequities in health and social outcomes between Aboriginal and Torres Strait Islander and non-Aboriginal people in Australia. This includes inequities in ear health outcomes, with Aboriginal and Torres Strait Islander children in Australia experiencing the highest rates of otitis media globally. ***Why do we care?*** Ear health and hearing is crucial for children to thrive and reach their life potential. The high rates of otitis media for Aboriginal and Torres Strait Islander children are underscored by inequities in social determinants of health. Additionally, experiences of otitis media can further perpetuate social determinants, the impact of colonisation and associated health inequities. ***What are the gaps?*** The literature highlights that most published evaluated ear health approaches within Aboriginal and Torres Strait Islander populations in Australia have been pharmaceutical in nature. Therefore, there is a need to better understand relationships between social determinants and otitis media to develop best-practice approaches for ear health prevention that address social determinants of health for Aboriginal and Torres Strait Islander children.

2.8.2 What are the solutions?

What existing solutions show promise? Health Navigators may play an important role in addressing many of the key determinants of ear health for Aboriginal and Torres Strait Islander children, and further research is required to understand their effectiveness in supporting children at risk of ear disease. ***What should solutions focus on?*** Strategies must support improved access, embed holistic approaches, provide cultural support and aid in the integration and navigation of services. Importantly, systemic reform is required to address social inequities such as racism and discrimination, and to make health and community services more accessible for Aboriginal and Torres Strait Islander people. ***How should we develop these solutions?*** To ensure effective, culturally safe and sustainable solutions for ear

health and hearing among Aboriginal and Torres Strait Islander children, approaches must be community-led and harness community strengths and lived-experience.

2.9 Chapter 2 References

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CHAPTER 3: HEARING WHAT COMMUNITY HAS TO SAY: INFORMING A CO-CREATED APPROACH TO IMPROVE EAR HEALTH AND HEARING AMONG ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN

3.1 Chapter 3 overview

This chapter reports perspectives of community members living in three communities in non-remote New South Wales about ear health and hearing among children living in their communities. Perspectives were captured via Yarning circles that were conducted at two metropolitan and one large regional Aboriginal Community Controlled Health Services in New South Wales. Yarning aligns with key Aboriginal and Torres Strait Islander methodologies underpinning this thesis, including co-creation, strengths-based approaches and decolonisation. Participants included Aboriginal and Torres Strait Islander and non-Aboriginal people with connections to the participating services. Participants included Elders, parents, educators, early childhood workers, executive staff, and health workers. The Yarning circles were recorded, transcribed verbatim and analysed using thematic analysis. A framework methodology was used to map themes onto a social and cultural determinants of health framework.

Rationale

Co-creation is an essential process for effective Aboriginal and Torres Strait Islander research, ensuring the voices, knowledge, and experiences of the community are central to the research process. By engaging directly with Aboriginal and Torres Strait Islander communities through Yarning circles, this project aims to gather valuable insights and foster genuine partnerships. This approach will enhance the cultural relevance and appropriateness of the Aboriginal Community Controlled Ear-health Support System (ACCESS) and empower the collaborating communities by involving them as active contributors in the design and implementation of healthcare solutions that directly affect them.

This chapter will:

1. Present the background and rationale for investigating and reporting community perspectives about ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales;
2. Describe the methodology for data collection and analysis;
3. Present, interpret and describe the implications of findings;
4. Highlight the strengths and limitations of this study; and

5. Provide research, service delivery and policy recommendations.

3.2 Submitted paper

DeLacy J, Dickson M, Woolfenden S, Rattos S, Hay E, Sperring A, et al. Hearing what Community has to say: informing a co-created approach for childhood ear health and hearing. *Ready for submission to BMC Public Health*

3.3 Chapter 3 Abstract

3.3.1 Introduction

We need novel interventions to close the health gap for Aboriginal and Torres Strait Islander children in Australia. We explore the perspectives of Aboriginal and Torres Strait Islander community members regarding culturally appropriate models of care for children at risk of ear disease.

3.3.2 Methods

Yarning circles (semi-structured focus groups using Aboriginal research methodologies) were conducted at three Aboriginal Community Controlled Health Services in New South Wales, Australia. Participants included Aboriginal and Torres Strait Islander and non-Aboriginal people with connections to the participating services. Across the sites, stakeholder groups and participants included Elders, parents, educators, early childhood workers, executive staff, and health workers. The Yarning circles were recorded, transcribed verbatim and analysed using thematic analysis. A framework methodology was used to map themes onto a social and cultural determinants of health framework for Aboriginal and Torres Strait Islander people in Australia.

3.3.3 Results

Four Yarning circles were held with 30 participants (approximately one hour per Yarning circle). Most positive factors related to ear health were associated with care through Aboriginal Community Controlled Health Services. Most negative factors were associated with mainstream health service care. Determinants of ear health discussed included racism and cultural safety, holistic and reactive care approaches, transport and cost barriers, extensive waitlists, challenges with continuity of care leading to loss to follow-up, poor quality and crowded housing, and the need for sustainable solutions. The impact of ear health and hearing

on health and wellbeing was recognised as important for healthy life-course trajectories. Ear health and hearing was recognised as impacting school and education, behaviour, social and emotional wellbeing, and the nurturing of future Elders.

3.3.4 Conclusions

Integrated and culturally responsive approaches are crucial to address ear disease effectively. Collaborative efforts between community controlled, mainstream health services, educators, policymakers, and community leaders are essential to bridge the gaps in access to early interventions, support services, and holistic care for children and families affected by ear disease. These efforts must ensure that clinical interventions are embedded within services that address social determinants, promote cultural safety, and foster supportive environments that nurture the health and wellbeing of individuals across the lifespan.

3.4 Chapter 3 Introduction

In Australia, there are over 150 traditional languages currently spoken by Aboriginal and Torres Strait Islander people.[1] Oral traditions and storytelling have served a vital role in the sharing and passing down of knowledge for millennia.[2] Good hearing during early childhood is crucial for the acquisition of spoken language, and consequently the fostering of spiritual and cultural wellbeing.[3-4] Hearing provides an important foundation for children to thrive academically, socially, and to reach their life potential.[5-6] The highest rates of ear disease globally are reported amongst Aboriginal and Torres Strait Islander children in remote regions of Australia.[7] However, most Aboriginal and Torres Strait Islander children live in non-remote areas and more needs to be done to investigate inequities in ear disease in these settings.[4,8-15] Inequities in ear health outcomes have been driven by a disproportionate burden of social determinants underpinned by ongoing colonisation.[4, 16-19] Therefore, it is important to emphasise that the problem does not emerge from Aboriginal and Torres Strait Islander people, but the fragmented and inequitable colonial systems Aboriginal and Torres Strait Islander people endure.[17-19]

A recent systematic content review highlighted that most literature on ear disease in Aboriginal and Torres Strait Islander populations in Australia report social determinants as playing a significant role in driving the high prevalence of ear disease.[16] The Study of Environment on Aboriginal Resilience and Child Health (SEARCH) is a large cohort study of Aboriginal and Torres Strait Islander children living in urban communities in New South

Wales.[15] SEARCH revealed that the high prevalence of ear disease identified was linked to social determinants, such as crowded homes.[4] Hearing EAr-health Language and Speech services (HEALS), an ongoing clinical service delivery program since 2013, arose from SEARCH to provide free Ear, Nose and Throat, audiology, and speech and language services to Aboriginal and Torres Strait Islander children living in some regions of New South Wales.[20] The success of HEALS was in part due to the effectiveness of the culturally safe care provided by the community project officers, who supported families with booking appointments, appointment reminders, following up missed appointments and organising transport to ensure families could get to appointments.[20]

There is growing recognition that models of Health Navigation are effective at enhancing service access and addressing unmet social determinants of health.[21-23] Similarly, Aboriginal and Torres Strait Islander Health Workers are recognised as effectively and safely facilitating holistic care and health navigation for Aboriginal and Torres Strait Islander people.[24] Notably, a scoping review exploring the role of Aboriginal and Torres Strait Islander Health Workers in ear screening programs in Australia emphasised that Aboriginal and Torres Strait Islander Health Workers play a significant role in promoting long-term ear health and sustainable prevention programs.[25] The Aboriginal Community Controlled Ear-health Support System (ACCESS) focusses on a Child Health Navigator model of care and was co-created to compliment HEALS and SEARCH.[26] ACCESS aims to support families by improving the integration of services, supporting health navigation and addressing underlying determinants of health. The objective of the current study is to build on the work of SEARCH and HEALS by exploring perspectives about ear health and to inform the ongoing co-creation of the ACCESS Child Health Navigator model of care.

3.5 Chapter 3 Methods

3.5.1 Study setting

The setting was two regional and one metropolitan Aboriginal Community Controlled Health Service in New South Wales, with four Yarning circles in total. The first two Yarning circles were held at one regional site in May 2021, the third at the metropolitan site in June 2021 and the final one was held at the second regional site in October 2022. All Yarning circles were conducted face-to-face at the Aboriginal Community Controlled Health Services, as these services are best placed to provide transport and culturally safe spaces for participants.

3.5.2 Participants

Participants were purposefully selected to capture a variety of community-relevant lived experience and perspectives. Participants were identified as mostly Aboriginal and Torres Strait Islander but there were some non-Aboriginal community members with lived experience caring for Aboriginal and Torres Strait Islander children. Participants included community Elders, caregivers, parents, early childhood educators and health workers.

3.5.3 Yarning methodology

Yarning methodology is an accepted and valued as a culturally relevant approach to qualitative data collection amongst Aboriginal and Torres Strait Islander populations. Yarning respects Aboriginal and Torres Strait Islander oral systems of knowledge sharing and traditions and addresses common power imbalances in research data collection.[27-29] Engagement with participants was initiated by consulting with each Aboriginal Community Controlled Health Service and a local community research team member contacted participants to outline the study and identify their interest in participating. Communication between the participants and the research team was facilitated through the local community research team member ensuring adherence to community research protocols. Participants were financially compensated for their time and provided lunch. Transport for the participants was provided by the partnering sites.

A predefined guideline was not used, in accordance with Aboriginal and Torres Strait Islander research methodology.[30] Alternatively, sensitising concepts were used in the development of the Yarning guides and analysis approach.[31] Yarning guides were developed by a collaboration between Aboriginal and Torres Strait Islander and non-Aboriginal research team members. The Yarning guide was informed by preliminary consultations with Aboriginal Community Controlled Health Service staff, including the Chief Executive Officers of each site. Aboriginal and Torres Strait Islander researchers, including those working in the partner sites, provided cultural advice in the development of the Yarning guide.

3.5.4 Data collection

Yarning circles were conducted at each partner site at a time and date that was determined most convenient for the community and participants. For two partner sites, Aboriginal and Torres Strait Islander researchers with extensive Yarning and qualitative experience (JS and MD) co-facilitated the Yarning circle with an early-career researcher (JD). For the third site,

an experienced researcher (HG) co-facilitated the Yarning circle with researcher JD with Aboriginal researchers from ACCESS in attendance. At the beginning of each Yarning circle, facilitators provided context by introducing the purpose of the discussion, including the focus on ear health and hearing and the ACCESS. This ensured that participants were aware of the relevant issues and could frame their contributions within the scope of the study. All Yarning facilitators (JS, MD, HG and JD) took notes during the Yarning circles. The Yarning circles were approximately 60 minutes in duration and continued until data saturation was achieved.

3.5.5 Data analysis

Yarning circles were audio recorded with consent. Audio recordings were transcribed verbatim by JD. Transcripts were reviewed and preliminary themes were identified by an Aboriginal and Torres Strait Islander researcher with vast qualitative research experience (JS) and an early career researcher (JD). A framework methodology[32] was used to map themes onto the My Life My Lead[33] priority areas to address the social and cultural determinants of health for Aboriginal and Torres Strait Islander people in Australia (Figure 3.1). Framework analysis allows researchers to systematically identify patterns and differences within data by mapping these findings onto a framework. This approach facilitates the drawing of descriptive or explanatory conclusions, which are then clustered around key themes, providing a structured and comprehensive understanding of the data.[33] My Life My Lead was considered an appropriate framework by Aboriginal and Torres Strait Islander and non-Aboriginal authors of this paper, as it emerged from consultations with Aboriginal and Torres Strait Islander communities and stakeholders from across Australia. These consultations explored the crucial and supportive role of culture and assessed how social factors like education, employment, justice, income, and housing affect health and wellbeing throughout a person's life.[33] Associations between Yarning themes and the My Life My Lead[33] priority areas were mapped, and associated themes were recorded as having a positive or negative impact on outcomes for health and wellbeing. Following identification and mapping of themes, results were presented back to the partnering sites to ensure accurate interpretation of the transcripts and to ensure all key themes had been captured and that there was no identifying information. Themes were then reviewed by the wider research team to develop a consensus. This approach follows a group consensus process for thematic analysis, reflecting an approach deeply rooted in Aboriginal and Torres Strait Islander cultural practices and collaborative decision making.

Figure 3.1: My Life My Lead priority areas to address social and cultural determinants of health.[33]

3.5.6 Ethics approval

The study received ethical approval from the Aboriginal Health & Medical Research Council of New South Wales (1917/22). Written consent was provided by all study participants for the Yarning circles to be recorded and transcribed.

3.6 Chapter 3 Results

A total of four Yarning circles were held. Two of the partnering Aboriginal Community Controlled Health Services held one Yarning circle each and a third site held two Yarning circles. There were 30 participants across all Yarning circles, with 12 in site one, 12 in site two and six in site three. Approximately three hours and 45 minutes of audio was recorded and transcribed, with an average time running time of 56 minutes per Yarning circle. Across the sites, stakeholder groups included Elders, parents, educators, early childhood workers, and health workers (see Table 3.1.)

Table 3.1: Participant characteristics

Stakeholder Group	Group description	Number of participants
Parent	Mother, father or primary caregiver of children (all participants identified as parents rather than caregiver, guardian or other relevant term).	6
Community Health Worker	Participant who is a staff member working at the Aboriginal Community Controlled Health Service, including administrative staff, Aboriginal Health Workers, General Practitioners, Ear Health Workers and Clinical Leads.	13
Community Health Worker and Parent	Participant who meets both criteria for Community Health Worker and Parent.	4
Mainstream Health Worker	Participant who is employed by a health service that is not an Aboriginal Community Controlled Health Service.	2
Early Childhood Educator	Participant who is working in an early childhood education setting such as childcare, preschool, primary school or other early childhood educational setting.	4
Elder	A highly respected person recognised within the community as a custodian of knowledge, Lore and someone who has permission to disclose traditional knowledge and beliefs.	1

Importantly, the Aboriginal and Torres Strait Islander social determinants of ear health shown in Figure 3.2. highlights that most associations with positive outcomes were attributed to Aboriginal Community Controlled Health Services. Conversely, most negative associations were attributed to mainstream health services or other factors that sit outside of the Community Controlled Health setting.

Figure 3.2: Aboriginal and Torres Strait Islander social determinants of ear health (adapted from My Life My Lead[33] priority areas to address the social and cultural determinants of health)

Themes derived from the Yarning sessions were mapped onto the My Life My Lead priority areas and highlighted a strong emphasis on the 'Health Service Access' and 'Foundations for a Health Life' priority areas. Importantly, determinants of ear health and hearing discussed throughout the Yarning circles included racism and cultural safety, holistic and reactive care, transport and cost, waitlists, loss to follow-up, housing and sustainable solutions. These factors were recognised as key components of the local health environment. Unfortunately,

many of these discussions highlighted deficits within local mainstream health settings, with inequitable access to care and services evident across the three community sites. These deficits were largely associated with mainstream health services. Local Aboriginal Community Controlled Health Services were highlighted as safe, holistic, culturally relevant and accessible. Furthermore, the importance of ear health and hearing was recognised by all participants as creating a strong foundation for a healthy life, emphasising the need address determinants and improve access to services for children at risk of ear disease.

3.6.1 Priority Area: Health Service Access

3.6.1.1 Racism and cultural Safety

A prominent theme that emerged from the data was the lack of cultural safety and the presence of racism within healthcare services, which adversely affects access to quality care and exacerbates health disparities. Participants expressed concerns over the neglect of ear health issues, articulating frustration and a sense of urgency for more proactive, evidence-based interventions. Comments revealed potential racial biases that may influence healthcare priorities, as well as experiences of undervaluation and stereotyping faced by Aboriginal and Torres Strait Islander health workers within mainstream settings.

> *Community Health Worker and Parent: "I can say to my manager but again, we're the bottom of the food chain, who are we?"*

Additionally, participants highlighted power dynamics and communication barriers that hinder effective interactions, particularly for marginalised communities, stressing the need for structural changes to enhance inclusivity and empowerment in healthcare. There was also a recognition of systemic failures and the call for accountability, with participants noting that meaningful change often occurs only in response to tragic events.

> *Community Health Worker and Parent: "Well look now [since the inquest] they don't get away with it, but you have to wait for someone to die for things to happen, which is wrong."*

3.6.1.2 Transport and cost

Physical access to healthcare services emerged as a significant barrier for both parents and healthcare workers. Participants highlighted the critical need for logistical support, noting that many specialist services, including Ear, Nose, and Throat services, do not provide transport.

This lack of awareness regarding access supports further compounds the issue, making it unlikely for families to attend.

> *Community Health Worker: "A lot of these specialist services, including [Ear, Nose & Throat], don't provide transport. So, unless we are made aware of the appointment, they won't go. So that's one of the biggest barriers I am finding with these kids."*

Cost was also identified as a major barrier, particularly for Ear, Nose, and Throat services, with one participant sharing the financial strain of being a working single parent. Concerns were raised about the inequity of requiring financial resources to access essential services, especially considering the long-term health implications for children.

> *"I think it's so unfair that to be able to access [Ear, Nose, and Throat] services, you have to have money to pay for that, but ear health is such a big thing that can cause such big problems for children long-term."*

Participants recognised the vital role of Aboriginal Community Controlled Health Services, which often provide transport and funding to facilitate access to both Aboriginal and mainstream services. These supports were seen as essential in addressing access barriers through culturally responsive and community-led healthcare initiatives.

3.6.1.3 Waitlists

Inadequate timely access to care due to long waitlists was a recurring issue highlighted across community sites. Participants reported extensive wait times for Ear, Nose, and Throat appointments, with some children without priority status facing waitlists exceeding two years. One participant shared their experience with public services, revealing an 18-month wait for their child to receive care, which negatively impacted the child's speech-language development. Additionally, the issue of lengthy wait times for Ear, Nose, and Throat surgery was underscored, with one participant noting a child who had waited 420 days for treatment. These accounts emphasised the urgent need for systemic improvements to reduce wait times and ensure equitable access to quality healthcare services, particularly given the potential adverse effects on speech-language development and educational outcomes.

> *Community Health Worker and Parent: "If you are going as public, which I have had to do with my own kids- we waited over 18 months before my boys got into the [Ear,*

Nose and Throat service]. And one of mine now does speech because his speech is affected."

3.6.1.4 Loss to follow-up

Participants identified significant barriers and gaps in continuity of care, particularly regarding follow-up procedures. One participant noted that loss to follow-up is a frequent issue, complicating efforts to get families to appointments and secure necessary referrals. Another expressed frustration with the lack of communication from specialists, explaining that once a referral is sent, there is often no further information until another referral is issued, leaving healthcare providers uninformed. This underscores the need for improved communication channels and feedback between healthcare providers and specialists to facilitate seamless follow-up care. One participant pointed out that without clear plans, General Practitioners frequently do not receive updates, leading to gaps in care. This is especially problematic as many General Practitioners are registrars who rotate every six months, resulting in limited continuity and understanding of patients' histories.

Community Health Worker: "Half or a third are registrars. Then we rotate every six months. So that loss to follow up. Yeah, you you're just seeing your patient for the first time off once every six months and then they see a new Doctor and then you just don't, they won't be aware other than reading the last notes and history of the patient."

Participants praised support systems that enhance culturally safe follow-up care, suggesting that the introduction of Health Navigators could improve their outreach efforts, as they are often hesitant to contact parents repeatedly. Additionally, the presence of a liaison officer in the HEALS program was highlighted as beneficial, assisting families in navigating appointments and requirements effectively.

Community Health Worker and Parent: "And I think the other good thing about HEALS was like when we had like a liaison officer that would help families like to be able to navigate like when their appointment was, what they had to do and stuff."

3.6.1.5 Sustainable solutions

A major political determinant of health that was identified was the lack of permanent solutions and the transient nature of funding and programs, leading to frustration among participants who noted that many individuals become lost in the system, prolonging health issues.

Participants called for an end to temporary fixes in favour of long-term strategies for addressing ear health concerns, while emphasising the need for systemic change, greater education, and reform.

> *Parent: "Yeah and you know then there's how many people that are well and truly lost you know, and it takes years to get back to where they should be. Band-Aid solutions. We need to get rid of Band-Aid solutions and put in permanent solutions."*

The reactive nature of government approaches was a key theme, with participants expressing a desire for more proactive measures and highlighting the challenges of ad hoc funding, which can negatively impact healthcare waiting lists. Participants described the disconnect between research and community action, stressing the need for meaningful community engagement, especially given the high rates of ear disease among Aboriginal and Torres Strait Islander children. Participants championed community-led initiatives as vital for sustainability, advocating for the Aboriginal Community Controlled Health Service model and calling for community voices to play a significant role in shaping healthcare planning and funding allocation.

> *Community Health Worker and Parent: "Yeah, I think it's unfair that they often go and give that funding and that money to mainstream services. Then like, even though it's been shown that [the Aboriginal Community Controlled Health Service model is] much more successful and works better to improve outcomes."*

3.6.2 Priority Area: Health Opportunities Through Education

3.6.2.1 Holistic and reactive care

Trust and confidence in health services emerged as a critical theme, revealing widespread concerns about the quality of care within mainstream healthcare settings. Participants expressed frustration with a cycle of reactive healthcare solutions, particularly the over-reliance on antibiotics, which often failed to address underlying health issues or provide preventive care.

> *Parent: "My daughter was in pain all the time and they just kept prescribing her antibiotics. I didn't get any sleep... Just here's another script, here's another script. And she couldn't sleep. And said she's fine. But I knew there was something going on."*

This led to feelings of disillusionment and helplessness regarding the adequacy of care received. Many participants indicated a lack of trust in mainstream providers, preferring to seek out a limited number of trusted doctors due to past negative experiences characterised by inadequate assessment and unaddressed concerns. In contrast, positive experiences with Aboriginal Community Controlled Health Services were noted, highlighting the importance of holistic and patient-centred care.

> *Community Health Worker and Parent: "And I think that's why I only go to like the one or two doctors because I go there, and I think he's got a sore ear. He's been pulling at it and this, [and the doctor says] oh no he's fine or they don't look at it and I can usually tell even before they put the little otoscope in there that they're not even looking properly. Like they don't pull the ear up and look in there, like so I just don't trust anyone other than about two doctors, or [the Community Ear Health Worker]. Because I know they're not even looking properly."*

Overall, these findings underscore the need for improved healthcare practices that prioritise effective communication, comprehensive health education, and a more proactive approach to health management.

3.6.3 Priority Area: Environmental Health

3.6.3.1 Housing

Housing emerged as a significant concern among participants, highlighting the strong link between health and housing conditions. Overcrowding was frequently identified, particularly affecting families with multiple children living in smaller homes. Healthcare professionals expressed alarm about the poor housing conditions some families face, including deteriorating roofs, severe mould issues, and decades-old carpets filled with grime.

> *Community Health Worker: "There are houses with the roofs falling down around them, and mould issues and yeah... The carpets that haven't been changed in 30 years and they've just built-up grime and yeah, that's what they're living in."*

The situation was illustrated by accounts of clients living in tents provided by public housing due to a lack of available homes, underscoring the urgent need for healthy housing for vulnerable families.

Community Health Worker: "I mean we've got clients that are living in a tent by the river. The tent was given to them by [public] housing because they couldn't give them a house, so you know it's a single mum and her kid are living in a tent by the river. We gotta do better."

Additionally, participants acknowledged the connection between housing and mental health, recognising inadequate housing as a crucial social determinant impacting overall wellbeing. These findings underscore the multifaceted effects of poor housing on health and highlight the necessity for improved housing solutions to support vulnerable communities.

3.6.4 Priority Area: Foundations for a Health Life

In addition to the health environments that contribute to ear health and hearing, ear health and hearing was recognised as significantly important for providing a foundation for healthy life. Themes associated with the impact of ear health and hearing included school and education, behaviour, social and emotional wellbeing of parents and children, and the importance of nurturing future Elders. Importantly, the wellbeing of children was intricately connected to the broader health and welfare of the community, including the transmission of knowledge through oral systems of communication and storytelling.

3.6.4.1 School and education

The intersection of early childhood development, education, and healthcare services emerged as a critical theme, with participants emphasising the need for integration between health and educational settings to address the complex needs of children. Ongoing support was highlighted as essential, particularly for children with histories of ear infections that can lead to speech delays and other developmental challenges.

Community Health Worker and Parent: "And he had his first ear infection at the age of eight weeks, and he was prone to ear infections and that is why his speech is delayed. Now he is four and still having speech [therapy]"

Concerns were raised about children entering high school without adequate follow-up care, effectively setting them up to fail in their academic pursuits. Participants noted systemic issues, where undiagnosed ear problems often result in misinterpretations of behaviour, causing children to be labelled as disruptive rather than receiving appropriate support.

Community Health Worker: "It's in our education system. It's in our prisons. It's everywhere 'cause a lot of people like a lot of kids that don't have the access to [Ear, Nose and Throat] specialists. Yeah, you know, they grow up in life not knowing any different. They learn to live with that 'cause that's how they adjust. Therefore, you know they're getting kicked out of school 'cause they're just the naughty child or they're sitting up the back of the class and they're getting into trouble 'cause they're not listening. In actual fact, there's an underlying ear problem."

The need for active engagement with schools was underscored, with participants expressing a desire for stronger collaboration between healthcare services and educational institutions. Aboriginal Community Controlled Health Services are taking proactive steps to establish these cross-sector partnerships, demonstrating a commitment to improving health and educational outcomes for children.

3.6.4.2 Behaviour and social and emotional wellbeing

A key theme that emerged was the perceived behaviours associated with hearing loss and the impact this has on social and emotional wellbeing. Participants highlighted how speech difficulties can undermine the confidence of children, affecting their social interactions and school participation. Emotional challenges were also noted, with some parents describing changes in their child's behaviour and mood linked to conditions like glue ear, leading to misunderstandings about their actions.

Parent: "But it's just been a really big struggle for him and because of his speech, he's not confident. So, with him meeting friends or getting up in school, like getting up in from the of the classroom and speaking. It's 'caused and created so many issues over one thing."

Instances were shared where behavioural issues were misinterpreted, resulting in negative labels, while others illustrated the positive effects of increased awareness and support in educational settings, such as the use of cue cards to assist children with hearing loss. Parents expressed feelings of guilt and judgement when navigating these health issues, often exacerbated by a lack of understanding within daycare and school environments. This underscores the need for better education and support for both children and their families to address the social and emotional challenges associated with hearing loss.

Community Health Worker and Parent: "But like I was trying my hardest to stop it. I was doing everything in my power but and antibiotics just weren't cutting it either. So, we end up stopping the antibiotics and 'cause she wasn't having fevers and stuff to go with it. And just yeah. It was quite difficult, and I felt judged from the daycare, and I think that was because of their lack of education around ear health."

3.6.5 Priority Areas: Healthy Living and Strong Communities & Culture at the Centre of Change

3.6.5.1 Future Elders and oral culture

Participants highlighted the essential role of oral knowledge sharing and storytelling as a vital cultural determinant of health within their communities. They expressed a deep commitment to ensuring that children, seen as the future Elders, receive the necessary support to thrive and maintain community strength. The intergenerational responsibility to nurture the younger generation was emphasised, recognising their importance in preserving and transmitting cultural knowledge and practices.

Parent: "These kids are the Elders of tomorrow and we need to make sure that they're good and strong. Because they're going to be raising my great grand babies."

Additionally, the significance of hearing in traditional learning was underscored, as effective storytelling relies on the ability to listen and accurately convey narratives. This reinforces the need for healthy communication pathways to facilitate cultural continuity and community wellbeing.

Parent: "Yes, it's how we learn. And of course, we are an oral society... How are you going to listen to someone telling you a Yarn or whatever. And then you go away to tell someone else, and you are telling it wrong, you are telling half of the story."

3.7 Chapter 3 Discussion

This study explored perspectives of community stakeholders regarding ear health for Aboriginal and Torres Strait Islander children. These perspectives will be harnessed to support the co-creation of a community-led ear Health Navigator model of care. The Yarning circles revealed factors influencing ear health, highlighting the complexity of determinants that contribute to ear disease in Aboriginal and Torres Strait Islander children. These determinants are deeply embedded in local health environments, and encompass racism and cultural safety,

holistic versus reactive healthcare approaches, transport and cost barriers, extensive waitlists, challenges with continuity of care leading to loss to follow-up, poor quality and crowded housing, and the need for sustainable solutions. The impact of ear health and hearing on health and wellbeing were discussed and recognised as important for healthy life-course trajectories. The consequences highlighted the impact of disease on school and education, behaviour, social and emotional wellbeing, and the nurturing of future Elders.

Experiences of poor cultural safety and racism within healthcare settings was recognised by participants as impacting access to care. Participants expressed frustration and urgency regarding the neglect of ear health and the need for proactive measures and evidence-based interventions. Discriminatory attitudes and perceptions within healthcare systems were highlighted by participants, recognising that this impacts trust, confidence, and communication between healthcare providers and Aboriginal and Torres Strait Islander individuals. Similarly, Thurber et al[34] highlight the negative impact this has on health and wellbeing for Aboriginal and Torres Strait Islander people. Racism has detrimental effects on health outcomes. Consequently, there have been long-standing calls to implement anti-racist policies.[17, 19] Jamieson et al[35] similarly argue that Aboriginal and Torres Strait Islander people are disproportionately affected by multiple oppressions, with a direct correlation between the number of oppressions experienced and the severity of self-reported health issues.

Findings underscore the need for holistic person-centred care approaches. Participants voiced concerns about reactive solutions that rely on medication without addressing broader health considerations or prevention. This leads to feelings of helplessness, frustration, and scepticism regarding the quality of care received, particularly in mainstream settings. This is supported by Davy et al[35] who emphasise that holistic healthcare approaches improve patient outcomes and satisfaction. Furthermore, Brickley et al[37] highlight the effectiveness of person-centred models in addressing health disparities and fostering trust, and a recent Yarning study of non-remote Aboriginal and Torres Strait Islander caregivers in New South Wales highlighted that optimising the health and wellbeing of Aboriginal and Torres Strait Islander children requires care that considers a wide range of child, family, and community factors.[38]

Physical access to healthcare was an often-identified barrier, compounded by cost of accessing specialist services, especially Ear, Nose and Throat services. Lack of transport support and high costs posed challenges for families, highlighting inequities in healthcare access. Long waitlists and challenges in continuity of care resulted in delayed access to timely

interventions and loss to follow-up. This underscores the need for systemic improvements to reduce wait times, enhancing communication channels, and fostering seamless follow-up care. This is consistent with previous reports of inequitable access to ear health services for Aboriginal and Torres Strait Islander children due to inequities build into the healthcare system. These inequities include longer wait times and lower rates of surgery despite higher prevalence of ear disease when compared to their non-Aboriginal counterparts.[39-40]

Community members understood the links between housing and health outcomes, particularly for families living in crowded and poor-quality housing. Participants expressed frustration with temporary fixes and ad hoc funding, advocating for permanent and sustainable solutions. High prevalence of housing problems within Aboriginal and Torres Strait Islander communities has been previously reported, with calls for further action, particularly in the public housing sector, to minimise the negative health and social consequences.[41-42] Community-led initiatives were highlighted by participants as key for sustainability and positive health outcomes, emphasising the need for inclusive decision-making processes and resource allocation to support community-driven housing models.

Participants understood the Lifecourse theory[43], highlighting the complex interplay between early childhood experiences, child development, educational settings, and healthcare services. Participant experiences underscore the long-term impact of untreated ear disease on educational outcomes, behaviour, and academic performance, emphasising the need for continuous support and collaboration between health and education sectors. These findings are consistent with a study exploring caregiver perspectives about a support program for ear health, hearing and speech-language for Aboriginal and Torres Strait Islander children in the Northern Territory.[44] This study highlighted the importance of hearing for wellbeing, and the potential benefits of holistic and culturally safe support for improved educational outcomes.45 Behavioural and social-emotional impacts revealed insights into how hearing-related speech difficulties can affect self-esteem, social interactions, and emotional wellbeing among children. Participants shared experiences of the emotional toll on children, parents, and caregivers, including feelings of frustration, judgment, and misconceptions about behaviour linked to hearing difficulties. Given the links between hearing loss, social and emotional wellbeing, problems in school and contact with the justice system these narratives shed light on the importance of awareness, support, and holistic approaches to address the behavioural and emotional aspects associated with ear disease.[5-7, 45, 46]

Furthermore, the study captured the cultural significance of hearing within Aboriginal and Torres Strait Islander communities, emphasising the importance of oral traditions, storytelling, and knowledge sharing. Participants emphasised that children are Elders of the future and the significance of ensuring their health and wellbeing to preserve culture and support the community. This notion is recognised across Aboriginal populations globally and is supported by Greenwood and de Leeuw[47p1] who state, *"Aboriginal children's health today is a vital precursor to the health and well-being of our future nations".* Moreover, participants highlighted the intrinsic connection between hearing, communication, cultural resilience, and community strength, reinforcing the need for culturally responsive approaches in healthcare and education for Aboriginal and Torres Strait Islander children and their families. Cultural determinants of health are recognised as important for Aboriginal and Torres Strait Islander people, which is support by Verbunt et al[48] who emphasise the significance of empowering Aboriginal and Torres Strait Islander people through self-determination, cultural connection, and community-led organisations to enhance resilience and overall health and wellbeing.

3.7.1 Strengths and limitations

A notable strength of this study is the decolonised research approach inherent to Yarning circles, which enabled genuine community participation in co-creating a community-led model of care for ear health and hearing. The Yarning process included diverse perspectives, cultural insights, and traditional knowledge, ensuring the model is culturally appropriate and responsive to community needs. This approach respects the expertise and agency of community members, fostering a collaborative research environment. Findings are grounded in lived experiences, enhancing the model's relevance and sustainability. As findings are specific to participating communities, generalisations should be made carefully, considering unique cultural, social, and geographical contexts. Further research in diverse communities is recommended.

3.7.2 Implications for services and research

This study highlights the importance of addressing underlying social determinants and access barriers to improve outcomes for Aboriginal and Torres Strait Islander children with ear disease. Findings suggest that health navigators can help to optimise local health systems by strengthening connections between local services, provide culturally safe support when using mainstream services, provide person-centred and culturally relevant care, assist with cost and transport barriers, provide bi-directional knowledge translation, minimise loss-to-follow-up,

enhance continuity of care, and link families with community services that address social determinants of health.

The study underscores the importance of capturing community voices and leveraging local and cultural knowledge in co-creating health programmes. Importantly, recognition by participants that Aboriginal Community Controlled Services effectively support families to address social determinants and overcome access barriers, particularly when these services are well-resourced, highlights the need for care to be centred within Community Controlled Services. Consequently, it is crucial that the Community Controlled Health sector is sufficiently supported to ensure Aboriginal and Torres Strait Islander children and families have access the best-practice, high-quality, integrated and culturally safe care.

3.7.3 Conclusions

Ear health is a priority for Aboriginal and Torres Strait Islander communities. This study highlights the interconnection of social determinants and cultural in shaping experiences within the health system. Crucially, the emphasis on oral traditions, storytelling, and the nurturing of children as future Elders underscores the deep-rooted cultural values that guide approaches to health and wellbeing. Health Navigators can play a critical role in integrating culturally responsive approaches to address ear disease. Furthermore, health navigators are well positioned to facilitate collaboration between community-controlled and mainstream health services, educators, policymakers, and leaders. This cross-sector collaboration is crucial to improve access to interventions and holistic care. It is recommended that health navigators are embedded in community-controlled services to address social determinants, promote cultural safety, and foster supportive environments for lifelong ear health and overall wellbeing.

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3.9 Declarations

- **Ethics approval and consent to participate:** This project was approved by the Aboriginal Health and Medical Research Council, the peak body for Aboriginal and Torres Strait Islander research within New South Wales, Australia (Application number: 1917/22)

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    - Aboriginal Community Controlled Ear-health Support System (ACCESS) research grants:

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- **Authors' contributions:** All authors contributed to the production of this manuscript. JD, HG, JS and SW were instrumental in the conception and design of the study. JD, JS, MD and HG facilitated the Yarning circles. JD completed the transcriptions. JD and JS performed the initial thematic analysis, with authors HG, SW, MD, JC and SR reviewing and confirming identified themes. JS, MD, AS, LJ and EH provided local, cultural and content expertise to ensure reported findings were accurately reported. JD was primarily responsible for writing the manuscript. All authors contributed to critical revisions and editing the manuscript for important intellectual content and approved the final manuscript for submission.

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3.9 Contribution of Chapter 3 to overall thesis

Contribution

The primary aim of this thesis is to inform the co-design and co-implementation of the ACCESS project. The perspectives and derived themes within this chapter are instrumental in ensuring that the design and implementation of ACCESS is community-led, adhering to the co-creation principles underpinning this project.

Next steps

Since capturing these community perspectives, the ACCESS Child Health Navigator has been supporting children in participating communities. The ongoing co-creation of ACCESS (outlined in ***Chapter 6***) requires continuous community consultation, including further Yarning circles with community stakeholders. Future Yarning circles will be conducted to evaluate the implementation the ACCESS Child Health Navigator and explore the future directions of the ACCESS project.

CHAPTER 4: EAR HEALTH AND HEARING IN URBAN ABORIGINAL CHILDREN

4.1 Chapter 4 overview

In response to the community-identified priority to investigate ear health and hearing, data was collected from 1430 children aged six months to 18 years with otitis media diagnoses attending Aboriginal Community Controlled Health Services, using baseline questionnaire data and ear health examinations and who were enrolled in the Study of Environment on Aboriginal Resilience and Child Health (SEARCH) (see ***Chapter 1.4.1***). Ear health outcomes were otitis media and hearing loss. Prevalence of otitis media and hearing loss, and relationships between otitis media, hearing loss, and associated child, family and social factors are presented in this chapter.

Rationale

By identifying and reporting the prevalence of otitis media, hearing loss and associated factors, this paper provides a detailed understanding of the extent and impact of ear health issues within Aboriginal and Torres Strait Islander communities. While most existing data on otitis media is derived from rural and remote populations, this study addresses a significant gap by contributing insights into non-remote settings, where data remain scarce even though the majority of Aboriginal people live in these regions. This quantitative approach compliments the community perspectives from the Yarning circles reported in ***Chapter 3*** and offers a comprehensive overview of the factors influencing ear health and areas for targeted intervention to be embedded into the Aboriginal Community Controlled Ear-health Support System (ACCESS).

This chapter will:

1. Present the background and rationale for investigating and reporting otitis media hearing outcomes, including relationships between otitis media, hearing loss and associated child, family and social factors,
2. Describe the methodology for data collection and analysis,
3. Present, interpret and describe the implications of findings,
4. Highlight the strengths and limitations of this study, and
5. Provide research, service delivery and policy recommendations.

4.2 Published paper

DeLacy, J, Burgess, L, Cutmore, M, Sherriff, S, Woolfenden, S, Falster, K, et al. Ear health and hearing in urban Aboriginal children. Aust N Z J Public Health. 2023;47(4):1-11.

Ear health and hearing in urban Aboriginal children

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Abstract

Objective: Evaluate ear health and hearing among urban Aboriginal children and quantify relationships with child, family and social factors.

Methods: Baseline questionnaire and ear health examinations from 1430 children with diagnoses (0.5-18 years) attending Aboriginal Health Services enrolled in SEARCH. Ear health outcomes were Otitis Media (OM), and hearing loss (three-frequency average hearing loss >20dB) diagnosed using pneumatic otoscopy, tympanometry, and audiometry.

Results: Half the children 0.5-3 years had OM (51.5%, 136/264). One third 0.5-18 years (30.4%; 435/1430) had OM, including 1.8% (26/1430) with perforation (0.8% chronic suppurative OM, 0.6% dry perforation and 0.4% acute OM with perforation). One quarter 0.5-18 years (25.7%; 279/1087) had hearing loss; 12.4% unilateral, 13.2% bilateral (70.6% with bilateral loss had concurrent OM). OM was associated with: younger age (0.5-<3 years versus 6-18 years) age-sex-site; adjusted prevalence ratio (aPR)=2.64, 95%, 2.18-3.19); attending childcare/preschool (aPR=1.24, 95%CI, 1.04-1.49); foster care (aPR=1.40, 95%CI, 1.10-1.79); previous ear infection/s (aPR=1.68, 95%CI, 1.42-1.98); and ≥2 people/bedroom (aPR=1.66, 95%CI, 1.24-2.21). Hearing impairment was associated with younger age (0.5-<6 years vs. ≥6 years aPR=1.89, 95%CI, 1.40-2.55) and previous ear infection (aPR=1.87, 95%CI, 1.31-2.68).

Conclusions: Half the urban Aboriginal children in this cohort had OM and two-thirds with hearing impairment had OM.

Implications for Public Health: Findings highlight importance of early detection and support for ear health, particularly in pre-school-aged children with risk factors.

Key words: otitis media, ear health, hearing, Indigenous, Aboriginal

Introduction

Aboriginal and Torres Strait Islander language systems are diverse, with more than 150 traditional languages currently spoken across Australia.[1] Oral systems of knowledge and storytelling are central to Aboriginal and Torres Strait Islander identity and culture.[2] Healthy ears early in life are essential for spoken language[3] and critical for spiritual and cultural wellbeing and, to meet academic, social, and life potential,[4] for Aboriginal and Torres Strait

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Islander children. In fact, hearing loss has been found to negatively influence self-concept, educational attainment and social skills that consequently increase the risk of contact with the justice system.[5] Despite this, otitis media (OM) has been a major public health issue for Aboriginal and Torres Strait Islander children, with the prevalence of OM in some remote areas over 90%.[6] However, there are limited data on OM subtype frequency or the factors related to ear health and hearing outcomes in urban settings.[7–13] These data are necessary to inform prevention and treatment strategies in the areas where most Aboriginal and Torres Strait Islander children live.[14]

OM risk factors include day care attendance, exposure to tobacco smoke, asthma, allergies, craniofacial abnormalities, living with siblings and age,[15–17] with breastfeeding being protective.[16–18] Amongst Aboriginal and Torres Strait Islander populations, determinants of OM are less clear and have largely been reported in rural and remote settings.[3] In urban settings, data are scarce, but household crowding has been identified as a determinant of both OM[18] and OM-associated bacterial colonisation.[20,21] These determinants are not choices, but rather are the consequences of policies,[22] and include racism, crowded and poor quality housing, poverty and exposure to tobacco smoke.[3,23] The deficit discourse continues to depict Aboriginal and Torres Strait Islander people as the problem rather than colonisation and government policies[22] that have contributed to, and perpetuated, the disproportionate burden of these OM determinants.

Study of Environment on Aboriginal Resilience and Child Health (SEARCH)[24] is the largest cohort study of urban Aboriginal and Torres Strait Islander children. It is grounded in co-creation and participatory action research principles to strengthen the cultural safety and redresses the power imbalance in Aboriginal and Torres Strait Islander research.[25,26] It is accepted that Aboriginal and Torres Strait Islander health research has historically been problematic and non-participatory.[27–29] There is an ongoing shift away from this traditional research paradigm, where research was 'done on' communities, toward co-created approaches where research is 'done with' communities. Furthermore, co-creation has been acknowledged as supporting community members and service users to be coactive participants rather than passive end users.[27] Importantly, co-creation acknowledges the importance of community knowledge and lived experience and ensures community and cultural relevance is central to the research and research translation.[27–29] For over a decade, SEARCH has built and maintained successful relationships with Aboriginal communities to support community ownership of the research and data and to ensure community voice guides policy, research and service provision.[27–29]

The SEARCH partnerships with Aboriginal and Torres Strait Islander communities highlighted ear health and hearing as research priorities. In this study, we report OM and hearing outcomes in the cohort and associated child, family and social characteristics to inform policy and practice initiatives to improve ear health and hearing outcomes.

Methods

Study design

SEARCH is a cohort study of 1669 urban Aboriginal and Torres Strait Islander children (aged 0-18 years) from four participating Aboriginal Medical Services.[24] The Aboriginal Medical Services supported investigators to enrol participants (2008-2012).[8] Children and caregivers were interviewed by an Aboriginal and Torres Strait Islander research officer and offered comprehensive ear health assessments. Carers completed a detailed health and wellbeing questionnaire.[7] We present cross-sectional ear health data at SEARCH enrolment.

Setting

Three metropolitan and one large regional Aboriginal Medical Services in New South Wales.

Participants

SEARCH ear health protocols have been previously published.[24] Overall, there were 1669 children enrolled (Figure 1) with differential diagnostic data for the presence or absence of OM in 1430. We excluded children younger than 6 months (n=24, 1.4%), as ear health assessments in this age are technically difficult and less reliable. We excluded assessments conducted by audiometrists (ear health workers) rather than audiologists (n=11). There were 152 children not assessed and a further 52 with missing OM diagnoses, following reclassification (see below). We examined for demographic differences between the 1430 children with and 215 children without ear health diagnoses. For hearing outcomes, children younger than 3 years were excluded (n=285) as assessment at this age is less reliable. A further 110 children did not have a hearing assessment, leaving 1087 children with hearing outcome data. The main reason for missing assessments was caregiver refusal.[11]

Outcomes

Otitis media

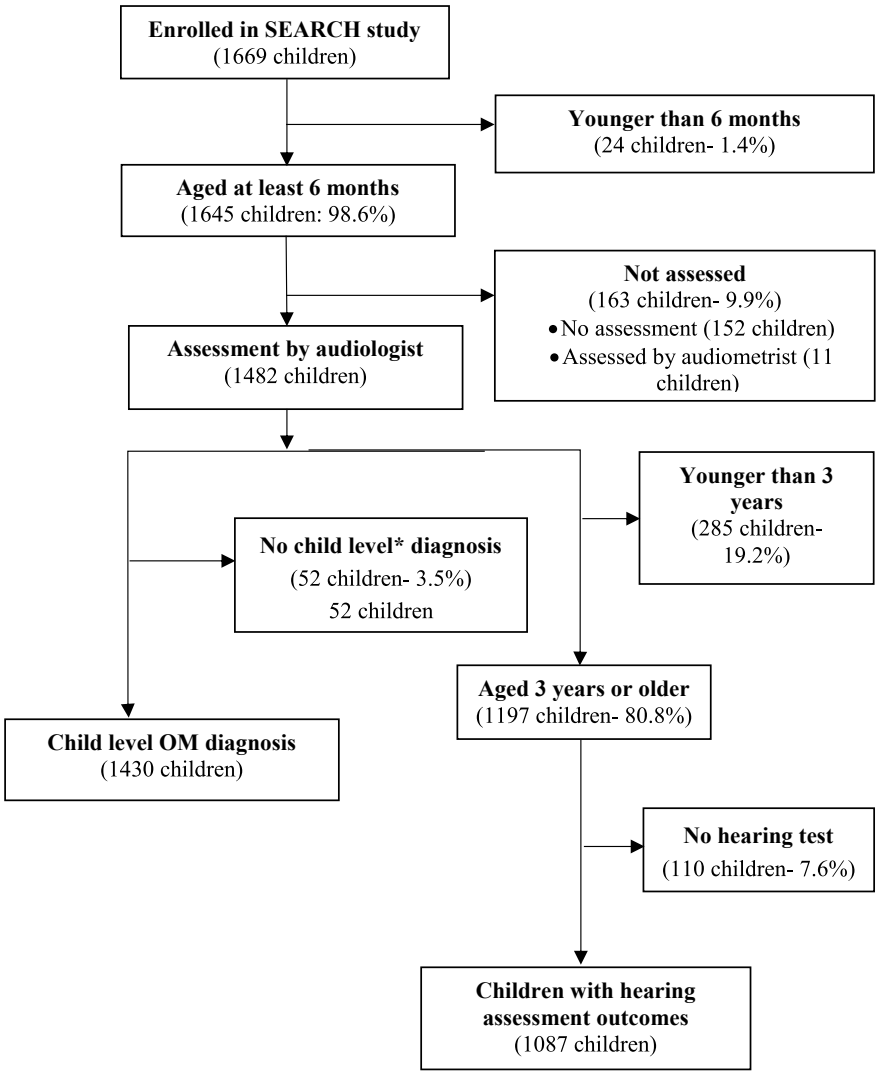
We reported rates by child (i.e. in either or both ears) and ear (i.e. separately right ear and left ear) and categorised diagnoses using this hierarchy: chronic suppurative OM; dry perforation; acute OM (with perforation, recurrent then without perforation), OM with effusion; OM undifferentiated. For the ear health analysis, we used a dichotomous variable (any OM/no OM).

Each child was assessed by one of five audiologists, and the results of these assessments were confirmed by one of three otolaryngologists. We reported the audiologists' findings here as we have previously demonstrated near perfect agreement between the audiologists and otolaryngologists, and the audiologist dataset is larger.[8] When audiologists did not choose a diagnosis, two independent reviewers (HG and JD) reclassified the comments 'wax', 'Eustachian tube dysfunction', 'ventilation tubes *in situ*' and 'tympanic membrane scarring' as 'No OM' and type B tympanograms (i.e. objective middle ear assessment suggestive of middle ear dysfunction) as 'OM' according to an *a priori* algorithm. If comments were insufficient for a reclassified diagnosis (n=95 ears), data were excluded. As OM diagnoses are subjective, we separately report type B tympanograms and tympanic perforation rates.

Hearing

Hearing loss was defined as 3 frequency averages (3FAHL 0.5, 1 and 2kHz) >20dB, consistent with contemporary recommendations.[30] Hearing impairment was defined as bilateral hearing loss and categorised by the results for the best ear as follows: mild (21 to 45dB); moderate (46 to 65 dB); severe (>65dB). For the hearing impairment analysis, we used a dichotomous variable (yes/no). We

Figure 1: Flowchart of children with otitis media (OM) and hearing data included in the analysis.



*Child level = results corresponding to either or both ears (using the hierarchy)

also report findings by the recently published World Health Organization hearing classifications.[19]

Child, family and social factors

Child-related outcome measures included sex, age group, in utero exposure to cigarettes, in utero exposure to marijuana, ever had an ear infection, and ever breastfed.

Family-related outcome measures included relationship to child, carer education, government financial support, carer allowance, parental psychological distress, parental/carer removal from family, fortnightly household income, employment status and carer regular smoker or more than one person smoking within home.

Social-related outcome measures included assessment season, number of houses lived in since birth, attends childcare, housing tenure, people per bedroom and housing problem.

The housing problems variable related to the participants current residence and was defined as 'yes' to any questions about: 'rising damp'; 'damp on walls/ceilings/windows'; 'major plumbing problems'; 'cockroaches/mice/vermin'; 'structural problems (cracks, sinking foundations, sagging floors, walls/windows not straight or wood rot/termite damage)' or the house being 'too small'. Time-specific survey data (e.g. ever had an ear infection, number of houses lived in since birth, current exposure to cigarette smoke) were set to missing if either (i) the audiology assessment was more than 6 months before or after the survey (for children <2 years at the time of the assessment) or (ii) the audiology assessment was more than 1 year before or after the survey (for children ≥2 years at the time of the assessment). If the audiology assessment was completed after a survey with a response 'yes' to 'ever had an ear infection?', we included these data as the response would not have changed.

Statistical methods

Log-binomial regression was used to calculate prevalence ratios (PRs) for the association between: (1) OM; (2) hearing loss; (3) each child, family and social characteristic and the two outcome measures. Parameter estimation was performed within the generalised estimating equations framework with an exchangeable correlation

structure to account for children within families. We report unadjusted PRs and PRs adjusted (aPR) for aboriginal medical services, age and sex. The functional form of age was checked using fractional polynomials. To assess for bias due to missing data, analyses were repeated with multiple-imputed data for the risk factors. Multilevel multiple imputations were performed using REALCOM-IMPUTE software[31] with the outcomes and all risk factors in the imputation models. We created 50 imputed datasets, which incorporated variability due to uncertainty in the exact values, with a burn-in period of 2500 iterations and 500 iterations between imputations. Estimates of coefficients obtained for each dataset were combined using Rubin's rules.[32] Sensitivity analyses were conducted varying the time period permitted between the child survey and the audiology assessment to assess if the choice of time period influenced the results. The first analysis included data for children with any length of time between the audiology assessment and the second limited the gap permitted to one month. All analyses were conducted in Stata version 16.1 (StataCorp, College Station, TX, USA).

Results

Of 1669 SEARCH participants, 1482 (88.8%) participants had an audiology assessment and 1430 (85.6%) had an ear health diagnosis and were included in the analysis (Table 1; Figure 1). Included children were similar to excluded children, except they were less likely to have been assessed in summer and were slightly older (see Supplementary Table 1).

Children were aged 6 months to 18.9 years (median 6.4 years; interquartile range 3.7-10.2 years) at the audiology assessment. Of the 1430 children, 995 (69.6%) had no OM and 435 (30.4%) had OM (Table 2), including 26/1430 (1.8%) with a perforated tympanic membrane. Audiologists were more likely to diagnose acute OM without perforation (110/1430; 7.7% children), than otolaryngologists (~1% children; with the rest labelled OM with effusion), but their diagnoses were otherwise similar. Of 2,354 ears with both tympanometry and otoscopic data, 436 (18.5%) had type B tympanograms (123/436 had bulging) and 1918 (81.5%) had non-type B tympanograms (37/1918 had bulging).

Hearing data were available for 1087 children (aged 3 to 18.9 years; median 8.2 years, interquartile range 5.7–11.5 years). Of these, 279/1087 (25.7%) had hearing loss; 144 (13.2%) bilateral and 135 (12.4%) unilateral. Of the 136 children with hearing impairment (bilateral hearing loss) and an ear health diagnosis, 96 (70.6%) had OM. Children with OM were more likely to have hearing impairment than those without OM (aPR=7.28, 95% CI 4.99-10.62).

OM and hearing impairment were most common among the youngest age groups, with OM identified in: 136/264 (51.5%) children <3 years, 148/396 (37.4%) children ≥3 years to <6 years, 123/537 (22.9%) children ≥6 to <12 years and 28/233 (12.0%) children ≥12 years. Compared to children six years or older, OM adjusted PRs for children ≥6 months to <3 years were 2.64 (95% confidence interval (CI) 2.18-3.19) and 1.86 (95%CI 1.53-2.26) for children ≥3 years to <6 years. Hearing impairment was identified in 63/316 (19.9%) children ≥3 to <6 years, 60/536 (11.2%) children aged ≥6 to <12 years and 21/235 (8.9%) children ≥12 years.

Boys had a similar likelihood of hearing impairment to girls (aPR=0.88, 95% CI 0.65-1.219). OM was more common among children who were younger, attended childcare or preschool (assessed for all children <6 years); were in foster care, ever had a previous ear infection; had more people per bedroom in the home (Table 3). Hearing impairment was more common among children who were younger and had a history of ear infection.

Sensitivity analyses

Supplementary Table 2 shows similar associations when using imputed data for missing values. Sensitivity analyses varying the time permitted between audiology assessments and surveys were also consistent with the primary analysis results.

Discussion

Approximately half of the children in our cohort aged six months to three years, a critical age for speech and language development,[3] had some form of OM. Overall, about one third of children aged six months to 18 years at baseline had OM. One in seven children had bilateral hearing impairment, two thirds of those with hearing impairment presented with concurrent OM and less than 2% had tympanic membrane perforation. Factors associated with OM and/or hearing impairment were childcare attendance, previous ear infection, younger age, foster care and living in crowded houses. Socioeconomic factors such as carer education level, household income, employment status, home ownership and having government financial support were not associated with OM or hearing impairment in this cohort.

Our study provides the first contemporary view of OM and hearing impairment in urban Aboriginal and Torres Strait Islander children since a small cross-sectional study of Aboriginal and Torres Strait Islander primary school children in Perth in 2009.[12] However, a recent study from Western Australia of 67 urban Aboriginal and Torres Strait Islander children aged 9-12 months[13] reported hearing loss prevalence of 31.3% of 67 children, and type B tympanograms in 46.2% of 65 children without reporting OM diagnoses or associated factors, and assessed only younger children. A 2023 follow-up to this study reported OM diagnoses in 125 Aboriginal infants aged two to 12 months.[6] In this study,[6] approximately half of the participants aged six months had OM, and those with OM at age two or six months were more likely than those without to have OM at age 12 months. This is consistent with the association between OM and previous ear infection found in our study. The earlier Perth study[12] found 19.3% of 119 children had OM (excluding Eustachian tube dysfunction) and 19.1% of 94 children tested had mild-moderate hearing impairment. In the SEARCH cohort, 30% of children had OM and 25.6% had a hearing impairment at baseline, although the sampling methods preclude reliable extrapolation to the overall population of urban Aboriginal and Torres Strait Islander children in NSW. Our higher prevalence of hearing impairment in SEARCH (13% bilateral hearing loss at 20dB vs. 4% bilateral hearing loss at 25dB in Perth study) may reflect differences in the decibel (dB) definition of impairment. Less than 2% of children in this study had tympanic membrane perforation, significantly lower than the 12-14% reported by a 2016 study[33] of 651 Aboriginal and Torres Strait Islander children in remote Northern Territory and the 21% reported in a 2022 study[34] of 19 Aboriginal and Torres Strait Islander children in remote South Australia. To date, the recent Western Australia study[6] of 125 infants is the only other reporting child, family and social factors in relation to OM among urban Aboriginal and Torres Strait Islander children.

Table 1: Child, family and social characteristics of participants, by otitis media and hearing impairment outcomes.

	Otitis Media at child level[a]			Hearing impairment[b] at child level		
	No Otitis Media	Any Otitis Media	Total	No	Yes	Total
	n =995	n =435	n =1430	n =943	n =144	n =1087
	n (%)	n (%)	n	n (%)	n (%)	n
Sex						
Female	447 (68.8)	203 (31.2)	650	432 (86.1)	70 (13.9)	502
Male	548 (70.3)	232 (29.7)	780	511 (87.4)	74 (12.6)	585
Age at audiology assessment						
6 months to <3 years	128 (48.5)	136 (51.5)	264			
3 to <6 years	248 (62.6)	148 (37.4)	396	253 (80.1)	63 (19.9)	316
6 to <12 years	414 (77.1)	123 (22.9)	537	476 (88.8)	60 (11.2)	536
12 to 18 years	205 (88.0)	28 (12.0)	233	214 (91.1)	21 (8.9)	235
Number of houses lived in since birth						
1	165 (59.6)	112 (40.4)	277	130 (81.8)	29 (18.2)	159
2	163 (65.2)	87 (34.8)	250	135 (84.9)	24 (15.1)	159
3	142 (68.6)	65 (31.4)	207	158 (86.3)	25 (13.7)	183
≥4	242 (81.2)	56 (18.8)	298	245 (89.7)	28 (10.3)	273
Missing	283 (71.1)	115 (28.9)	398	275 (87.9)	38 (12.1)	313
Attends childcare/preschool (<6 years)						
No	190 (59.7)	128 (40.3)	318	114 (82.6)	24 (17.4)	138
Yes	150 (53.8)	129 (46.2)	279	115 (76.2)	36 (23.8)	151
Missing	36 (57.1)	27 (42.9)	63	24 (88.9)	3 (11.1)	27
Assessment season						
Winter/Spring	603 (67.4)	292 (32.6)	895	577 (85.5)	98 (14.5)	675
Summer/Autumn	392 (73.3)	143 (26.7)	535	366 (88.8)	46 (11.2)	412
Relationship to child						
Parent	842 (70.3)	355 (29.7)	1197	774 (86.6)	120 (13.4)	894
Other relative	95 (68.8)	43 (31.2)	138	106 (86.9)	16 (13.1)	122
Foster carer	53 (59.6)	36 (40.4)	89	60 (88.2)	8 (11.8)	68
Missing	5 (83.3)	1 (16.7)	6	3 (100.0)	0 (0)	3
In utero exposure to cigarettes						
No	403 (71.3)	162 (28.7)	565	362 (86.8)	55 (13.2)	417
Yes	415 (67.6)	199 (32.4)	614	397 (85.6)	67 (14.4)	464
Missing	177 (70.5)	74 (29.5)	251	184 (89.3)	22 (10.7)	206
In utero exposure to marijuana						
No	657 (69.7)	286 (30.3)	943	601 (85.6)	101 (14.4)	702
Yes	144 (67.3)	70 (32.7)	214	146 (88.5)	19 (11.5)	165
Missing	194 (71.1)	79 (28.9)	273	196 (89.1)	24 (10.9)	220
Ear infection (parent report)						
No	465 (76.6)	142 (23.4)	607	403 (91.0)	40 (9.0)	443
Yes	299 (60.5)	195 (39.5)	494	326 (81.7)	73 (18.3)	399
Missing	231 (70.2)	98 (29.8)	329	214 (87.3)	31 (12.7)	245
Ever breastfed						
Yes	455 (68.6)	208 (31.4)	663	418 (87.1)	62 (12.9)	480
No	351 (70.1)	150 (29.9)	501	328 (84.1)	62 (15.9)	390
Missing	189 (71.1)	77 (28.9)	266	197 (90.8)	20 (9.2)	217
Carer regular smoker or ≥1 person smokes inside house						
No	272 (69.6)	119 (30.4)	391	271 (88.0)	37 (12.0)	308
Yes	500 (69.3)	222 (30.7)	722	467 (85.5)	79 (14.5)	546
Missing	223 (70.3)	94 (29.7)	317	205 (88.0)	28 (12.0)	233
Carer education						
< Year 10	156 (64.5)	86 (35.5)	242	138 (84.7)	25 (15.3)	163
Year 10	199 (72.6)	75 (27.4)	274	181 (87.0)	27 (13.0)	208
Year 11 - 12	102 (70.3)	43 (29.7)	145	80 (80.0)	20 (20.0)	100
Trade/certificate/diploma	362 (71.5)	144 (28.5)	506	344 (87.8)	48 (12.2)	392
University	60 (69.0)	27 (31.0)	87	71 (89.9)	8 (10.1)	79
Missing	116 (65.9)	60 (34.1)	176	129 (89.0)	16 (11.0)	145
Fortnightly household income						
≤ $599	216 (67.5)	104 (32.5)	320	198 (87.6)	28 (12.4)	226

(continued)

TABLE 1. Continued

	Otitis Media at child level[a]			Hearing impairment[b] at child level		
	No Otitis Media	Any Otitis Media	Total	No	Yes	Total
	n =995	n =435	n =1430	n =943	n =144	n =1087
	n (%)	n (%)	n	n (%)	n (%)	n
$600 - $799	138 (67.0)	68 (33.0)	206	129 (85.4)	22 (14.6)	151
$800 - $1999	378 (71.2)	153 (28.8)	531	358 (86.3)	57 (13.7)	415
≥$2000	80 (69.6)	35 (30.4)	115	74 (88.1)	10 (11.9)	84
Missing	183 (70.9)	75 (29.1)	258	184 (87.2)	27 (12.8)	211
Employment status						
Employed/Studying (full or part-time)	288 (72.5)	109 (27.5)	397	291 (88.7)	37 (11.3)	328
Unemployed/Home duties/Retired	621 (68.7)	283 (31.3)	904	560 (85.9)	92 (14.1)	652
Missing	86 (66.7)	43 (33.3)	129	92 (86.0)	15 (14.0)	107
Housing tenure						
Own/Mortgage	160 (71.7)	63 (28.3)	223	160 (89.4)	19 (10.6)	179
Rent	167 (70.8)	69 (29.2)	236	152 (86.4)	24 (13.6)	176
Public housing	557 (68.8)	253 (31.2)	810	519 (85.6)	87 (14.4)	606
Missing	111 (68.9)	50 (31.1)	161	112 (88.9)	14 (11.1)	126
Average people per bedroom						
≤1	210 (77.5)	61 (22.5)	271	182 (89.7)	21 (10.3)	203
>1, <2	485 (69.8)	210 (30.2)	695	458 (87.1)	68 (12.9)	526
≥2	191 (63.2)	111 (36.8)	302	190 (84.4)	35 (15.6)	225
Missing	109 (67.3)	53 (32.7)	162	113 (85.0)	20 (15.0)	133
Housing problem[c]						
No	229 (70.7)	95 (29.3)	324	209 (86.0)	34 (14.0)	243
Yes	652 (69.2)	290 (30.8)	942	615 (86.6)	95 (13.4)	710
Missing	114 (69.5)	50 (30.5)	164	119 (88.8)	15 (11.2)	134
Govt financial support						
None	100 (71.9)	39 (28.1)	139	97 (91.5)	9 (8.5)	106
Family/parent/age only	740 (69.4)	327 (30.6)	1067	702 (86.5)	110 (13.5)	812
Disability/Sickness/ Unemployment	83 (72.8)	31 (27.2)	114	67 (84.8)	12 (15.2)	79
Missing	72 (65.5)	38 (34.5)	110	77 (85.6)	13 (14.4)	90
Carer allowance						
No	784 (69.4)	345 (30.6)	1129	741 (87.0)	111 (13.0)	852
Yes	139 (72.8)	52 (27.2)	191	125 (86.2)	20 (13.8)	145
Missing	72 (65.5)	38 (34.5)	110	77 (85.6)	13 (14.4)	90
Parent/carer psychological distress (K10 score ≥22)[d]						
No	811 (69.9)	349 (30.1)	1160	761 (86.9)	115 (13.1)	876
Yes	51 (65.4)	27 (34.6)	78	50 (89.3)	6 (10.7)	56
Missing	133 (69.3)	59 (30.7)	192	132 (85.2)	23 (14.8)	155

[a]Child level=results corresponding to either or both ears (using the hierarchy).
[b]Hearing impairment=bilateral hearing loss at least 20dB based on 3 frequency average.
[c]Housing problem = rising damp, damp on walls/ceilings/windows, major plumbing problems, cockroaches/mice/vermin, structural problems (cracks, sinking foundations, sagging floors, walls/windows not straight, wood rot/termite damage) or house too small.
[d]The Kessler 10 question psychological distress scale.

This study[6] reports an association with OM and having more than one person per room living in the home. Our finding that was associated with OM is consistent with this and other studies of OM among Aboriginal and Torres Strait Islander children in regional and remote areas.[3] OM was more common among children attending childcare in our study, similar to studies of other populations of children, likely from increased exposure to upper respiratory infections.[21] Although previous studies in remote settings have shown that socioeconomic factors are associated with OM among Aboriginal and Torres Strait Islander children, we did not find an association between ear health outcomes and income or education, only crowded housing and out of home care. However, we have previously shown that Aboriginal and Torres Strait Islander children had fewer ventilation tube insertions compared with same-age non-Aboriginal children in NSW, and socio-economic indicators were associated with this inequity.[35]

The timeframes for implementing authentic co-design and community-controlled research partnerships have meant that these data are a decade old but remain the most comprehensive and most contemporary ear health and hearing loss analysis in this population to date. These data are essential to inform policy, practice and public health approaches. Our diagnostic assessments were gold standard (tympanometry and pneumatic otoscopy) and conducted by experts (audiologists with confirmation by otolaryngologists with near perfect agreement).[8] We acknowledge OM and associated hearing loss fluctuates and assessments at one time point are not synonymous with lifetime burden of OM. Within the dataset, acute OM diagnoses were lower for otolaryngologists than audiologists (otolaryngologists ~1%; Audiologists ~7%). This did not impact the analysis, which was at the level of OM vs. 'No OM'. This difference in acute OM could be due to otolaryngologist reviews being asynchronous and without

Table 2: Otitis media and hearing loss diagnoses in participating children and for each ear.

Otitis media (N=1430)							
Diagnosis by ear	Right ear		Left ear		Diagnosis at child level	Child level	
	n	%	n	%		n	%
Chronic suppurative OM[b]	6	0.4	7	0.5	Chronic suppurative OM	11	0.8
Dry perforation	7	0.5	6	0.4	Dry perforation	9	0.6
Acute OM with perforation	2	0.1	6	0.4	Acute OM with perforation	6	0.4
Recurrent acute OM	3	0.2	4	0.3	Recurrent acute OM	4	0.3
Acute OM without perforation	92	6.4	86	6.0	Acute OM without perforation	110	7.7
Chronic OM with effusion	25	1.7	28	2.0	Chronic OM with effusion	30	2.1
OM with effusion	101	7.1	95	6.6	OM with effusion	119	8.3
OM (undifferentiated)	103	7.2	96	6.7	OM (undifferentiated)	137	9.6
No OM	1086	75.9	1097	76.7	No OM in either ear	995	69.6
Missing	5	0.3	5	0.3	Missing	9	0.6
Total	1430	100	1430	100	Total	1430	100
Hearing impairment (N=1087)							
Hearing loss by ear	Right ear		Left ear		Hearing impairment by child	Child level	
	n	%	n	%		n	%
Normal hearing	880	81.0	869	79.9	No impairment	806	74.1
Mild hearing impairment	190	17.5	199	18.3	Unilateral impairment	135	12.4
Moderate hearing impairment	17	1.6	17	1.6	Bilateral impairment	144	13.2
Missing	0	0	2	0.2	Missing	2	0.2
Total	1087	100	1087	100	Total	1087	100
Hearing impairment using World Health Organization Hearing (WHO) classification (N=1087)[a]							
Hearing loss by ear	Right ear		Left ear		Hearing loss by ear	Child level	
	n	%	n	%		n	%
Normal hearing	822	75.6	812	74.7	No impairment	730	67.2
Mild hearing loss	206	19.0	214	19.7	Unilateral impairment	172	15.8
Moderate hearing loss	48	4.4	50	4.6	Bilateral impairment	183	16.8
Moderately severe hearing loss	10	0.9	7	0.6	Missing	2	0.2
Severe hearing loss	1	0.1	2	0.2			
Missing	0	0.0	2	0.2			
Total	1087	100	1087	100	Total	1087	100

[a]The WHO hearing classification[19] was not used in the analysis for this paper, as the analysis was performed prior to its publication. For transparency, we have presented relevant hearing loss data here and note a lower percentage of 'normal hearing' and higher percentage of mild and moderate hearing impairment in this cohort when using the updated WHO guidelines. Hearing impairment as classified by WHO: mild (20 to <35dB); moderate (35 to <50dB); moderately severe (55 to <65dB); and severe (65 to <80dB).
[b]Otitis media.

patient histories. We excluded Eustachian tube dysfunction, although it can be associated with recent or impending OM and may have underestimated the burden of disease. Although SEARCH participants may not be representative of the urban Aboriginal and Torres Strait Islander child population, findings based on internal comparisons, such as PRs, do not require representative sampling.[36] Finally, we acknowledge that missing questionnaire data may have resulted in differential misclassification and affected the aPRs.

OM is treatable and preventable. Early intervention may reduce hearing loss and other downstream adverse health and social outcomes such as involvement in the juvenile justice system.[5] We have identified characteristics of urban Aboriginal and Torres Strait Islander children who may benefit from targeted prevention and early intervention services, including children who: are aged <6 years; have a history of ear disease; live in foster care; attend childcare; live in crowded homes. Younger children, especially those attending childcare, may benefit from routine ear health surveillance. Preschool has important developmental benefits[37] and may be an ideal setting for targeted ear health surveillance, as well as other settings where children and parents are connected with health professionals, such as mother's groups and Aboriginal Medical Services. We found that OM was more common among children in foster care compared with those living with family members, highlighting the importance of health checks and management plans for children in out-of-home care. OM was more common among children living in homes with more than two people per bedroom, emphasising the importance of culturally safe, integrated health and social care to address the social determinants of health, such as crowded housing.[3,38] Increased funding to Australia's Aboriginal Medical Services to ensure this level of culturally safe access to early childhood ear health, speech, language and social services could improve child health outcomes.

The majority of the children in our cohort younger than three years had some form of OM. Given this age period is critical for speech, language and auditory processing development, our findings highlight the potential for long-term health gain, as OM and hearing

Table 3: Unadjusted and adjusted associations between child, family and social factors to ear health and hearing outcomes.

	Otitis media diagnosis at child level				Hearing impairment in better ear			
	Unadjusted		Adjusted[a]		Unadjusted		Adjusted[a]	
	Prevalence ratio (PR) (95% CI)	P value	PR (95% CI)	P value	PR (95% CI)	P value	PR (95% CI)	P value
CHILD FACTORS								
Sex		0.641		0.543		0.593		0.409
Female (ref)	1		1		1		1	
Male	0.96 (0.81,1.13)		0.95 (0.82,1.11)		0.92 (0.68,1.25)		0.88 (0.65,1.19)	
Age group		<0.001		<0.001		<0.001		<0.001
≥6 months to <3 years	2.65 (2.20, 3.21)		2.64 (2.18, 3.19)					
≥3 to <6 years	1.90 (1.56, 2.31)		1.86 (1.53, 2.26)		1.93 (1.42, 2.61)		1.89 (1.40, 2.55)	
≥6 to 18 years (ref)	1		1		1		1	
In utero exposure to cigarettes		0.222		0.092		0.603		0.489
No (ref)	1		1		1		1	
Yes	1.12 (0.93,1.35)		1.16 (0.98,1.37)		1.10 (0.78,1.54)		1.13 (0.80,1.59)	
In utero exposure to marijuana		0.701		0.412		0.250		0.248
No (ref)	1		1		1		1	
Yes	1.05 (0.82,1.33)		1.10 (0.88,1.37)		0.74 (0.45,1.23)		0.74 (0.45,1.23)	
Ever ear infection (parent report)		<0.001		<0.001		<0.001		0.001
No (ref)	1		1		1		1	
Yes	1.72 (1.43,2.07)		1.68 (1.42,1.98)		2.04 (1.42,2.94)		1.87 (1.31,2.68)	
Ever breastfed		0.534		0.935		0.262		0.259
Yes (ref)	1		1		1		1	
No	0.94 (0.77,1.14)		0.99 (0.83,1.19)		1.22 (0.86,1.72)		1.22 (0.86,1.72)	
FAMILY FACTORS								
Relationship to child		0.072		0.022		0.948		0.694
Parent (ref)	1		1		1		1	
Other relative	0.98 (0.73,1.30)		1.09 (0.84,1.41)		0.96 (0.61,1.50)		0.88 (0.56,1.39)	
Foster carer	1.39 (1.05,1.85)		1.40 (1.10,1.79)		0.91 (0.48,1.72)		0.80 (0.43,1.48)	
Carer education		0.323		0.342		0.330		0.373
< Year 10 (ref)	1		1		1		1	
Year 10	0.78 (0.59,1.04)		0.80 (0.62,1.04)		0.87 (0.51,1.50)		0.91 (0.53,1.55)	
Year 11 - 12	0.80 (0.58,1.11)		0.81 (0.61,1.09)		1.32 (0.77,2.28)		1.29 (0.74,2.24)	
Trade/certificate/diploma	0.80 (0.64,1.01)		0.86 (0.71,1.05)		0.83 (0.52,1.32)		0.85 (0.53,1.37)	
University	0.87 (0.59,1.29)		0.96 (0.67,1.39)		0.69 (0.31,1.55)		0.67 (0.31,1.47)	
Govt financial support		0.600		0.575		0.340		0.510
None (ref)	1		1		1		1	
Family/Parent/Age only	1.11 (0.80,1.54)		1.01 (0.77,1.34)		1.57 (0.84,2.95)		1.41 (0.78,2.55)	
Disability/Sickness/ Unemployment	0.95 (0.60,1.53)		0.84 (0.55,1.29)		1.74 (0.72,4.20)		1.46 (0.60,3.54)	
Carer allowance		0.172		0.896		0.783		0.606
No (ref)	1		1		1		1	
Yes	0.83 (0.63,1.09)		0.99 (0.79,1.23)		1.06 (0.69,1.64)		1.12 (0.73,1.72)	

(continued)

TABLE 3. Continued

	Otitis media diagnosis at child level				Hearing im		better ear	
	Unadjusted		Adjusted[a]		Unadjusted		Adjusted[a]	
	Prevalence ratio (PR) (95% CI)	P value	PR (95% CI)	P value	PR (95% CI)	P value	PR (95% CI)	P value
Parent/carer psychological distress (K10 score ≥ 22)[b]		0.357		**0.211**		0.360		0.239
No (ref)	1		1		1		1	
Yes	1.11 (0.89,1.38)		1.14 (0.93,1.39)		1.21 (0.80,1.82)		1.27 (0.85,1.90)	
Fortnightly household income		0.752		0.751		0.831		0.664
≤ $599 (ref)	1		1		1		1	
$600 - $799	1.04 (0.78,1.39)		1.09 (0.84,1.40)		1.19 (0.71,1.98)		1.22 (0.74,2.01)	
$800 - $1999	0.91 (0.72,1.15)		0.97 (0.79,1.20)		1.12 (0.71,1.78)		1.10 (0.69,1.75)	
≥ $2000	0.96 (0.70,1.33)		0.92 (0.67,1.26)		0.92 (0.48,1.75)		0.86 (0.46,1.60)	
Employment status		0.251		0.930		0.265		0.430
Employed/Studying (full or part-time) (ref)	1		1		1		1	
Unemployed/Home duties/Retired	1.13 (0.92,1.39)		0.99 (0.82,1.20)		1.25 (0.84,1.85)		1.17 (0.80,1.71)	
Carer regular smoker or ≥1 person smokes inside house		0.921		0.691		0.357		0.250
No (ref)	1		1		1		1	
Yes	0.99 (0.80,1.22)		0.96 (0.80,1.16)		1.19 (0.82,1.73)		1.24 (0.86,1.80)	
SOCIAL FACTORS								
Assessment season		0.056		0.072		0.119		0.190
Winter/Spring (ref)	1		1		1		1	
Summer/Autumn	0.83 (0.69,1.00)		0.85 (0.71,1.01)		0.76 (0.53,1.07)		0.79 (0.56,1.12)	
No. houses lived in since birth		<0.001		0.078		0.165		0.359
1 (ref)	1		1		1		1	
2	0.84 (0.66,1.06)		0.89 (0.71,1.10)		0.82 (0.47,1.43)		0.82 (0.48,1.38)	
3	0.74 (0.57,0.96)		1.00 (0.77,1.28)		0.75 (0.44,1.28)		0.77 (0.46,1.29)	
≥4	0.46 (0.35,0.60)		0.72 (0.55,0.95)		0.57 (0.35,0.94)		0.65 (0.40,1.05)	
Attends childcare/preschool (<6 years)		0.195		0.019		0.175		0.421
No (ref)	1		1		1		1	
Yes	1.13 (0.94,1.37)		1.24 (1.04,1.49)		1.37 (0.87,2.17)		1.23 (0.74,2.06)	
Housing tenure		0.714		0.694		0.466		0.298
Own/Mortgage (ref)	1		1		1		1	
Rent	1.07 (0.77,1.47)		0.92 (0.69,1.22)		1.29 (0.71,2.33)		1.21 (0.67,2.16)	
Public housing	1.11 (0.85,1.46)		1.01 (0.80,1.28)		1.36 (0.84,2.21)		1.44 (0.89,2.32)	
People per bedroom		0.002		0.003		0.311		0.276
≤1 (ref)	1		1		1		1	
>1, <2	1.39 (1.05,1.85)		1.38 (1.06,1.80)		1.24 (0.78,1.96)		1.27 (0.82,1.97)	
≥2	1.71 (1.26,2.31)		1.66 (1.24,2.21)		1.50 (0.89,2.53)		1.49 (0.91,2.44)	
Housing problem		0.618		0.562		0.924		0.957
No (ref)	1		1		1		1	
Yes	1.06 (0.85,1.32)		1.06 (0.87,1.30)		0.98 (0.66,1.45)		0.99 (0.68,1.45)	

[a]Adjusted for age (continuous), sex & Aboriginal Medical Services as appropriate.
[b]The Kessler 10 question psychological distress scale.

impairment are treatable. We need culturally safe integrated models of health and social care addressing the social determinants of health and continuity of care for this priority population. Community-driven, holistic, targeted approaches for urban Aboriginal and Torres Strait Islander children with OM and hearing impairment should be facilitated through community engagement and the delivery of high quality, comprehensive, culturally safe community-based initiatives.

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Ethical approval

All research activities reported in this manuscript received explicit ethical approval from relevant Human Research Ethics Committees including the Aboriginal Health and Medical Research Council.

Conflicts of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.anzjph.2023.100075.

4.3 Contribution of Chapter 4 to overall thesis

Contribution

This chapter provides novel and detailed information about ear health, hearing, and associated factors among children living in the same communities and regions supported by the ACCESS Child Health Navigators. Given the scarcity of data on otitis media and hearing loss in non-remote Aboriginal and Torres Strait Islander settings, this chapter addresses a critical knowledge gap. It also contributes unique insights into the social determinants of otitis media, including child, family, and social factors, which are often underrepresented in existing literature. These data are essential for the co-design and co-implementation of ACCESS, enabling a deeper understanding of the extent of ear disease and hearing burden. Furthermore, the findings provide a foundation for prioritising children at risk of ear disease and tailoring interventions to address both health and social factors influencing ear health outcomes.

Next steps

Timeframes for implementing 'true co-creation' mean that the data from this paper are over a decade old. Nevertheless, this data represents the most comprehensive and contemporary data on ear health, hearing and associated factors among Aboriginal and Torres Strait Islander children living in non-remote settings in Australia. Despite the relatively large sample, this paper reports data from a small number of culturally and locally distinct communities. Therefore, generalisations should be made with caution. Consequently, efforts should be made to capture contemporary data at local, state and national levels to best inform research, policy and practice across disparate Aboriginal and Torres Strait Islander populations.

CHAPTER 5: HEALTH NAVIGATORS SUPPORTING INDIGENOUS CHILDREN AND ADOLESCENTS: A SYSTEMATIC REVIEW

5.1 Chapter 5 overview

This chapter consists of a systematic review that explores peer-reviewed literature to identify the role and scope of Health Navigators supporting Indigenous children and adolescents. Included papers were qualitative and quantitative research studies that provided an evaluation of Health Navigators or equivalent models of care providing support to Indigenous populations aged zero to 18. Quality appraisal, study characteristics, key recommendations and findings are reported. Furthermore, a meta-narrative and framework analysis was undertaken to map themes onto a Conceptual Framework of Integrated Community Care. This mapping was used to produce an adapted model of Indigenous Health Navigation and care integration. This approach aligns with key Indigenous methodologies underpinning this thesis, including co-creation, strengths-based approaches and decolonisation.

Rationale

There is recognition that modes of care like Health Navigators are potentially beneficial in addressing underlying social determinants of health. Given the overarching focus of this thesis is to explore the social determinants of ear health, this is an important avenue of inquiry. By synthesising evidence on the effectiveness of Health Navigators, this work aims to inform the co-design and co-implementation of the Aboriginal Community Controlled Ear-health Support System (ACCESS) Child Health Navigator model, ensuring that it is grounded in best practices and tailored to the specific needs of Indigenous communities.

This chapter will:

1. Present the background and rationale for investigating the role and scope of health navigators supporting Aboriginal and Torres Strait Islander youth populations,
2. Describe the methodology of conducting the systematic literature search, literature screening, data extraction and data analysis,
3. Present, interpret and describe the implications of findings,
4. Highlight the strengths and limitations of this study, and
5. Provide research, service delivery and policy recommendations.

5.2 Submitted paper

DeLacy J, Cutmore M, Woolfenden S, Dickson M, Rattos S, Rowley C, et al. Health Navigators supporting Indigenous children and adolescents: a systematic review. *Submitted to PLOS ONE*

5.3 Chapter 5 Abstract

5.3.1 Introduction

Indigenous communities possess rich cultural knowledge and resilience, offering valuable strengths-based approaches to improving health outcomes and wellbeing. However, Indigenous populations face significant health inequities, including barriers to accessing culturally safe and integrated healthcare, contributing to a higher burden of chronic disease. Health Navigators have been shown to enhance access, reduce costs, and improve outcomes for various populations, presenting a promising strategy for Indigenous children, adolescents, and their families, though data are limited. This review systematically examines the role and scope of Health Navigators in influencing service use and health outcomes for Indigenous youth, aiming to inform future models of care.

5.3.2 Methods

PRISMA reporting guidelines were followed to describe the systematic search and analysis of peer-reviewed literature on health navigation models supporting Indigenous children and adolescents aged zero to 18 years. Searches were performed in Medline, Embase, CINAHL, Informit, PsycINFO, and Scopus in August 2022 and updated in November 2023. Two reviewers were paired for each title, abstract and full-text screening to reach consensus on inclusion, with different combinations of two reviewers assessing the various papers. Data extraction utilised a Cochrane-adapted form, and quality appraisal was conducted using the Mixed Methods Appraisal Tool (MMAT) and the CONSIDER statement for Indigenous research. Thematic analysis identified key themes, which were mapped to an adapted Conceptual Framework of Integrated Community Care.

5.3.3 Results

Ten studies from three high-income countries with Indigenous populations, published between 2003 and 2024, were included. Most studies supported the use of Health Navigators

in improving access to care or enhancing quality of care. Ten studies from three high-income countries with Indigenous populations, published between 2003 and 2024, were included. Most studies supported the use of Health Navigators in improving access to care or enhancing quality of care.

5.3.4 Conclusion

There is promising evidence that Health Navigators improve access to culturally safe and holistic healthcare for Indigenous children and adolescents. However, further investigation is essential to fully understand their effectiveness in addressing health inequities among Indigenous child and adolescent populations.

5.4 Chapter 5 Introduction

Indigenous communities possess rich cultural knowledge and resilience, offering valuable strengths-based approaches to improving health outcomes and wellbeing.[1] However, Indigenous children and adolescents experience significant health and social inequities.[1] This includes higher rates of accidents and injuries, skin diseases, respiratory diseases, diabetes, renal disease and rheumatic fever.[1] Importantly, illness and disease in early life impacts upon development across the life-course for many Indigenous children and adolescents. A recent study of Indigenous children living in non-remote communities in Australia found that while 40% of caregivers had no significant concerns about their children's development, two thirds had significant concerns requiring further action.[2] This is twice the estimated global prevalence.[3] Stable housing, no ear disease, parental wellbeing and not being in out-of-home care were all associated with less developmental concern.[2] A more recent study involving the same cohort of Indigenous children reported ear health and hearing outcomes. Crucially, good ear health and hearing is a strong predictor of healthy life-course trajectories. However, this study showed that approximately a third of the cohort, and over half of those aged three and younger, had some form of otitis media. Furthermore, a study reporting Australian National Assessment Program - Literacy and Numeracy (NAPLAN) data for Year 3 students, showed that while 45.1% of Indigenous children met the National Minimum Standard results for reading and 48.9% for numeracy, 54.9% of Indigenous children did not meet reading standards compared to 12.5% for non-Indigenous Children, and 51.1% of Indigenous children scored lower than the National Minimum Standard for Numeracy compared to 8.5% for non-Indigenous children.[4]

These early-life inequities are largely a consequence of historical dispossession, intergenerational trauma and ongoing systems of colonisation.[5-9] Underlying social, historical and cultural determinants have perpetuated intergenerational inequities and create significant challenges for health services to deliver improved health and wellbeing outcomes for Indigenous families.[5-9] Access to culturally safe and high-quality healthcare is a human right.[9] However, healthcare systems are often fragmented and poorly integrated, preventing access to care.[10-12] Amongst Indigenous populations, this complexity is compounded by further access barriers such as racism, culturally unsafe or inappropriate care, and cost.[5, 10-13] Indigenous peoples and communities have demonstrated remarkable resilience in the face of these persistent inequities. A key aspect of this resilience is the strength drawn from community, kinship, and cultural practices that continue to sustain and empower individuals and families.[14] Aboriginal Community Controlled Health Services play a crucial role in this resilience by providing culturally safe, holistic care that addresses not only physical health but also the social, emotional, and cultural wellbeing of their communities.[15] They have pioneered innovative approaches to address psychosocial needs of children and their families for decades.[16] In addition to the sizeable efforts of the Indigenous community-controlled health sector, there is growing evidence demonstrating the effectiveness of Health Navigators to overcome social and systemic barriers, and consequently improve health and wellbeing for non-Indigenous pediatric populations.[17]

Health Navigators are health workers who support families and patients to navigate health services, overcome modifiable access barriers, translate knowledge, and provide social, cultural and emotional support.[17] Internationally, evidence suggests Health Navigators enhance service access, address social determinants of health, improve parental satisfaction, lower avoidable hospitalisations and improve health outcomes.[10, 17-20] In Indigenous settings, a recent scoping review of Health Navigators, identified the absence of published literature within Australia and New Zealand in comparison to other countries with similar histories of colonisation.[21] Furthermore, this review identifies six key roles for Health Navigators, including social service navigation, holistic support for Indigenous people, advocacy and capacity building, health assessment, administrative navigation and community outreach.[21] However, this review was not focussed on child and adolescent health.

Despite existing evidence on Health Navigators, there is scant literature about Health Navigators within Indigenous child and adolescent populations. [10, 17-20] Therefore, the primary objective of this research is to systematically search and synthesise peer reviewed literature

to identify key considerations for the implementation of Health Navigators supporting Indigenous children and adolescents. This review will report the role and scope of Health Navigators on health outcomes and service use. Furthermore, this review aims to build upon existing recommendations to guide the design, implementation and evaluation of Health Navigation-focussed models of care supporting Indigenous children and adolescents.

5.5 Chapter 5 Methods

5.5.1 Eligibility criteria

This review included literature written in English or translatable into English. No restrictions were placed on the date of publication. Publications were included if they were published, peer reviewed and reported an evaluation of an implemented model of health care intervention that employed Health Navigators to support Indigenous children and adolescents aged zero to 18 years. The literature search, selection and analysis follow the PRISMA guidelines for reporting systematic reviews.[22]

5.5.2 Search strategy

The databases used to perform the literature search were Medline, Embase, CINAHL, Informit, PsycINFO and Scopus. The literature search included terms for 1) Indigenous populations; 2) children and adolescents; 3) and Health Navigator. Names for Health Navigators are varied. Therefore, we used a highly sensitive approach (i.e. 36 terms for Health Navigator), ensuring inclusivity at the search stage, and excluding after more detailed review. The literature search was completed in August 2022, and then repeated in November 2023.

5.5.3 Selection process

Search results were imported into EndNote™. Following the deletion of duplicates, results were entered into Covidence™. All title and abstract, and full-text screens were reviewed by two reviewers. Title and abstract screens were completed by JD, with MC, SW, CR and HE as secondary reviewers. All full text screens were completed by JD, with CR and HE providing secondary reviews. Conflicts were resolved upon consensus by JD, HG, CR and HE.

5.5.4 Data extraction

Data were extracted by author JD by using a data extraction form adapted from the Cochrane Collaboration Effective Practice and Organisation of Care Group (EPOC)[23]. Extracted data were categorised by the following: study title; first author; publication year; journal; study design and setting; demographics; health condition(s); description of intervention; study aims; sample size; reported outcomes; data collection method; qualitative themes; quantitative results; intervention delivered within Indigenous community service; intervention delivered within mainstream services; intervention is delivered within both Indigenous community and mainstream services; summary of findings; if the Health Navigator impact was specifically evaluated; and if program evaluation did not specifically focus on the Health Navigator impact.

5.5.5 Quality appraisal

Author JD completed a quality appraisal of the included literature using The Mixed Methods Appraisal Tool (MMAT)[24]. The MMAT is designed to appraise the methodological quality of five categories to studies: qualitative research, randomised controlled trials, non-randomised studies, quantitative descriptive studies, and mixed methods studies.[24] he MMAT consists of two screening questions for all five study types, and a unique set of five questions for each study type.[24] There are three possible responses to each question: Yes; No; and Can't Tell. In addition to the MMAT, the CONSolIDated critERtia for Strengthening reporting of health research involving indigenous peoples: the CONSIDER Statement[24] was used. The CONSIDER Statement is a checklist designed for the reporting of Indigenous research.[24] This tool consists of seven checklist items: Governance, Prioritisation, Relationships, Methodologies, Participation, Capacity, Analysis and Dissemination. Each checklist item has a set of open-ended reporting items, with 17 reporting items distributed across the seven checklist items. Two copies of the CONSIDER Statement[25] completed, one with written responses and the other scored numerically with each reporting item marked as stated (1), not stated (2) or partially stated (0.5). Scores were tallied for each paper, with the lowest possible score of zero (i.e. none of the 17 reporting items were clearly stated in the paper) and highest possible score of 17 (i.e. all of the 17 reporting items were clearly stated). The MMAT[23] and CONSIDER Statement[25] quality appraisals were reviewed by senior Indigenous researchers JS and MD and senior non-Indigenous researchers HG and SW to form a consensus.

5.5.6 Synthesis of results

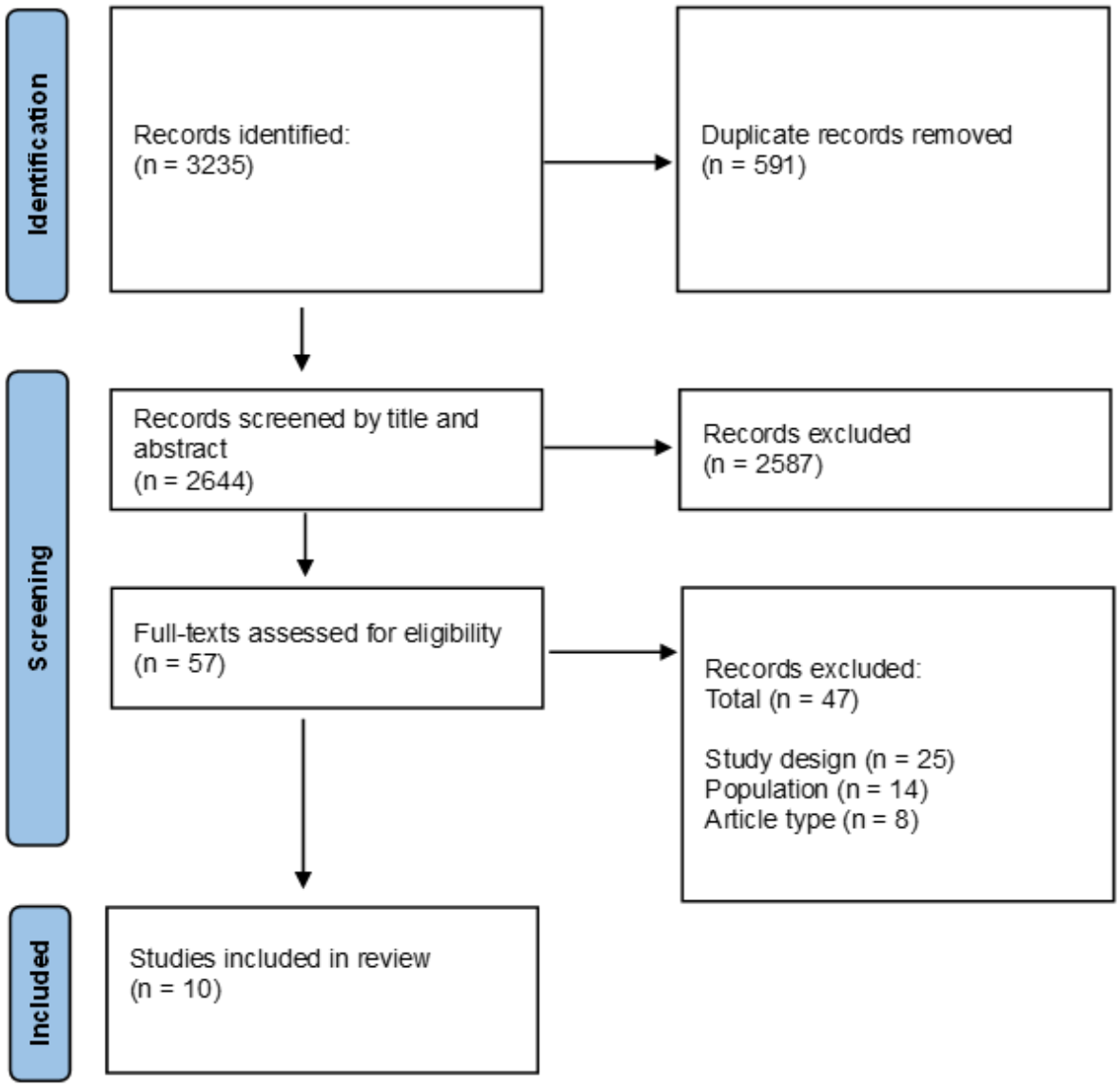
Due to the small number, and heterogenous nature, of the included quantitative papers, a meta-analysis could not be completed. Synthesis of results involved the use of a framework analysis approach and meta-narrative synthesis.[26] Framework analysis allows researchers to systematically identify patterns and differences within data by mapping these findings onto a framework. This approach facilitates the drawing of descriptive or explanatory conclusions that are then clustered around key themes, providing a structured and comprehensive understanding of the data.[26] JD identified key themes that corresponded to the six core concepts of the Conceptual Framework of Integrated Community Care: Local area; social care; health care; temporality; proximity; and integration.[27] Cultural safety and racism was included under the health care concept within the framework, to account for systemic access barriers often experienced by Indigenous peoples.[28] Themes were mapped to this adapted framework to produce a Conceptual Model for Indigenous Health Navigation and Care Integration (see Figure 3.2). This framework was used due to its comprehensive approach to integrated community care. Although this framework has not been explicitly validated within Indigenous populations, Indigenous authors on this paper agree that its emphasis on place-based and holistic care aligns well with Indigenous concepts of health and wellness. Therefore, this was determined to be a suitable tool for mapping and analysing the themes.

5.6 Chapter 5 Results

5.6.1 Literature selection

The literature search yielded 3,235 results. After the removal of duplicates, 2,644 articles were reviewed by title and abstract and 2,587 papers excluded, as they were not relevant. 58 papers were reviewed in full-text and 47 excluded, as they did not meet the eligibility criteria. 10 papers were included for synthesis (see Figure 5.1).

Figure 5.1: Prisma Flow Chart



5.6.2 Literature characteristics

From the 10 studies included in this review, seven were from Australia, two from Canada and one from the United States of America with a total of 23,024 participants (one study did not report the sample size). Studies were published between 2004 and 2023. Under the five MMAT study type categories, there were three qualitative, four quantitative non-randomised, two quantitative descriptive, one quantitative randomised controlled study and no mixed methods studies.[24] All studies, except for one that did not specify sex, included male and female participants aged between zero to 18 years of age. Four papers focused on oral health, three focused on child health, with the remaining three papers individually focused on mental health, immunisation and ear health. Five papers reported on studies delivered within

community settings, two in mainstream settings and three in both community and mainstream settings. Eight studies evaluated the overall program without impact analysis of the Health Navigator (i.e. did not evaluate its specific impact but rather, the implementation and acceptability of the overall program). Two studies provided a specific impact evaluation of the Health Navigator. One of these two studies reported an improvement in vaccination rates, and the other study reported improved program enrollment and increased attendance to preventative services.[33, 34] All papers except for two reported that Health Navigators improved access to care or enhanced quality of care (see Table 1).

Table 5.1: Study Characteristics

ID	First Author (Year)	Country	Study Type	Sample	Key findings	Setting (health focus)
1	Schroth (2023)[29]	Canada	Qualitative	22	*"Overall, the participants reported that the COHI program positively contributes to early childhood oral health in Indigenous communities."*	Community home and school dental service (oral health)
2	Smith (2018)[30]	Australia	Quantitative non-randomised	189	*"These results suggest that the Smiles not Tears dental education program has a positive impact on reducing the caries prevalence in young Aboriginal children."*	Aboriginal Community Controlled Health Services (oral health)
3	Stathis (2007)[31]	Australia	Quantitative non-randomised	527	*"MHATODS has achieved equity in referral and service provision between Indigenous and non-Indigenous youth admitted into detention."*	Mental health and substance abuse service in youth detention (mental health)
4	Campbell (2018)[32]	Australia	Qualitative	48	*"This study describes an evolving process and explores how health providers connect with families and how the program responds to family and cultural issues."*	Home visiting child and family health service (child health)
5	Hendry (2018)[33]	Australia	Quantitative Descriptive	Not specified	"*Our findings suggest that a dedicated program can help overcome barriers to timely vaccination and significantly improve timely vaccination rates in Indigenous Australian children."*	Community and primary care (childhood immunisation)
6	Mathu-Muju (2018)[34]	Canada	Quantitative non-randomised	21174	*"Community health workers were beneficial in promoting programme enrolment, as well as facilitating and augmenting the delivery of preventive dental services."*	Community home and school dental service (oral health)
7	Cresp (2016)[35]	Australia	Quantitative non-randomised	942	"*Health-seeking behaviour and health outcomes for Aboriginal children can be improved by engaging Aboriginal families in their health care, providing effective communication between health service providers, and delivering a coordinated program of Aboriginal service provider-led care."*	Community and primary care (child health)

8	Strobel (2020)[36]	Australia	Qualitative	18	*"Dedicated Aboriginal programs in mainstream services can successfully improve cultural care to their clients, which is fundamental to improving service delivery for families."*	Community and primary care (child health)
9	Braun (2016)[37]	USA	Quantitative RCT	52	"T*he severity of dental disease in Navajo Head Start children is extreme and difficult to improve. The authors argue that successful approaches to prevention may require even more highly personalised approaches shaped by cultural perspectives and attentive to the social determinants of oral health"*	Community and school-based dental care (oral health)
10	Adams (2004)[38]	Australia	Quantitative Descriptive	354	"*Aboriginal Health Workers, in co-ordinating follow-up appointments and assessments, must be recognised as a crucial component in achieving ear health for Indigenous Australians."*	Aboriginal Community Controlled Health Services (ear health)

5.6.3 Quality Appraisal Results

5.6.3.1 Mixed Methods Appraisal Tool (MMAT)

MMAT: Using the Mixed Methods Quality Appraisal Tool, eight (80%) of the studies were identified as meeting all seven methodological criteria (i.e., Yes response) for the relevant study types. Two papers that were quantitative studies received a single No response each. Both papers received the No response for not adequately accounting for confounding factors (see Table 5.2).

Table 5.2: Mixed Methods Appraisal Tool (MMAT)

ID	First Author (Year)	Study Type	Questions addressed Yes/No
1	Schroth (2023)	Qualitative	Yes = 7; No = 0
2	Smith (2018)	Quantitative non-randomised	Yes = 6; **No = 1**
3	Stathis (2007)	Quantitative non-randomised	Yes = 6; **No = 1**
4	Campbell (2018)	Qualitative	Yes = 7; No = 0
5	Hendry (2018)	Quantitative Descriptive	Yes = 7; No = 0
6	Mathu-Muju (2018)	Quantitative non-randomised	Yes = 7; No = 0
7	Cresp (2016)	Quantitative non-randomised	Yes = 7; No = 0
8	Strobel (2020)	Qualitative	Yes = 7; No = 0
9	Braun (2016)	Quantitative RCT	Yes = 7; No = 0
10	Adam (2004)	Quantitative Descriptive	Yes = 7; No = 0

5.6.3.2 CONSolIDated critERia for strengthening reporting of health research involving Indigenous peoples: CONSIDER Statement

CONSIDER: Using the CONSIDER Statement reporting guidelines, scores ranged from one to 9.5, out of a possible 17. The average score was 3.95, equating to a low rating for quality of Indigenous research methodology and reporting. Across all papers, Governance, Prioritisation, Participation, Capacity, Analysis and Interpreting, and Dissemination were poorly reported, with ≤15% of items clearly stated under these domains. Relationships and Methodologies were poor to moderately reported, with approximately 43% of items clearly stated under these domains (see Table 5.3)

Table 5.3: CONSolIDated critERia for strengthening reporting of health research involving Indigenous peoples: CONSIDER Statement

Governance (out of 3)	Prioritisation (out of 1)	Relationships (out of 3)	Methodologies (out of 2)	Participation (out of 3)	Capacity (out of 2)	Analysis & interpretation (out of 1)	Dissemination (out of 2)	Total (out of 17)
1. Schroth (2023)								
0	0	1	1	0	0	0.5	0.5	**Total = 3**
2. Smith (2018)								
0.5	0.5	1.5	0.5	1	0	0	0	**Total = 4**
3. Stathis (2007)								
0	0	1.5	0.5	0	0	1	0	**Total = 3**
4. Campbell (2018)								
1	0.5	2	1.5	0	1.5	1	2	**Total = 9.5**
5. Hendry (2018)								
0.5	0	0.5	0	0	0	0	0	**Total = 1**
6. Mathu-Muju (2018)								
0.5	0.5	1	1	1	0	0	0	**Total = 4**
7. Cresp (2016)								
0	0	1.5	1	0	0	1	0	**Total = 3.5**
8. Strobel (2020)								
0	0	2.5	2	0.5	0.5	1	0.5	**Total = 7**
9. Braun (2016)								
0	0	1	0.5	1.5	0	0	0	**Total = 3**
10. Adam (2004)								
0	0	0.5	0.5	0.5	0	0	0	**Total = 1.5**

5.6.4 Conceptual Framework of Integrated Community Care

All included papers report themes aligning with the six key concepts from the Conceptual framework for health navigation and community care.[27] There was consensus across the literature about the importance of place-based understanding, delivery of holistic care, overcoming access barriers, ensuring timely access to care, facilitating care that is physically accessible, and enhancing the integration of services within the local health system.

5.6.4.1 Local area (adapted title: 'Local knowledge' see Figure 5.2)

The local area was recognised as highly relevant for health navigation. Each community has unique cultural, social, and environmental factors that shape health needs and challenges. Therefore, place-based understanding was a key rationale for the use of Navigators, and it was recognised that health navigation is person-centered and contextually informed, leading to more meaningful and sustainable health outcomes for Indigenous youth. Moreover, place-based knowledge was identified as directly influencing the accessibility, relevance, and effectiveness of care. Understanding the local area allowed Health Navigators to tailor their approach with consideration for transport needs, culturally appropriate services, and local health and social resources. A deep understanding of the local community was acknowledged as enabling trust, by respecting local practices and integrating traditional, cultural or community-relevant knowledge into care.

5.6.4.2 Social care

Social care was reported as highly relevant for in addressing the broader determinants of health that extend beyond biomedical care. Many health challenges faced by Indigenous youth are rooted in social factors such as housing stability, education, access to nutritious food, and family support. Therefore, social care was described as an important element of care provided by Health Navigators. By incorporating social care into their role, Health Navigators could provide more holistic and family-centred support. This approach enabled navigators to connect youth and their families with essential social and community services.

5.6.4.3 Health care

Understanding the healthcare system was reported as essential to effectively guide individuals and families through complex and often fragmented care pathways. Health Navigators needed to be familiar with the available services, referral processes, eligibility criteria and facilitate

knowledge translation to ensure that Indigenous young people can access the care they need without unnecessary delays or obstacles. Moreover, a deep understanding of the healthcare system was seen to help navigators advocate for their clients, addressing any systemic barriers that may arise.

Cultural safety and racism within the healthcare system were critical considerations for Health Navigators. Cultural safety, as described by the included literature, involved providing care that is respectful of and responsive to the cultural identities of Indigenous people, ensuring that they feel safe and respected within healthcare settings. Health Navigators played a key role in fostering cultural safety by advocating for care that acknowledges and values Indigenous cultural practices and by challenging any instances of discrimination or racism. Racism, whether overt or subtle, was described as severely impacting the willingness of Indigenous young people to seek care and their overall health outcomes. Health Navigators needed to recognise and address racism within the healthcare system, advocating for equitable treatment and supporting youth in navigating a system that has historically marginalised them. This dual focus on understanding the healthcare system and promoting cultural safety was vital for creating environments where Indigenous young people could receive the health care, they needed in a way that honoured their identity and protected them from harm.

5.6.4.4 Temporality

Temporality refers to the timing and sequence of care, which is especially important in managing conditions that require early detection and intervention, such as ear disease or other chronic health issues common among Indigenous young people. Temporality and timely access to care were described as crucial factors for Health Navigators supporting Indigenous young people, as these factors directly impact the effectiveness of healthcare interventions and overall health outcomes. Health Navigators were reported as helping to ensure that care was received at the right time to prevent complications, reduce the progression of illnesses, and improve long-term health outcomes. Concerns were expressed about delays in receiving healthcare exacerbating health disparities faced by Indigenous communities. Health Navigators were recognised as playing a role in facilitating quick access to necessary services, helping youth and their families overcome barriers such as long wait times and geographic distance. Importantly, consistent contact and follow-up was described as important to achieve early access and access at the right time.

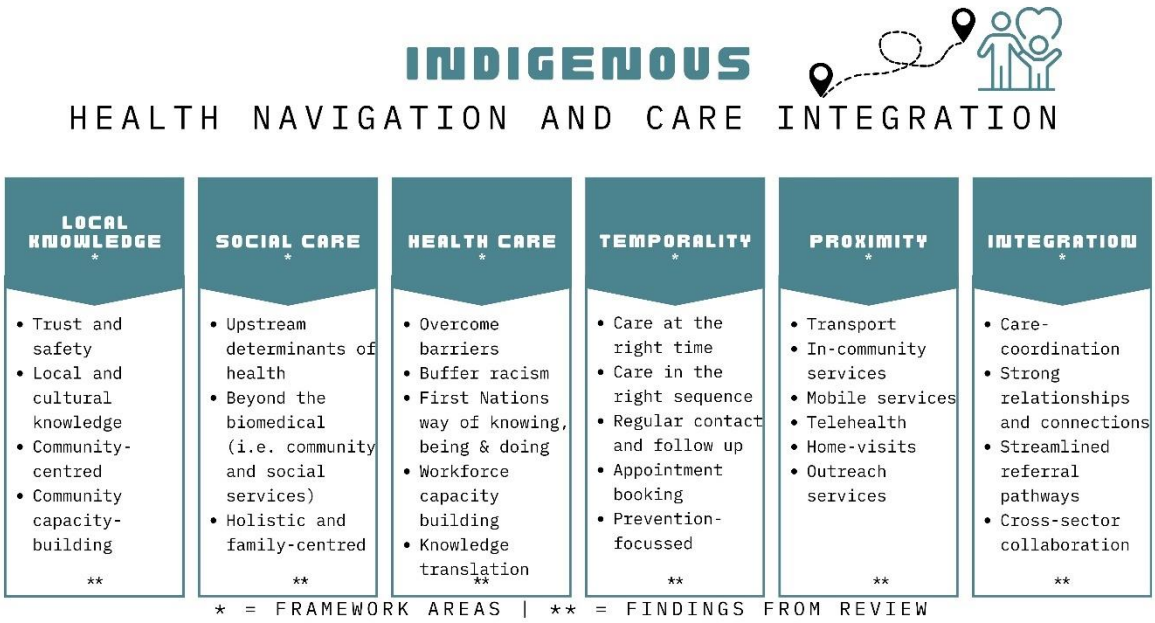
5.6.4.5 Proximity

Proximity, transport, distance, and physical access to services were critical considerations, as these factors significantly influence the ability to access healthcare. In many communities, especially those in rural or remote areas, key health services were reported as significantly distant, limiting physical access and making it difficult for families to attend appointments or receive timely care. The lack of reliable transportation options further exacerbates this issue, creating substantial barriers to accessing necessary services. Health Navigators were identified as playing an essential role in coordinating transport, identifying the most accessible services, and advocating for mobile, telehealth and outreach services. Additionally, conducting home-visits was highlighted as helping to overcome physical access barriers, whilst facilitating care in a safe and familiar environment. By focusing on proximity and physical access, Health Navigators were seen to reduce the impact of distance-related barriers, ensuring that Indigenous young people receive the care they need without the added burden of long travel times or logistical difficulties. This support was acknowledged as vital for promoting equity in healthcare access and improving health outcomes for youth in geographically isolated or underserved communities.

5.6.4.6 Integration

Improved integration of systems and services was consistently reported as a key outcome from the implementation of Health Navigators, or models involving navigation. Furthermore, integration was seen as essential for overcoming the fragmented systems and challenging referral pathways that often complicate healthcare access for Indigenous young people. Health Navigators played a pivotal role in unifying these disparate systems, helping to ensure that care is coordinated, seamless, and easier for families to navigate. This involved helping with building and maintaining relationships between stakeholders and organisations, fostering collaboration, and streamlining referrals. By integrating social care - including the education sector - with healthcare, Health Navigators ensured that interventions were comprehensive, culturally sensitive, and aligned with the intricate needs of Indigenous communities. This holistic approach helps create more effective and sustainable outcomes, addressing both health and social determinants, and potentially improving the prevention of conditions by addressing upstream factors rather than downstream symptoms.

Figure 5.2: Adapted model of Indigenous health navigation and care integration (adapted from the Conceptual framework of health navigation and community care[26])



5.7 Chapter 5 Discussion

This review included ten studies from high-income countries with Indigenous populations and histories of colonisation. The studies varied in design, including qualitative, quantitative non-randomised, quantitative descriptive, and one randomised controlled trial. Most (80%) papers reported subjective outcomes that Health Navigators improved access to care or enhanced quality of care. Key findings from the review highlighted the benefit of Health Navigators in improving access to culturally safe and effective healthcare for Indigenous children and adolescents. Overall, Health Navigators were found to enhance self-reported service access, address social determinants of health, and improve health outcomes by providing holistic support, advocating for families, and facilitating timely and appropriate care.

Health Navigators were reported as playing a crucial role in addressing the unique health needs of Indigenous children and adolescents by incorporating a deep understanding of local communities, cultural safety, and social care into their practice. Their place-based knowledge allows them to tailor care by considering transport needs, culturally appropriate services, and local resources, building trust and delivering more meaningful health outcomes. By integrating social care into their roles, Health Navigators connect children, adolescents and their families with essential services that address broader determinants of health, such as housing and education. Their understanding of the healthcare system enables them to guide families through complex care pathways, advocate for their clients, and address systemic barriers like racism. Timely access to care is facilitated by Health Navigators, who ensure that

interventions are provided at the right time to prevent complications. They also mitigate barriers related to distance and transport by coordinating services and advocating for mobile and telehealth solutions. Overall, Health Navigators were found to enhance the integration of fragmented systems, fostering collaboration among stakeholders to provide seamless, culturally sensitive, and comprehensive care that addresses both health and social determinants.

Previous reviews on Health Navigators within Indigenous populations are scant. However, a recent scoping review on the role of Indigenous Patient Navigators in Canada, the United States, Australia, and New Zealand was published.[21] The review identified six key roles for Health Navigators: social service navigation; holistic support for Indigenous people; advocacy and capacity building; health assessment; administrative navigation; and community outreach.[21] Key findings align with the current paper, but differed in that it did not focus on populations aged younger than 18 years and revealed a significant gap in literature from Australia and New Zealand. Conversely, our review yielded many papers from Australia. A systematic review published in 2022 investigated the role of Indigenous Health Workers in oral health, reporting key findings that included systemic barriers limiting Indigenous Health Worker support, benefits of Indigenous Health Worker involvement, and avenues to increase their participation in healthcare provision.[39] Findings from this review align with the current paper in highlighting the importance of Indigenous leadership to address systematic challenges, improve service provision, and enhance community wellbeing. Similarly, a 2020 systematic review identified factors contributing to continuity of care for Indigenous families during the first 1000 days of life, describing the importance of culturally safe and coordinated healthcare services to improve maternal and infant health outcomes.[40] Lastly, a systematic review from 2018 exploring the factors influencing accountability relationships of Indigenous Health Workers in the Australian health system, revealed that Indigenous Health Worker roles are often misunderstood and undervalued, with significant tensions between their cultural obligations and the expectations of non-Indigenous colleagues, impacting their ability to work to their full capacity.[41]

This is the first known systematic review to synthesise literature focused on Health Navigators, and equivalent models of care, supporting Indigenous populations aged zero to 18 years. The use of a meta-narrative synthesis aligns with Indigenous Yarning methodology and was recognised as a decolonised approach to conducting a systematic review by senior Indigenous authors on this paper.[42] This review yielded few studies and were heterogenous in

nature. Therefore, a meta-analysis could not be completed and only a small sample was reviewed to produce findings. Given the diversity of Indigenous populations within and between countries, generalisation of findings should be done cautiously. It was not clear if papers that were rated poorly using the CONSIDER Statement did not undertake associated research activities for the relevant reporting items, or if the authors did not report them.[25] It is possible that journal submission requirements do not account for the comprehensive requirements to undertake culturally safe Indigenous research, consequently limiting the reporting of key recommendations within the CONSIDER Statement.[25] Therefore, it is recommended that evaluative studies within Indigenous populations produce accompanying research protocols to document key methods and methodologies for conducting high-quality and culturally safe Indigenous research.

Given the few studies identified by this review, there is a critical need to fill this gap in the literature. Future research should focus on longitudinal studies to assess long-term outcomes, as well as studies that specifically evaluate the role of Health Navigators in reducing experiences of racism and improving cultural safety in healthcare settings. Policymakers should consider the integration of Health Navigators into healthcare systems as a strategy to address health inequities faced by Indigenous children and adolescents. Policies should support the training and employment of Health Navigators within both community-controlled and mainstream settings, ensuring that they are equipped to provide culturally safe and effective care. Efforts should be made to incorporate Health Navigators into multidisciplinary teams, and to provide ongoing training and support to ensure that they can effectively address the unique needs of Indigenous communities. There was a strong emphasis on the need to better resource Indigenous community health services, including ensuring the sustainability of community-led programs. There is promising evidence that Health Navigators improve access to culturally safe and holistic healthcare for Indigenous children and adolescents. However, further investigation is essential to fully understand their effectiveness in addressing health inequities among Indigenous child and adolescent populations. This review highlights the need for further research, and to strengthen policy and practice to enhance the integration and effectiveness of Health Navigators within Indigenous populations.

5.8 Chapter 5 References

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**Included in analysis*

5.9 Declarations

- **Prospero registration:** CRD42022384508 (registered 26 December 2022).
- **Ethics approval and consent:** Not applicable
- **Funding:**
    - The Study of Environment on Aboriginal Resilience and Child Health (SEARCH), The Sax Institute National Health and Medical Research Council Grants (#358457, #1023998 and #1035378)
    - Aboriginal Community Controlled Ear-health Support System (ACCESS) research grants:
    - Australian National Health and Medical Research Council, Medical Research Futures Fund (#1211077; 2020-2023)
    - Centre for Research Excellence Partnership Pathways to better care AND Outcomes for Aboriginal young people (#1135271; 2018-2023)
- **Author contributions:** JD with the support of the Academic Liaison Librarian developed the search strategy and completed the literature search. Screening of articles was completed by JD with the support of MC, SW, HE and CR, with HG supporting with conflicts. Data extraction, quality appraisal and synthesis were completed by JD, with the appraisal and synthesis reviewed by HG, SW, JS and MD. AS, EH, LJ shared their Indigenous care navigation expertise to assist in accurately capturing and reporting themes. JS and MD provided Indigenous cultural expertise and support for this paper. JD was chiefly responsible for the drafting and completion of the manuscript. All authors contributed to critical revisions and editing the manuscript for important intellectual content and approved the final manuscript for submission.
- **Acknowledgements:** The authors thank the Study of Environment on Aboriginal Resilience and Child Health, Hearing, Ear-health And Language Services, and Aboriginal Community Controlled Ear-health Support System community partners who have supported and guided this work and associated research activities. We thank Jessica Hughes, Academic Liaison Librarian at the University of Sydney for her guidance in developing the search strategy.

5.10 Contribution of Chapter 5 to overall thesis

Contribution

This chapter provides a detailed synthesis of literature describing peer-reviewed studies evaluating models of care involving a Health Navigator or equivalent role supporting Indigenous young people in Australia, Canada and the United States of America. This paper reports key findings, recommendations, and research gaps, and provides an adapted model of Indigenous Health Navigation and care integration to guide the co-creation of Health Navigator models of care within Indigenous populations. This adapted model will be used to support the ongoing co-creation of the Aboriginal Community Controlled Ear-health Support System.

Next steps

This review identified only 10 studies that met the inclusion criteria. Therefore, there is a clear need for more evaluated studies exploring the impact and implementation of health navigators and Indigenous health workers supporting Indigenous young people. Moreover, there was only one included paper that focussed on ear health and hearing. Given the importance of underlying social determinants and access barriers for ear health and hearing, more research is needed to explore the impact of Health Navigators on ear health and hearing for Indigenous young people. The ongoing co-creation of ACCESS will involve implementation and impact evaluations to assess the potential adaptability and scalability across diverse Aboriginal and Torres Strait Islander and Indigenous and priority populations.

CHAPTER 6: ABORIGINAL COMMUNITY-CONTROLLED EAR-HEALTH SUPPORT SYSTEM (ACCESS): STUDY PROTOCOL FOR A CO-CREATED MODEL OF CARE

6.1 Chapter 6 overview

This chapter consists of a published protocol that includes the research activities for this PhD project. This chapter reports the methodological approach for the co-creation of the Aboriginal Community Controlled Ear-health Support System (ACCESS) project, including the Yarning circles detailed in ***Chapter 3***. This thesis focusses on 'Stream 1 Co-design' and 'Stream 2 Co-implementation', with Streams 3 (Co-evaluation and Stream 4 (Population-level surveillance) auxiliary to this work, and yet to occur as of the date of thesis submission (September 2024). The co-creation approaches described throughout this protocol align with key Aboriginal and Torres Strait Islander methodologies underpinning this thesis, including co-creation, strengths-based approaches and decolonisation.

Rationale

The purpose of publishing the research protocol for ACCESS is to provide a comprehensive framework and detailed methodology for the project, ensuring transparency, reproducibility, and rigor in the research approach. The protocol outlines the collaborative and community-led strategies employed in the project, highlighting the significance of cultural safety and community engagement in enhancing ear health outcomes for Aboriginal and Torres Strait Islander children.

This chapter will:

1. Present the background and rationale for investigating and reporting community perspectives about ear health and hearing for Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales,
2. Describe the methodology for data collection and analysis, and
3. Highlight the strengths and limitations of this study.

6.2 Paper ready for submission

DeLacy J, Woolfenden S, Sherwood J, Wright D, Newman J, Bailey S, et al. Aboriginal Community Controlled Ear-health Support System (ACCESS): a study protocol for a co-created health navigator model of care. *Ready for submission to BMJ Open*

6.3 Chapter 6 Abstract

6.3.1 Introduction

Healthy ears and hearing are vital for Aboriginal and Torres Strait Islander children to thrive, particularly when faced with systemic inequities. Many aspects of Aboriginal and Torres Strait Islander wellbeing have been eroded by colonisation and policy. Importantly, to improve hearing and health, we must address the sociocultural and political determinants that undermine wellbeing. The primary aim of the Aboriginal Community Controlled Ear-health Support System (ACCESS) is to develop, embed and evaluate a novel co-designed Child Health Navigator program, responding to community feedback highlighting the need for this service. ACCESS aims to address knowledge and service gaps and enhance accessibility to ear health and hearing services by supporting Aboriginal and Torres Strait Islander families to navigate the complex health system. The Child Health Navigator will augment existing integrated models of care and is the central focus of the ACCESS project. This person will be identified by the collaborating services as connected to and living within the local community and will be employed within the local Aboriginal Community Controlled Health Service. Thus, ensuring that the Child Health Navigator possesses local knowledge and health experience.

6.3.2 Methods and analysis

ACCESS will be delivered, developed and implemented across three collaborating Aboriginal Community Controlled Health Services located in urban and regional settings in New South Wales. The four ACCESS streams of work are: codesign; co-implementation; co-evaluation; and a future data-linkage stream. ACCESS will compare children with and without ear disease and hearing impairment. Educational outcomes will be collected by the Child Health Navigator via parent or carer reported school attendance and reports. ACCESS will evaluate the effectiveness of the national Aboriginal Child Health Check as a mechanism to link children to effective prevention and support services. Primary outcome: comparing the proportion of attended consultations over the total number of planned consultations for all participating children (target = 105) during the Child Health Navigator period versus the same months in the previous year (see power calculation). Economic evaluation will compare costs and health and service outcomes over the 12 months with the Child Health Navigator compared to the 12 months before (pseudo control period), taking a healthcare funder

perspective. Data-linkage will be used to better understand the scale and patterns of ear health and related outcomes, and the impact of health service delivery innovations on ear health and related outcomes, at the population-level, among Aboriginal and Torres Strait Islander children in New South Wales.

6.3.3 Ethics and dissemination

ACCESS has ethics approval from the Aboriginal Health and Medical Research Council (the primary Human Research Ethics Committee for research conducted within New South Wales Aboriginal and Torres Strait Islander populations). Findings will be fed back to communities and then submitted for publication in peer-reviewed journals; presented at conferences; and disseminated to policymakers to facilitate evidence-based decision-making and translation.

Registration: ACTRN12622000824763 (Australian and New Zealand Clinical Trials Registry).

Funding: ACCESS was funded by two Australian National Health and Medical Research Council grants. 1) Medical Research Futures Fund (#1211077; 2020-2023) and 2) Centre for Research Excellence Partnership Pathways to better care AND Outcomes for Aboriginal young people (#1135271; 2018-2023).

6.3.6 Strengths and limitations

- Community driven research question
- Research team balancing Aboriginal and non-Aboriginal members
- Aboriginal clinician researcher delivers the intervention and data capture
- Multi-modal analysis plan to capture the breadth of likely intervention impacts
- Randomisation was not feasible in short timeframe available and not acceptable to communities

6.4 Chapter 6 Introduction

Aboriginal and Torres Strait Islander people make up the oldest living cultures in the world and their survival over 60,000 years is linked to scientific ingenuity, vast knowledge systems, oral literacies and sharing methodologies.[1-4] Literacy development and sharing knowledge

requires listening, which is a vital skill that is regularly promoted by Aboriginal and Torres Strait Islander Elders.[4-6] Hence, healthy ears and hearing are vital for Aboriginal and Torres Strait Islander children to thrive, particularly when faced with systemic inequities.[7] Many aspects of Aboriginal and Torres Strait Islander wellbeing have been eroded by colonisation and policy.[6] Importantly, to improve hearing and health, we must address the sociocultural and political determinants that undermine wellbeing.[7-9] Furthermore, these determinants act as a barrier for cultural and spiritual wellbeing, and a barrier to meet academic, social, and life potential.[9] Hearing loss has been found to negatively influence self-concept, educational attainment and social skills that consequently increase risk of contact with the justice system, and youth suicide.[10-12] Ear disease has been a major public health issue for Aboriginal and Torres Strait Islander children for decades,[5,7] with a 2016 Northern Territory study, reporting less than 10% of the 633 Aboriginal and Torres Strait Islander children assessed had healthy ears bilaterally.[13] Prevalence within urban areas, where most Aboriginal and Torres Strait Islander children live, has been shown to be close to 30%,[14] or approximately three times the prevalence within the general population.[8]

6.4.1 Study of Environment on Aboriginal Resilience and Child Health - SEARCH

The Study of Environment on Aboriginal Resilience and Child Health (SEARCH) was the largest cohort study of urban Aboriginal children, established through Aboriginal Community Controlled Health Service partnerships spanning two decades (2004-2023).[15] Ear health was a research priority from the inception of SEARCH as Aboriginal and Torres Strait Islander communities and Aboriginal Community Controlled Health Service staff understood its importance and impact on education and life trajectories. The SEARCH-Aboriginal Community Controlled Health Services partnerships worked to prevent and ameliorate the adverse outcomes of ear disease through a program of translational research resulting in innovative service models that meet the need of their communities. Early support is critical for a comprehensive strategy for healthy life course trajectories. Aboriginal Community Controlled Health Service are essential in providing this support, given their connection to community and strong integrated services that are underpinned by Aboriginal and Torres Strait Islander concepts of health and wellbeing. At the SEARCH enrolment ear assessment, one in three children had ear disease,[14] and 55% of children <3 years had ear disease[14]- this is the critical age for language development.[11] SEARCH demonstrated the relationships between ear disease and childcare attendance, previous ear infection, younger age, foster care and living in crowded housing.[14] There was a clear association between children at

moderate/high developmental risk on Parent-Evaluated Developmental Status (PEDS) screening and ear disease.[16] We note that these determinants are not choices, but rather consequences of policies,[7-9] including racism, crowded and poor-quality housing, poverty and exposure to tobacco smoke.[7,14] The deficit discourse portrays Aboriginal and Torres Strait Islander people as the problem rather than colonisation and government policies that have contributed to, and perpetuated, the disproportionate burden of these sociocultural determinants of health.[6] Therefore, early support targeting underlying factors is necessary for the health and wellbeing of Aboriginal and Torres Strait Islander children and families.[9]

6.4.2 Hearing EAr-health speech and Language Services - HEALS

Hearing EAr-health speech and Language Services (HEALS), an ongoing clinical service delivery program since 2013, arose from SEARCH to provide free ear, nose and throat, audiology, and speech and language services to urban Aboriginal children living in New South Wales. These Aboriginal Community Controlled Health coordinated services are culturally safe and help overcome access barriers for Aboriginal and Torres Strait Islander families. HEALS leveraged existing SEARCH-Aboriginal Community Controlled Health Service relationships but also expanded to other Aboriginal Health Units (n=7).

6.4.3 The Aboriginal Community Controlled Ear-health Support System - ACCESS

Aboriginal Community Controlled Ear-health Support System (ACCESS) is a co-created[17] project centred around integrated models of care,[18-19] social prescribing[20-21] and health navigation.[22] ACCESS complements ongoing work by SEARCH and HEALS. Importantly, ACCESS builds upon community knowledge and priorities identified by local Aboriginal and Torres Strait Islander voices. ACCESS will address key knowledge and service gaps and address how to enhance accessibility to ear health and hearing services by supporting Aboriginal and Torres Strait Islander families navigate the complex health system. Service providers struggle to coordinate the care that children with chronic and complex conditions in a fragmented and often racist health system.[18,23] However, coordination of care has been shown to improve when children and their families are supported by navigators to facilitate culturally safe and holistic care, communication, support appointments, and address family priorities.[24] There are also significant savings associated with reduced unplanned hospital presentations, missed school days, and accessing health care that is closer to home.[24] Internationally, child health navigators have been shown to support children living in adversity presenting to routine health care by improving access to health care services and

addressing unmet social determinants of health. Navigators result in increased parental satisfaction, reduced avoidable hospitalisations, and improved child health.[21,22,24,25]

6.4.4 Objectives

ACCESS aims to develop, embed and evaluate a novel co-designed Child Health Navigator program in three urban and regional Aboriginal Community Controlled Health Services. We aim to minimise avoidable deafness through prevention, early detection, and improved access to ear-health services, achieving long-term developmental, educational and vocational benefits. We will support families to address underlying social determinants and modifiable drivers of ear disease and hearing loss. ACCESS will establish the feasibility of the Child Health Navigator model of care to upscale and extended to other chronic diseases that impact Aboriginal and Torres Strait Islander children and their families. Lastly, we will support bi-directional capacity building for researchers, Aboriginal Community Controlled Health Service staff and health workers.

6.5 Chapter 6 Methods

We used the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) reporting guidelines.[26]

6.5.1 Study design and setting

ACCESS will be delivered, developed and implemented across three collaborating Aboriginal Community Controlled Health Services; two regional services (Western New South Wales and Murrumbidgee Local Health Districts), and one metropolitan service (South Western Sydney Local Health District).

6.5.2 Child Health Navigator

The ACCESS-employed Child Health Navigator will be a local Aboriginal and Torres Strait Islander community member with health-system experience. The Navigator will augment existing integrated models of care within their communities. Integrated models of care aim to connect services by addressing barriers between care providers, including health, social and community services, with the overarching goal of strengthening holistic and patient-centred care.[18-19] Given the appeals to better address the sociocultural and political determinants in Aboriginal and Torres Strait Islander communities,[1,2,7,9] ACCESS will add further tools to screen for social determinants of health in addition to the "715 Aboriginal health check". The

715 Aboriginal health check is an annual Medicare (Australian Universal Healthcare Program) funded health check for Aboriginal and Torres Strait Islander people, to enhance early identification and facilitate early referral for a broad range of health services.[27] The 715 consists of a health assessment performed by a General Practitioner, often supported by a multidisciplinary team.[28]. The aggregated risk factors identified in these health checks will help identify children who may be at heightened risk of ear and other health problems. Further screening tools will be used, including: an ACCESS team-developed self-reported questionnaire on service use; Parent-evaluated Listening and Understanding Measure (PLUM);[29] Hearing and Talking Scale (HATS);[30] Kessler-5;[31] Pediatric Integrated Care Survey (PICS);[32] and the Pediatric Quality of Life Inventory (PedsQL).[33] These tools will be used to identify need for services, such as housing and educational services, that may mediate some of the social factors placing children at increased risk. The Child Health Navigator will support families, health workers and health services with many aspects of health service use, navigation, knowledge translation and cultural support. The priorities for each community will be informed by the co-creation activities detailed in the Co-design Stream. In addition to the community identified priorities, the potential roles and activities of the Child Health Navigator are likely to undergo iterative changes guided by ongoing community consultation. ACCESS includes a budget for personal professional development for the Navigators, negotiated with them and their Aboriginal Community Controlled Health Service employers.

6.5.3 Eligibility criteria

Aboriginal and Torres Strait Islander children and adolescents aged 18 years or younger, who have, or are anticipated to have, high health service needs. Navigators will decide which children and families access their service in consultation with local Aboriginal Community Controlled Health Service staff. However, this will be informed by the Co-design Stream, and we anticipate that Navigators will prioritise Aboriginal and Torres Strait Islander infants and young children recognised as requiring augmented service support due to poor ear health from otitis media and hearing loss (e.g., those identified through SEARCH and HEALS). Furthermore, the Child Health Navigators will prioritise Aboriginal and Torres Strait Islander children and adolescents (<18 years; specifically targeting <6 years) who are at risk of otitis media, hearing loss and poor developmental outcomes due to risk factors that include involvement with child protection services and placement in out of home care, and having other indicators of familial, social and health disadvantage that would indicate higher risk.

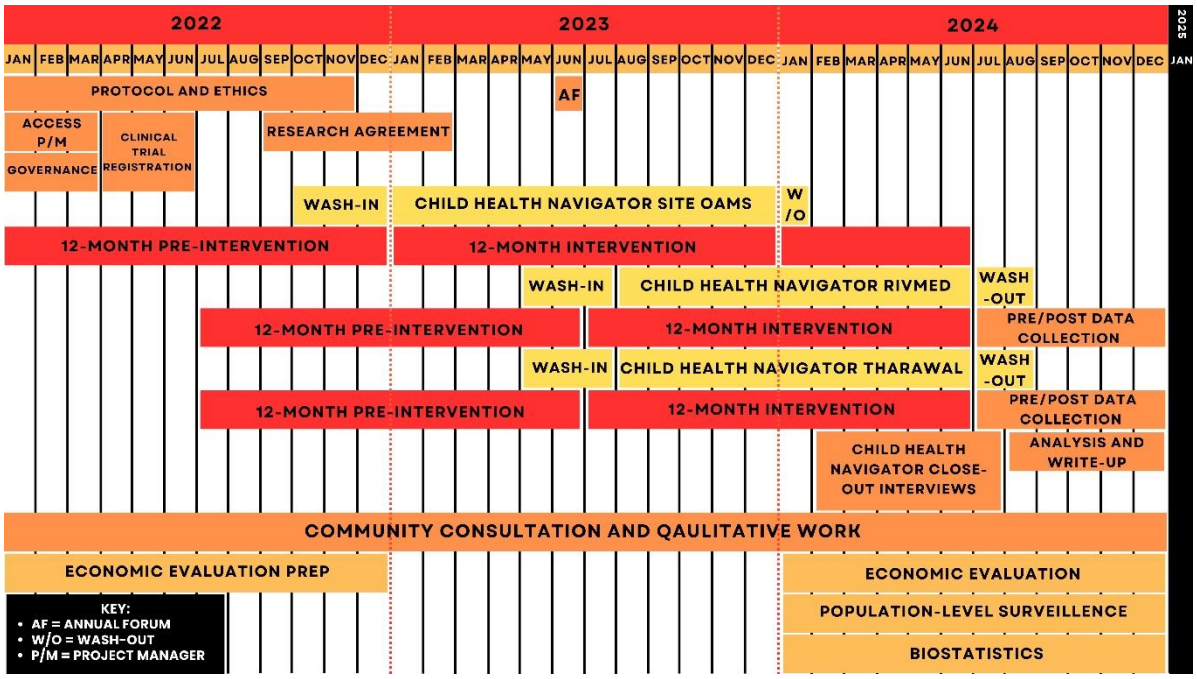
6.5.4 Recruitment

The Navigator will collaborate with Aboriginal Community Controlled Health Service workers, including child health, ear health and other health workers at the sites to identify participants who may benefit from support by the Navigator. Recruitment could occur through the Aboriginal Child Health Check (715), with support from Aboriginal Community Controlled Health Service staff, out of home care consultations, high risk antenatal visit clinic lists and other means. The health worker, with support from the Navigator, will explain the details and purpose of the study to ensure informed consent is obtained prior to inclusion.

6.5.5 Participant sample size and timeline

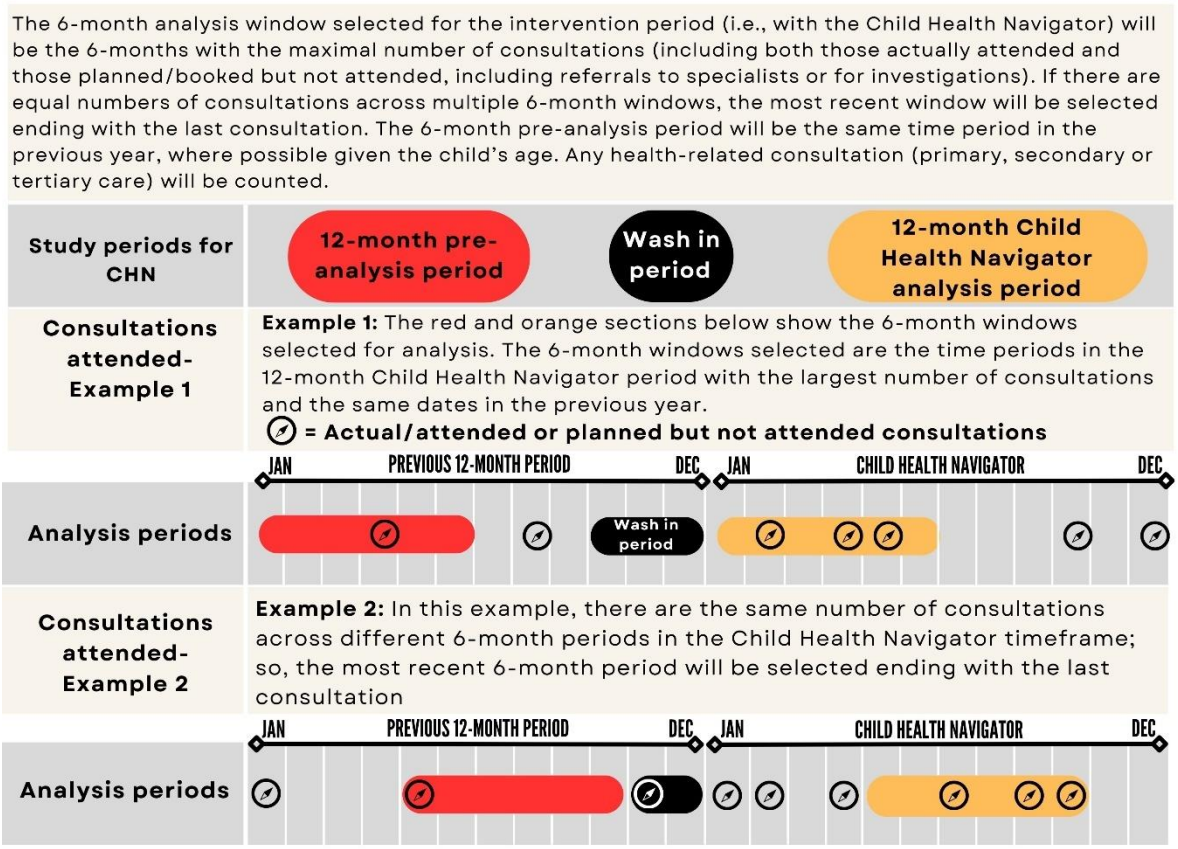
We ran simulations computing power to detect changes under different settings. Assuming each child has an average four referrals in six months (Navigator analysis period) and a 50% baseline medical appointment attendance rate, a sample size of 105 children receiving Navigator services provides 90% power to detect a 20% increase in attendance (50% to 60%) and 99% power to detect an increase of 26%. These calculations are based on Poisson regression to model the number of attended appointments, with number of scheduled appointments as an offset (alpha=0.05). Even accounting for the expected clustering correlation from children in the same family, we will have power to detect meaningful changes in the access to care. This sample size will allow detection of differences from baseline of 0.3 standard deviations for continuous outcomes and changes of 10% in dichotomous outcomes, with 80% power.

Figure 6.1: ACCESS Participant Timeline



The Navigator commencement will be staggered across all three partner sites. We plan a two to three-month wash-in phase where we work with Navigators and the local Aboriginal Community Controlled Health Service to develop the role to be locally relevant and to specifically address the determinants and consequences of ear health, hearing problems and developmental issues. Subsequently, there will be a 12-month Navigator period, which will be the analysis period. The comparator will be the 12-month period before the Navigator's wash-in phase. From the 12-month Navigator period and the 12-month pre-Navigator period a 6-month analysis period will be determined as per Figure 6.2.

Figure 6.2: Example cases for the 6-month pre-analysis and Child Health Navigator periods



6.5.6 Outcomes

6.5.6.1 Consultations

A child health consultation will be defined as any interaction, whether in person or telehealth, between a patient, parent/carer and any healthcare professional. This includes all consultations in the Aboriginal Community Controlled Health Service with general practitioners, audiologists, speech therapists, and specialists (e.g., paediatricians, Ear Nose and Throat surgeons or psychologists). This will also include all consultations with healthcare professionals where the child was referred to a specialist or tertiary institution for a procedure or asked to come back to the Aboriginal Community Controlled Health Service for a review or follow-up. Given the importance of education in terms of child health outcomes, consultations will also include any engagement with community services, specifically including any meeting with education (e.g., parent teacher evenings, or individual meetings with school staff). The unit of analysis will be the consultations within the specified time windows for the 12-month Child Health Navigator period and 12-month pre-Child Health Navigator period (see Figure 6.2). The specific Child Health Navigator analysis period will

be the six-month period of the Child Health Navigator's involvement with the child that has the largest number of consultations (see Figure 6.3). The comparator period will be the six-month period of the same calendar months in the prior year, or as close as possible to avoid the Wash-in period (see Figure 6.2 and Figure 6.3). This period will remain irrespective of whether the Child Health Navigator's involvement was shorter or longer than this six-month period so that we have a single unit of analysis to compare across all participants. Where there are multiple six-month periods with the same number of consultations, we will use the most recent six-month period that falls within the respective time windows, ending with the last consultation.

6.5.6.2 715/Aboriginal Health Check

ACCESS will examine the 715-item Child Health Checks for Aboriginal and Torres Strait Islander children (<15 years). The Navigator will work with General Practitioners and use this information to identify families who need support and help develop their individual support plan using the 715-health check as an identification and referral tool. The 715 will be examined for completion rates and utility.

6.5.6.3 Paediatric Integrated Care Survey (PICS)

ACCESS will use only the specific questions from the PICS tool that have been identified as suitable by Aboriginal and Torres Strait Islander investigators on this project, and that have been collectively selected by the research team. The appropriateness of the selected questions will be monitored and adapted upon continual consultation with Aboriginal and Torres Strait Islander investigators and Aboriginal Community Controlled Health Service staff throughout this project. Amendments (including ethics amendments) will be made wherever changes are recommended by Aboriginal and Torres Strait Islander stakeholders and investigators.

6.5.6.4 Parent-evaluated Listening and Understanding Measure (PLUM) and Hearing and Talking Scale (HATS)

PLUM and HATS are validated communication screening tools that have been validated within Aboriginal and Torres Strait Islander populations by Hearing Australia.[29-30] The Child Health Navigators will utilise these tools will during health child health consultations, to screen and identify communication concerns. This information will be used to guide support plans for children and their families.

6.5.7 Data analysis

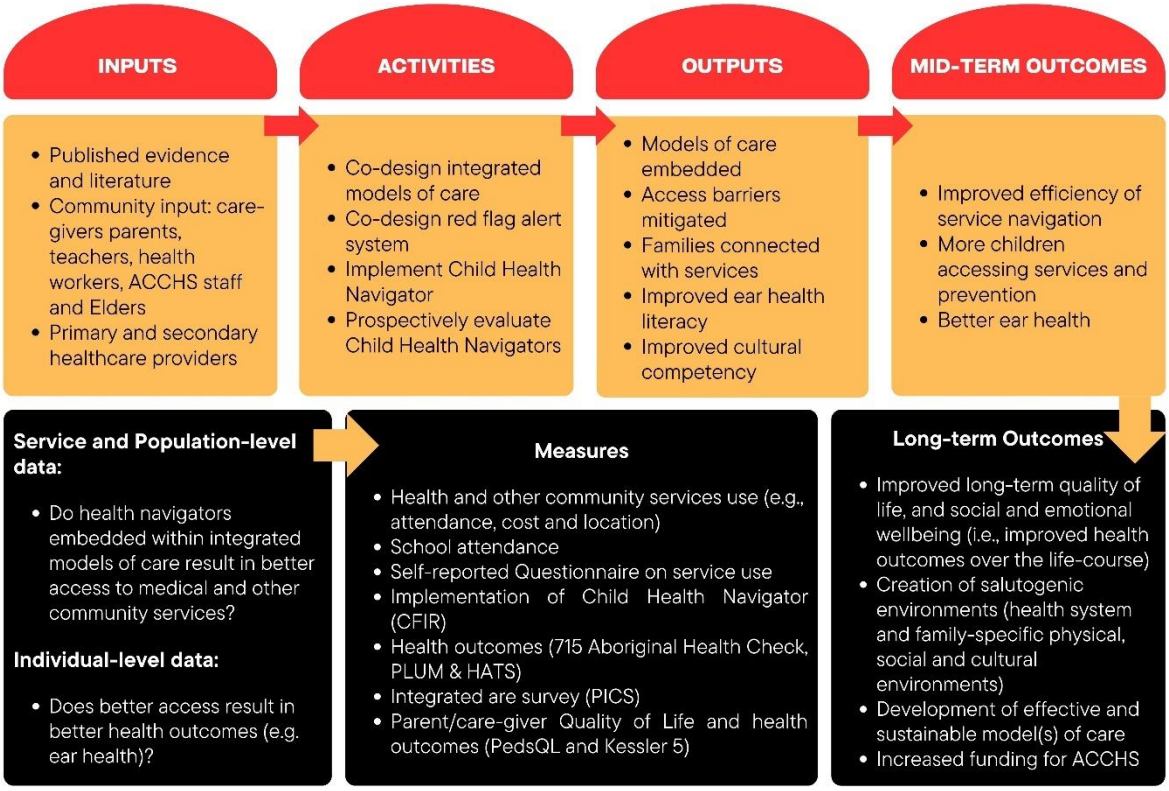
6.5.7.1 Stream 1: Co-design

The Child Health Navigator model of care and its integration into enhanced service models will be informed through a series of ongoing community Yarning Circles (i.e., community focus groups using Aboriginal qualitative research methods) and semi-structured interviews with key informants including health workers, parents, carers, teachers, Elders and others. Interview guides were co-designed with community stakeholders. This community consultation work compliments existing insights gained from workshops conducted in all sites over several years, and via interviews with community paediatricians. The Yarning circles, which commenced in 2021, capture perspectives on ear health and hearing of children living within these communities. Captured themes will inform the development of the ACCESS model of care, including an understanding of how Navigators will empower families and communities to access prevention, early support and ear health and hearing services. Furthermore, we will draw upon community knowledge to develop 'red flags' and clear referral pathways to HEALS to help families access timely clinical support. Community consultation will continue across the lifespan of ACCESS, informing all project Streams.

6.5.7.2 Stream 2: Co-Implementation

The ACCESS team and Aboriginal Community Controlled Health Service partners will use key findings from Stream 1 Co-design to refine key components of the theory of change of the Navigator component (see Figure 6.3). The adapted theory of change model and final ACCESS model of care will then be reviewed with the Aboriginal Community Controlled Health Service, communities, children, and their families before being adopted.

Figure 6.3: Conceptual diagram of the ACCESS Child Health Navigator model of care



The Consolidated Framework for Implementation Research (CFIR)[34] is a framework for assessing context in terms of existing or potential barriers and facilitators to successful implementation. Service providers, clinicians and caregivers of children who accessed Navigators will be asked qualitative/quantitative questions focussed on the following five CFIR domains by the research team at the end of the Navigator period: innovation, outer setting, inner setting, individual and implementation process.[34]

6.5.7.2.1 Individual-level data collection

ACCESS will enable tracking of SEARCH participant outcomes comparing those with and without access to best practice prevention and early support. Further, ACCESS will compare children with and without ear disease and hearing impairment. Educational outcomes will be collected by the Navigator via parent or carer reported school attendance and reports. Self-reported data will be provided by the parent/carer on service use. Within the hospital setting, service use data will include emergency presentations, admissions, and surgery. Service use for non-hospital settings will be primary health, allied health, and relevant social services. Self-reported data will be collected via a questionnaire developed by the ACCESS research team. Data captured will include appointment type, date of the appointment, reason for the

appointment, appointment status (booked, attended, did not attend, cancelled or rescheduled), location of service, cost of service excluding rebates, other associated costs and mode of transport including cost or distance travelled).

6.5.7.2.2 Service-level data collection

ACCESS will evaluate the effectiveness of the 715 Aboriginal Child Health Check as a mechanism to link children to effective prevention and support services. The 715 includes questions about social and emotional wellbeing, and environmental and social factors. Questions can be modified to target specified health factors and outcome measures. ACCESS will consult with collaborating communities and review available literature to evaluate the efficacy of questionnaires used to facilitate integrated paediatric care supported by the Child Health Navigator.

The Child Health Navigator will monitor and track access to prevention services, access to pre-school, referrals made and attended, and access to surgery and therapy, including audiology, speech therapy and Ear Nose & Throat surgery. Tracking will occur at the service level with consent.

6.5.7.3 Stream 3: Co-Evaluation

6.5.7.3.1 Primary analysis

The primary outcome unit of analysis will be the proportion of consultations attended during the Navigator period vs. the same period in the previous year. We will conduct a sensitivity analysis in the logistic regression with the type of consultation as a covariate taking into consideration clustering at three levels (child, family and Aboriginal Community Controlled Health Service).

We will report secondary analyses such as the total number of consultations by type, including parent-initiated primary care presentations versus referrals to other healthcare professionals and the proportion of children attending the majority of actual or planned consultations during the analysis period and attendance by season (winter months versus other nine months). For other outcomes, we will report descriptive statistics (e.g., 715 consultations; and questionnaire data).

For the very small number of children who may be enrolled through High-risk antenatal clinics, we will compare the proportion of attended consultations for infants with Navigators versus historical controls from the year prior to Navigator engagement.

6.5.7.3.2 Economic evaluation

We will compare costs and health and service outcomes over the 12 months with the Child Health Navigator compared to the 12 months before (pseudo control period), taking a healthcare funder perspective. Data will be pooled across the three sites for each time. Given the multitude of relevant outcomes we will conduct a cost-consequence analysis, which uses incremental costs and outcomes presented in disaggregated form. Costs in the pseudo control period will include administrative costs, any infrastructure costs and health service utilisation costs (collected via data linkage, as above); in the intervention period, costs will include these, plus the cost of the Health Navigator. Outcomes for the cost-consequence analysis for ACCESS will include access to child health prevention services, preschool, Aboriginal Child Health Checks; referrals and attendance at referrals; ear, nose and throat surgical procedures, emergency department presentations and educational outcomes. We will also examine changes in child and parent/carer health outcomes including the PedsQL Quality of Life measure, and the Kessler 5.[31] The PedsQL is a paediatric health-related quality of life measure consisting for four key domains: physical functioning, emotional functioning, social functioning, and school functioning.[33] The Kessler 5 consists of five sub-set questions taken from the Kessler 10, a screening scale of psychological distress. The Kessler 5 and 10 have been demonstrated as reliable tools for measuring psychological distress among Aboriginal and Torres Strait Islander adults.[35] These measures will be captured at the start of the Child Health Navigator period, 4-months into this period and at the end of this period. Sensitivity analyses will be conducted around key variables or assumptions.

6.5.7.4 Stream 4: Population-level Surveillance

6.5.7.4.1 Population-level outcomes

This project will provide an exemplar population-level ear health surveillance model to inform and monitor ear health service delivery innovations to improve ear health outcomes for Aboriginal and Torres Strait Islander children in New South Wales. To do this, we will use health and human services data for all New South Wales Aboriginal and Torres Strait Islander children born since 2001 (>10,000 children) that have been linked for the existing

New South Wales Child E-Cohort Project (ethics approvals: PHSREC 2020/ETH01265; AH&MRC 1688/20). Briefly, we will quantify the scale and pattens of ear health outcomes among Aboriginal and Torres Strait Islander children and describe the health and social circumstances of Aboriginal and Torres Strait Islander children who experience ear health outcomes during childhood and adolescence. We will also investigate the population-level impact of health service innovations on ear health and related outcomes.

6.5.8 Data management

Individual-level and Aboriginal Community Controlled Health Service-level data will be collected, stored and de-identified using coding. The investigators are responsible for ensuring the accuracy, completeness, legibility and timeliness of the data reported. All source documents will be completed in a neat and legible manner to ensure accurate interpretation of the data. Data will be securely stored following The University of Sydney's strict data policy and guidelines- including de-identification, password protection and secure storage.

Data will be stored, accessed, and archived using the University of Sydney's Research Data Store during the project. The Research Data Store is a secure, enterprise-grade Network Attached Storage device located within New South Wales. Study materials may be stored on the University's enterprise edition of OneDrive during the project or physically stored on-site using the Aboriginal Community Controlled Health Service lockable and secure file storage facilities, accessible only by research team members. OneDrive is a cloud file storage service that stores data on secure servers within New South Wales. Additionally, study materials will be stored on the University's licensed tool, REDCap™ during the project. REDCap™ is an online data capture tool that stores data on secure servers. The investigators are responsible for ensuring the accuracy, completeness, legibility and timeliness of the data reported. All source documents will be completed in a neat and legible manner to ensure accurate interpretation of the data. Participants will have the opportunity to amend responses and ensure any data stored is done so in a way that accurately represents the information they have consented to share, and in a way that does not identify them or put them at risk of inferred identification.

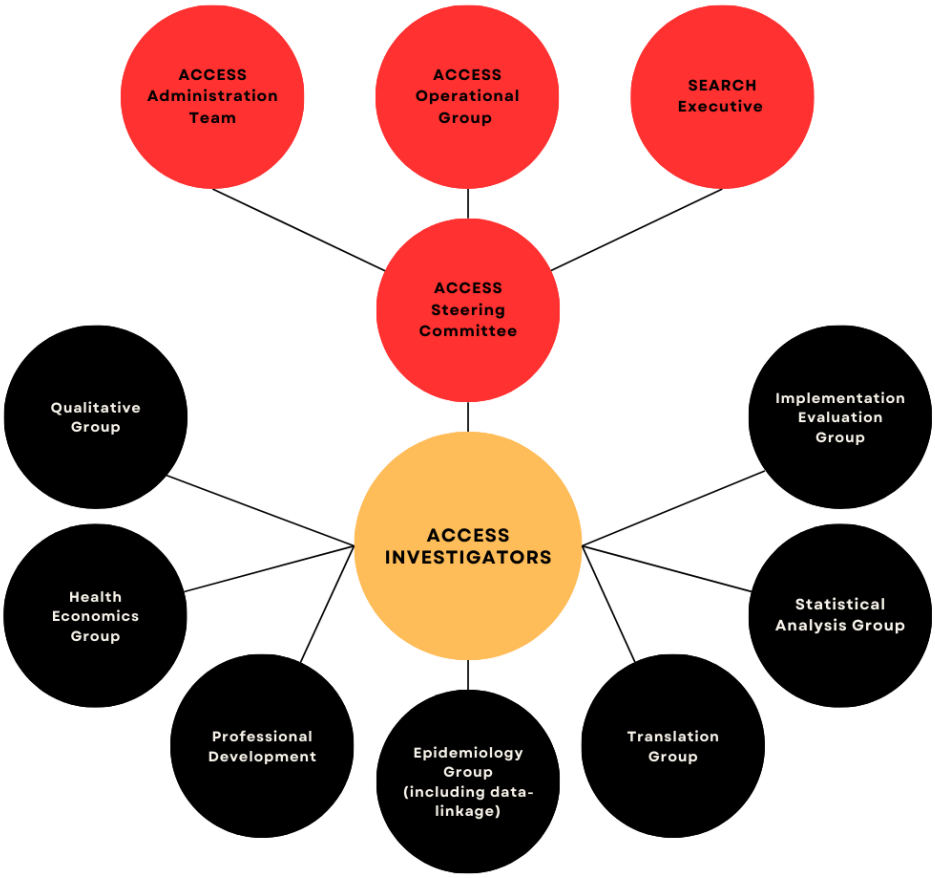
Consent forms will be stored electronically as password protected PDF files on a secure server (REDCap™) at The University of Sydney. Hard copy data will be destroyed in accordance with the University of Sydney's data management policy once it has been securely stored on the server.

All data will be deidentified and coded to ensure anonymity of the participants. Feedback sessions will be held prior to data analysis to ensure the verbatim transcripts have accurately recorded the participants perspectives. During this process, we will ask the participants to identify if the transcripts may directly or indirectly identify them. If the participants indicate that this is a possibility, we will not use the data as direct quotes in any published document. The data will still be used in the thematic analysis. There is no possibility of identification of an individual, as themes are derived from multiple participant responses.

6.5.9 Governance

The ACCESS investigator team is comprised of equal Aboriginal and Torres Strait Islander researchers, and non-First Nation researchers with extensive experience in Aboriginal and Torres Strait Islander health research. The ACCESS Operational Group is comprised of the administration team (HG, SW, JD, SR), and senior Aboriginal and Torres Strait Islander researchers (MD, JS, SB, KK). The Steering Committee will consist of the ACCESS Operational Group, senior Aboriginal and Torres Strait Islander researchers (PF, AP) and Aboriginal Community Controlled Health Services Chief Executive Officers (JN and DW). There will be annual face to face meetings and additional online meetings to monitor and evaluate ACCESS progress. Senior Aboriginal and Torres Strait Islander researchers will lead the Co-design stream (JS), and ACCESS professional development plans (MD). The co-evaluation stream will be led by SW and the data-linkage stream will be led by KF. The overall ACCESS project will be led by (HG) and the core management group (HG, SW, JD and the ACCESS Project Manager; SR). The Project Manager will work closely with the Navigators to ensure the smooth running of ACCESS, coordinate the budget in liaison with HG and the University of Sydney research office, and manage all ACCESS investigator meetings.

Figure 6.4: ACCESS Governance Structure



6.6 Chapter 6 Ethics and dissemination

6.6.1 Research ethics approval

Aboriginal Health and Medical Research Council Human Research Ethics Committee approvals: co-design/Yarning stream (6/4/20; #1627/20); and Child Health Navigator intervention (4/12/22; #1917/22). Approved by New South Wales PHSREC approval (7.7.20; #615 2020/ETH01265; Au RED Study Registration Number: 2020.20; ACCESS AHMRC Registration Number 1688/20 (Protocol version 616 6.0 approved on 05/05/2022). The economic evaluation work at the end of ACCESS: not yet submitted.

6.6.2 Consent/assent

All three participating Aboriginal Community Controlled Health Service Chief Executive Officers have provided letters of support and agreement to participate. Informed consent will be obtained following provision of a participant information sheet to prospective participants.

6.6.3 Confidentiality

The confidentiality procedures described here adhere to the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines.[26]

6.6.4 Participant Identification and Registration

At enrolment, each participant is assigned a unique identification number. Personal identifying information (e.g., name, address, contact details), is collected and stored securely in a password-protected database accessible only to authorised personnel in accordance with Human Research Ethics Committee approvals.

6.6.5 Result reporting/publication

All ACCESS dissemination will only present deidentified data. Pseudonyms or descriptions (e.g., “parent”) will be used to refer to study participants to prevent identification. All dissemination will be approved by Aboriginal Health and Medical Research Ethics Committee and reviewed by our Aboriginal co-investigators prior to dissemination.

6.6.6 Declaration of interest

No competing interests.

6.6.7 Dissemination policy

The target audience includes researchers and academics in the field of public health, epidemiology, and related disciplines, public health practitioners, policymakers, and program managers. The research team will present the findings at national and international conferences. The manuscript will be made available on the research team's website and/or institutional repositories. The research team will utilise social media platforms to disseminate key findings, updates, and highlights from the manuscript. Infographics, short videos, and other visually appealing content will be developed to engage a broader audience. The research team will develop policy briefs and practice guidelines based on the research findings. These documents will be disseminated to policymakers and practitioners to facilitate evidence-based decision-making and implementation. The research team will work with media partners, both traditional and online. Press releases and media interviews will be used to reach a wider audience and stimulate public interest.

6.7 Chapter 6 References

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6.8Declarations

- **Funding:** ACCESS was supported by two Australian National Health and Medical Research Council grants - 1. Medical Research Futures Fund (#1211077; 2020-2023); 2. Centre for Research Excellence Partnership Pathways to better care AND Outcomes for Aboriginal young people (#1135271; 2018-2023).

- **Author contributions:** HG, SW, JD and JN conceived the study and collaborated with DW, SB, KF, EB, JC, JS, AT-P, MD, TI, KK, KH, AP, MC, PF, RL to design and refine the protocol. DW, JN, SB, JS, MD, TI, KK, MC, and PF provided guidance and advice to ensure ACCESS was culturally safe for all investigators and participants. Authors JD, HG, SR and SW were the primary contributors to the production of this manuscript. All authors contributed to critical revisions and editing the manuscript for important intellectual content and approved the final manuscript for submission.

6.9 Contribution of Chapter 6 to overall thesis

Contribution

The primary aim of this thesis is to embed relevant findings into the co-design and co-implementation of the ACCESS. This chapter provides a detailed description of the co-creation activities, including co-design and co-implementation for ACCESS. This chapter follows the preceding chapters as their findings were integral to informing the design and implementation of the ACCESS project, underscoring its position within the overall sequence of the thesis. This chapter provides a robust description of co-creation research activities that may enable adaptability and scalability for future iterations of ACCESS, and other projects developing and evaluating health navigation models of care for Aboriginal and Torres Strait Islander and other priority populations.

Next steps

To date, Stream 1 (co-design) and Stream 2 (co-implementation) have been completed (Stream 1) or commenced (Stream 2). Moving forward, implementation evaluation (part of Stream 2), impact and economic evaluation (Stream 3), and population-level surveillance (Stream 4) will commence to assess the benefits and opportunities for the Child Health Navigator, identify population-level ear health, hearing and associated outcomes, and evaluate

the impact of the HEALS (see ***Chapter 1.4.2***). Research output across all streams will be used to inform the adaptability and scalability of ACCESS.

CHAPTER 7: THESIS DISCUSSION AND CONCLUSION

7.1 Chapter 7 overview

This concluding chapter will:

1. Summarise the design of the thesis and key chapter findings,
2. Present the findings of the thesis in relation to the four original aims that were to:
    a. **Aim 1:** to **a)** identify social determinants of ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales and **b)** embed relevant findings into the co-design and co-implementation of a community-led model of care that targets the underlying determinants of ear health.
    b. **Aim 2:** to explore and report community perspectives about ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales.
    c. **Aim 3:** to **a)** report ear health and hearing outcomes among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales, and **b)** to identify associations between otitis media, hearing loss, and child, family and social factors.
    d. **Aim 4:** to systematically search and synthesise peer reviewed literature to identify key considerations for health navigators supporting Indigenous children and adolescents. Report the impact of health navigators on health outcomes and service use, and build upon existing recommendations to guide the design, implementation and evaluation of health navigation-focussed models of care supporting Indigenous children and adolescents
3. Highlight the strengths and limitations of this thesis,
4. Set out the research and theoretical recommendations from this thesis,
5. Make policy and service recommendations from the thesis, and
6. Provide a summary of how this thesis has contributed to the current evidence base on the topic of best practice models of ear health and hearing for Aboriginal and Torres Strait Islander children.

7.2 Design of this thesis

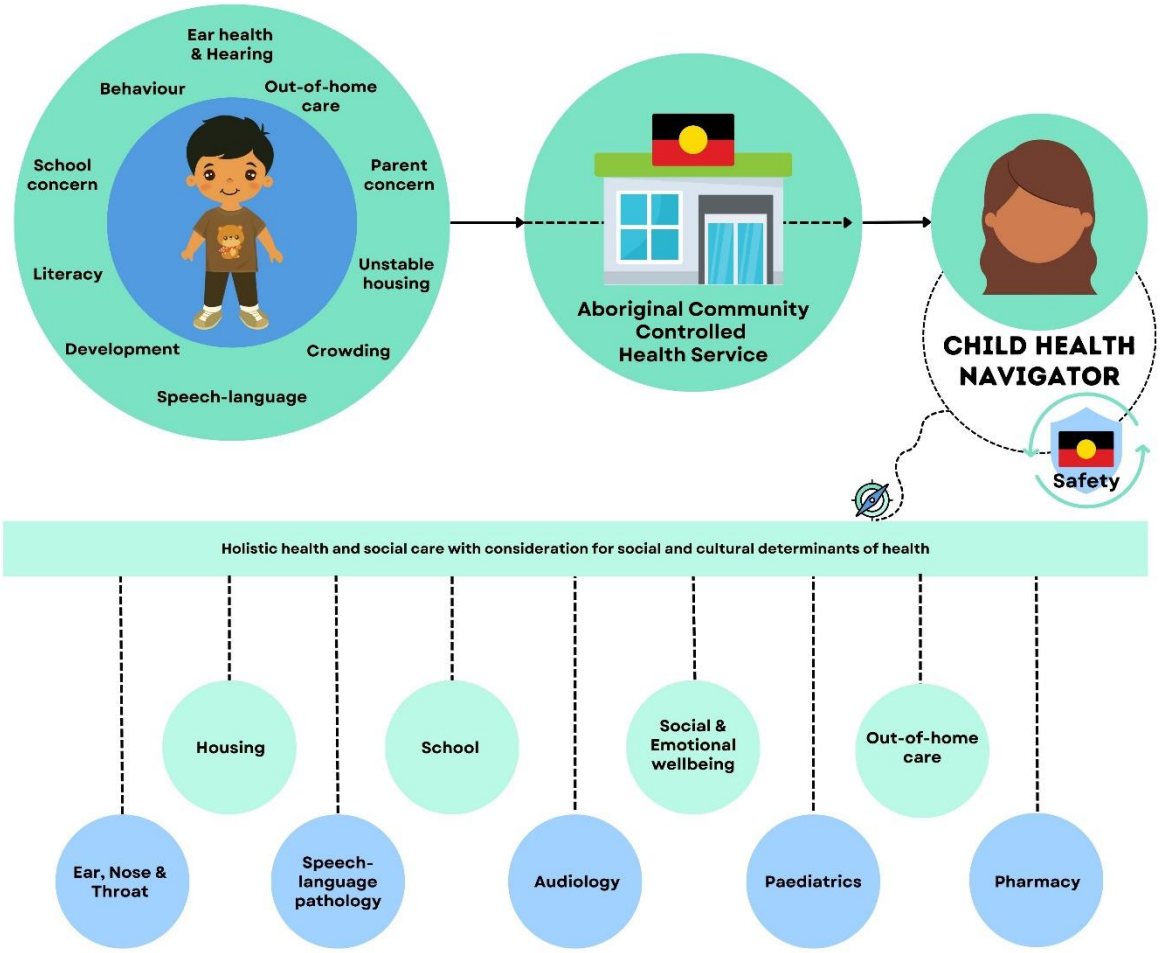
7.2.1 Summary

This thesis provides an overview and description of some social determinants of ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales, with related research findings used to guide and co-create a community-led model of care called the Aboriginal Community Controlled Ear-health Support System (ACCESS).

The preceding chapters of this thesis have explored the complex factors influencing ear health among Aboriginal and Torres Strait Islander children. Through a comprehensive exploration of social determinants, colonisation, co-created research, healthcare access and community perspectives, a nuanced understanding of the complex landscape surrounding ear health has been established. This work serves as the foundation for this discussion chapter, which focusses on the development and implications for the co-created ACCESS Child Health Navigator model of care.

This model, co-created in collaboration with Aboriginal and Torres Strait Islander communities, represents a transformative approach to addressing the multifaceted barriers faced by families navigating the healthcare system and contending with unmet social determinants of health (see Figure 7.1). Drawing upon insights from the literature and systematic content review ***(Chapter 2)*** review, Community Yarning circles ***(Chapter 3)***, quantitative data ***(Chapter 4)***, systematic review ***(Chapter 5)*** and ACCESS research protocol ***(Chapter 6)***, this discussion ***(Chapter 7)*** critically examines the impact, challenges and opportunities to best support Aboriginal and Torres Strait Islander families with children at risk of ear disease. Importantly, this thesis has contributed to ongoing discussions and research into culturally safe and effective healthcare approaches for Aboriginal and Torres Strait Islander children, with a specific focus on ear health and its underlying social and cultural determinants of health.

Figure 7.1: Aboriginal and Torres Strait Islander Child Health Navigator Conceptual Diagram



7.2.2 Hearing what Community has to say: informing a co-created approach to improve ear health and hearing for Aboriginal and Torres Strait Islander children (Chapter 3)

This section described the co-design activities for the ACCESS project. The Yarning circles, which played a central role in this co-design, were conducted at three Aboriginal Community Controlled Health Services in New South Wales. The Yarning circles revealed significant insights into the health environments impacting ear health among Aboriginal and Torres Strait Islander children. Barriers to access including transport limitations, financial constraints, and concerns about cultural safety were identified by participants as critical challenges. Notably, mainstream health services were often described negatively, characterised by racism, cultural insensitivity, high cost, lacking transport assistance and being fragmented. In contrast, Aboriginal Community Controlled Health Services were praised for their culturally safe, holistic and integrated approaches, offering no-cost services and transportation to support patients.

The impact of otitis media and poor overall ear health featured as a central theme in the Yarning sessions. This included significant consequences on speech-language development, social and emotional wellbeing, behaviour and educational outcomes. Community members emphasised the importance of addressing ear health issues early, highlighting that children are the Elders of the future and need optimal hearing for their overall development and success in adulthood. This perspective underscores the critical role of ear health in ensuring the wellbeing of not only Aboriginal and Torres Strait Islander children, but the community as a whole.

Furthermore, the Yarning circles highlighted the cultural significance of hearing within Aboriginal and Torres Strait Islander communities. Hearing was described as essential for maintaining traditional oral systems of knowledge sharing and storytelling, which are foundational aspects of Aboriginal and Torres Strait Islander cultures. This cultural context further emphasises the broader implications for ear health beyond individual wellbeing, extending the preservation of cultural heritage and community resilience. These findings support the need for culturally responsive and community-driven approaches to ear health that recognise and address the unique and complex determinants of health for Aboriginal and Torres Strait Islander communities. Importantly, this community knowledge provides critical insights to help guide the co-creation of the ACCESS Child Health Navigator model of care.

7.2.3 Ear health and hearing in urban Aboriginal Children (Chapter 4)

The Study of Environment on Aboriginal Resilience and Child Health (SEARCH) partnerships with Aboriginal Community Controlled Health Services highlighted ear health hearing as research priorities. This paper reports otitis media and hearing outcomes, including associated child, family and social characteristics, within the SEARCH cohort. These data are critical to inform policy and practice initiatives to improve ear health and hearing outcomes for Aboriginal and Torres Strait Islander children.

Findings from this study revealed half of the cohort aged six months to three years had otitis media. One third of the cohort aged six months to 18 years had otitis media, including 1.8% (26/1430) with perforation (0.8% chronic suppurative otitis media, 0.6% dry perforation and 0.4% acute otitis media with perforation). One quarter of the cohort aged 6 months to 18 years (25.7%; 279/1087) had hearing loss; 12.4% unilateral, 13.2% bilateral (70.6% with bilateral hearing loss had concurrent otitis media). Otitis media was associated with the following: younger age (six months to younger than three years versus six to 18 years) attending

childcare or preschool; foster care; previous ear infection/s; and greater than or equal to two people per bedroom. Hearing impairment was associated with younger age and previous ear infection.

Otitis media is treatable and preventable. Early intervention may reduce hearing loss and other downstream adverse health and social outcomes such as contact with the justice system. This study identifies characteristics of urban Aboriginal and Torres Strait Islander children who may benefit from targeted prevention and early intervention services, including children who are aged younger than six years, have a significant history of ear disease, live in out-of-home care, attend childcare, and live in crowded housing.

Younger children, especially those attending childcare, are likely to benefit from routine ear health surveillance. Preschool has important developmental benefits and may be an idea setting for targeted ear health support. Furthermore, other settings where children and parents are connected with health professionals, such as mother's groups and Aboriginal Community Controlled Health Services are likely to be beneficial settings for routine ear health surveillance. This study identified that otitis media was more common among children in foster care compared to children living with family members, highlighting the importance of health checks and management plan for children in out-of-home care. Otitis media was more common among children living in homes with more than two people per bedroom, emphasising the need for culturally safe, integrated health and social care to address the social determinants of health, such as crowded housing. Increased funding to Aboriginal Community Controlled Health Services to ensure this level of culturally safe access to early childhood ear health, speech-language, and social services could improve child health outcomes.

Over half of the children in this cohort younger than three years had otitis media. Importantly, this is a crucial age for speech-language and auditory processing development. Findings from this study emphasise the potential for long-term health gain, as otitis media and hearing loss are treatable. This paper emphasises the need for culturally safe integrated models of health and social care addressing the social determinants of health and continuity of care. Community-driven, holistic, targeted approaches for Aboriginal and Torres Strait Islander children with otitis media and hearing loss should be facilitated through community engagement and the delivery of high-quality, comprehensive, culturally safe and community-based initiatives.

7.2.4 Health Navigators supporting Indigenous children and adolescents: a meta-narrative review (Chapter 5)

The focus of this review was to systematically search and synthesise peer reviewed literature to identify key considerations for health navigators supporting Indigenous children and adolescents. This review reports the impact of health navigators on health outcomes and service use. Furthermore, this review builds upon existing recommendations to guide the design, implementation and evaluation of Health Navigator-focussed models of care supporting Indigenous children and adolescents.

This review underscored the critical importance of cultural competence in health navigation programs for Indigenous children and adolescents. Programs that prioritise culture and integrate Indigenous worldviews, values and practices in service delivery were found to significantly enhance trust and engagement. Effective navigation extends beyond traditional clinical care and encompasses a holistic approach that addresses the social determinants of health. This includes but is not limited to housing, education, employment, and community connections. By considering the broader context of youth wellbeing, navigation programs can promote a wide range of support services that contribute to comprehensive and sustainable improvements in health outcomes. Holistic approaches are particularly crucial for Indigenous children and adolescents, whose health and wellbeing are intricately linked to social, cultural and environmental factors.

This review highlighted the proactive roles of health navigators in addressing barriers to care experienced by Indigenous families. These carriers may include transport, cost, stigma, and cultural safety. Health Navigators play a vital advocacy role, working to reduce these barriers and facilitate improved access to health services. By advocating for the needs of Indigenous families, Health Navigators contribute to promoting equity and ensure timely and appropriate care that aligns with cultural values and preferences.

Findings from this review enabled the development of recommendations to inform the design, implementation and evaluation of effective health navigation programs for Indigenous children and adolescents. These recommendations emphases the ongoing need for culturally competent services, holistic approaches that address social determinants of health, proactive support to overcome access barriers, and meaningful advocacy on behalf of Indigenous families. Incorporating these recommendations into Health Navigator programs can lead to more equitable, accessible, and effective services for Indigenous children and adolescents,

ultimately, contributing to improved health outcomes and wellbeing.

7.2.5 Aboriginal Community-Controlled Ear-health Support System (ACCESS): study protocol for a co-created model of care (Chapter 6)

The ACCESS protocol paper detailed in ***Chapter 6*** provides a comprehensive outline of the approach to co-designing, co-implementing and co-evaluating the Child Health Navigator model of care supporting Aboriginal and Torres Strait Islander children at risk of ear disease and otitis media. Through community Yarning circles, valuable insights were gathered, highlighting the importance of culturally sensitive and community-driven healthcare initiatives. This collaborative process informed the development if ACCESS and helped to foster meaningful partnerships with Aboriginal and Torres Strait Islander communities, ensuring that the resulting model of care is tailored to specific community needs and priorities.

The protocol emphasises the significance of ongoing evaluation and translation of activities throughout the life of the project. By systematically assessing the implementation of the Child Health Navigator model of care and its impact on improving ear health and associated outcomes, we aim to generate actionable insights for healthcare providers, policymakers and community stakeholders. This approach aligns with principles of participatory research, where knowledge generation is not limited to academic circles, but actively involves and benefits the participating communities and service end-users.

Although the protocol does not present empirical findings, key outcomes lie in the robust methodology established for the ACCESS project. The structured approach to co-design, co-implementation and co-evaluation establishes a strong foundation for future research and the potential scalability of the ACCESS Child Health Navigator model of care. Importantly, it underscores the importance of harnessing Aboriginal and Torres Strait Islander voices and experiences in healthcare research and practice, promoting equity, cultural safety, and improved health outcomes for marginalised populations.

Lessons about effective co-created research within Aboriginal and Torres Strait Islander communities learnt since the initiation of ACCESS include the need for continuous formal (i.e., Yarning Circles) and informal dialogue (i.e., phone calls and emails) with community stakeholders. Correspondence with community stakeholders since initiation of ACCESS exceeds 679 recorded instances of correspondence over four years. This continued dialogue led to ACCESS reaching its target recruitment (105 children) and being on track to complete

follow-up data collection by the conclusion of the project in 2025. Recorded correspondence includes phone calls, emails, text messages, virtual meetings, and face-to-face meetings. This emphasises the importance of continuing efforts in relationship-building and ensuring that community is guiding project activities across every stage of research. A testament to the strong relationships developed, and success of the project overall, is the growth of health navigation teams within partnering sites. In recognition of the value ACCESS Child Health Navigators have added to community service delivery, additional navigators have been employed by community partners independent of ACCESS research grant funding.

7.3 Findings in relation to thesis aims

7.3.1 Aim 1

To **a)** identify social determinants of ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales and **b)** embed relevant findings into the co-design and co-implementation of a community-led model of care that targets the underlying determinants of ear health. ***(Thesis)***

7.3.2 Aim 1 Findings

a) The systematic content review in ***Chapter 2.4*** revealed that most literature focussed on otitis media among First Nation children in Australia report social determinants of health playing a key role in the high prevalence within Aboriginal and Torres Strait Islander populations. Despite this, few studies have investigated models of care that address these underlying social determinants of health.

Similarly, the Yarning study in Chapter 3 identified key determinants of ear health and hearing, including racism, cultural safety, reactive care approaches, transport and cost barriers, long waitlists, continuity-of-care challenges, poor-quality housing, and overcrowding. Participants highlighted the importance of ear health and hearing for healthy life-course trajectories, noting their impact on education, behaviour, social and emotional wellbeing, and the nurturing of future Elders.

The ear health and hearing paper reported in ***Chapter 4*** identified child, family and social factors associated with ear health and hearing among children living in partner communities. Associated factors included younger age, a history of ear infections, living in out-of-home care, attending childcare or preschool, and living in crowded homes.

The systematic review in ***Chapter 5*** identifies relevant social determinants impacting health, wellbeing and access to services, including racism and cultural safety, community and cultural knowledge, holistic views of health and wellbeing, access barriers, timely access to services and fragmented healthcare systems.

b) During over 679 instances of contact with partnering communities, the ACCESS research team has been able to adapt the Child Health Navigator model of care to community needs and priorities. This involved listening to community and embedding findings from the systematic content review ***(Chapter 2.4)***, community Yarns ***(Chapter 3)***, community ear health and hearing data ***(Chapter 4)*** and systematic review ***(Chapter 5)*** into this model of care. Moreover, the co-design and co-implementation activities discussed in this thesis, and future research activities were compiled into a research protocol ***(Chapter 6)*** for the ACCESS project and Child Health Navigator model of care.

7.3.3 Aim 2

To explore and report community perspectives about ear health and hearing among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales. ***(Chapter 3)***

7.3.4 Aim 2 Findings

This study identified that integrated and culturally responsive approaches to address ear disease effectively are critical. Furthermore, collaboration between community-controlled, mainstream health services, educators, policymakers, and community leaders are essential to improve access to early support for children and families. These efforts must ensure that clinical services address social determinants, promote cultural safety, and foster supportive environments that nurture the wellbeing of individuals across the lifespan.

7.3.5 Aim 3

To **a)** report ear health and hearing outcomes among Aboriginal and Torres Strait Islander children living in non-remote communities in New South Wales, and **b)** to identify associations between otitis media, hearing loss, and child, family and social factors. ***(Chapter 4)***

7.3.6 Aim 3 Findings

a) Half of the children aged six months to three years had otitis media. One third of the children aged six months to 18 years had otitis media, including 1.8% with tympanic membrane perforation (0.8% chronic suppurative otitis media, 0.6% dry perforation and 0.4% acute otitis media with perforation). One quarter of children aged six months to 18 years had hearing loss; 12.4% unilateral, 13.2% bilateral (70.6% with bilateral loss had concurrent otitis media).

b) Otitis media was associated with the following: younger age; attending childcare or preschool; living in out-of-home care; if the child had a history of ear infection; and two or more people per bedroom living in the home. Hearing impairment was associated with younger age and if the child had a history of ear infection.

7.3.7 Aim 4

To systematically search and synthesise peer reviewed literature to identify key considerations for implementation of Health Navigators supporting Indigenous children and adolescents. This review will report the role and scope of Health Navigators on health outcomes and service use. Furthermore, this review aims to build upon existing recommendations to guide the design, implementation and evaluation of Health Navigation-focussed models of care supporting Indigenous children and adolescents. ***(Chapter 5)***

7.3.8 Aim 4 Findings

Findings highlight the benefit of health navigators in improving access to culturally safe and effective healthcare for Indigenous children and adolescents. Overall, Navigators were found to enhance service access, address determinants of health, and improve health outcomes through holistic support, advocating for families, and facilitating timely and appropriate care. This study supports for the integration of Health Navigators into healthcare systems to address health inequities. Insights reveal policymakers should support the training and employment of Navigators and to strengthen Indigenous community health services to ensure sustainable, community-led programs.

7.3.9 Aim 5

To accurately and systematically describe the research activities involved in the co-creation of ACCESS, with particular focus on the development and implementation of the Child Health Navigator model of care. ***(Chapter 6)***

7.3.10 Aim 5 Findings

A research protocol was produced that reports co-created research activities across each stream of the ACCESS project. This protocol has been submitted for publication and helps to inform the adaptability and scalability of ACCESS.

7.4 How this thesis has contributed to the evidence base

7.4.1 Overview

This section highlights the key contributions of the thesis in advancing the understanding of ear health and hearing among Aboriginal and Torres Strait Islander children. ***Chapter 2.4*** presents the first systematic review focusing on the social determinants of otitis media among Aboriginal and Torres Strait Islander children, identifying key factors like overcrowding and poor housing but noting a lack of evaluated interventions. ***Chapter 3*** introduces a novel qualitative study using Yarning methodology to capture community perspectives on ear health. ***Chapter 4*** provides contemporary data on the prevalence of ear disease, emphasising the need for targeted interventions. ***Chapter 5*** offers the first systematic narrative review of Health Navigators for Indigenous children and adolescent populations, while ***Chapter 6*** presents a research protocol for a co-created health navigation model of care, emphasising community-led approaches and offering a guide for future research and practice.

7.4.2 Chapter 2.4

This systematic content review is the first known review to investigate the social determinants of otitis media among Aboriginal and Torres Strait Islander children, addressing a critical gap in the evidence base. It highlights the significant role of social determinants, such as overcrowding, poor housing quality, socioeconomic status, and household tobacco smoke exposure, in driving the high prevalence of otitis media. Notably, the review reveals a lack of evaluations on approaches to address these underlying factors, underscoring a major limitation in the current literature. By identifying these gaps, this review makes a key contribution by providing actionable recommendations for future research, including the

urgent need for community-led and co-created models of care that target the social determinants of ear health and hearing.

7.4.3 Chapter 3

The Yarning study described in this chapter is one of only two known published studies to capture community stakeholder perspectives on ear health and hearing among Aboriginal and Torres Strait Islander children, while explicitly employing the culturally appropriate methodology of Yarning. It contributes novel insights by focusing on perspectives from metropolitan and regional areas, which are often underrepresented in the literature. Importantly, this study offers contemporary and community-informed recommendations on how Health Navigators can improve support for Aboriginal and Torres Strait Islander children at risk of ear disease, addressing a critical gap in evidence and guiding the development of culturally safe and effective care models.

7.4.4 Chapter 4

This chapter presents the most contemporary and extensive dataset on ear health and hearing among Aboriginal and Torres Strait Islander children living in metropolitan and regional areas of Australia, addressing a critical gap in the literature. Prior to this study, data from these settings were scarce, with most existing research focused on rural and remote populations. This paper highlights a high prevalence of ear disease, aligning with findings from remote settings, while offering a detailed analysis of the prevalence of otitis media subtypes, hearing loss, and associated child, family, and social factors. By identifying key risk factors such as younger age, overcrowded housing, out-of-home care, childcare or preschool attendance, and a history of ear infections, this paper provides actionable recommendations to inform targeted interventions and practice, particularly in non-remote contexts.

7.4.5 Chapter 5

This chapter presents the only known systematic review of health navigators specifically supporting Indigenous children and adolescents, addressing a significant gap in the evidence base. While one other review exists on Indigenous Health Navigators, it does not focus on children and adolescent populations. This review uniquely contributes by synthesising evidence to inform the development of an adapted model of Indigenous Health Navigation and Care Integration. It offers contemporary recommendations and key considerations for designing and implementing culturally appropriate Health Navigation models tailored to the

needs of Indigenous children and adolescents, providing critical guidance for future research and practice.

7.4.6 Chapter 6

The protocol described in this chapter is the first known protocol for a Health Navigation model of care focused on ear health and hearing among Aboriginal and Torres Strait Islander children, filling a critical gap in the literature. It provides key considerations for the co-creation of community-led models of care, encompassing co-design, co-implementation, co-evaluation, and co-translation within Aboriginal and Torres Strait Islander settings. This protocol promotes methodological rigor and consistency and serves as a comprehensive guide for adapting and replicating the model in diverse settings. By emphasising the importance of community involvement in research, it has the potential to shape future studies and drive the development of culturally safe and effective interventions for Aboriginal and Torres Strait Islander communities and other priority populations.

7.5 Strengths and limitations

7.5.1 Strengths

The primary strengths of this thesis were:

1. The use of underlying theoretical frameworks: decolonisation, co-creation and strengths-based approaches
2. Establishing an evidence base through undertaking a literature review ***(Chapter 2)***, including a systematic content review ***(Chapter 2.4)***
3. The use of mixed methods across the thesis
4. The inclusion of priority populations (Aboriginal and Torres Strait Islander) by participation as service end-users and co-creation partners
5. This work will be critical for our data-linkage work (ongoing) and this will inform population-level ear health surveillance

7.5.1.1 The use of underlying theoretical frameworks: decolonisation, co-creation and strengths-based approaches

One of the key strengths of this research is that it is co-created with Aboriginal and Torres

Strait Islander communities through Aboriginal and Torres Strait Islander Governance, community-driven decision-making and ongoing Yarning circles. This approach helped to ensure cultural relevance and appropriateness, fostered trust, and empowered the community by given them ownership of research activities and captured data. It enhanced validity and reliability of the findings by grounded them in the community's lived experiences and perspectives. Moreover, co-creation aligns with ethical research practices, promotes sustainable outcomes, and builds capacity within the community, ultimately leading to more effective and accepted service provision and health approaches. Research activities helped to foster bidirectional capacity building, where both community members and researchers benefited from the collaborative process. Community members enhanced their research skills and knowledge. Simultaneously, researchers developed their ability to work in a culturally safe and effective manner, gaining a deeper understanding of community protocols and the importance of respecting culture in health and research. This reciprocal learning created mutual respect and enriched the research process, ensuring that both stakeholder groups were better equipped to contribute meaningfully to the project's success.

7.5.1.2 Establishing an evidence base through undertaking a literature review (Chapter 2)

A key strength of this thesis is its foundation in an extensive literature review, which provides a comprehensive understanding of the research landscape. This review was further enriched by the inclusion of a published systematic content review, offering a rigorous and detailed analysis of existing studies and evidence. By integrating these insights, the thesis ensures that its findings are well-grounded in current knowledge and address gaps identified in the literature. This thorough approach enhances the credibility and relevance of the research, contributing to robust and informed conclusions.

7.5.1.3 The use of mixed methods across the thesis

The strengths of using mixed methods in this thesis are highlighted by the integration of diverse research approaches, including two systematic reviews, a Yarning study, a quantitative study reporting cohort data, and a research protocol paper. This allows for a comprehensive exploration of the research questions from multiple perspectives, enhancing the depth and breadth of the findings. Importantly, these methodologies are underpinned by Aboriginal and Torres Strait Islander approaches, such as co-creation, decolonisation, and strengths-based frameworks, which ensure that the research is culturally respectful and

aligned with the values and priorities of the communities involved. This combination of methods and cultural principles strengthens the overall validity and relevance of the research outcomes.

7.5.1.4 The inclusion of priority populations (Aboriginal and Torres Strait Islander) by participation as service end-users and co-creation partners

The inclusion of priority populations, specifically Aboriginal and Torres Strait Islander communities, as both service end-users and co-creation partners is a significant strength of this research. By involving these communities, particularly Aboriginal and Torres Strait Islander children, in the development and delivery of enhanced ear health and hearing services, the study addresses the critical needs of a population with high prevalence rates of ear disease. This approach ensures that the interventions are specifically tailored to the unique needs and cultural contexts of those most in need. Engaging Aboriginal and Torres Strait Islander people in the co-creation process not only improves the relevance and effectiveness of the services but also fosters community ownership and empowerment, making the enhanced services more impactful and sustainable for this priority group.

7.5.1.5 The future use of population-level surveillance

Despite findings not being representative of all Aboriginal and Torres Strait Islander communities in Australia, the embedded data-linkage within the ACCESS project will provide state and national-level data. Data-linkage allows for integration of diverse data sources, providing a more comprehensive and robust dataset. This enhances the generalisability of some findings, as it offers a broader context and facilitates comparisons across different regions and populations. Additionally, data linkage can improve the accuracy and reliability of findings by cross-verifying information and identifying patterns or trends that may not be apparent from isolated datasets. This comprehensive approach, although not yet implemented, will provide a more holistic understanding of ear health issues, and support the upscale and development of more effective and wide-reaching approaches.

7.5.2 Limitations

The primary limitations of this thesis were:

1. Selection bias
2. Measurement bias of the outcome
3. Measurement bias,
4. Limitations in investigating implementation and impact

7.5.2.1 Selection bias

A limitation of this research project is that findings are not generalisable across Aboriginal and Torres Strait Islander and Indigenous communities nation-wide or globally. Given the significant cultural, geographical and social diversity among Aboriginal and Torres Strait Islander and Indigenous populations, the experiences and issues identified in the specific communities represented in this thesis may not reflect those of other Aboriginal and Torres Strait Islander and Indigenous populations. Also, within a community, those attending the ACCHS are more likely to view the ACCHS positively and had we conducted the Yarning circles via population-level recruitment rather than through the ACCHS we may have had different results. Consequently, while the study provides valuable insights, an understanding for the need to be flexible and adaptable is required when applying findings in broader settings both inter- and intra-community.

7.5.2.2 Measurement bias of the outcome

Another limitation of this study is the inherent complexity in researching otitis media, due to multiple sub-types and diagnostic challenges. Otitis media can manifest in various forms, each with distinct characteristics and implications for diagnosis and treatment. Accurately identifying otitis-prone children necessitates multiple reliable diagnostic data points over time to distinguish between children who are chronically affected and those who may only present with otitis media on the day of testing. This limitation is not unique to this project and is common across otitis media-focussed research.

7.5.2.3 Measurement bias

In this cohort study, measurement bias of risk factors emerged due to quantitative data ***(Chapter 4)*** being collected at only a single time point, which constrained the ability to track changes or developments over time. Children with ear disease at enrolment into the cohort may not be the children most at risk of ear health complications over their life-course, but it was not feasible to re-examine the children multiple times in order to determine those most at risk and then assess for associated factors. Our study methods limit the capacity to establish causal relationships between risk factors and outcomes over time, as it does not account for the dynamic nature of these factors. Furthermore, some collected data relied on self-reported data from parents and caregivers about their child's health. It is possible that some parents and caregivers misreported information (e.g., reporting on previous ear infections), potentially leading to inaccurate analyses. Similarly, questionnaires are not equally valid across different populations or settings, and the lack of validated tools within Aboriginal and Torres Strait Islander settings (i.e., questionnaire capturing information about child, family and social factors) may have introduced bias.

7.5.2.4 Limitations in investigating causality

This PhD thesis presents information up until the implementation of the ACCESS Child Health Navigator, with evaluation and translation of the project yet to occur. As a result, the thesis does not provide insights into the effectiveness, impact and scalability of the model of care in practice. The absence of post-implementation data means that conclusions about the models' success, sustainability and potential for broader application remain speculative at this stage. This limitation highlights the need for ongoing research to fully assess and understand the outcomes of ACCESS and the Child Health Navigator model of care.

7.6 Implications for research, policy and practice

7.6.1 Overview of implications

This section describes the implications of this work for future research, policy, and practice recommendations to improve ear health and hearing outcomes within Aboriginal and Torres Strait Islander communities. It highlights the importance of capturing comprehensive data, addressing research limitations, and exploring effective approaches to housing and health navigator roles. Policy recommendations focus on supporting Aboriginal Community

Controlled Health Services, addressing social determinants of health, and ensuring sustainable, community-led solutions. Practice recommendations underscore the importance of community-centred, holistic care, and the integration of services to provide comprehensive support for ear health and hearing in Aboriginal and Torres Strait Islander communities.

7.6.2 Research

Future research is needed to capture perspectives on ear health and hearing from Aboriginal and Torres Strait Islander populations in rural and remote regions, as their experiences may differ significantly from those in metropolitan and large regional areas. Moreover, Aboriginal and Torres Strait Islander people living in rural and remote areas receive less healthcare funding per capita, with very remote areas receiving less than a third of the funding of major cities.[2] Additionally, people in these areas often need to travel to metropolitan areas to access healthcare services, particularly specialist services.[2] This geographical disparity amplifies the barriers to accessing healthcare, making it crucial to understand and address the specific challenges that exist with increasing remoteness. Our study focused on metropolitan and regional contexts, but rural and remote communities face unique challenges related to healthcare access, cultural safety, and social determinants of health. By exploring these diverse experiences, researchers can develop a more comprehensive understanding of ear health issues across different settings, ensuring that policies and interventions are tailored to meet the specific needs of all Aboriginal and Torres Strait Islander populations.

Research is needed to explore ear health and hearing among older children and adolescents, a group that is often overlooked in research and targeted service provision. Throughout this study, community discussions revealed concerns about the impact of ongoing otitis media and hearing loss on high school students, particularly regarding their academic performance, social and emotional wellbeing, and self-confidence. face. Aboriginal and Torres Strait Islander and Indigenous young people are five times more likely to die by suicide than their non-Aboriginal peers, due to a complex web of personal, social, political, and historical factors.[3] These include interpersonal conflict, involvement with the justice system, poor access to education, and unemployment, all of which intersect with cultural and gender identity formation.[3] By broadening the research focus to older ages groups, future research can address these gaps and inform the development of programs and services that better support the needs of older children and adolescents facing ear health challenges, particularly as they transition toward higher education and future employment.

There is a need to capture comprehensive ear health and hearing data from diverse Aboriginal and Torres Strait Islander settings, including at local, state and national levels. The availability and quality of data on Aboriginal and Torres Strait Islander health are known to have significant limitations. These include issues with the completeness and accuracy of Aboriginal and Torres Strait Islander identification in key health metrics such as mortality and morbidity, uncertainty regarding the size and makeup of the Aboriginal and Torres Strait Islander population, and a lack of comprehensive data on other health-related aspects like access to healthcare services.[4] Moreover, the National Best Practice Guidelines for Data Linkage Activities for Aboriginal and Torres Strait Islander people indicate that data linkage provides an economical method to improve the completeness and consistency of Aboriginal and Torres Strait Islander datasets across geographical settings.[5] While our study concentrated on metropolitan and large regional communities, robust data across different settings are needed to gain a full understanding of Aboriginal and Torres Strait Islander ear health. The ongoing ACCESS project includes a data-linkage component designed to provide population-level surveillance of ear health and hearing. Although this research is still in progress and will continue post-PhD, it will be instrumental in generating the evidence base needed to develop targeted and responsive policies and interventions for diverse Aboriginal and Torres Strait Islander populations.

One significant limitation in current otitis media research is the challenge of capturing reliable data due to the intermittent and fluctuating nature of the condition. A single time point of data may not accurately represent a child who is otitis-prone and may miss ongoing issues that affect ear health and hearing. Persistent otitis media, rather than a diagnosis made on the day of testing, is what significantly impacts health and well-being outcomes across the life-course. An otitis-prone child is defined within the literature as experiencing recurrent acute otitis media, defined as three distinct episodes of acute otitis media within six months, or four times within one year.[6] Therefore, further research is needed that apply methods, such as conducting multiple ear assessments across six months to one year, for reliably identifying children who are otitis-prone. This will help to ensure that data reflect those with ongoing, chronic conditions. This approach will help researchers, policy makers and service providers to better understand the long-term implications of otitis media and guide more effective programs.

Given the established links between otitis media and overcrowded living conditions, more research is needed to explore effective approaches to improve housing for Aboriginal and Torres Strait Islander communities. Addressing the social determinants of health, such as

housing, is crucial for reducing the prevalence of otitis media. Working with communities that are registered housing providers presents a promising solution, as these organisations are better positioned to offer culturally suitable and healthy housing options compared to standard public housing. A preference for Aboriginal Community Controlled Health Services to provide housing services for Aboriginal and Torres Strait Islander people is reported in the Joint Council for Closing the Gap's Aboriginal and Torres Strait Islander Housing Sector Strengthening Plan.[7] Within this plan, the Joint Council recognises that Aboriginal Community Controlled Organisations are more effective at supporting Aboriginal and Torres Strait Islander people; delivering better outcomes, employing more Aboriginal and Torres Strait Islander staff, and being generally preferred over mainstream services, and therefore, there is a strong push to enhance the capacity of the Aboriginal Community Controlled housing sector.[7] Understanding and supporting these community-led housing initiatives is essential for creating healthy home environments that support better ear health and overall wellbeing.

There is a notable gap in the literature regarding the role of Health Navigators in supporting Indigenous children and adolescents. Although a recent review[8] identified critical factors about the role and scope of Indigenous Health Navigators, this review did not focus on child health and yielded few studies from Australia. The limited research highlights a critical need for further studies that evaluate the impact of Health Navigators on access to care, particularly for child and adolescent populations within Aboriginal and Torres Strait Islander and Indigenous settings. Further research in this area will help to develop evidence-based practices and policies that support the effective implementation of Health Navigator programs tailored to the unique needs of Aboriginal and Torres Strait Islander and Indigenous communities.

Lastly, it is crucial to address the significant lack of young Aboriginal and Torres Strait Islander voices within the ear health and hearing literature, particularly in relation to their experiences with otitis media and hearing loss. Currently, the perspectives and contributions of young people are underrepresented in the research base, and their involvement in the co-creation of services is equally absent.[9] This is despite the fact that young people make up over 50% of the total Aboriginal and Torres Strait Islander population in Australia.[9] Moving forward, it is imperative to actively engage young Aboriginal and Torres Strait Islander voices in both research and service design to ensure that solutions are relevant, culturally appropriate, and truly reflective of their needs. This inclusion will not only enrich the research landscape but also lead to more effective and sustainable outcomes for Aboriginal and Torres Strait

Islander communities.

7.6.3 Policy

Policy efforts must prioritise the support and resourcing of Aboriginal Community Controlled Health Services, which are uniquely positioned to provide culturally safe, holistic care for Aboriginal and Torres Strait Islander communities.[10] This is supported by a 2015 Australian Institute of Family Studies literature review on Aboriginal and Torres Strait Islander community managed programs and organisations, which highlights barriers for the effectiveness of these community programs and organisations.[11] These barriers include an absence of long-term commitment from funding agencies, limited human capital and capacity for economic development, and social and health issues affecting the social and cultural capital within these communities.[11] Aboriginal Community Controlled Health Services are deeply embedded within their communities, offering tailored services that address the specific health needs and social determinants impacting Aboriginal and Torres Strait Islander peoples.[10] By increasing funding, resources, and support for these services, policymakers can strengthen the capacity of Aboriginal Community Controlled Health Services to continue delivering high-quality care that is culturally resonant and community-driven, ultimately improving ear health outcomes for Aboriginal and Torres Strait Islander populations.

Policies must focus on addressing the social determinants of health to improve ear health outcomes for Aboriginal and Torres Strait Islander communities. The need for policies to address social determinants and health inequity is echoed in a 2022 review[12] of Australian child and youth health, and education wellbeing policies. The review highlights there has been a failure to address the social determinants of health effectively.[12] Instead, these policies tend to focus on isolated, acute care approaches.[12] Despite a lack of action, there is a consistent acknowledgment of equity, a strong emphasis on housing as a key health determinant, and a connection between health and education departments, particularly in addressing mental health issues.[12] Barriers to implementing social determinants of health focussed policies have been shown to include belief systems that oppose a social determinants of health approach, including neoliberalism, the medicalisation of health, and racism.[13] Additionally, factors such as civil society mobilisation, leadership, and changes in government play a role.[13]Despite these challenges, there is a need to better support services to address underlying determinants and implementing broader policies that tackle systemic barriers to health. Key issues such as cost barriers, poorly integrated and fragmented health systems, racism, and a lack of essential

services, infrastructure, and workforce must be addressed to create a more equitable and effective healthcare environment.[2, 14, 15] By targeting these underlying factors, policymakers can help ensure that Aboriginal and Torres Strait Islander communities have access to the resources and opportunities necessary for achieving and maintaining good ear health.

As mentioned above, housing is a critical health issue for Aboriginal and Torres Strait Islander communities, and Aboriginal Community Controlled Health Services are recognised as being better equipped to provide healthy, culturally appropriate housing. However, for these services to effectively address housing needs, they must be adequately funded and supported.[7] Ensuring that Aboriginal Community Controlled Health Services have the necessary resources will enable them to develop and maintain housing solutions that contribute to improved ear health outcomes, further solidifying their role as essential providers in Aboriginal and Torres Strait Islander health and wellbeing.[7]

7.6.4 Practice

It is crucial that ear health and hearing care is community-centred, recognising that community is a fundamental social determinant of health for Aboriginal and Torres Strait Islander people. This is supported by Nash et al[16p1] who state, "*Programs should be governed and evaluated by [Indigenous] communities to further ensure programs are sustainable and are designed to meet community needs"*. Community-centred care involves not only providing culturally safe and responsive services but also ensuring that care is tailored to the unique needs and priorities of each community.[17] This approach includes actively involving community members in decision-making, fostering strong relationships and trust, and leveraging the strengths and knowledge within the community.[18]

Services should actively work to build strong intra- and intersectoral relationships to enhance the integration of health services within the often-fragmented healthcare system. This is supported by a 2014 systematic review[19] reporting the move towards inter-sector collaboration offers a chance for the health, education, and social service sectors to work together in innovative ways, enhancing service access for Aboriginal and Torres Strait Islander children with disabilities and their families.[19] By fostering collaboration across different sectors and disciplines, services can create more cohesive and streamlined care pathways for ear health and hearing in Aboriginal and Torres Strait Islander children. This approach ensures that children receive comprehensive, coordinated care that addresses their needs holistically, reducing gaps in service delivery and improving overall health outcomes.

Providing holistic care that is person- and family-centred is essential in meeting the needs of Aboriginal and Torres Strait Islander communities. A recent Cochrane Review[20] reports that family-centred care has the potential to enhance the overall health and wellbeing of Aboriginal and Torres Strait Islander and Indigenous children and their families. This approach must encompass Aboriginal and Torres Strait Islander and Indigenous understandings of health and wellbeing, recognising that true health extends beyond the biomedical model to include cultural and social dimensions.[21] Care should address not only physical health but also the spiritual, emotional, and cultural needs of individuals and their families.[21] By integrating these aspects into healthcare delivery, services can offer more comprehensive, culturally safe care that resonates with the values and experiences of Aboriginal and Torres Strait Islander people, ultimately leading to better ear health and hearing outcomes and stronger community wellbeing.

Models of ear health and hearing care within Aboriginal and Torres Strait Islander communities should embrace the use of Health Navigators, who can play a crucial role in supporting individuals and families.[8, 22] Health navigators help bridge gaps in care by guiding people through the healthcare system, advocating for their needs, and addressing the social determinants of health that contribute to conditions like otitis media.[8, 22-27] By providing personalised support and fostering connections to culturally appropriate services, health navigators can enhance access to care, improve health outcomes, and empower Aboriginal and Torres Strait Islander communities to better manage ear health and hearing.

Social prescribing is an essential approach that extends beyond the biomedical model of healthcare. Furthermore, this is considered an Aboriginal and Torres Strait Islander way of knowing and doing.[28] For conditions like otitis media, it's important for clinical management including the prescription of antibiotics. However, it is also important to address the broader social needs of families by connecting them to community services, such as housing support.[29] Health Navigators can play a key role in this process, helping to identify and link families to these crucial resources, ensuring that care is comprehensive and addresses the underlying social determinants of health. This approach leads to more holistic and effective care, ultimately improving outcomes for Aboriginal and Torres Strait Islander communities.

7.7 Reflection on Aboriginal and Torres Strait Islander ways of knowing, being and doing

7.7.1 Overview

This section reflects on engaging with Aboriginal and Torres Strait Islander ways of knowing, being, and doing in research and healthcare and highlights the importance of holistic, culturally safe, and community-driven approaches. These perspectives, grounded in thousands of years of knowledge, emphasise the interconnectedness of physical, emotional, spiritual, and social well-being. Aboriginal Community Controlled Health Services exemplify this by providing care that is not only clinically effective but also culturally resonant and community specific. Integrating these principles into mainstream practice challenges conventional models, fostering more inclusive, respectful, and effective healthcare systems.

7.7.2 Reflecting on Aboriginal and Torres Strait Islander ways of knowing, being and doing

Reflecting on the methods and processes of this research, I have found Aboriginal and Torres Strait Islander ways of doing and knowing to be incredibly enriching both professionally and personally. As a non-Aboriginal person, engaging with Aboriginal and Torres Strait Islander ways of doing research has expanded my understanding of the importance of culturally safe and community-driven methodologies. Aboriginal and Torres Strait Islander communities are inherently skilled at creating safe spaces, not only for their own community members, but for everyone engaging with them. This innate ability to foster inclusivity and safety is a testament to their deep-rooted cultural practices and communal values[21, 30], which have been refined over thousands of years.

Aboriginal and Torres Strait Islander concepts of health and wellbeing are profoundly holistic, recognising the interconnectedness of physical, emotional, spiritual and social factors.[31] Unlike Western biomedical models that often compartmentalise health, Aboriginal and Torres Strait Islander approaches integrate a multitude of influences, understanding that true wellbeing is achieved through balance and harmony in all aspects of life. This holistic view is informed by over 60 000 years of accumulated knowledge and lived experience, forming long-standing systems of health and wellbeing that have sustained communities for millennia.[32]

In light of this extensive knowledge and holistic perspective, it is evident that Aboriginal Community Controlled Health Services are uniquely positioned to offer well-integrated, holistic, and culturally safe care.[10] These services are tailored to address the underlying determinants of health, ensuring that care is not only clinically effective but also culturally resonant and community specific. The success of Aboriginal Community Controlled Health Services underscores the importance of community control and self-determination in health service delivery, as these factors are crucial for fostering trust, engagement, and positive health outcomes within Aboriginal and Torres Strait Islander communities.

Working within these settings has highlighted the significance of co-creation and community-led approaches in research and healthcare. It has reinforced the value of deep listening and learning from Aboriginal and Torres Strait Islander people, whose expertise and perspectives are vital for developing effective and culturally appropriate health initiatives.[33] As we continue to address health disparities and work toward health equity, it is essential to prioritise and respect Aboriginal and Torres Strait Islander ways of knowing, being and doing, and recognise their invaluable contributions to effective models of holistic and culturally safe care. This requires ongoing collaboration, partnership, and capacity-building efforts that empower Aboriginal and Torres Strait Islander communities to lead and shape their own healthcare systems.[33]

Furthermore, the recognition of Aboriginal and Torres Strait Islander knowledge systems challenges us to re-evaluate dominant paradigms and broaden our understanding of health and wellness. This includes acknowledging the interconnectedness of land, culture, spirituality, and community in promoting overall wellbeing.[30] Embracing these holistic perspectives not only enhances the effectiveness of healthcare, but also fosters a deeper sense of cultural humility and respect within the healthcare sector.[30] Integrating Aboriginal and Torres Strait Islander ways of knowing and doing into research and healthcare practices is not only ethically imperative but also enhances the quality and impact of our work.[14] By centring Aboriginal and Torres Strait Islander voices, honouring community protocols, and fostering genuine relationships, we can create more inclusive, equitable and effective healthcare systems that benefit all. This journey of reconciliation and collaboration is an ongoing process that requires continuous learning, humility and commitment to positive change.

7.8 Chapter 7 References

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8. Appendix

8.1 Chapter 3 Supplementary Tables

Supplementary Table 8.1 Participant Quotes (Chapter 3)

Priority Area: Health Service Access	
Racism and cultural safety	*Early Childhood Educator: "Hearing has dropped off the radar. Like how much longer or evidence do they need. Or is it just because it's the black fella?"*
	Community Health Worker: "Because they look at us like we're not able to do our job or we don't know what we're doing."
	Community Health Worker and Parent: "Depends, if they don't want to hear me that day. Yes and no."
	Community Health Worker and Parent: "I can say to my manager but again, we're the bottom of the food chain, who are we?"
	Community Health Worker and Parent: "Well look now [since the inquest] they don't get away with it, but you have to wait for someone to die for things to happen, which is wrong."
Transport and Cost	*Parent: "Then transport and home visits come into play. If parents and kids can't make it to the appointments... transport will be just as big as getting the appointment."*
	Community Health Worker: "A lot of these specialist services, including [Ear, Nose & Throat], don't provide transport. So, unless we are made aware of the appointment, they won't go. So that's one of the biggest barriers I am finding with these kids."
	Parent: "I'm a working single parent and they said to me to prepare $450 for [my child] to go in. And so I went in and had her appointment. We were in there for about 5 to 10 minutes, and it was $400."
	Community Health Worker and Parent: "I think it's so unfair that to be able to access [Ear, Nose, and Throat] services, you have to have money to pay for that, but ear health is such a big thing that can cause such big problems for children long-term."
Timely access to care	*Community Health Worker and Parent: "And once you do see the [Ear, Nose and Throat specialist], it's just the waiting list. The hospital is just ridiculous... If you don't have priority, you're on there for two years, plus. Easy two years."*
	Community Health Worker and Parent: "If you are going as public, which I have had to do with my own kids- we waited over 18 months before my boys got into the [Ear, Nose and Throat service]. And one of mine now does speech because his speech is affected."
	Community Health Worker: "When we were doing HEALS and we got access to the waitlist through Orange Health Service, there was one child that had been on there for 420 days."

Loss to follow-up	*Early Childhood Educator: "Yeah that's one of the common things we see is that loss to follow up, getting them to appointments, getting them a referral."*
	Community Health Worker: "And there's just that follow up from specialists as well because a lot of the time, as soon as we send through the referral, we don't hear anything until we get a referral, so we don't know."
	Community Health Worker: "Half the [General Practitioners] here half or a third are registrars. Then we rotate every six months. So that loss to follow up. Yeah, you you're just seeing your patient for the first time off once every six months and then they see a new Doctor and then you just don't, they won't be aware other than reading the last notes and history of the patient."
	Community Health Worker: "Yeah it would help my work as well because I have parents come through the program and then after a while when I try and get them to come for follow ups and stuff it's a bit like me just ringing constantly and I am just like am I being a nuisance just calling all the time. So, it would be good to have that support with following families up."
	Community Health Worker and Parent: "And I think the other good thing about HEALS was like when we had like a liaison officer that would help families like to be able to navigate like when their appointment was, what they had to do and stuff."
	Community Health Worker: "I think it's not one thing we see quite a lot with our clients too is the transient nature of their, you know, visits. So we'll often see families that will come, and we've got them on a pathway. We've got, you know, an appointment in the future with the [Ear, Nose and Throat specialist] and then they moved to Queensland. Yeah, so they missed that appointment and then they come back and then we have to start the process all over again and re refer they go back on the waiting list and then you've lost two years, yeah? That's that's challenging. Yeah, that is yeah. It would be nice if we could have like a token system where they could say, you know I'm on the list here and it was interchangeable."
Sustainable solutions	*Parent: "Yeah and you know then there's how many people that are well and truly lost you know, and it takes years to get back to where they should be. Band-Aid solutions. We need to get rid of Band-Aid solutions and put in permanent solutions."*
	Community Health Worker and Parent: "Like there's so much focus on the parents actually should be doing this, but like maybe they need to get more education and like change the system."
	Community Health Worker: "Like I'd really love to see a government that is proactive rather than reactive but unfortunately it doesn't exist. Yet."
	Community Health Worker and Parent: "That was the other problem with HEALS. It was always ad hoc funding that the government would be like, oh we've got this leftover money. Can you spend it in three months? Yeah, and like the [Aboriginal Community Controlled Health Services] all did like so well 'cause they already had these waiting lists of people waiting for speech and [Ear, Nose and Throat] and they got rid of the waiting list."
	Community Health Worker: "With the research and everything else, how much of that is being fed back to the community. And what are we saying? What input do they need? Like we can sit here and talk all day every day, but we need some action."

	Community Health Worker: "Worldwide [Aboriginal and Torres Strait Islander people] have the highest percentage of [ear disease] and yet we're still sitting at the table today discussing this stuff."
	Community Health Worker and Parent: "Yeah, I think it's unfair that they often go and give that funding and that money to mainstream services. Then like, even though it's been shown that [the Aboriginal Community Controlled Health Service model is] much more successful and works better to improve outcomes."
	Community Health Worker: "But these people are the ones that are living in the community. You need to hear a bit more from them and their input when you're writing all this up."
	Community Health Worker: "With the research and everything else how much of that is being fed back to the community. And what are we saying? What input do they need? Like we can sit here and talk all day everyday but we need some action. We've really struggled. Yeah, we can't get an [Ear, Nose and Throat surgeon]. We've now lost the speech pathologist. We've gone through three of those in the last 12 months. Yeah, so that's another thing."
Priority Area: Health Opportunities Through Education	
Holistic and reactive care	*Parent: "My daughter was in pain all the time and they just kept prescribing her antibiotics. I didn't get any sleep... Just here's another script, here's another script. And she couldn't sleep. And said she's fine. But I knew there was something going on."*
	Community Health Worker and Parent: "My cousin's little daughter went to the pediatrician 'cause, so she wasn't really speaking, and I didn't know whether she had hearing problems or whatever, and the pediatrician was like, oh, she's too young to do anything 'cause she was three and a half. Come back when she starts school. I was like that's not right."
	Community Health Worker and Parent: "And it's literally I just have antibiotics, have antibiotics, have antibiotics."
	Parent: "They could see the tear [in the eardrum] and I was like, well where do I go from here? And they were like okay, we'll give you a script for antibiotics and use it if he gets a fever. And I'm like okay."
	Community Health Worker and Parent: "And I think that's why I only go to like the one or two doctors because I go there, and I think he's got a sore ear. He's been pulling at it and this, [and the doctor says] oh no he's fine or they don't look at it and I can usually tell even before they put the little otoscope in there that they're not even looking properly. Like they don't pull the ear up and look in there, like so I just don't trust anyone other than about two doctors, or [the Community Ear Health Worker]. Because I know they're not even looking properly."
Priority Area: Environmental Health	
Housing	*Parent: "Then the overcrowding, it's so normal with all our families. Especially when they've got multiple kids and they're in smaller homes."*
	Community Health Worker: "There are houses with the roofs falling down around them, and mold issues and yeah... The carpets that haven't been changed in 30 years and they've just built-up grime and yeah, that's what they're living in."

	Community Health Worker: "I mean we've got clients that are living in a tent by the river. The tent was given to them by [public] housing because they couldn't give them a house, so you know it's a single mum and her kid are living in a tent by the river. We gotta do better."
	Community Health Worker: "I mean, housing is just a whole lot of big social determinant for Mental health and everything else as well."
	Community Health Worker and Parent: "I think the other problem is, well like around housing as well, like it's hard to get housing then you might have problems with your house and you report it to housing and they take so long to come and fix it and those things also happen to a young child, yeah."
	Community Health Worker: So then the flip side of that is they come to us with a housing form saying we need to give them a valid medical reason as to why they have to have their carpets changed or why they need the roof fixed or, I mean like come on. Because it's a basic human right.
Priority Area: Foundations for a Health Life	
School and education	*Parent: "Even high schools, like my oldest son he's about to turn 13. So, he had grommets put in both ears when he was three or four. He's now as I said, turning 13 and in boarding school. And this whole process we've had [occupational therapists], speech [pathology], and you know, it's been one thing after another. It's not just that he has antibiotics and its gone. It's ongoing and he's in high school and he's struggling."*
	Community Health Worker and Parent: "And he had his first ear infection at the age of eight weeks, and he was prone to ear infections and that is why his speech is delayed. Now he is four and still having speech [therapy]"
	Community Health Worker: "They're all children who will be going into high school in the next couple of years too, so we're basically setting them up to fail. If they're not followed-up."
	Community Health Worker: "It's in our education system. It's in our prisons. It's everywhere 'cause a lot of people like a lot of kids that don't have the access to [Ear, Nose and Throat] specialists. Yeah, you know, they grow up in life not knowing any different. They learn to live with that 'cause that's how they adjust. Therefore, you know they're getting kicked out of school 'cause they're just the naughty child or they're sitting up the back of the class and they're getting into trouble 'cause they're not listening. In actual fact, there's an underlying ear problem."
	Community Health Worker: "We're trying to be more involved in Schools. I saw nineteen children and I mean, they're all actively being followed up in the clinic and stuff that we will hopefully get them in to be reviewed and stuff, but I know that they want more of that, they (Aboriginal Community Controlled Health Service Managers) want us in the schools more."
Behaviour and social and emotional wellbeing	*Parent: "But it's just been a really big struggle for him and because of his speech, he's not confident. So, with him meeting friends or getting up in school, like getting up in from the of the classroom and speaking. It's 'caused and created so many issues over one thing."*
	Parent: "[My daughter] also had glue ear and then all of a sudden, I thought she hated me. She won't listen to me. She'll be angry at you."
	Community Health worker and Parent: "I know myself with my young daughter at daycare, I was constantly picking her up. She was biting kids, and I was always made to feel that like my child was just a biter. She was one of those kids."

	Parent: "...As soon as I told them he's got a bit of hearing loss, they started to use like cue cards and stuff like he was acting out towards other kids. He's sort of calmed that down a bit."
	Community Health Worker and Parent: "But like I was trying my hardest to stop it. I was doing everything in my power but and antibiotics just weren't cutting it either. So, we end up stopping the antibiotics and 'cause she wasn't having fevers and stuff to go with it. And just yeah. It was quite difficult, and I felt judged from the daycare, and I think that was because of their lack of education around ear health."
Priority Areas: Healthy Living and Strong Communities & Culture at the Centre of Change	
Future Elders and importance of hearing for culture	*Parent: "These kids are the Elders of tomorrow and we need to make sure that they're good and strong. Because they're going to be raising my great grand babies."*
	Parent: "Yes, it's how we learn. And of course, we are an oral society... How are you going to listen to someone telling you a Yarn or whatever. And then you go away to tell someone else, and you are telling it wrong, you are telling half of the story."

8.2 Chapter 4 Supplementary Tables

Supplementary Table 8.2: Characteristics of children included vs. excluded from the analysis (Chapter 4)

	Otitis media (n=1645 eligible children >= 6 months)				Hearing loss (n=1315 eligible children >= 3 years)			
	Participants n (%)	**Non-participants n (%)**	**Total n (%)**	**p value**	**Participants n (%)**	**Non-participants n (%)**	**Total n (%)**	**p value**
Sex				**0.118***				**0.876***
Female	650 (45.5)	110 (51.2)	760 (46.2)		502 (46.2)	104 (45.6)	606 (46.1)	
Male	780 (54.5)	105 (48.8)	885 (53.8)		585 (53.8)	124 (54.4)	709 (53.9)	
Total	1430 (100)	215 (100)	1645 (100)		1087 (100)	228 (100)	1315 (100)	
Age group				**0.001†**				**<0.001†**
6 months to <3 years	264 (18.5)	66 (30.7)	330 (20.1)		N/A	N/A	N/A	
3 to <6 years	396 (27.7)	56 (26.0)	452 (27.5)		316 (29.1)	136 (59.6)	452 (34.4)	
6 to <12 years	537 (37.6)	61 (28.4)	598 (36.4)		536 (49.3)	62 (27.2)	598 (45.5)	
≥12 years	233 (16.3)	32 (14.9)	265 (16.1)		235 (21.6)	30 (13.2)	265 (20.2)	
Total	1430 (100)	215 (100)	1645 (100)		1087 (100)	228 (100)	1315 (100)	
Assessment season				**<0.001***				**0.007***
Summer	172 (12.0)	48 (22.3)	220 (13.4)		130 (12.0)	40 (17.5)	170 (12.9)	
Autumn	363 (25.4)	40 (18.6)	403 (24.5)		282 (25.9)	42 (18.4)	324 (24.6)	
Winter	484 (33.8)	80 (37.2)	564 (34.3)		363 (33.4)	90 (39.5)	453 (34.4)	
Spring	411 (28.7)	47 (21.9)	458 (27.8)		312 (28.7)	56 (24.6)	368 (28.0)	
Total	1430 (100)	215 (100)	1645 (100)		1087 (100)	228 (100)	1315 (100)	

* χ^2 test.
† Wilcoxon rank sum test.

Supplementary Table 8.3: Relation of child, family and social factors to ear health and hearing outcomes using imputed data (Chapter 4)

	Outcome: Diagnosis at child level (no OM, any OM)				Outcome: Hearing impairment in better ear (N, Y)			
	Unadjusted		Adjusted*		Unadjusted		Adjusted*	
	PR (95% CI)	P value	PR (95% CI)	P value	PR (95% CI)	P value	PR (95% CI)	P value
CHILD FACTORS								
Sex		**0.641**		**0.543**		**0.593**		**0.409**
Female (ref)	1		1		1		1	
Male	0.96 (0.81,1.13)		0.95 (0.82,1.11)		0.92 (0.68,1.25)		0.88 (0.65,1.19)	
Age group		**<0.001**		**<0.001**		**<0.001**		**<0.001**
≥6 months to <3 years	2.65 (2.20,3.21)		2.63 (2.18,3.19)					
≥3 to <6 years	1.90 (1.56,2.31)		1.86 (1.53,2.26)		1.93 (1.42,2.61)		1.89 (1.40,2.55)	
≥6 years (ref)	1		1		1		1	
In utero exposure to cigarettes		**0.168**		**0.100**		**0.426**		**0.348**
No (ref)	1		1		1		1	
Yes	1.13 (0.95,1.36)		1.15 (0.97,1.36)		1.14 (0.82,1.59)		1.17 (0.84,1.63)	
In utero exposure to marijuana		**0.670**		**0.422**		**0.547**		**0.534**
No (ref)	1		1		1		1	
Yes	1.05 (0.82,1.33)		1.09 (0.88,1.34)		0.88 (0.57,1.34)		0.88 (0.58,1.33)	
Ever ear infection (parent report)		**<0.001**		**<0.001**		**<0.001**		**0.001**
No (ref)	1		1		1		1	
Yes	1.62 (1.36,1.94)		1.57 (1.33,1.86)		2.03 (1.41,2.94)		1.90 (1.32,2.72)	
Ever breastfed		**0.439**		**0.649**		**0.455**		**0.426**
Yes (ref)	1		1		1		1	
No	0.93 (0.77,1.12)		0.96 (0.80,1.15)		1.14 (0.81,1.60)		1.15 (0.82,1.60)	
FAMILY FACTORS								
Relationship to child		**0.073**		**0.030**		**0.940**		**0.678**
Parent (ref)	1		1		1		1	
Other relative	0.97 (0.73,1.29)		1.07 (0.83,1.40)		0.95 (0.61,1.49)		0.87 (0.55,1.38)	
Foster carer	1.39 (1.05,1.85)		1.39 (1.09,1.79)		0.91 (0.48,1.72)		0.79 (0.43,1.48)	
Carer education		**0.384**		**0.366**		**0.444**		**0.471**
< Year 10 (ref)	1		1		1		1	
Year 10	0.80 (0.60,1.06)		0.81 (0.62,1.05)		0.87 (0.51,1.49)		0.90 (0.53,1.53)	

Year 11 - 12	0.81 (0.58,1.12)		0.81 (0.60,1.09)		1.27 (0.74,2.19)		1.25 (0.72,2.16)	
Trade/certificate/diploma	0.81 (0.64,1.02)		0.85 (0.70,1.04)		0.84 (0.53,1.33)		0.85 (0.54,1.36)	
University	0.85 (0.57,1.27)		0.94 (0.66,1.36)		0.71 (0.32,1.56)		0.68 (0.32,1.48)	
Govt financial support		**0.572**		**0.547**		**0.335**		**0.491**
None (ref)	1		1		1		1	
Family/Parent/Age only	1.12 (0.81,1.55)		1.03 (0.78,1.37)		1.59 (0.85,2.97)		1.43 (0.79,2.59)	
	0.96 (0.60,1.54)		0.85 (0.56,1.31)		1.71 (0.71,4.11)		1.44 (0.60,3.47)	
Carer allowance		**0.193**		**0.839**		**0.761**		**0.602**
No (ref)	1		1		1		1	
Yes	0.83 (0.63,1.10)		0.98 (0.78,1.23)		1.07 (0.70,1.64)		1.12 (0.73,1.71)	
Parent/carer psychological distress (K10 score ≥ 22)		**0.365**		**0.233**		**0.404**		**0.299**
No (ref)	1		1		1		1	
Yes	1.11 (0.89,1.39)		1.13 (0.92,1.38)		1.19 (0.79,1.80)		1.24 (0.83,1.85)	
Fortnightly household income		**0.790**		**0.784**		**0.880**		**0.754**
≤ $599 (ref)	1		1		1		1	
$600 - $799	1.03 (0.78,1.37)		1.07 (0.83,1.38)		1.17 (0.70,1.94)		1.19 (0.72,1.98)	
$800 - $1999	0.91 (0.73,1.15)		0.96 (0.78,1.18)		1.12 (0.72,1.76)		1.09 (0.69,1.72)	
≥ $2000	0.96 (0.70,1.32)		0.93 (0.69,1.27)		0.94 (0.48,1.85)		0.86 (0.45,1.65)	
Employment status		**0.201**		**0.883**		**0.224**		**0.369**
Employed/Studying (full or part-time) (ref)	1		1		1		1	
Unemployed/Home duties/Retired	1.14 (0.93,1.40)		1.01 (0.84,1.23)		1.26 (0.87,1.85)		1.18 (0.82,1.71)	
Carer regular smoker or ≥1 person smokes inside house		**0.945**		**0.958**		**0.687**		**0.476**
No (ref)	1		1		1		1	
Yes	1.01 (0.82,1.23)		1.00 (0.83,1.21)		1.08 (0.75,1.55)		1.14 (0.80,1.62)	
SOCIAL FACTORS								
Assessment season		**0.056**		**0.072**		**0.119**		**0.190**
Winter/Spring (ref)	1		1		1		1	
Summer/Autumn	0.83 (0.69,1.00)		0.85 (0.71,1.01)		0.76 (0.53,1.07)		0.79 (0.56,1.12)	
No. houses lived in since birth		**<0.001**		**0.122**		**0.228**		**0.463**
1 (ref)	1		1		1		1	

2	0.83 (0.66,1.04)		0.88 (0.71,1.08)		0.86 (0.52,1.43)		0.87 (0.54,1.40)	
3	0.77 (0.60,0.98)		0.96 (0.76,1.22)		0.74 (0.44,1.23)		0.77 (0.47,1.26)	
≥4	0.53 (0.41,0.67)		0.75 (0.59,0.96)		0.63 (0.39,1.01)		0.71 (0.45,1.11)	
Attends childcare/preschool (<6 years)		**0.154**		**0.024**		**0.136**		**0.077**
No (ref)	1		1		1		1	
Yes	1.14 (0.95,1.38)		1.23 (1.03,1.47)		1.41 (0.90,2.22)		1.49 (0.96,2.30)	
Housing tenure		**0.683**		**0.727**		**0.516**		**0.319**
Own/Mortgage (ref)	1		1		1		1	
Rent	1.09 (0.79,1.50)		0.95 (0.71,1.28)		1.29 (0.71,2.34)		1.21 (0.68,2.16)	
Public housing	1.13 (0.86,1.47)		1.04 (0.82,1.33)		1.33 (0.82,2.15)		1.43 (0.88,2.30)	
People per bedroom		**0.004**		**0.004**		**0.349**		**0.371**
≤1 (ref)	1		1		1		1	
>1, <2	1.37 (1.03,1.80)		1.35 (1.04,1.75)		1.25 (0.80,1.95)		1.26 (0.82,1.94)	
≥2	1.64 (1.22,2.21)		1.61 (1.21,2.13)		1.47 (0.87,2.48)		1.43 (0.86,2.36)	
Housing problem		**0.540**		**0.518**		**0.981**		**0.992**
No (ref)	1		1		1		1	
Yes	1.07 (0.86,1.34)		1.07 (0.87,1.31)		1.00 (0.68,1.46)		1.00 (0.68,1.47)	

* Adjusted for age (continuous), sex & Aboriginal Medical Services as appropriate

8.3 Chapter 5 Supplementary Tables

Supplementary Table 8.4: Search Strategy (Chapter 5)

Medline	
1	(aborigin* or Indigen* or Torres Strait).mp.
2	First Nations.mp.
3	(M?ori or Wh?nua).mp.
4	(Inuit* or Aleut* or M?tis or amerind*).mp.
5	(pasifika or pacific island*).mp.
6	"Native Hawaiian or Other Pacific Islander"/
7	exp American Native Continental Ancestry Group/
8	(child* or youth* or student* or infant* or adolescen* or teen* or young people or preschool* or pre-school*).mp.
9	Adolescent/ or child/
10	child/ or child, preschool/ or infant/
11	(navigator* or coordinator* or co-ordinator* or link worker* or community linker* or care support worker* or integrated care or community health worker* or health advisor* or outreach worker* or lay health or village health worker* or intercultural mediator* or cultural case worker* or multicultural health broker* or multicultural health worker* or ethnic health care advisor*).mp.
12	(guided care nurse* or advanced practice nurse* or transitional care or patient centred care coach* or patient-centred care facilitator* or case management coach* or case management facilitator* or adherence supporter* or community health advocate* or community health promoter* or community health representative* or health aide* or health coach* or health communicator* or health guide* or health volunteer* or peer counsellor* or peer educator* or peer health counsellor* or peer health educator* or peer health promoter* or peer leader* or cultural liaison*).mp.
13	Health Services, Indigenous/ or Community Health Services/ or Community Health Workers/ or Patient navigation/
14	1 or 2 or 3 or 4 or 5 or 6 or 7
15	8 or 9 or 10
16	11 or 12 or 13
17	14 and 15 and 16
18	18 limit 17 to "all child (0 to 18 years)"
Embase	
1	(aborigin* or Indigen* or Torres Strait).mp.
2	First Nations.mp.
3	(M?ori or Wh?nua).mp.
4	(Inuit* or Aleut* or M?tis or amerind*).mp.
5	(pasifika or pacific island*).mp.
6	native hawaiian/
7	pacific islander/

8	8 indigenous people/ or alaska native/ or american indian/ or canadian aboriginal/ or first nation/ or indigenous australian/
9	(child* or youth* or student* or infant* or adolescen* or teen* or young people or preschool* or pre-school*).mp.
10	Adolescent/ or child/
11	child/ or child, preschool/ or infant/
12	(navigator* or coordinator* or co-ordinator* or link worker* or community linker* or care support worker* or integrated care or community health worker* or health advisor* or outreach worker* or lay health or village health worker* or intercultural mediator* or cultural case worker* or multicultural health broker* or multicultural health worker* or ethnic health care advisor*).mp.
13	(guided care nurse* or advanced practice nurse* or transitional care or patient centred care coach* or patient-centred care facilitator* or case management coach* or case management facilitator* or adherence supporter* or community health advocate* or community health promoter* or community health representative* or health aide* or health coach* or health communicator* or health guide* or health volunteer* or peer counsellor* or peer educator* or peer health counsellor* or peer health educator* or peer health promoter* or peer leader* or cultural liaison*).mp.
14	Health Services, Indigenous/ or Community Health Services/ or Community Health Workers/ or Patient navigation/
15	indigenous health care/
16	patient care/
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
18	9 or 10 or 11
19	12 or 13 or 14 or 15 or 16
20	17 and 18 and 19
21	limit 20 to (infant <to one year> or child <unspecified age> or preschool child <1 to 6 years> or school child <7 to 12 years> or adolescent <13 to 17 years>)
CINAHL	
1	aborigin* OR Indigen* OR Torres Strait*
2	"First Nations"
3	M?ori OR Wh?nua
4	Inuit* OR Aleut* OR m?tis OR amerind*
5	pasifika OR "pacific island*"
6	(MH "Maori") OR (MH "Inuit") OR (MH "First Nations of Australia+") OR (MH "Aboriginal Canadians+")
7	(MH "Infant, Newborn") OR (MH "Infant") OR (MH "Child") OR (MH "Adolescence")
8	child* OR youth* OR student* OR infant* OR adolescen* OR teen* OR "young people" OR preschool* OR pre-school
9	(MH "Health Services, Indigenous")
10	(MH "Community Health Services") OR (MH "Community Health Workers") OR (MH "Community Health Nursing")
11	(MH "Patient Navigation")
12	navigator* OR coordinator* OR coordinator* OR “link worker*” OR “community linker*” OR “care support worker*” OR “integrated care” OR “community health worker*” OR “health advisor*” OR “outreach worker*” OR “lay health” OR “village health worker*” OR “intercultural mediator*” OR “cultural case worker*” OR “multicultural health broker*” OR “multicultural health worker*” OR “ethnic health care advisor*”
13	“guided care nurse*” OR “advanced practice nurse*” OR “transitional care” OR “patient centred care coach*” OR “patient centred care facilitator*” OR “case management coach*” OR “case management facilitator*” OR “adherence supporter*” OR “community health advocate*” OR “community health promoter*”

	OR “community health representative*” OR “health aide*” OR “health coach*” OR “health communicator*” OR “health guide*” OR “health volunteer*” OR “peer counsellor*” OR “peer educator*” OR “peer health counsellor*” OR “peer health educator*” OR “peer health promoter*” OR “peer leader*” OR “cultural liaison*”
14	1 OR 2 OR 3 OR 4 OR 5 OR 6
15	7 OR 8
16	9 OR 10 OR 11 OR 12 OR 13
17	14 AND 15 AND 16 **Limited by - Age Groups: Infant, Newborn: birth-1 month, Infant: 1-23 months, Child, Preschool: 2-5 years, Child: 6-12 years, Adolescent: 13-18 years*
Informit	
	(aborigin* or indigen or "torres strait" or "first nation*" or m?ori or inuit* or aleut* or m?tis or amerind* or wh?nua or pasifika or "pacific island*")
AND	(child* or youth or student* or infant* or adolescen* or teen* or "young people" or preschool* or pre-school*)
AND	(navigator* or coordinator* or co-ordinator* or “link worker*” or “community linker*” or “care support worker*” or “integrated care” or “community health worker*” or “health advisor*” or “outreach worker*” or “lay health” or “village health worker*” or “intercultural mediator*” or “cultural case worker*” or “multicultural health broker*” or “multicultural health worker*” or “ethnic health care advisor*” or “guided care nurse*” or “advanced practice nurse*” or “transitional care” or “patient centred care coach*” or “patient-centred care facilitator*” or “case management coach*” or “case management facilitator*” or “adherence supporter*” or “community health advocate*” or “community health promoter*” or “community health representative*” or “health aide*” or “health coach*” or “health communicator*” or “health guide*” or “health volunteer*” or “peer counsellor*” or “peer educator*” or “peer health counsellor*” or “peer health educator*” or “peer health promoter*” or “peer leader*” or “cultural liaison*”)
PsycINFO	
1	(aborigin* or Indigen* or Torres Strait).mp.
2	First Nations.mp.
3	(M?ori or Wh?nua).mp.
4	(Inuit* or Aleut* or M?tis or amerind*).mp.
5	(pasifika or pacific island*).mp.
6	hawaii natives/ or pacific islanders/
7	exp Indigenous Populations/
8	(child* or youth* or student* or infant* or adolescen* or teen* or young people or preschool* or pre-school*).mp.
9	(navigator* or coordinator* or co-ordinator* or link worker* or community linker* or care support worker* or integrated care or community health worker* or health advisor* or outreach worker* or lay health or village health worker* or intercultural mediator* or cultural case worker* or multicultural health broker* or multicultural health worker* or ethnic health care advisor*).mp.
10	(guided care nurse* or advanced practice nurse* or transitional care or patient centred care coach* or patient-centred care facilitator* or case management coach* or case management facilitator* or adherence supporter* or community health advocate* or community health promoter* or community health representative* or health aide* or health coach* or health communicator* or health guide* or health volunteer* or peer counsellor* or peer educator* or peer health counsellor* or peer health educator* or peer health promoter* or peer leader* or cultural liaison*).mp.
11	community health/

12	integrated services/
13	1 or 2 or 3 or 4 or 5 or 6 or 7
14	9 or 10 or 11 or 12
15	8 and 13 and 14
16	limit 15 to (100 childhood <birth to age 12 yrs> or 120 neonatal <birth to age 1 mo> or 140 infancy <2 to 23 mo> or 160 preschool age <age 2 to 5 yrs> or 180 school age <age 6 to 12 yrs> or 200 adolescence <age 13 to 17 yrs>)
Scopus	
	ALL FIELDS: aborigin* OR indigen* OR "torres strait"OR "first nation" OR m?ori OR inuit* OR aleut* m?tis OR amerind* OR wh?nua OR pasifika OR "pacific island"
AND	**ALL FIELDS:** child* OR youth OR student* OR infant* OR adolescen* OR teen* OR "young people" OR preschool* OR pre-school*
AND	**ALL FIELDS:** navigator* OR coordinator* OR co-ordinator* OR “link worker*” OR “community linker*” OR “care support worker*” OR “integrated care” OR “community health worker*” OR “health advisor*” OR “outreach worker*” OR “lay health” OR “village health worker*” OR “intercultural mediator*” OR “cultural case worker*” OR “multicultural health broker*” OR “multicultural health worker*” OR “ethnic health care advisor*” OR “guided care nurse*” OR “advanced practice nurse*” OR “transitional care” OR “patient centred care coach*” OR “patient-centred care facilitator*” OR “case management coach*” OR “case management facilitator*” OR “adherence supporter*” OR “community health advocate*” OR “community health promoter*” OR “community health representative*” OR “health aide*” OR “health coach*” OR “health communicator*” OR “health guide*” OR “health volunteer*” OR “peer counsellor*” OR “peer educator*” OR “peer health counsellor*” OR “peer health educator*” OR “peer health promoter*” OR “peer leader*” OR “cultural liaison*”