

Aboriginal People's Perspectives on Accessing Primary Health Care During Crises: A Case Study of the Lakes Entrance Community

Submitted by

Rebecca Louise Woodland

Bachelor of Adult Learning and Development, 2009, Monash University

Master of Business Management, 2013, Monash University

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School of Allied Health, Human Services and Sport

La Trobe University

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Contents

Acknowledgements	ii
List of Tables.....	vii
List of Figures	viii
List of Abbreviations	ix
Abstract	x
Statement of Authorship	xi
Chapter 1 Introduction	1
1.1 Introduction.....	1
1.2 Knowledge Gap Addressed by This Thesis	3
1.3 The Research Question.....	4
1.4 Research in an Aboriginal Community	4
1.5 Method	5
1.6 Theoretical Framework to Understand Health Service Utilisation.....	6
1.7 The Lakes Entrance Community	9
1.8 Thesis Structure	10
Chapter 2 Effects of Colonisation on Aboriginal People's Health.....	15
2.1 Introduction.....	15
2.2 Colonisation.....	15
2.3 Manifestations of Colonisation that Impact Health.....	16
2.4 Impacts of Colonisation on the Primary Healthcare Choices of Aboriginal People.....	19
2.4.1 Intergenerational, Collective and Historical Trauma	21
2.5 Gunaikurnai People's History Under Colonisation	23
2.6 Lakes Entrance Aboriginal People's Community Health Data	28
2.7 Conclusion.....	29
Chapter 3 Aboriginal Health and Primary Health Care	31
3.1 Introduction.....	31
3.2 Background to the Health of Australian Aboriginal People	31
3.3 Primary Health Care	32
3.4 Primary Health Care and the Role of Aboriginal Community Controlled Health Organisations	33
3.5 Aboriginal People's Use of Health Services During the 2019–2020 Bushfires and the COVID-19 Pandemic: The Australian National Context	35
3.6 Closing the Gap.....	37
3.7 Australian Policies and Plans for Aboriginal Health	38
3.8 Impacts of Past Crises on Aboriginal People.....	40
3.9 Background to the 2019–2020 Bushfires in East Gippsland.....	41
3.10 Background of the COVID-19 Pandemic	43
3.11 Conclusion.....	46
Chapter 4 Literature Review	47
4.1 Review Structure	47
4.2 Review Methodology	47
4.3 Literature Search	48
4.4 Service Delivery Factors.....	52

4.4.1 Culturally Appropriate Services	52
4.4.2 Physical Health Care Setting.....	53
4.4.3 Continuity of Care.....	54
4.4.4 Communication	55
4.4.5 Racism	57
4.4.6 Adverse Prior Experiences.....	58
4.5 Personal Factors	59
4.5.1 Shame and Fear.....	59
4.6 Environmental Factors.....	60
4.6.1 Reception Staff.....	60
4.6.2 Transport.....	61
4.6.3 Appointment Availability	61
4.7 International Literature.....	61
4.8 Conclusion.....	63
Chapter 5 Methodology and Research Design.....	64
5.1 Introduction.....	64
5.2 Methodology	66
5.3 Axiology	67
5.4 Ontology	69
5.5 Epistemology	70
5.6 Sociocultural Position	70
5.7 Qualitative Research Design	71
5.8 Case Study	72
5.8.1 Method and Phases of the Research	73
5.9 Phase 1: Literature Review	73
5.10 Phase 2: Identification and Recruitment of Participants	73
5.11 Phase 3: Data Collection	74
5.11.1 Data Analysis	76
5.12 Stages of Analysis	77
5.12.1 Comprehending.....	77
5.12.2 Synthesising: Data Organising and Sorting.....	79
5.12.3 Theorising	79
5.12.4 Recontextualising: Displaying, Verifying and Drawing Conclusions	80
5.13 Communication of Research Outcomes	81
5.14 Conclusion.....	81
Chapter 6 The Impact of Service Delivery Factors on the Healthcare Experience for the Lakes Entrance Aboriginal Community.....	82
6.1 Introduction.....	82
6.2 Service Delivery Factors.....	83
6.2.1 Lakes Entrance Community Medical Options.....	83
6.2.2 The Impacts of the Type of Healthcare Service on the Participants' Healthcare Experience.....	83
6.2.3 Experiences of Access During Crises	86
6.3 The Impacts of Continuity of Care on the Healthcare Experience	89
6.3.1 Continuity of Care During Usual Times	89
6.3.2 Continuity of Care During Crises.....	90
6.4 The Impacts of Communication on the Healthcare Experience	91
6.4.1 Communication	91
6.4.2 Health Care Communication Experiences During Times of Crises	93

6.4.3 Discussion of Communication During Times of Crisis and the Impact on the Healthcare Experience	95
6.5 Conclusion.....	96
Chapter 7 The Influence of Personal Experience on the Healthcare Experiences of the Lakes Entrance Aboriginal Community	99
7.1 Introduction.....	99
7.2 The Influence of Shame and Fear on Participants' Experiences of Healthcare Access.....	99
7.2.1 Shame.....	99
7.2.2 The Influence of Fear on the Participants' Healthcare Experiences	100
7.3 The Influence of Fear on the Participants' Healthcare Experiences During Crises.....	102
7.4 The Influence of Intergenerational Trauma on Healthcare Access and Experiences.....	104
7.4.1 Intergenerational Trauma.....	104
7.4.2 The Influence of Intergenerational Trauma on the Healthcare Experiences of Younger Participants	105
7.4.3 The Impact of Intergenerational Trauma on Participants' Healthcare Experiences During Times of Crisis.....	106
7.5 The Impact of Prior Experience and Racism on the Participants' Healthcare Experience	108
7.5.1 The Influence of Prior Experience and Racism	108
7.5.2 The Influence of Prior and Racist Experiences on the Participants' Healthcare Experiences During Times of Crisis.....	112
7.6 Conclusion.....	114
Chapter 8 The Influence of Environmental Factors on the Healthcare Experiences of the Lakes Entrance Aboriginal Community	117
8.1 Introduction.....	117
8.2 Journal Article.....	117
8.3 Conclusion.....	134
Chapter 9 Discussion and Implications for Practice	136
9.1 Introduction.....	136
9.2 The Impact of Service Delivery Factors on the Healthcare Experience and Implications for Practice.....	136
9.3 Continuity of Care.....	138
9.3.1 Implications for Practice: Continuity of Care Findings	140
9.4 Communication.....	141
9.4.1 Communication and the Community	141
9.4.2 Implications for Practice: Communication to the Community	142
9.4.3 Communication Between Health Care Providers and Aboriginal People.....	143
9.4.4 Implications for Practice: Communication Between Healthcare Providers and Aboriginal People.....	144
9.5 The Impact of Personal Factors on the Healthcare Experience and Implications for Practice.....	146
9.6 Shame and Fear.....	146
9.6.1 Implications for Practice: Shame and Fear Findings	147
9.7 Trauma: Intergenerational and Collective.....	148
9.7.1 Implications for Practice: Trauma.....	150
9.8 The Impact of Environmental Factors on the Healthcare Experience and Implications for Practice.....	150

9.9 Priorities Other Than Health	151
9.9.1 Implications for Practice: Priorities Other Than Health	151
9.10 Transport Barriers.....	151
9.10.1 Implications for Practice: Transport	152
9.11 Medical Bureaucracy and Processes	153
9.11.1 Implications for Practice: Medical Bureaucracy and Processes	154
9.12 Racism	156
9.12.1 Implications for Practice: Racism Findings.....	157
9.13 Conclusion.....	159
Chapter 10 Implications for Policy and the Conclusion	160
10.1 Introduction.....	160
10.2 Australian Centre for Disease Control	161
10.3 The Role of the Aboriginal Community Controlled Health Sector	163
10.3.1 Impacts of Natural Disasters	164
10.4 Implications of Findings for Policy	164
10.4.1 Health Communication in a Crisis	165
10.4.2 Culturally Safe and Appropriate Healthcare Provided by Aboriginal Community Controlled Health Organisations	166
10.4.3 Appropriate Funding and Resourcing.....	168
10.4.4 Aboriginal Community Involvement in Crisis Planning	169
10.5 Implications of Findings for Future Research	171
10.6 Implications of Findings for Theory	173
10.7 Strengths and Limitations of this Research	173
10.7.1 Strengths: Methodology	173
10.7.2 Strengths: Prioritisation of Aboriginal Voices.....	174
10.7.3 Limitations: Sample Size	174
10.7.4 Limitations: Sample Composition	175
10.7.5 Limitations: Research into Different Perspectives	175
10.7.6 Limitations: Research Timing	176
10.8 Conclusion.....	176
References	179
Appendix A: Ethics Approval	226
Appendix B: Research Partnership Agreement	227
Appendix C: Consent Form and Participant Information Sheet	230
Appendix D: Semi-structured Interview Questions	236
Appendix E: Australian Journal of Rural Health Publication Acceptance	241

List of Tables

Table 1.1	Graphic Depiction of Research Themes	8
Table 5.1	Interview Participant Details	75
Table 5.2	Overview of Framework Analysis	77
Table 6.1	Graphic Depiction of Research Themes	82

List of Figures

Figure 1.1 Andersen’s Behavioural Model of Health Service Usage	7
Figure 1.2 Map of the Geographic Area Covered by the East Gippsland Shire in Victoria.....	9
Figure 1.3 Map of the Lakes Entrance Geographic Area.	10
Figure 3.1 The Impact of the 2019–2020 Bushfires	43
Figure 4.1 Literature Search Graphic	49
Figure 5.1 Conceptualisation of a Methodology	66

List of Abbreviations

ABS	Australian Bureau of Statistics
ACCHOs	Aboriginal Community Controlled Health Organisations
ACSQHC	Australian Commission on Safety and Quality in Health Care
AHMAC	Australian Health Ministers' Advisory Council
AIATSIS	Aboriginal Institute of Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
BMHSU	Andersen Behavioural Model of Health Service Usage
BMVP	Gelberg-Andersen Behavioural Model for Vulnerable Populations
CDC	Australian Centre for Disease Control
CoA	Commonwealth of Australia
CTG	Closing the Gap
DOHAC	Department of Health and Aged Care
GEGAC	Gippsland & East Gippsland Aboriginal Co-Operative
GLaWAC	Gunaikurnai Land and Waters Aboriginal Corporation
GP	general practitioner
GPHN	Gippsland Primary Health Network
LEAHA	Lakes Entrance Aboriginal Health Association
LGA	Local Government Authority
LTH&CS	Lake Tyers Health and Children's Services
NACCHO	National Aboriginal Community Controlled Health Organisation
NHMRC	National Health and Medical Research Council
NMA	National Museum of Australia
PHIDU	Public Health Information Development Unit
SLV	State Library of Victoria
VSG	Victoria State Government
WHO	World Health Organization

Abstract

The importance of primary health care (PHC) to the health and wellbeing of Aboriginal and Torres Strait Islander Australians is widely acknowledged, as is the underservicing of these populations. During crises, access to PHC can be limited or disrupted. PHC disruptions disproportionately impact the Aboriginal and Torres Strait Islander communities due to their high levels of health disadvantage. Scant attention has been paid in the Australian literature to how crises affect access to PHC for these communities in regional areas. This research project aimed to address this, using a case study method to identify the barriers and enablers Aboriginal people faced when accessing PHC in a regional Victorian community during crises associated with bushfires and pandemic restrictions in 2019–2021. The study distinguished service delivery, personal and environmental factors that influenced participants' experiences. Research findings indicated that the overarching impact of colonisation on Aboriginal people's PHC access is intensified during times of crisis, offering opportunities to identify service improvements. Impacts of colonisation that were magnified included shame and fear, intergenerational and collective trauma, prioritising other issues over health, impacts of racism and prior experience, mistrust of mainstream organisations and the preference of participants to access PHC via their local Aboriginal Community Controlled Health Organisation (ACCHO). The study highlighted the potential of ACCHOs to mobilise and meet the needs of clients and the local community during crises. Disaster and pandemic planning, preparedness and recovery must embed mechanisms for leadership by Aboriginal and Torres Strait Islander communities, including advice and guidance on culturally specific responses and communication strategies.

Statement of Authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution. As referenced in the text of the thesis, material accepted for publication where I am a co-author include:

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Co-Author Name	Contribution	Percentage of contribution
Rebecca Woodland	Conceptualisation Formal analysis Investigation Methodology Writing - original draft Writing - review & editing Data curation Project administration	60%
Paula Morgan	Conceptualisation Validation Writing - review & editing	10%
Dr Sarah MacLean	Writing - review & editing, Conceptualisation Supervision	15%
Dr Heather Downey	Writing - review & editing Conceptualisation, Supervision	15%

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Terminology

The terms 'Aboriginal' and 'Torres Strait Islander' refer to the many people and language groups who were living in Australia before European settlement and who have experienced colonialism for more than 200 years. Throughout this project, the term 'Aboriginal' is respectfully used to represent both Australian Aboriginal and Torres Strait Islander people, unless specifically referring to Torres Strait Islander people or referring to literature. The term 'Indigenous' is used to refer to Aboriginal people of other countries and when discussing broader contextual issues. This terminology is supported and endorsed by the research project's cultural adviser.

Chapter 1 Introduction

1.1 Introduction

A gap in the life expectancy and health outcomes of Aboriginal people compared to non-Aboriginal Australians is widely acknowledged (Commonwealth of Australia [CoA], 2022). Against virtually all markers of health and social status, across the lifespan, Aboriginal people are the most marginalised and disadvantaged in Australian society (Canuto et al., 2018). Internationally, the health disparities of Aboriginal people 'are as large as those seen in any other high-income country' (Canuto et al., 2018, p. 2). The life expectancy gap and health disparities between Aboriginal and non-Aboriginal Australians have many causes flowing from colonisation, including the broader social determinants of health such as nutrition, education, life control, racism, housing, transport, addiction, employment and issues of poverty (Australian Institute of Health and Welfare [AIHW], 2022d).

While social determinants of health affect a person's health outcomes and life expectancy, PHC access is a critically important factor in health outcomes, with access differentials associated with a widening life expectancy gap (Griew et al., 2008). PHC is typically the first contact an individual with a health concern has with the health system. Aboriginal Australians can access PHC in either home or community-based settings, such as general practices, private medical practices and community health centres, and local government and non-government service settings, such as Aboriginal Community Controlled Health Organisations (ACCHOs; Department of Health and Aged Care [DOHAC], 2022c).

High-quality PHC can contribute to health and wellbeing outcomes for Aboriginal community members by improving health literacy, supporting the self-management of chronic diseases (providing linkages to services within and outside the health system) and improving screening and treatment of acute and chronic illnesses (AIHW, 2020). PHC aims not just to prevent mortality but also to prevent and treat sickness and improve wellbeing. Increased PHC resources are 'shown to be able to offset some of the harmful health effects of socio-economic disadvantage and inequality' (Griew et al., 2008, p. 5). The latest data

shows that while access for Aboriginal people to some health services has improved over time, they do not always have the same level of access to health services as non-Aboriginal Australians (AIHW, 2022e).

Aboriginal perspectives and voices are prioritised throughout this research project. Aboriginal people's involvement in health research is fundamental to producing research findings that address Aboriginal health priorities, benefit Aboriginal people and build Aboriginal research capacity and expertise (DOHAC, 2021a). This research is intended to benefit the participants by learning from their experiences and, consequently, providing more targeted, informed and locally contextualised planning for future disasters or crises. As explained above, PHC is essential for the management of health issues, and access to PHC during crises is of critical importance to sectors of society that suffer disproportionately from acute and chronic diseases, such as Aboriginal people (AIHW, 2021; Davy et al., 2016).

Disasters can be defined as complex social phenomena that intersect with human populations, resulting in a range of disruptions, threats and impacts (Brady et al., 2021). Additionally, McFarlane and Norris (2006) define disasters as potentially traumatic events that are collectively experienced, have an acute onset, are time-delimited and can be attributed to natural, technological or human causes. There is broad agreement in disaster literature that disasters are increasing in severity, frequency and scale, and this trajectory is predicted to worsen over the coming years (Brady et al., 2021; Glasser, 2019; IPCC, 2021; Saya et al., 2017).

The definition of a public health emergency is not solely determined by its causes and precipitating events but also by the extent of its health consequences (Nelson et al., 2007). A public health emergency is deemed emergent when projected health impacts have the potential to surpass the capacity of regular community resources to handle them (Nelson et al., 2007). The 2019–2020 bushfires were commonly referred to as a (natural) disaster, and the COVID-19 pandemic restriction periods were referred to as a crisis or public health crisis. Throughout this thesis, the terms *disaster* and *crisis* are used interchangeably, as both disaster and crises can impact access and availability to PHC.

During times of disaster or crisis, access to PHC can be limited and regular health care arrangements disrupted. When a crisis impacts access to PHC, Aboriginal people are disproportionately affected compared to the wider community due to the high morbidities and comorbidities experienced (Australian Bureau of Statistics [ABS], 2022). Consequently, disaster preparedness and planning that ensures continuity of PHC access for Aboriginal communities is becoming increasingly important.

First, it is important to clearly understand Aboriginal people's experiences with the PHC system, barriers and enablers that affect their experiences, to address the access level differentials between Aboriginal and non-Aboriginal Australians in accessing PHC during crises. When these factors are understood, they can be influenced to improve PHC access for Aboriginal people and their health and wellbeing outcomes.

1.2 Knowledge Gap Addressed by This Thesis

There is an acknowledged knowledge gap concerning Aboriginal people accessing PHC during times of crisis and a lack of comprehensive research and understanding of their specific needs, barriers and experiences in these situations (Williamson, 2022). Research on how Aboriginal communities effectively navigate PHC systems during crises, including natural disasters and pandemics, is an underexplored topic in the Australian literature. It is, however, evident that unique challenges are faced by Aboriginal people accessing PHC during such critical periods (Williamson, 2022).

This research reflects the cultural perspectives of the Aboriginal people of the Lakes Entrance community. At this point, it is essential to note that Aboriginal communities are not homogenous. Despite important similarities, diversity exists in Aboriginal communities, such as localised cultural practices, relational ties, the social determinants of health relevant to that individual community and numerous other factors. While this research is a case study of the Lakes Entrance Aboriginal community and their experiences, the findings may benefit other Aboriginal communities to inform and assist their access to PHC during future disasters and crises. The findings from this study have already been used successfully by the Lakes Entrance Aboriginal Health

Association (LEAHA) when advocating federal agencies for increased resourcing to address local community PHC requirements.

1.3 The Research Question

The question I ask in this thesis is: How do Aboriginal people in the Lakes Entrance community describe their experiences of accessing PHC before and during crises or disasters? This research concerns how the PHC needs of adults within this community were met during crises or disasters, specifically during the 2019–2020 bushfires and the COVID-19 pandemic restrictions periods and how this could be improved in future crises.

I am a non-Aboriginal Australian who has worked with the local Aboriginal community in the education and health sectors for almost 20 years. My experience includes teaching vocational education courses at the Lake Tyers Aboriginal Trust, managing the Koori Unit and Aboriginal Liaison Officers at the local hospital and collaborating closely with LEAHA in my current community health management role. Over these years, I have observed the impact of the social and cultural determinants of health, including education, employment, housing and access to health care, on the health and wellbeing of the local Aboriginal community.

I am proud to know Aboriginal community members working hard to support their community and to affect positive change in health outcomes. Numerous actions and strategies have been enacted locally to close the gaps in educational, health and social disparities between Aboriginal and non-Aboriginal people. I am proud to be an ally of the Aboriginal community. I am humbled by the community's permission to conduct this research, write the thesis and work with the community.

1.4 Research in an Aboriginal Community

This research acknowledges that the sovereignty of Victorian Aboriginal communities, including sovereign knowledges, governance, worldviews and social systems, is tens of thousands of years old (McMahon, 2021). This position aligns with the United Nations Declaration of Indigenous Rights (United Nations General Assembly, 2007), the Aboriginal Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics (AIATSIS, 2020), the Victorian Closing the Gap Implementation Plan 2021–2023 (Victoria State

Government [VSG], 2021b), the Korin Korin Balit Djak: Aboriginal health, wellbeing, and strategic safety plan 2017–2027 (VSG, 2017) and the Victorian Government Self-Determination Reform Framework (VSG, 2019).

Victorian Aboriginal communities, since time immemorial, have held scientific, experiential and relational knowledge systems for health, wellbeing and healing (McMahon, 2021). My foundational position in this research is to acknowledge that Aboriginal people hold the knowledge and expertise about what is best for them, their families and their communities.

As a non-Aboriginal woman involved in the local Aboriginal community and planning to undertake research within that community, it was of utmost importance to actively involve and engage with the community at every stage of the research process. As such, I partnered with LEAHA to plan, conduct and analyse this research. The research methodology used in this study, including the engagement with Aboriginal people and organisations it entailed, is detailed in Chapter 5.

1.5 Method

Research has long been used as an instrument of oppression, imperialism and colonialism, and has a long and problematic history among the Aboriginal community (National Health and Medical Research Council [NHMRC], 2018; Tuhiwai Smith, 1999; Walter & Suina, 2019). Therefore, as a non-Aboriginal researcher conducting research in an Aboriginal community, it was important that my research methods were co-created with the local Aboriginal community. A formal partnership agreement was created between myself and LEAHA to ensure local Aboriginal community input and oversight of the research proposal, methodology, analysis and dissemination and usage. LEAHA CEO, Ms Paula Morgan, played two roles during this research process: that of a critical friend, as well as a cultural adviser and reviewer of findings.

A qualitative research approach was used to address the research question. Qualitative research aims to illuminate the contextual understanding of participants and their perspectives—exploring, describing and generating arguments and explanations for social phenomena. Consequently, my cultural adviser and I deemed that a qualitative design—here, a case study approach—was appropriate for exploring the research question.

Utilising case study research to address this research question enabled data analysis to be conducted within the context of its use (Yin, 2014), that is, within the Lakes Entrance community. Attempting to understand the factors affecting how Aboriginal people in East Gippsland describe their experiences of accessing PHC, both before and during natural disasters and pandemics, would have been difficult without the contextual picture provided by the case study approach (Patton, 2002). The qualitative case study research design provided rich data and resulted in the shedding of light on previously unstudied aspects of disaster health care for a minority and marginalised cohort.

While many sources and methods of data collection and analysis methods can be used in case study research, interviews and observations are the preferred and dominant data collection methods (Stake, 2010). I utilised semi-structured interviews as the method for my research, on the advice of my cultural adviser. This approach was suggested as the most culturally appropriate data collection method for the local Aboriginal community members due to the oral tradition of storytelling favoured by Aboriginal people as a form of communication, and it allowed for prolific data to be gathered from participants. Additionally, in case study research, Stake (2010) recommends vignettes—episodes of storytelling—to illustrate aspects of the case and thick descriptions to convey findings. Consequently, vignettes demonstrate my research findings in Chapters 6, 7 and 8. A full description and explanation of my methodology and research design are detailed in Chapter 5.

1.6 Theoretical Framework to Understand Health Service Utilisation

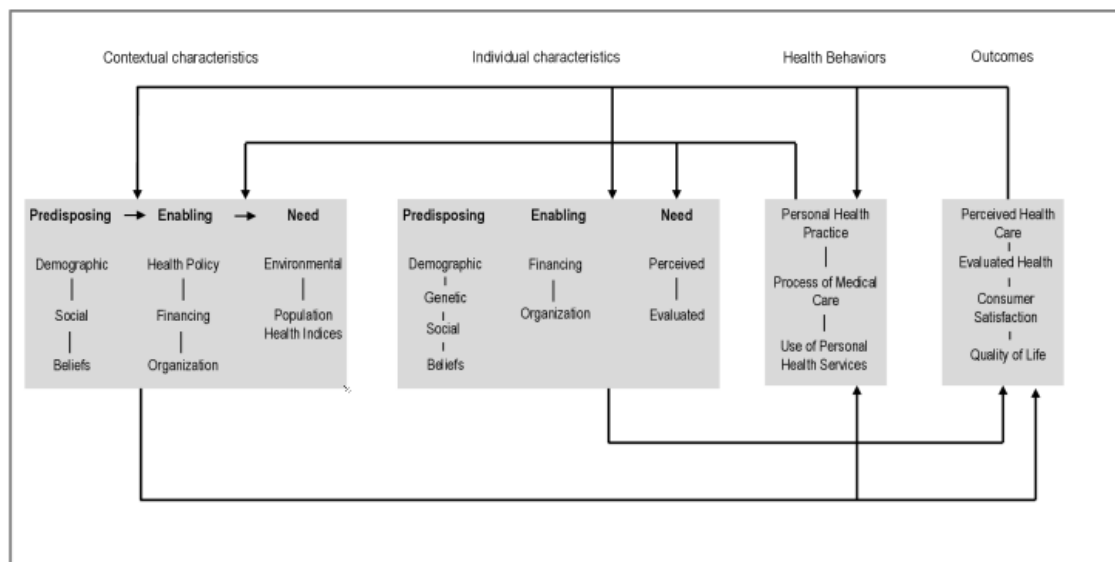
The Andersen Behavioural Model of Health Service Usage (BMHSU; see Figure 1.1) was originally proposed by Andersen (1968) as a theoretical framework to understand and explain how and why people use certain or general types of health services. The original model consisted of four elements: three determinant components comprising (a) individual predisposing characteristics, (b) individual enabling resources and (c) individual needs, and one outcome component—health services use (Andersen, 1968). In this model, predisposing factors are considered to affect enabling factors, then needs and eventually the outcome. Andersen and colleagues then revised the original

BMHSU numerous times in response to changes in use patterns over time and to incorporate advances in the field (C. Chen & Gu, 2021).

Variants of the BMHSU were examined for suitability and application to this research study. These included the Gelberg-Andersen Behavioural Model for Vulnerable Populations (BMVP) (Gelberg et al., 2000), which was designed to determine predictors of health care utilisation for homeless populations, and Andersen's Expanded Behavioural Model of Health Services Use (Travers et al., 2020), which describes factors associated with the use of long-term service and supports. Given the focus of both these adapted models, they were not deemed suitable for this research project without significant adaptation.

Figure 1.1

Andersen's Behavioural Model of Health Service Usage



Note. Adapted from *Changing the U.S. health care system: Key issues in health services policy and management*, by G. F. Kominski (Ed.), 2013. Copyright 2023 American Psychological Association.

The BMHSU and its various iterations are the most frequently cited models of access to health care services (Ricketts & Goldsmith, 2005). However, Lederle et al. (2021, p.2) argue that 'an overview of the development and application of the BHMSU over the past 50 years is lacking, particularly in relation to qualitative research'. Lederle et al. (2021) attribute this absence to health service utilisation being primarily measured through quantitative surveys.

Critically, several authors (Andrasik et al., 2008; Artuso et al., 2013; Bascur-Castillo et al., 2019; Bayuo, 2017) have critiqued the BMHSU specifically by noting the absence of any consideration of cultural factors. Further critiques of the BMHSU include a lack of attention to relevant factors that impact healthcare utilisation, including psychosocial factors (Andrasik et al., 2008), health literacy factors (Andrasik et al., 2008; Hawk et al., 2017; Serna, 2014), competing priorities (Hawk et al., 2017; Riang'a et al., 2018), fear and mistrust (Andrasik et al., 2008; Riang'a et al., 2018), previous experiences (Andrasik et al., 2008; Riang'a et al., 2018), billing factors (Herrmann et al., 2017) and service experience factors (Rachlis et al., 2016).

As others have adapted Andersen et al. (2013) BHMSU for research with particular populations, I have adapted the model to suit the context of my research with the Aboriginal community of Lakes Entrance. My adaptation categorises all factors influencing health care usage under the overarching and all-pervasive impact of colonisation. Andersen et al.'s (2013), three determinant categories, predisposing, enabling and need factors, are replaced in this study by three themes: (a) service delivery factors, (b) personal experiences and (c) environmental factors and their sub-themes. The structure utilised to present findings from this research project is outlined in Table 1.1 as follows:

Table 1.1

Graphic Depiction of Research Themes

Overarching theme		Colonisation	
Themes	Service delivery factors that were found to impact the healthcare experience	Personal experiences that were found to impact the healthcare experience	Environmental factors that were found to impact the healthcare experience
Sub-themes	• Type of service provider • Continuity of care • Communication	• Shame and fear • Intergenerational trauma • Prior experience or racism	• Transport • Medical bureaucracy and infrastructure • Priorities other than health

The cultural adviser for this research project approved the themes that emerged from the data and the thematic presentation of the research findings as per the adaptation. In this adaptation of the BMHSU, it is possible to recognise, acknowledge and highlight the themes and sub-themes that all result from the overarching impact of colonisation. The elements of the BMHSU (Andersen et al., 2013) that are outside the scope of this research, such as health behaviours, feedback loops and health outcomes, are not included in this adaptation.

1.7 The Lakes Entrance Community

The community that participated in this research, the Lakes Entrance community, is in Victoria, Australia. It is bounded by Buchan South in the north; the localities of Bete Bolong and Wombat Creek in the east; Bass Strait in the south; and The Narrows, the localities of Nyerimilang and Nungurner, Tambo Upper, Bruthen and the Tambo River in the west (see Figures 1.2 and 1.3). These are the traditional lands of the Gunaikurnai people. The 2022 population for Lakes Entrance is currently 8,524 and is predicted to grow to 9,398 by 2041 (Informed Decisions, 2022).

Figure 1.2

Map of the Geographic Area Covered by the East Gippsland Shire in Victoria



Note. From 'whereis.com'. Copyright 2022 OpenStreetMap contributors.

Figure 1.3

Map of the Lakes Entrance Geographic Area.



Note. From 'whereis.com'. Copyright 2022 OpenStreetMap contributors.

The East Gippsland Local Government Authority (LGA) covers Lakes Entrance and has the fourth highest proportion of Aboriginal people of any Victorian LGA, with 3.5% of the total LGA population (ABS, 2018). The 2016 Census results for the East Gippsland LGA indicated a population of 45,600 residents, with 1,576 residents self-identifying as Aboriginal or Torres Strait Islander (ABS, 2018).

1.8 Thesis Structure

Chapter 1, the introductory chapter, presents an overview of the research project. First, it outlines the research question, which serves as the central focus of the study, highlighting the specific inquiry that will be addressed throughout the research project. This research question sets the foundation for the subsequent chapters and guides the overall trajectory of the study. The chapter also provides an insight into my background and personal connection to the research. The knowledge gaps that this research aims to address are also outlined. The lack of existing literature on PHC access during crises for Aboriginal people represents an area within the existing body of knowledge where further investigation is required to enhance understanding and inform future planning and practice. Additionally, the location of the community where the research is situated is described, providing contextual information and setting the stage for subsequent chapters.

Colonisation stands as the pervasive, overarching factor that profoundly influences the health outcomes of Aboriginal people. In Chapter 2, the historical context of colonisation is comprehensively explained to provide an understanding of its far-reaching consequences. The chapter explains how

colonisation has impacted health care accessibility for Aboriginal people and their socio-economic status. Additionally, the chapter sheds light on the existing health data pertaining to Aboriginal populations. The chapter also provides an overview of the federal government's Closing the Gap strategy, exploring its inception, objectives and progress in addressing the health disparities experienced by Aboriginal communities.

Moreover, the chapter extends its focus to the history of the Gunaikurnai people under colonisation, analysing their experiences and identifying the specific manifestations of colonisation that have had enduring impacts on their health and wellbeing.

Next, I turn to an analysis of relevant literature, structured as two chapters. Chapter 3 commences the literature review by considering the health status and PHC utilisation of Aboriginal people. The chapter explains PHC, highlighting its significance within the broader healthcare landscape. It then emphasises the critical role of ACCHOs in providing PHC services to Aboriginal Australians, focusing on their unique approach and the culturally appropriate care they provide.

The chapter then outlines the 2019–2020 bushfires and subsequent COVID-19 pandemic restriction periods. These two distinct crises serve as the foundation for the case study and provide important background context for understanding the research findings and discussion. The chapter emphasises the unique challenges faced by Aboriginal communities during these periods and the implications for their access to healthcare services. The impact of past crises on the health of Aboriginal people is considered. Finally, the chapter describes the changes observed in the utilisation of health services by Aboriginal people during the initial stages of the COVID-19 pandemic.

Chapter 4 of this thesis extends the literature review to identify existing literature concerning the experiences of Aboriginal people in regional areas when accessing PHC during times of disaster or crises. The review identifies rare extant literature and notes the paucity of literature on the topic before explaining the approach taken to review the available literature. The chapter outlines and analyses the sub-themes in the literature under an overarching theme of colonisation, including the cultural appropriateness of services, the

physical location of services, provider experience, prior experience and racism, medical bureaucracy and attitudes of shame and fear.

Chapter 5 comprehensively describes the research methodology and methods employed in this study. It serves to justify the epistemological and ontological perspectives adopted and the choices made regarding the methodology and methods. The research project embraced an interpretivist position, utilising a case study approach to investigate the subject matter, and the chapter elaborates on the rationale behind this choice. Further, the data collection method for conducting in-depth interviews is explained, including the underlying principles and procedures employed. The chapter also outlines the strategies for analysing the collected data, shedding light on the systematic approaches undertaken to derive meaningful insights and draw reliable conclusions from the gathered information.

Chapters 6, 7 and 8 present the research findings relating to pre-crisis and post-crisis PHC experiences for the Lakes Entrance Aboriginal community. Each chapter addresses a different sub-theme under the overarching impact of colonialism.

Chapter 6 delves into the sub-theme of service delivery factors, illuminating key issues influencing participants' experiences when accessing PHC. This chapter sheds light on factors that shape these experiences, offering insights into the complexities and challenges faced within service delivery. A prominent issue explored in Chapter 6 is the type of PHC service offered, which includes consideration of mainstream versus ACCHO PHC options and the impact these have on participants' ability to access timely and appropriate care. The mistrust of mainstream organisations and the preference for community-controlled organisations can be attributed to the ongoing impacts of colonisation. Participants' experiences concerning continuity of care are also described and analysed to identify how this impacts access and decision-making during crises. Further, the chapter demonstrates the importance of effective communication in PHC settings. It explores participants' experiences communicating with healthcare providers and their impact on their PHC experiences during usual times and times of crisis.

Chapter 7 addresses the research findings within the sub-theme of attitudinal and behavioural factors that significantly affect the healthcare experiences of participants. This chapter explores key factors such as shame and fear, intergenerational and collective trauma and the influence of prior experiences and racism on participants' interactions with healthcare services. A significant factor is how shame and fear among participants impacted their healthcare access. The impact of shame and fear on healthcare-seeking behaviour and engagement with healthcare services is described, providing insights into the complex interplay between these emotions and individuals' willingness to seek care.

Intergenerational and collective trauma is another crucial element explored in this chapter. It describes how historical traumas, such as forced removals, cultural disconnection and the ongoing impacts of colonisation, all shape individuals' perceptions and behaviours concerning health care. Further, Chapter 7 addresses the influence of prior experiences and racism on healthcare interactions. I demonstrate that previous encounters with healthcare providers, whether positive or negative, shape participants' trust, confidence and expectations. The chapter also explores the impact of racism within healthcare settings on participants' experiences and perceptions of healthcare services.

Chapter 8 explains and discusses the research findings relating to the sub-theme of environmental factors, shedding light on their influence on participants' healthcare experiences. This chapter focuses on three key sub-themes: transport, medical bureaucracy and infrastructure and priorities other than health, discussing how these factors impacted participants' experiences. Explaining and discussing these environmental factor sub-themes, Chapter 8 provides insights into the multifaceted challenges participants encounter in accessing PHC. In this chapter, I argue that by understanding and addressing these environmental factors, healthcare providers and policymakers can work towards creating a more accessible, efficient and client-centred healthcare system, ultimately improving the healthcare experiences and outcomes for Aboriginal individuals. Chapter 8 has been submitted to the *Australian Journal of Rural Health* for publication.

Chapter 9 discusses and analyses the research findings from Chapters 6, 7 and 8. This chapter shows how the impact of colonisation on Aboriginal people's PHC access is intensified during times of crisis and how it also offers opportunities to identify service improvements. Implications of the findings for practice in crisis situations are outlined, as well as the findings' implications for mainstream PHC providers. The key implication for practice during times of crisis was the importance of understanding the critical role ACCHOs and their PHC delivery models play in the Aboriginal community. Further, this leads to the need to maintain ACCHO service delivery during a crisis to provide culturally appropriate care, mitigate the influence of shame and fear on PHC access, maintain continuity of care and be in the best position to understand pre-existing trauma and the need to address these sensitively and appropriately.

The requirement for social and cultural determinants of health, such as housing and poverty, to be addressed before healthcare needs become a focus and a priority was an additional implication. Crisis planning and management strategies must also consider transport barriers. Research findings indicate that modes and methods of service delivery during crises must consider the difficulty that the Aboriginal community have in physically accessing services due to transport restrictions. Healthcare organisations must also be aware that front-facing staff, such as receptionists and administrative staff, understand the range of barriers Aboriginal people may face in accessing PHC. These implications for practice are all explained in detail in Chapter 9.

Chapter 10 furthers the argument that colonisation's impacts on Aboriginal PHC are intensified during times of crisis and offers opportunities to identify service improvements. The chapter identifies the implications of findings for policy and policymakers. It describes these in relation to the ACCHO sector and the wider policy implications. These include suggestions concerning health communication in times of crisis, the provision of culturally safe and appropriate PHC during times of crisis, recognising the increased scope of practice for the ACCHO sector organisations, providing appropriate funding and financial commitment and ensuring Aboriginal community involvement in crisis planning concerning health. It also identifies areas for future research based on the research findings and identified gaps in knowledge and identifies strengths and weaknesses of the research project.

Chapter 2 Effects of Colonisation on Aboriginal People's Health

It was we who did the dispossessing. We took the traditional lands and smashed the traditional way of life. We brought the diseases. The alcohol. We committed the murders. We took the children from their mothers. We practiced discrimination and exclusion. (Prime Minister Paul Keating, Redfern Park address, 1992)

2.1 Introduction

This chapter synthesises relevant literature on Australian history, Aboriginal history and Aboriginal health to describe colonisation's impact on Aboriginal people's health. This chapter is essential in setting the context for this research project, as it explains the overarching impacts of colonisation on all aspects of the lives of Aboriginal people. The chapter then details the history of the Gunaikurnai people under colonisation and concludes with a description of the health data of the Lakes Entrance Aboriginal community.

2.2 Colonisation

Colonisation can be defined as the forcible takeover of the land of Indigenous people and the exploitation of the land and the people, ignoring their laws, customs and rights (Horvath, 1972, as cited in Griffiths et al., 2016). Colonialism has agreed-on manifestations, including a range of predominantly historical practices such as war, displacement, forced labour, removal of children, relocation, ecological destruction, massacres, genocide, slavery, (un)intentional spread of deadly diseases, banning of Indigenous languages, regulation of marriage, assimilation and eradication of social, cultural and spiritual practices (Paradies, 2016). These practices were all in evidence during the colonisation of Australia. While noting that some of these practices were predominantly historical, it is important to clarify that colonialism is a continual practice with ongoing implications (Axelsson et al., 2016; Lipscombe et al., 2020). These continuing implications are explained and discussed later in this chapter and throughout the rest of this thesis.

Colonisation commenced in Australia in 1788 when the first British fleet entered the coastline of Warrange, now known as Sydney (Moreton-Robinson, 2015). The British fleet claimed the land of the Aboriginal people under the legality of terra nullius, meaning 'land belonging to no-one' (Banner, 2005, p.96). This claim occurred despite an estimated Aboriginal population of 750,000 people in Australia (Moreton-Robinson, 2015), comprising approximately 500 Aboriginal collectives with established legal, social, cultural, economic and political institutions (Perkins & Langton, 2008). The evidence of explorers and early settlers also provided evidence that prior to colonisation, Aboriginal people had well-established systems of land and water use (Pascoe, 2018).

The colonisation of Australia began with the attempted annihilation of the Aboriginal people through widespread massacres and the introduction of previously unknown infectious diseases, and by 1850, only 10% of the Aboriginal population remained alive (Markwick et al., 2014). Further, colonial policies and actions were underpinned by ideological views that Aboriginal people were the property of the colonisers, resulting in the subordination of Aboriginal people (Arabena, 2006). The colonisers' views also included the misconception that Aboriginal people were depraved, in decline and in need of protection (Anderson & Kowal, 2012; Blyton, 2009; Gracey & King, 2009; Thomas et al., 2014). The British believed introducing Western education and Christianity to Australia would transform a morally decadent society (Prenn & Ezzy, 2020).

2.3 Manifestations of Colonisation that Impact Health

The devastating impact of colonialism on Aboriginal people, their communities, culture and health is widely recognised, both in Australia and in other colonised countries (Axelsson et al., 2016; Czyzewski, 2011; Griffiths et al., 2016; MacLean et al., 2017). Colonialism is:

The guiding force that manipulated the historic, political, social, and economic contexts shaping Indigenous/state/non-Indigenous relations, and account(s) for the public erasure of political and economic marginalisation, and racism today. These combined components shape the health of Indigenous people (Czyzewski, 2011, p. 4).

This impact has been so strong that colonialism is recognised as the distal determinant, or the underlying *cause of causes*, of Aboriginal health disparities (Axelsson et al., 2016; Czyzewski, 2011; Griffiths et al., 2016). The extensive evidence supporting the relationship between health status and the enduring social, political and economic impacts of colonialism highlights the far-reaching consequences of historical and ongoing colonial practices across the globe (Axelsson et al., 2016; Marmot, 2011; Siggers & Gray, 2007). Globally, colonialism has been instrumental in shaping forces and systems such as economic policies, social norms, social policies and political systems, all of which have profound implications for the health of Indigenous people (World Health Organization [WHO], 2022).

The social systems established by colonisation created and perpetuated disparities, leading to significant disadvantages and adverse physical and mental health outcomes for Indigenous people globally (Paradies, 2016; Paradies & Cunningham, 2012). These social systems result from a systematic process that determines the distribution and administration of resources, power dynamics and operational mechanisms. In Australia, colonisation vested ownership of the entire continent to the British government (Banner, 2005), effectively shifting systemic power away from the traditional custodians. Despite resistance and activism, systemic power in Australia has never reverted to the traditional custodians. Since colonisation, Aboriginal people have been marginalised and have not held decision-making powers and positions of influence in social systems. The historical dispossession and marginalisation, rooted in the legacy of colonisation, continue to contribute to persisting health inequities between Aboriginal and non-Aboriginal people today (Lau et al., 2012).

The policies and actions resulting from colonisation have also been recognised as contributors to the health outcomes of Aboriginal people (Oliver, 2013; Sherwood, 2013; Tsey et al., 2010). The forced removal of Aboriginal children, government regulation and management of the income of Aboriginal people, displacement and regulation of Aboriginal people and forced disconnection from Aboriginal identity, traditional lands and culture have had negative health impacts on Aboriginal people (Anderson & Kowal, 2012; Arabena, 2006; Oliver, 2013; Sherwood, 2013; Tsey et al., 2010).

The enduring social determinants of health impacted by colonisation are a further source of ongoing harm to Indigenous people's health and social and emotional wellbeing (McCalman et al., 2006; Saunders, 2003; Wenitong, 2006). The social determinants of health are the non-medical factors that influence health outcomes, such as the conditions in which people are born, grow, work, live and age, and the broader set of forces and systems shaping the conditions of daily life (WHO, 2022). Social determinants of health are estimated to be responsible for more than one-third of the differences in health outcomes between Aboriginal and non-Aboriginal people (AIHW, 2022a), and these determinants have been influenced by colonialism in numerous ways.

Another manifestation of colonialism that impacts health has been the trauma resulting from colonialist practices and acculturation, in particular anxiety, resentment, sadness and grief, which, for many Aboriginal people, is intergenerational and felt as a collective throughout the community (Griffiths et al., 2016; Zambas & Wright, 2016). Indigenous people worldwide continue to be over-represented in prisons, suicide death tolls and mental health services, directly attributed to the trauma induced by colonialism (Axelsson et al., 2016; Cunneen et al., 2015; Zambas & Wright, 2016). Research supports the understanding that trauma impacts psychological wellbeing and significantly affects physical health (Felitti & Anda, 2010; Schnurr et al., 2014).

It has been argued that while research on the contemporary health outcomes of Indigenous people continues, colonisation or colonialism rarely figures as part of the explanation (Axelsson et al., 2016; Wolfe, 2022). It is further argued that on the rare occasions when colonisation is mentioned in the research, it is usually situated as a historical event rather than an ongoing process that continues to impact negatively on Indigenous people's health outcomes (Axelsson et al., 2016; Vincent, 2017; Wolfe, 2022). Colonisation must be recognised as having shaped and still actively shaping current Australia. To do otherwise fails to recognise the enduring colonial structures that continue to influence the outcomes and inequities in evidence today, including the mainstream Australian health system.

The impact of colonisation on the health of Aboriginal people is highly complex and ongoing, and the legacies are experienced both intra-

generationally and inter-generationally (Griffiths et al., 2016). However, recognising and understanding the contemporary impact of colonisation on Aboriginal people remains a significant challenge in understanding the determinants of health among Aboriginal communities (Markwick et al., 2014). This societal issue is important and pervasive, and in March 2021, the Victorian Government announced an inquiry into the impacts of colonisation on Aboriginal people – the Yoorrook Justice Commission (Emergency Management Victoria, 2021). The Yoorrook Justice Commission is the first of its kind in Australia and will examine the social, economic and health impacts of colonisation on Aboriginal people and communities (Yoorrook Justice Commission, 2023).

2.4 Impacts of Colonisation on the Primary Healthcare

Choices of Aboriginal People

As described above, the forceful establishment of colonial empires has resulted in significant socio-economic disadvantages for Indigenous people worldwide. Indigenous people are more likely to experience socio-economic deprivation and inequity in areas such as employment, total household income, justice, education and health care, all of which prohibit effective participation in contemporary society (Marmot, 2011). Societal and economic factors resulting from colonisation impact the decisions of Australian Aboriginal people in relation to health care. Colonisation has ‘actively placed Aboriginal and Torres Strait Islander people at the bottom of the socioeconomic ladder’ (Calma, 2022). Socio-economic deprivation is associated with higher rates of morbidity and co-morbidity, thereby increasing the need for access to PHC services (Booth & Carrol, 2008).

Aboriginal people have explained their reluctance to access mainstream PHC services concerning their painful history of oppression, dispossession and ongoing marginalisation, all of which have been described as significant barriers to accessing care (Lau et al., 2012). Historical and current political disadvantage directly produces power imbalances with an acknowledged detrimental effect on health (Zambas & Wright, 2016). Processes of social marginalisation are often enabled by political disempowerment. Ziersch et al. (2011) argue that highly racial political histories produce an entrenched culture of political disadvantage (P. Jones, 2020; Waller & McCallum, 2021). Aboriginal people were excluded from accessing welfare services such as unemployment and sickness benefits

until 1944 (P. Jones, 2020). Although selected states had permitted Aboriginal people to vote in federal and state elections, this right was not granted to all Aboriginal people until 1962. However, unlike non-Aboriginal people, Aboriginal people did not need to register on the electoral roll until 1984 (AIATSIS, 2022). Since colonisation, political actions undertaken by the Australian government, including removing Aboriginal children from their families, have negatively impacted how safe Aboriginal people feel when accessing health care services (Ware, 2013). As a result, Aboriginal people are less likely to access services until later in the disease process and more likely to either leave the hospital early or not attend at all (Nolan-Isles et al., 2021).

Australia's Aboriginal people are diverse. They comprise numerous traditional tribes and clans with diverse perspectives, traditions and linguistic backgrounds. Therefore, no one version or model of health care is optimal for all Aboriginal people. However, there are factors in common among Australian Aboriginal people's conception of health, namely that it is complex and holistic compared to the Western biomedical model of health (Baba et al., 2014; Pearson et al., 2020). The health of Aboriginal people intertwines spiritual, emotional, psychological and physical dimensions, intricately linked to the ancestral lands and the collective narrative of their past, present and future (Baba et al., 2014; Oliver, 2013). The health status of Aboriginal people cannot be isolated from their social, economic and historical experiences of colonisation, disconnection from their land and kin and continuing marginalisation (Baba et al., 2014). The Aboriginal conceptualisation of health is poorly aligned with the Western deficit model of health (Gatwiri et al., 2021; Maher, 1999). The deficit model of health perceives individuals with health concerns as having underlying characteristics which require correction or repair in the form of clinical treatment (McCormack et al., 2016).

In contrast, Aboriginal cultural identity, participation in cultural activities, access to traditional lands, and connection to family and kinship are recognised as protective factors and can positively influence overall health and wellbeing (AIHW, 2022c). *Country* is the term Aboriginal people use to describe the lands, waterways and seas to which they are connected. The term contains complex ideas about law, place, custom, language, spiritual belief, cultural practice, material sustenance, family and identity (Ristevski et al., 2020). Since

colonisation, however, some traditional Country is inaccessible to Aboriginal Australians, as it is now privately owned by farmers, pastoralists or mining corporations. Aboriginal people who lived on their homelands or traditional Country were more likely to assess their own health as excellent/very good/good, than those who were not allowed, or were unable to, visit their homelands or traditional Country (AIHW, 2022c).

Colonial processes of acculturation can produce elements of xenophobia in society, characterised by fear or avoidance of anything perceived as foreign or different from the dominant culture (Johnstone & Kanitsaki, 2009). Consequently, this xenophobia leads to sociopolitical mechanisms that disregard ethnic and cultural minorities, leaving them feeling insignificant and excluded from society (Johnstone & Kanitsaki, 2009). Despite social inclusion being recognised as a human right and determinant of health (Marmot, 2011), Indigenous people have been, and continue to be, marginalised within the countries they have occupied for thousands of years (Durie, 2004; Forbes, 2020). Social marginalisation conceals the injustices experienced by Aboriginal people, hindering cultural healing from these processes, as their trauma is not validated by society (Bryant-Davis, 2007). The broad force of racism grounded in ideological racialised hierarchies directly affects the choices of Aboriginal people to access health care, which is discussed fully in Chapter 4.

2.4.1 Intergenerational, Collective and Historical Trauma

Colonisation is a widely acknowledged factor impacting Aboriginal people and their health, as described in this chapter. In a growing body of research to investigate the role of historical trauma in health disparities, researchers have argued that historical trauma affects health by influencing Aboriginal people's health behaviours (Gone & Kirmayer, 2020; Hartmann et al., 2019), including their choices concerning PHC.

Historical trauma is defined by Evans-Campbell (2008, p. 320) as 'a collective complex trauma inflicted on a group of people who share a specific group identity or affiliation'. This term was first used to understand trauma among Holocaust survivors; however, it has become useful to capture the experiences of colonised people worldwide (Menzies, 2019). Other applicable terms authors use include intergenerational, transgenerational and collective,

mass or social trauma (Menzies, 2019). Funston (2013) also describes it as invisible trauma due to the widespread denial of the history of invasion, genocide and ongoing oppression of Aboriginal people.

Despite widespread recognition of these impacts, only in the past two decades has evidence-based literature emerged to assist understanding of the trauma and the impacts colonisation has had on the health and wellbeing of Aboriginal people (Paradies, 2016). Krieg (2009) identifies interpersonal racism, prejudice, stress, depression and violence as contributing factors in the ongoing impact of collective trauma in the Australian Aboriginal population. Stress, grief and loss (of language, Country and family) are also recognised determinants (Sherwood, 2013). Commonly identified manifestations of colonisation impacting the health of Indigenous people worldwide include higher rates of family violence, substance abuse and economic deprivation (Blyton, 2009; Sherwood, 2013), as well as higher rates of incarceration (Cunneen, 2015; Sherwood, 2013).

Atkinson (2002) and Ratnavale (2007) examine collective and intergenerational trauma among Aboriginal people and propose that trauma originates from ongoing colonising practices such as social marginalisation, incarceration and racism in all its forms. These practices contribute to re-traumatisation associated with family violence, sexual abuse, self-harm and substance misuse (Atkinson, 2002; Ratnavale, 2007). The symptomology of trauma is prevalent in many Aboriginal communities, indicating shared and collective trauma (Menzies & McNamara, 2008).

Research supports the understanding that trauma impacts psychological wellbeing and significantly affects physical health. Comprehensive studies demonstrate a clear association between trauma and impaired health (Felitti & Anda, 2010; Schnurr et al., 2014). The forcible separation of Aboriginal children over several generations until 1969 has left a traumatic legacy and profound impact on Aboriginal people (Grace et al., 2016).

Milroy (2018) offers a comprehensive description of the multi-layered effects of intergenerational trauma on Aboriginal people by explaining:

The transgenerational effects of trauma occur via a variety of mechanisms including the impact of attachment relationships with care

givers; the impact on parenting and family functioning; the association with parental physical and mental illness; disconnection and alienation from the extended family, culture and society. These effects are exacerbated by exposure to continuing high levels of stress and trauma including multiple bereavements and other losses, the process of vicarious traumatising where children witness the on-going effects of the original trauma which a parent or care giver has experienced. Even where children are protected from the traumatic stories of their ancestors, the effects of past traumas still impact on children in the form of ill health, family dysfunction, community violence, psychological morbidity and early mortality. (p. 11)

Collective and intergenerational trauma have typical symptoms such as deep mistrust of self and others, fear of betrayal, shame, loss of traditional values, violence against women, self-directed violence, substance abuse, persistent grief, intergenerational conflict, role diffusion, sexual abuse, boundary violations, secrecy and silence (Atkinson, 2002; Evans-Campbell, 2008; Tilbury, 2009). Understanding the *causes of the causes* of health issues faced by Aboriginal people (Marmot, 2016) necessitates viewing current challenges through a trauma lens (Menzies, 2019).

2.5 Gunaikurnai People's History Under Colonisation

Aboriginal people have inhabited Gunaikurnai land (now known as the Gippsland region) for over 18,000 years (Ramahyuck, 2023). The Gunaikurnai people have a holistic worldview where the land (Wurruk), waters (Yarnda), air (Watpootjan) and all living beings are interconnected. Wurruk, Yarnda and Watpootjan are viewed as spiritual life-giving entities, providing people with resources and forming the foundation of their cultural practices (Gunaikurnai Land and Waters Aboriginal Corporation [GLaWAC], 2022). There are five Gunaikurnai clans: Bratwoloong, Brayakooloong, Brabraloong, Tatungooloong and Krowathunkooloong (Gippsland & East Gippsland Aboriginal Co-Operative [GEGAC], 2022). The Lakes Entrance and Lake Tyers Trust communities are situated in the region traditionally occupied by the Tatungooloong and Krowathunkooloong clans (GEGAC, 2022).

The impact of colonialism on the Aboriginal people of East Gippsland was and is profound. Despite the resistance of the Gunaikurnai people against the European invasion of their land, the technological superiority of the Europeans prevailed (GEGAC, 2022). In the 1830s, when Europeans first entered Gunaikurnai Country, the region was home to a significant population of Aboriginal people. However, within 20 years, due to battles, the introduction of diseases and massacres, the number of Gunaikurnai residing in their traditional lands dwindled to less than one hundred (GEGAC, 2022).

Several massacres took place in East Gippsland, further exacerbating the devastating impact of colonisation. One such massacre occurred at Butcher's Creek in 1841, resulting in the deaths of approximately 41 Aboriginal people (Gardner, 2001). Another massacre took place at Skull Creek in 1842, where the number of Aboriginal casualties remains unknown (Gardner, 2001). In 1846, eight Aboriginal people were killed at Snowy River, while over 50 Aboriginal people lost their lives during a search for a white woman in 1846–1847 (GEGAC, 2022). Additionally, in 1850, three separate massacres near Orbost resulted in the deaths of 22 individuals through shootings and poisoning (Gardner, 2001). These acts of violence further contributed to the suffering endured by Aboriginal communities in the region.

The systematic hunting and killing of Aboriginal people in East Gippsland is starkly exemplified in this 1846 letter by Gippsland squatter Henry Meyrick, sent home to his relatives in England:

The Blacks are very quiet here now, poor wretches. No wild beast of the forest was ever hunted down with such unsparing perseverance as they are. Men, women and children are shot whenever they can be met with... I have protested against it at every station I have been in Gippsland, in the strongest language, but these things are kept very secret as the penalty would certainly be hanging... For myself, if I caught a Black actually killing my sheep, I would shoot him with as little remorse as I would a wild dog, but no consideration on earth would induce me to ride into a camp and fire on them indiscriminately, as is the custom whenever the smoke is seen. They [the Aborigines] will very shortly be extinct. It is

impossible to say how many have been shot, but I am convinced that not less than 450 have been murdered altogether. (GEGAC, 2022)

The impacts of colonisation on the Aboriginal community of East Gippsland extended beyond the initial invasion. In 1863, the Lake Tyers Mission was established as a religious mission by John Bulmer, marking a significant change in the lives of the local Aboriginal people (Lake Tyers Aboriginal Trust, 2023). In 1906, a considerable number of Aboriginal people from Ramahyuck Station near Sale, Gippsland, were relocated to the Lake Tyers Mission due to the closure of Ramahyuck Station (National Museum of Australia [NMA], 2022). By 1917, Lake Tyers Mission remained the only government-run reserve in Victoria. In the following years, the Aborigines Protection Board began transferring people from Coranderrk, Ebenezer and Lake Condah reserves to Lake Tyers (NMA, 2022).

In 1961, a delegate from the Council for Aboriginal Rights visited Lake Tyers Mission and discovered unacceptable living conditions (NMA, 2022). The residents' homes lacked basic amenities such as running water, bathrooms, laundries and a drainage system, and the community bathhouse was far from the homes (NMA, 2022). The residents relied on rations that were distributed twice a month. The mission gate was locked, and residents faced fines if they left without permission (NMA, 2022). Seeing a doctor required approval from the manager's wife, and owning a car was against the regulations, forcing residents to walk 25 kilometres to the nearest town of Lakes Entrance if they had permission to leave the mission (NMA, 2022). These conditions persisted within the lifetime of some Lakes Entrance residents and certainly within the lives of their parents and grandparents. Stories of this era continue to be passed down through local families, transmitting the legacy of historical and collective trauma.

In 1962, the Aborigines Welfare Board and the Victorian Government announced that the Lake Tyers Mission would be closed (NMA, 2022). This announcement caused dissent and two opposing viewpoints. The Victorian Government believed Aboriginal residents could only gain equal rights and treatment if they lived and worked among white people; however, they also believed that no more than two or three Aboriginal families should be able to settle in the same town (Manning, 2002). The opposing view was that the

Victorian Government's position was coercive assimilation, that Lake Tyers residents had not been prepared practically or emotionally for this radical change and that residents were legally and morally entitled to ownership of the remaining reserve lands (NMA, 2022). Some families were persuaded to move away from the Lake Tyers Mission with offers of houses; however, they were poorly prepared for the move. Residents had no experience handling their own money, living in a house with power, water and sewerage connected, and working or mixing socially with a white community (NMA, 2022). Once residents left Lake Tyers, they were not permitted to return. Many were unhappy in their new situations and tried to return to Lake Tyers, but the state government refused permission. By 1966, less than half of the Aboriginal families rehoused by the Aboriginal Welfare Board lived in the houses provided (NMA, 2022).

During the government's pursuit of what was termed *coercive assimilation* by the Council for Aboriginal Rights, the Aborigines Advancement League, the Federal Council for Aboriginal Advancement, several churches and unions and the Aboriginal community fought for ownership of the Lake Tyers Mission (State Library of Victoria [SLV], 2023). Ironically, the National Museum of Australia holds a copy of the letter that Lake Tyers residents wrote to the manager of the Trust, asking for permission to leave the Trust to travel to Melbourne and protest the closure (NMA, 2022). The campaign received public attention, and finally, in 1970, the Victorian Government handed back 4,000 acres at Lake Tyers to an Aboriginal Trust via a share system (NMA, 2022). The share system was not well implemented, as non-Gunaikurnai people residing at Lake Tyers at the time were eligible for shares, and Gunaikurnai people who had already been persuaded to leave were not. This system caused conflict among the community, as members of clans other than Gunaikurnai, who had been forcibly moved to the Lake Tyers settlement, now received shares in the Trust.

The state government's handling of ownership of the Trust can be viewed as evidence of the official disregard for the importance of place to the Aboriginal people, who had been moved from one reserve to another to suit the needs of the colonising culture. This history assists in explaining the context of Lakes Entrance Aboriginal people's distrust for government and authority figures, which is evident in respondents' interviews in Chapters 6, 7 and 8.

This local context played out against a broader Victorian backdrop. The Aboriginal Protection Act 1869 (Vic), or 'An Act to provide for the Protection and Management of the Aboriginal Natives of Victoria', made Victoria the first colony to create an Act allowing the government to regulate Aboriginal people's lives. The Act prescribed where 'any Aboriginal or any tribe of Aborigines shall reside' set out restrictions on contracts, earnings and employment, the care, custody and education of children; bedding and clothing was 'on loan only and shall remain the property of Her Majesty' (SLV, 2023). Any interactions with non-Aboriginal people regarding administering of alcohol (unless as medicine), harbouring, unless ill or injured, or taking or selling chattels were governed by the Act (SLV, 2023). The Act also allowed the removal of Aboriginal children to reformatory or industrial schools (CoA, 1997). In 1901, when Australia became a Federation, the Australian Constitution stated that Aboriginal people would not be counted in the national census. The 1937 State and Commonwealth Conference on Native Welfare stated that 'the destiny of the natives of Aboriginal origin, but not of the full blood, lies in ultimate absorption ... with a view to taking their place in the white community on an equal footing with the whites' (CoA, 1997, p. 26).

A succession of legislative acts and government bodies followed, all aimed at regulating the lives of Aboriginal people. The Aborigines Protection Act 1886 (Vic), the Aborigines Act 1890 (Vic), the Aborigines Act 1910 (Vic), Aborigines Act 1915 (Vic), the Aborigines Act 1928 (Vic), the Aborigines Act 1958 (Vic), the Aborigines Houses Act 1959 (Vic), the Aboriginal Affairs Act 1967 and the Aboriginal Land Act 1970 (Vic) all covered the regulation of Aboriginal affairs in Victoria until the state handed control of Aboriginal affairs over to the Commonwealth (State Library of Victoria, 2022).

The effects of colonisation, from massacres to government oversight, have influenced every aspect of Aboriginal people's lives. The paragraphs above describe how the lives of the Gunaikurnai people have been affected by massacres, displacement, loss of Country and loss of freedom and autonomy over their daily lives. Their tribes, language, customs and practices have all been impacted. For the Gunaikurnai people, not only have all aspects of their culture and society been affected, but Pascoe (2018) asserts that their history has also been rewritten. Bruce Pascoe (2018), a local Aboriginal author, argued

in his book *Dark Emu* for a reconsideration of the *hunter-gatherer* tag for pre-colonial Aboriginal Australians and attempts to rebut the colonial myths that have worked to justify dispossession. He provides compelling evidence from the diaries of early explorers that suggests that food production and land management systems have been blatantly understated in modern retellings of early Aboriginal history (Pascoe, 2018).

2.6 Lakes Entrance Aboriginal People's Community Health

Data

An estimated 1,855 Aboriginal people live in East Gippsland, which constitutes 4.2% of the total East Gippsland population (Informed Decisions, 2022). The health data on hospital admissions, emergency department presentations and general practice are outlined below. The data provide a context for understanding the current health profile of the Aboriginal community in Lakes Entrance and the research findings, which are compiled in Chapters 6, 7 and 8. It is important to note that unless specified otherwise, the data below relates to the entire Gippsland region and cannot be broken down into the East Gippsland region or Lakes Entrance specifically.

Hospital admissions for people identifying as Aboriginal in Gippsland are almost three times as common as those for non-Aboriginal people (Gippsland Primary Health Network [GPHN], 2023). The total potentially preventable hospitalisation rates for Aboriginal people were high in Gippsland at 5,133 per 100,000 people compared to 3,010 in Victoria (2016–17 to 2018–19) (Public Health Information Development Unit [PHIDU], 2023). The top five potentially preventable hospitalised conditions for Aboriginal people were diabetes, chronic obstructive pulmonary disease, iron deficiency anaemia, dental and convulsions or epilepsy (GPHN, 2021). The high level of potentially preventable hospital admissions for the Aboriginal community can indicate healthcare conditions that are not well understood, managed or controlled by the health sector.

Emergency department presentation rates for Aboriginal people were higher than for non-Aboriginal people in Gippsland in 2019–20 across conditions (GPHN, 2023). A total of 4,518 emergency department presentations for Aboriginal people occurred in Gippsland in 2019–20 (to public hospitals), up from 3,252 in 2015–16, (Gippsland Primary Health Network, 2021). Emergency

department presentation statistics by presentation category, such as *1 = immediate care* and *5 = non-urgent care*, evidence a high level of presentations by Aboriginal people in Gippsland for non-urgent care (GPHN, 2023). This finding suggests Aboriginal people in Gippsland are utilising hospital emergency departments for their non-urgent health care needs instead of accessing PHC. The reasons why this may occur are discussed in Chapters 6, 7 and 8.

General practice service utilisation statistics for Aboriginal people in Gippsland show that the top diagnoses among service users in general practice are asthma, depression and hypertension (GPHN, 2023). All Aboriginal people, regardless of age, are eligible for an Aboriginal-specific health assessment each year (DOHAC, 2022a). While Aboriginal-specific health assessments were performed for 13.5% of Aboriginal people in Gippsland in 2019–20 (730 services; GPHN, 2023), the proportion of clients who received follow-up services was 19.6% in Gippsland compared to 39.4% in Victoria (GPHN, 2023). The low levels of follow-up services post-Aboriginal-specific health assessments could be caused by several factors, and determining these could be a future area of research. However, the low levels of follow up do mean that service users with potentially manageable diseases and conditions are not receiving the appropriate support, education, advice and treatment to manage these conditions effectively. The high hospital admission rates and hospital ED presentation data for the Aboriginal community in Gippsland provide a further reason why maintaining PHC during crises is critically essential for the health of the Lakes Entrance Aboriginal community.

2.7 Conclusion

This chapter has explained the overarching impacts of colonisation on all aspects of the lives of Aboriginal people. It defined colonisation and how it has impacted Aboriginal people historically and in an ongoing capacity. It also provided an overview of the history of the Gunaikurnai people under colonisation and the resultant impacts. It ended with an overview of the current health data for Aboriginal people in Lakes Entrance. The information covered in this chapter assists in situating this research project. The historical experiences of Aboriginal people since colonisation need to be explicitly stated to understand the context of this research. Australian colonialism, which started 250 years ago, has not ended; instead, Australia has been shaped and continues to shape itself, via

white possession. The next chapter moves to a description of the health of Aboriginal people and the role of PHC.

Chapter 3 Aboriginal Health and Primary Health Care

3.1 Introduction

This chapter moves beyond a description of the overarching effects of colonialism to provide background and context for the health inequities Aboriginal people face. Where the previous chapter considered the historical and ongoing impacts of colonisation, this chapter explains the impact of additional past crises, such as historic epidemics and pandemics, on Aboriginal people's health. The chapter provides contextual information on the two main crises that are relevant to this research and have impacted the Lakes Entrance Aboriginal community in the past five years: the 2019–2020 bushfires in East Gippsland and the COVID-19 lockdown periods. This chapter also reviews data on Aboriginal people's use of health services during the COVID-19 lockdown and their use of PHC services in general to provide background knowledge and inform an understanding of Aboriginal health in Australia. The national Closing the Gap strategy and policy (Closing the Gap [CTG], 2021) are also explained, as are the role of ACCHOs in providing culturally safe and appropriate PHC to the Aboriginal community.

3.2 Background to the Health of Australian Aboriginal People

The health of individuals is influenced by several factors, including genetics, health behaviours, access to quality health care and the impact of varying determinants of health. Social determinants have been found to account for approximately one-third (34%) of the health gap between Aboriginal and non-Aboriginal Australians, while health risk factors, such as smoking and alcohol use, contribute to just under one-fifth (19%) of the gap (AIHW, 2022c). Critically, the remaining portion of the health gap (around 47%) is attributed to disparities in healthcare access and the impact of cultural and historical factors on health (AIHW, 2022c).

The number of Aboriginal people who access primary health care is a metric measured in the Aboriginal and Torres Strait Islander Health Performance Framework (AIHW, 2023). The July 2023 Framework summary report, based on 2018–2019 data, stated that 30% of the Aboriginal population reported that they needed to but did not see a PHC provider on at least one occasion in the

previous 12 months (AIHW, 2023). The report attributes cost, health service unavailability, distance and wait times as reasons why three-in-10 Aboriginal people did not go to a healthcare provider when needed (AIHW, 2023).

A comparison of the burden of disease between Aboriginal and non-Aboriginal people reveals that Aboriginal people experience the burden at a rate 2.3 times higher than non-Aboriginal Australians. However, the absolute gap narrowed between 2003 and 2018 (AIHW, 2022c). Psychological distress and chronic diseases are higher among Aboriginal people than non-Aboriginal people (AIHW, 2022c). In Victoria, for example, 50.3% of Aboriginal individuals report suffering from one or more selected chronic conditions (ABS, 2019).

This thesis addresses how Aboriginal people in the Lakes Entrance community describe their experiences of accessing PHC before and during crises or disasters, namely the 2019–2020 bushfires and the COVID-19 pandemic restriction periods. To address this question, it is important first to understand the interplay between social, cultural and historical determinants of health and their impact on the burden of disease within the Aboriginal community, covered in the previous chapter. This chapter provides an underpinning context for this research by explaining (a) PHC and the role of ACCHOs, (b) the use of health services by Aboriginal people during the COVID-19 lockdown restrictions and the 2019–2020 bushfires, (c) the Closing the Gap strategy, (d) the impact of past crises on the health of the Aboriginal community and (e) the background of both the 2019–2020 bushfires and the COVID-19 pandemic restrictions.

3.3 Primary Health Care

The importance of PHC in improving health outcomes is well-established and acknowledged both domestically and internationally (Starfield et al., 2005; van Weel & Kidd, 2018). In the context of PHC, there is general agreement that the achievement of the four well-known core primary care functions is associated with better quality services, lower costs, less inequality in health care and better population health (Baicker & Chandra, 2004; Lewin et al., 2008; Starfield et al., 2005). These four core primary functions of PHC are defined as:

- First contact—access and use of health services whenever necessary.

- Comprehensiveness—promotion, prevention, treatment and rehabilitation appropriate to the PC context.
- Coordination—the integration of all the care the user receives and needs with the other health services.
- Continuity—a professional-subject-of-care temporal relationship, leading to the establishment of strong mutual trust (Prates et al., 2017).

These four core functions are analysed in Chapter 9 with their relevance to the research findings and their implications for practice.

3.4 Primary Health Care and the Role of Aboriginal Community Controlled Health Organisations

When people are unwell, a general practitioner (GP) is generally the first clinical point of call in the health system (Australian Medical Association, 2020). General practice 'is the cornerstone of successful PHC, which underpins population health outcomes and is key to ensuring we have a high-quality, equitable and sustainable health system into the future' (Australian Medical Association, 2020, p. 3). PHC services are delivered in general practices, community health centres, ACCHOs and allied health practices. GPs are registered specialists in the discipline of general practice recognised by the Australian Health Practitioner Regulation Agency (Australian Medical Association, 2020). General Practice has also been described as the central discipline of medicine around which medical and allied health disciplines are arranged to form a cooperative team for the benefit of the individual, the family and the community. People reluctant to engage with a GP can fall through the cracks of our healthcare system and may not access timely and necessary care.

Access to PHC services is critically important to providing clinical and social or emotional support to all Australians; however, Griew et al. (2008, p. 8) state that Aboriginal people have yet to reap the full benefits of PHC. Canuto et al. (2018, p. 815) suggest that 'improving access to primary care stands as a critical target for improving health status among Aboriginal People'. High-quality PHC can improve health and wellbeing by enhancing health literacy, self-management of chronic disease, and screening and treatment of acute and chronic illnesses (AIHW, 2022h). PHC access and action on the social

determinants of health are both considered critically important for improving the health of Aboriginal people (Griew et al., 2008). The importance of access to culturally appropriate PHC for Aboriginal people cannot be underestimated. While it is one factor among the many cultural, social and environmental factors affecting health, there is evidence of a strong link between PHC and health outcomes, particularly mortality and life expectancy for Aboriginal people (Basu et al., 2019).

For Aboriginal people to feel comfortable participating in PHC, the health care must be culturally safe (P. Dudgeon et al., 2014; Griew et al., 2008). Improving the cultural safety and cultural responsiveness of the health system can improve access to and the quality of health care for Aboriginal people (AIHW, 2022b). A culturally safe health system respects Aboriginal cultural values, strengths and differences and addresses racism and inequity. It also requires health professionals and health services to be culturally responsive, to take action to overcome racism and power imbalances and to actively engage with Aboriginal clients to ensure that the system meets their needs (W. Dudgeon et al., 2010). There is also evidence of a link between PHC visits and an increase in the utilisation of evidence-based preventative health measures (Hostetter et al., 2020).

Compared with non-Aboriginal people, Aboriginal people face more significant barriers in accessing primary care, and being able to access health care is widely accepted as fundamental to improving health outcomes (AIHW, 2022a). Unfortunately, PHC services remain underutilised by Aboriginal people, and the reasons for this are complex and not well documented (Canuto et al., 2015). The reasons for these barriers and the under-utilisation of PHC are explored in Chapter 4.

ACCHOs are important providers of comprehensive and culturally appropriate PHC services to Aboriginal people nationwide. Alternative Aboriginal PHC services have arisen from mainstream services being unable to adequately meet the needs of Aboriginal communities (Bainbridge et al., 2015a; Harfield et al., 2018; Hayman et al., 2009; Spurling et al., 2009). ACCHOs address many of the healthcare access barriers Aboriginal people face because services and programs are grounded in local values and culture; they adopt the Aboriginal

concept of holistic health that encompasses social, political and cultural determinants of health and are accountable to the interests, needs, values, vision and concerns of community members (M. A. Campbell et al., 2018; NACCHO, 2013). They address affordability barriers by providing free PHC and accessibility barriers by providing transport, outreach and childcare support services (M. A. Campbell et al., 2018).

ACCHOs operate in over 140 urban, regional and remote areas across Australia, and consistent with the aspirations of Aboriginal people for community control of healthcare services, 63% of Australia's Aboriginal-specific primary healthcare services are community controlled (McCalman et al., 2021). It is asserted (Calma, 2007) that only with self-determination will Aboriginal people fully overcome the legacy of Australia's colonisation and dispossession, described in Chapter 2. This self-determination in a healthcare setting can be realised, in a small measure, through the Aboriginal community control of healthcare services, as per the ACCHOs.

3.5 Aboriginal People's Use of Health Services During the 2019–2020 Bushfires and the COVID-19 Pandemic: The Australian National Context

No data are available on the utilisation of PHC services by Aboriginal people during the 2019–2020 bushfire period. During the first 18 months of the pandemic (January 2020 – June 2021), 171 cases of COVID-19 were confirmed among Aboriginal people, representing less than 1% of all cases in Australia (AIHW, 2022b). Beginning in July 2021, COVID-19 case numbers among Aboriginal people began to rise due to outbreaks of the Delta and then the Omicron variants. The cumulative number of cases for Aboriginal people was around 14,400 by the end of 2021, more than 63,800 by the end of January 2022 and nearly 175,000 by 22 May 2022 (AIHW, 2022b).

The use of selected PHC services by Aboriginal people during this time was compared with pre-pandemic patterns and trends, with the comparison showing that telehealth consultations with GPs rose dramatically. Approximately 412,800 of the 4.7 million claims for GP consultations in 2019–20 (8.8%) were telehealth, compared with just under 3,300 claims for GP consultations by videoconference in 2018–19 (AIHW, 2022g). The highest proportions of claims

by telehealth were for Aboriginal people living in inner regional areas, Aboriginal women and Aboriginal people aged 25 and older; the lowest proportions were for Aboriginal people living in very remote areas and for children aged 0–4 for whom less than 5% of consultations were conducted through telehealth (AIHW, 2022b). However, claims through Medicare for Aboriginal health checks declined across all age groups from March 2020 and continued to decline through 2020–21 (AIHW, 2022b). This statistic may reflect that Aboriginal health checks, being preventative, were not prioritised by Aboriginal people during this time, while acute and chronic health condition needs were addressed via telehealth.

Medicare is an Australian national insurance scheme providing all Australians with free or subsidised health care. Aboriginal people can receive a specifically designed annual Medicare-funded health check. These customised health checks were introduced following calls by Aboriginal health leaders, recognising that many Aboriginal people have increased risk factors for several conditions. Health checks support engagement in comprehensive PHC in a culturally safe way; they are an opportunity to identify clients' health goals and priorities, provide risk assessment and healthy lifestyle information and support and encourage early detection and treatment of common conditions that cause ill health and early death, such as diabetes and heart disease (AIHW, 2021; Butler et al., 2022).

The changes in health-seeking and health-accessing behaviours described above are likely to result from interactions among a mix of factors, including worry about contracting COVID-19, underlying health needs, ability to access services when needed, and adjustments to the health sector and service delivery arrangements. Healthcare needs may have changed due to reduced infection rates from other illnesses due to public health measures or increased mental health needs or emotional wellbeing due to worries about the disease and the impact of restrictions on social, cultural or family gatherings. Some of these changes may be directly linked to pandemic-related policies, such as expanding Medicare rebates for telehealth consultations, which did not include Aboriginal health checks. These data illustrate changes in how health services were delivered and accessed by Aboriginal people during the COVID-19 pandemic, as well as changes in the volume of service use. This study explored how the Aboriginal community in Lakes Entrance described their experiences of

accessing primary health care during the 2019–2020 bushfires and the COVID-19 restrictions periods and highlighted how these disasters exacerbated existing PHC inequities.

3.6 Closing the Gap

The Closing the Gap framework (CTG, 2021) was established in 2008 to address Aboriginal disadvantage across many domains. At the time of establishment, the gap in life expectancy between Aboriginal and non-Aboriginal males was approximately 18 years and 17 years between Aboriginal and non-Aboriginal Australian females. Infant mortality for Aboriginal infants in 2002–06 was 12.3 deaths per 1,000 live births, compared with 4.2 deaths for non-Aboriginal infants (Australian Health Ministers' Advisory Council [AHMAC], 2008).

While there have been many government strategies and initiatives to improve Aboriginal people's health, wellbeing and societal outcomes, most notably the federal government's Closing the Gap strategy, a considerable gap remains between Aboriginal and non-Aboriginal health outcomes. In February 2020, the (then) most recent Closing the Gap outcome report was tabled in the Federal Parliament. The Prime Minister's foreword states, 'these results are not what we had hoped for, and it's important to acknowledge them' (CoA, 2020, foreword). The 2020 Closing the Gap report states, 'achieving equality in life expectancy and closing the gap in life expectancy within a generation is not on track to be met by 2031. Aboriginal people still have a lower life expectancy than non-Aboriginal people' (CoA, 2020, foreword). After more than a decade of tabling annual reports of policy failure in closing the gap in Aboriginal health inequality, rather than a rethink of the policy approach, in 2019, the Morrison government announced a refresh of the targets (Biddle, 2019). Whether such engagement will 'engender the radical reimagining required to transform persisting Indigenous health disparities remains to be seen' (Bond & Singh, 2020, p. 198).

Bond and Singh (2020) assert that one issue with Closing the Gap strategies has been the disproportionate focus on the behaviour of individuals, suggesting that health inequalities are a product of Aboriginal lack, morally and intellectually. The notion that health outcomes are determined solely by an

individual, without recognising their history, culture, environment, social determinants of health and system factors is simplistic and lacking in nuance and understanding. Bond and Singh (2020) further argue that there are explicit and implicit racial imaginings in epidemiological understandings of Aboriginal health inequality that measure and frame Closing the Gap targets and strategies. This position implies that Closing the Gap targets and strategies themselves are unlikely to be successful in affecting Aboriginal health outcomes until there is similar attention to and investment in improvement in the socio-economic and environmental conditions of Aboriginal people.

To be clear, I am not suggesting that improved access to PHC for Aboriginal people is a *silver bullet* that would close the health outcomes gap between Aboriginal and non-Aboriginal people. As previously outlined, the complex social determinants of health are also relevant, and the factors and intersectionality affecting Aboriginal people's health are many and varied. However, the under-utilisation of PHC services by Aboriginal people is of grave concern, particularly during the Covid-19 lockdown period. It has been stated that 'improving access to primary care stands as a critical target for improving health status among Aboriginal People' (Canuto et al., 2018, p. 815). It is acknowledged (Panaretto et al., 2013) that PHC services, particularly ACCHOs, are an essential and significant component of the effort to close the gap in health disparity.

3.7 Australian Policies and Plans for Aboriginal Health

The National Agreement on Closing the Gap is the overarching policy context for the National Aboriginal and Torres Strait Islander Health and Wellbeing Plan 2021–2031 (DOHAC, 2021c). This plan is the action vehicle for achieving the four priority reforms of the National Agreement on Closing the Gap: formal partnerships and shared decision-making, building the community-controlled sector, transforming government organisations and shared access to data and information at a regional level (DOHAC, 2021c).

The National Agreement on Closing the Gap is also an essential policy and accountability mechanism. It monitors progress on several targets for improving outcomes for Aboriginal people. The National Aboriginal and Torres Strait Islander Health Plan 2021-2031 will drive progress against the three

health-specific targets of the National Agreement on Closing the Gap; they are to close the gap in life expectancy within a generation by 2031, increase the proportion of Aboriginal babies with a healthy birthweight to 91% by 2031 and achieve a significant and sustained reduction in suicide of Aboriginal people towards zero (DOHAC, 2021c).

The Australian federal government leads a range of mainstream and Aboriginal-specific policies that aim to improve Aboriginal people's health outcomes (DOHAC, 2021c). The National and Aboriginal and Torres Strait Islander Health Plan 2021-2031 (DOHAC, 2021c) is the overarching plan that commits all state and territory governments to working in partnership with Aboriginal people to drive solutions in the health sector and build the community-controlled health sector. This plan aligns with key existing policies and those under development across child and family support, education, employment, housing, community safety and natural and cultural resource management.

The National Aboriginal and Torres Strait Islander Health Plan 2021–2031 (DOHAC, 2021c) comprises the following priorities:

- Priority 1: Genuine shared decision-making and partnerships
- Priority 2: Aboriginal and Torres Strait Islander community-controlled comprehensive primary health care
- Priority 3: Workforce
- Priority 4: Health promotion
- Priority 5: Early intervention
- Priority 6: Social and emotional wellbeing and trauma-aware, healing-informed approaches
- Priority 7: Healthy environments, sustainability and preparedness
- Priority 8: Identify and eliminate racism
- Priority 9: Access to person-centred and family-centred care
- Priority 10: Mental health and suicide prevention
- Priority 11: Culturally informed and evidence-based evaluation, research and practice
- Priority 12: Shared access to data and information at a regional level

Priorities 2, 3, 4, 7 and 8 contain objectives relevant to this research and are discussed in depth in Chapter 10.

3.8 Impacts of Past Crises on Aboriginal People

A public health emergency, such as a natural disaster, places substantial burdens on the affected population's health and wellbeing and on the relevant health system's capacity to respond to changes in health needs. The extent to which a disaster disrupts a health system's capacity to care for population groups at a greater risk of poor health is an under-studied but critical aspect of health system responsiveness during and after a disaster (Fitzpatrick et al., 2021).

As outlined in Chapter 2, Aboriginal people face the burden of significant chronic and acute diseases (AIHW, 2022c). Due to these conditions, they are impacted disproportionately than the general population when affected by a disaster (Lansbury Hall & Crosby, 2022). Disasters can impact in multiple ways. Direct impacts can include injuries and death from extreme events, while indirect impacts can affect human systems, including mental health, productivity and damage to housing and healthcare facilities (Lansbury Hall & Crosby, 2022). Due to their isolated locations, infrastructure, economic resources, limited transport and existing health vulnerabilities, regional and remote Aboriginal communities are additionally exposed to the impacts of disasters and the associated health effects (Lansbury Hall & Crosby, 2022).

Historic epidemics and pandemics, such as two major pox epidemics in 1789 and 1829-31, severely impacted the Aboriginal population, with as many as three-quarters of Victoria's pre-colonial population estimated to have been killed (J. Campbell, 2007). The 1918–19 influenza pandemic, or Spanish flu, was one of the worst natural disasters in history (J. Campbell, 2007). In Australia, the pandemic was a major demographic and social tragedy, affecting the lives of millions of people (Curson & McCracken, 2006). Australia's Aboriginal community was severely affected, with a mortality rate approaching 50% in some communities and the pandemic creating terror among the inhabitants of Aboriginal stations and missions (Cleland, 1928).

More recently, the first H1N1 influenza case reported in Victoria occurred on 20 May 2009, with 3,089 cases and 26 deaths reported in Victoria (Looker et

al., 2010). Aboriginal people were four times more likely to be admitted to hospital with pandemic (H1N1) 2009 influenza than non-Aboriginal people (Rudge & Massey, 2010). During the 2009 H1N1 influenza pandemic, Aboriginal people in Central Australia experienced infection rates five times higher than the wider population (Mousseau, 2013).

During the 2009 H1N1 pandemic and the 2003 SARS outbreak, much attention was directed towards protecting members of the population at heightened risk of medical complications from the virus or bacteria (O'Sullivan & Bourgoin, 2010). However, it is also important to acknowledge vulnerability through the lens of the social determinants of health, which influence daily resilience and can exacerbate the impacts of a disaster (Garoon & Duggan, 2008). A caveat was noted in the literature: ascribing *vulnerability* to race, ethnicity or Indigeneity—in the context of COVID-19 or otherwise—is described by Thurber et al. (2021) as a form of systemic racism. It has consequences, including exacerbating narratives of racial inferiority, which can confirm and reinforce prejudices and stereotypes (Thurber et al., 2021). It can also lead to internalised racism for the affected population, impairing self-esteem and compounding complex trauma. Therefore, it is important to acknowledge that Aboriginality in and of itself is not a risk factor and must be viewed in the broader context of inequities that impact health.

3.9 Background to the 2019–2020 Bushfires in East Gippsland

The 2019–2020 bushfires in East Gippsland resulted in loss of life, thousands of displaced people and numerous communities being temporarily isolated (VSG, 2022). The bushfires were unlike any previous fire events due to their longevity and the amount of land affected. They burned over many months alongside bushfires across the eastern seaboard and other parts of Australia.

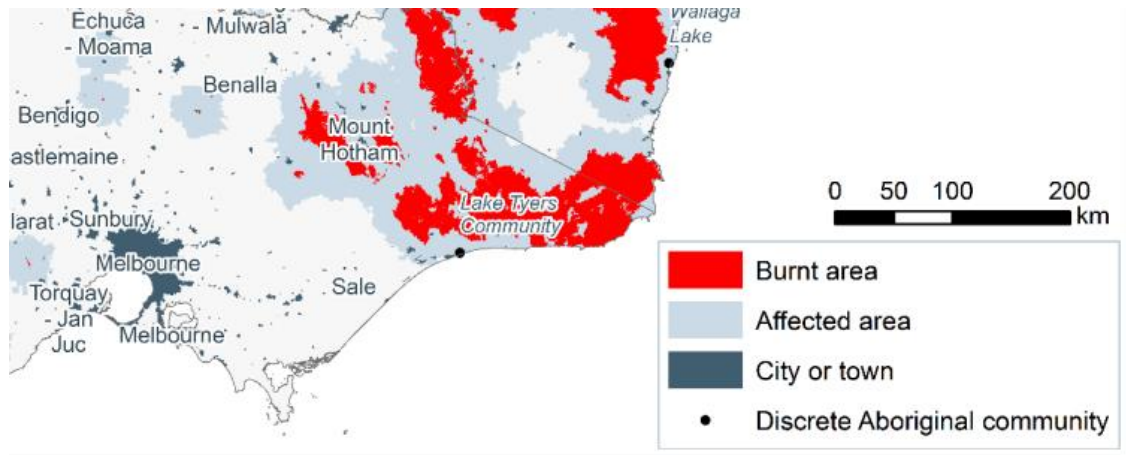
On 31 December 2019, approximately 4,000 people were forced to shelter on the Mallacoota foreshore as fire threatened the East Gippsland town, and over the next two days, almost 2,000 were evacuated by air and sea (VSG, 2022). On 2 January 2020, a State of Disaster was declared in parts of Victoria that would last 10 days (VSG, 2022). More than 60,000 people are estimated to

have evacuated East Gippsland due to the warnings and the State of Disaster declaration (VSG, 2021a).

The bushfires had a significant impact on land (see Figure 3.1). By the time, all significant fires across Victoria had been contained in February 2020, over 15 million hectares had been burned, including more than half of the East Gippsland LGA: over 1.1 million hectares (VSG, 2021a). This area contained over 1,000 registered Aboriginal heritage places (VSG, 2021a). The fires affected 248 Aboriginal people, and 42 homes were destroyed or made unliveable (VSG, 2021a). Key regional industries such as agriculture, tourism, forestry, and retail were severely affected. Homes, businesses, community facilities and thousands of kilometres of roads and fences were damaged or destroyed.

During the 2019–2020 bushfires, access to PHC for residents of the Lakes Entrance community was impacted for numerous reasons, including homes being destroyed, road closures, evacuations and power outages and due to other impacts of the fire, residents could not access their usual health care arrangements. This situation reduced their ability to maintain continuity of health care.

Due to the imminent threat of fire impact, residents of the Lake Tyers Trust were evacuated from the Trust and moved to the evacuation centre at the Bairnsdale Football Oval. Temporary accommodation comprising tents was set up, and food was provided via the evacuation centre. Medical services were set up at the evacuation centre, including ambulance and nursing volunteers and GPs from local practices who attended in a volunteer capacity to provide emergency care.

Figure 3.1*The Impact of the 2019–2020 Bushfires*

Note: Williamson, B., Markham, F. & Weir, J. K. (2020). Aboriginal people and the response to the 2019–2020 bushfires (Working Paper No. 134/2020). Centre for Aboriginal Economic Policy Research, (134). <https://doi.org/10.25911/5e7882623186c>

3.10 Background of the COVID-19 Pandemic

An impact of the COVID-19 pandemic has been the restrictions and lockdowns imposed on the public in attempts to restrict the spread of the disease. The capital city of Victoria, Melbourne, underwent six separate lockdowns between March 2020 and October 2021, totalling 263 days during that period. The Gippsland region underwent six separate lockdowns totalling 133 days during the same period. During lockdowns, non-essential shops were closed, curfews were imposed, social distancing rules were enforced and stay-at-home orders were imposed. These orders only allowed people to leave their homes to access essential food and health care, with social gatherings prohibited.

While Australia has fared better than many other countries in relation to mortality from the COVID-19 pandemic (AIHW, 2022d), the disease has still had a substantial health impact. By 30 April 2022, nearly 6 million cases had been confirmed in Australia since the start of the pandemic, with more than 7,000 COVID-19-related deaths (DOHAC, 2022b). In early 2022, it rose rapidly following the introduction of the Omicron variant and easing restrictions. By this time, however, vaccination levels were high, with more than 92% of Australians

aged 16 and over fully vaccinated with the initial two-dose protocol by 2 January 2022 and booster doses being rolled out (DOHAC, 2023b). Aboriginal Australians, however, have been and will continue to be affected by this crisis in ways that differ from the effects on other Australians.

Reflecting broader health disparities, the COVID-19 vaccination status of Aboriginal Australians was less than that of the wider population, with only 53% of the Aboriginal community over the age of 16 having received three or more doses by 30 April 2022 (DOHAC, 2023b). Only 60% of Aboriginal children aged 12–15 were fully vaccinated with two doses by April 2022, compared with 80% for all 12–15-year-olds (AIHW, 2022b, p. 18).

The impacts of COVID-19 on Aboriginal people evolved. As of 31 January 2021, there were 151 confirmed cases of COVID-19 and no deaths reported among Aboriginal Australians, representing around 0.5% of all confirmed cases throughout the pandemic (AIHW, 2022b). By 24 October 2021, the cases among Aboriginal people had increased to 6,084, or 4.6% of all confirmed cases (AIHW, 2022b). The age distribution of COVID-19 cases among the Aboriginal population was similar to that for the Australian population generally, with people aged 18–29 having the highest number and incidence of COVID-19 cases; 53% of cases were female. (AIHW, 2022b, p. 41).

As of 10 April 2022, 107 deaths had been reported among Aboriginal Australians, and 275 cases had been admitted to intensive care units (AIHW, 2022b). The overall rate of severe disease (defined as intensive care unit admission or death) for Aboriginal Australians during the Delta wave (June to December 2021) was 16.2 per 100,000. It rose to 26.9 per 100,000 by 10 April 2022 during the Omicron wave (AIHW, 2022b). Based on surveillance data supplied by DOHAC, the rate of severe disease during the Omicron wave to 3 July 2022 for Aboriginal people was 1.4 times as high compared with non-Aboriginal Australians (54.0 per 100,000 compared with 37.8 per 100,000 respectively) (AIHW, 2022b). Around 42% of Aboriginal Australians who contracted COVID-19 lived in a rural area, either regional or remote (AIHW, 2022b, p. 42).

Up to 22 May 2022, there were 175,000 COVID-19 cases among Aboriginal people, representing 2.5% of all cases in Australia; most cases

(166,000) occurred since December 2021 during the Omicron wave (DOHAC, 2022b). The number of COVID-19 cases is likely to be underestimated as Aboriginality status is unknown for 20% of confirmed cases, particularly in 2022 where the rapid increase in cases impacted the collection of detailed epidemiological data (AIHW, 2022b).

Since the COVID-19 pandemic commenced in January 2020, protecting the health, safety and wellbeing of Aboriginal people has been a key, stated national priority (DOHAC, 2022c). The national response has been proactively led by the Aboriginal and Torres Strait Islander Advisory Group on COVID-19, co-chaired by NACCHO with DOHAC, working on principles of shared decision-making, power-sharing, two-way communication, self-determination, leadership and empowerment (AIHW, 2022b). Many individual communities, particularly in remote and isolated areas, were empowered to make their own decisions about local restrictions and policies to keep their communities safe and demonstrated strength and resilience (Crooks et al., 2020; Keene, 2020). ACCHOs needed to be at the centre of driving COVID-19 outbreak health measures while continuing to provide other essential primary healthcare services (McCalman, Longbottom et al., 2021). This response was in the context of local and national responses, including a range of public health measures implemented periodically during the pandemic to prevent the spread of COVID-19: community closures, travel restrictions and border closures; bans on social gatherings; closure of schools, workplaces and retail shops; mask wearing; closures or reduction of key services and vaccine mandates (AIHW, 2022d).

However, although pandemics such as COVID-19 are a serious public health risk for Aboriginal communities, it is acknowledged that PHC systems are not well-resourced to respond to such urgent events (McCalman, Longbottom et al., 2021). Strengthening systems at the community and peripheral health facility level contributes to building resilience, which is critical for withstanding shocks to the health system (WHO, 2021, as cited in McCalman, Longbottom et al., 2021). Despite acknowledging the under-resourcing, relatively little attention has been paid to strengthening the under-resourced primary healthcare systems (McCalman, Longbottom et al., 2021).

3.11 Conclusion

This chapter has provided background and explanatory context for the health inequities faced by Aboriginal people. This chapter has described the persistent health disparities faced by Aboriginal people compared to the wider Australian population and the high rates of chronic and acute disease prevalent in the Aboriginal community. The role of PHC and its proven efficacy in addressing chronic disease was explained. The importance of ACCHOs in delivering culturally safe and appropriate PHC was also described, as was the health outcomes that ACCHOs have achieved in the Aboriginal community. The high rates of chronic and acute disease affecting Aboriginal people were described, and why crises and disasters that interrupt PHC access impact Aboriginal people disproportionately to the non-Aboriginal population was addressed. The chapter also described the failure, to date, of the Closing the Gap strategy in effectively addressing inequitable health outcomes in the Aboriginal community.

Chapter 4 Literature Review

4.1 Review Structure

This chapter reviews the literature to address how Aboriginal people in rural and regional areas have described their experiences of accessing PHC, both in usual times and during a crisis. It seeks to understand the barriers and enablers to accessing rural and regional PHC from the perspective of Aboriginal people. It attempts to clarify what, if any, impact past crises or disasters have had on Aboriginal people accessing PHC and how they described their experiences in this situation. The review focuses on adult experiences and only on access to PHC, whether delivered through private general practices, community health centres, ACCHOs or allied health practices. Limited studies were found regarding the experiences of rural and regional Aboriginal people when accessing PHC during a disaster or crisis, an issue detailed in this chapter. Due to these limited results—five were found—a revised search strategy was utilised.

The revised search strategy uses a modified review question, which removed the requirement for PHC access during a time of crisis or disaster, resulting in a new search question: How do Aboriginal people living in regional and rural areas describe their experiences of accessing PHC? This narrative review synthesises a wide range of literature, including systematic reviews and grey literature, that examines the experiences of Aboriginal Australians when accessing PHC. The chapter concludes with results from hand-searching international literature relevant to Indigenous people accessing PHC during crises to identify what could be determined from their experiences.

4.2 Review Methodology

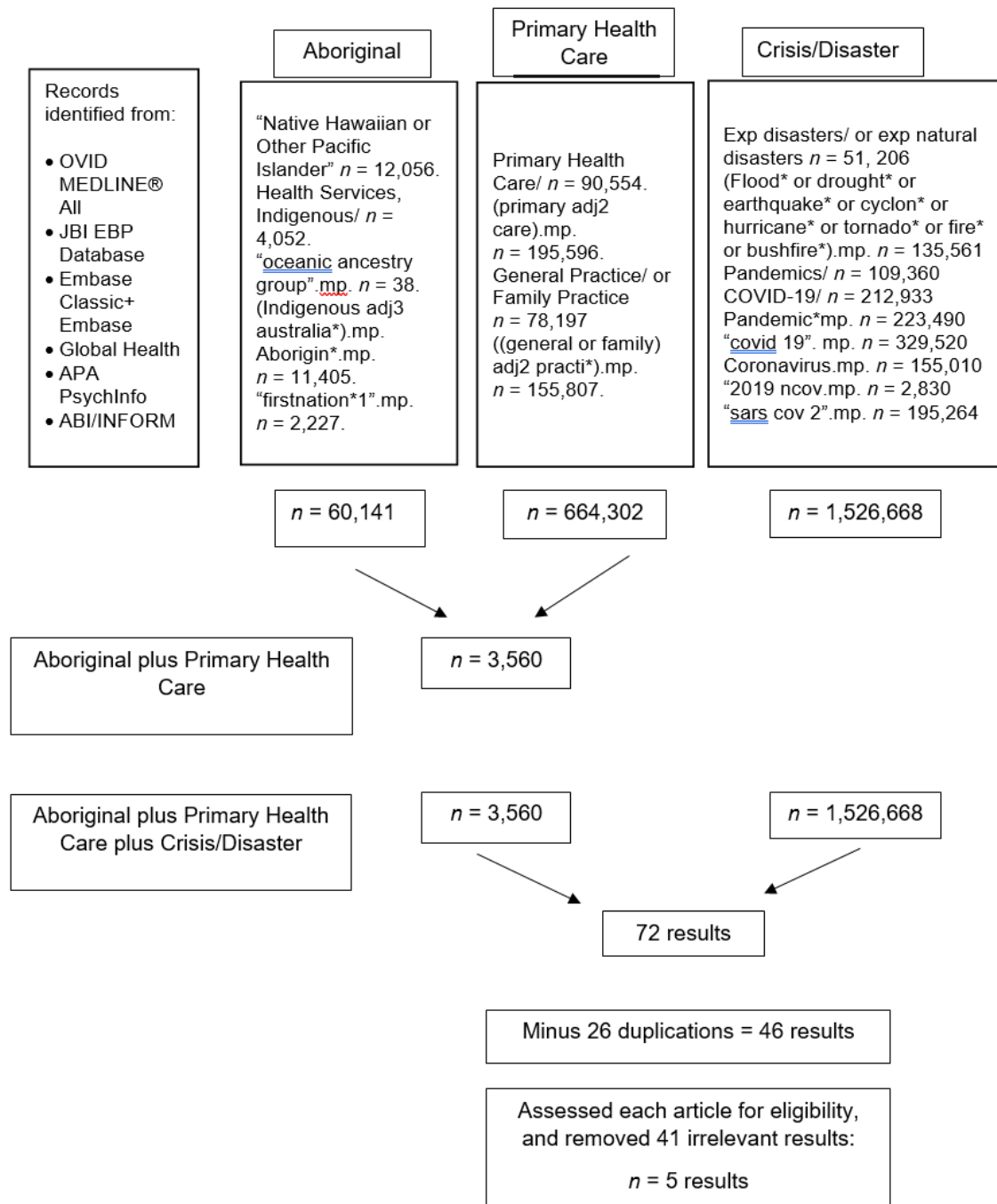
This narrative literature review synthesises the findings retrieved from searches of computerised databases, hand searches and authoritative texts to understand Aboriginal people's experiences when accessing PHC as usual and during crises or disasters. The questions the review aimed to address were:

- What impact have past crises or disasters had on Aboriginal people's ability in rural or regional areas to access PHC, and how do they describe their experiences in this situation?

- What are the barriers and enablers that Aboriginal people have identified in relation to their accessing rural and regional PHC during crises?

4.3 Literature Search

An initial broad literature search was conducted using Ovid Medline, JBI EBP Database, Embase Classic and Embase, Global Health, APA Psycinfo and ABI/Inform. Various combinations of search terms were used, as shown in Figure 4.1.

Figure 4.1*Literature Search Graphic*

Of the initial 46 results, few were relevant to Australian Aboriginal people accessing primary care in a rural or regional location and describing their own experiences. The literature provided numerous examples of Aboriginal people engaging with tertiary or hospital care (Amarasena et al., 2022; Mitchell et al., 2020), with varying medical interventions (Drovandi et al., 2022; Eer et al., 2022; Guppy et al., 2021; Sebastian et al., 2022); from the perspectives of the medical practitioners or health care staff (de Witt et al., 2020; Fatima et al., 2022; Topp

et al., 2021), dealing with urban care (Lakhan et al., 2020; Milroy et al., 2022), from countries other than Australia (Enright et al., 2021; Imlach et al., 2021) and concerning children and adolescents instead of adults (Chando et al., 2022; Ritchie et al., 2021). However, the literature concerning the experiences of rural Australian Aboriginal people accessing PHC during crises was limited.

There are examples of research into medical interventions with Aboriginal people in remote areas such as Cape York, northern Western Australia and the Northern Territory (Hare et al., 2022; Weaver et al., 2022; Zhao et al., 2022), but these are not related to PHC access. There is limited research focused on the utilisation of PHC by a specific cohort, such as Aboriginal men, with a systematic review finding only four published research articles (Canuto et al., 2018). Of those four articles, three were related to urban PHC, and one was from overseas research (Canuto et al., 2018). From the identified papers, Aboriginal men described factors impacting their PHC utilisation, which were then categorised into three primary organising themes: health services, the attitudes of Aboriginal men and their knowledge of available services. Canuto et al. (2018) concluded that improvements in Aboriginal health can only occur if future programs are developed in collaboration with health services and Aboriginal men to address differing requirements. A systematic review of culturally safe healthcare communication (Jennings et al., 2018) found 65 articles concerning the experiences of Aboriginal people with healthcare communication across both primary, tertiary and specialist healthcare in urban, remote, rural and regional settings; however, the review did not cover any aspect of the user experience beyond communication.

Of the five articles relevant to Aboriginal people accessing PHC in a rural or regional location during a crises, one focused on the impact of telehealth on clinic revenue (Couch et al., 2021), one focused on how to define high quality Indigenous health care (with a worldwide focus) when delivered virtually (Fitzpatrick et al., 2022), one focused on the provision of PHC to a regional Victorian Aboriginal community via a mobile clinic and the effectiveness and acceptability of this mode of delivery to the local Aboriginal community (Beks et al., 2022b), one explored the research on person-centred care that has been conducted during the pandemic, with a contextual focus on care delivered by GPs to Aboriginal communities (Brickley et al., 2023) and one provided a

grounded theory study of the success of a locally led, holistic, comprehensive and culturally safe response by an ACCHO to the COVID-19 pandemic in an Aboriginal community, Yarrabah (McCalman et al., 2021).

Of these five articles, only two were relevant. They shed light on the review question concerning the impact of crises or disasters on PHC access for Aboriginal people in rural areas—those of Beks et al. (2022b) and McCalman et al. (2021). Beks et al. (2022b) identified barriers for a regional Aboriginal community in accessing PHC, such as transport—lack of access to own or shared private transport, no public transport, travel cost and time and cultural barriers—and cultural issues, including the need for culturally safe and appropriate care. These barriers were successfully addressed using a mobile clinic, which delivered culturally appropriate, face-to-face health care on Country. The research confirmed the acceptability of the PHC mobile clinic to Aboriginal people residing in rural Victoria, their increased PHC attendance, and the successful use of the mobile clinic to offer integrated telehealth and face-to-face services during COVID-19 restriction periods (Beks et al., 2022b). Key to the mobile clinic being acceptable from clients' perspectives was the care provided by health service personnel delivering the mobile clinic service, which was achieved by building trust and relationships with individual clients over time. McCalman et al. (2021) identified the success of the locally led, holistic, comprehensive and culturally safe response of Gurriny (ACCHO), with the authors suggesting that such tailored place-based approaches to pandemics (and other health issues) are appropriate but require dedicated resourcing.

Given the limited applicability of the research identified through the initial broad literature search using the strategy above, with only Beks' (2022b) and McCalman et al.'s (2021) research applicable to addressing the research question, a new strategy was pursued. The review question was modified to remove the requirement for PHC access during a time of crisis or disaster, resulting in a new search question: How do Aboriginal people living in regional and rural areas describe their experiences of accessing PHC?

Additional searches of the literature, relevant websites and the Google Scholar search engine were included. Bibliographies and citations from identified literature and research were hand searched, and additional literature

was identified. Research relating to access factors for Aboriginal communities in urban and remote communities was used to address the review question, as was research that addressed barriers in terms of hospital care or specific interventions, not necessarily PHC.

Results from the new search strategy clearly identified the impacts of colonisation on Aboriginal people when accessing PHC. Results regarding these impacts were classified into three themes. The first theme pertains to service delivery factors, which include the location of services, provider experience, continuity of care, treatment decisions, communication, prior experiences and instances of racism. The second theme comprises personal factors, including feelings of shame, fear, and embarrassment and intergenerational/collective and historical trauma. The third theme relates to environmental factors, which involve barriers such as transportation, medical bureaucracy, infrastructure and competing priorities that overshadow health as a priority. The research data have also been structured around these themes and sub-themes.

4.4 Service Delivery Factors

Service delivery factors were identified in the literature review as impacting access to PHC for Aboriginal people. These included the availability of culturally appropriate services, the location and physical setting of the health care options, the continuity of care provided, communication from the health care provider and prior experiences. These factors and their impacts are described below.

4.4.1 Culturally Appropriate Services

Culturally appropriate services encompass various factors and can be defined in different ways. According to AIHW (2015), cultural competence goes beyond cultural awareness and involves behaviours, attitudes and policies that enable effective cross-cultural interactions. Providing culturally safe health care for Aboriginal people means being aware of and responsive to their cultural needs and experiences (AIHW, 2021).

To effectively meet the needs of Aboriginal people, PHC options must be culturally appropriate. Aboriginal people have a complex and holistic understanding of health, incorporating spiritual, social and cultural factors (Pearson et al., 2020). The literature focuses on narrow biomedical and

individualistic models of health in general practice, neglecting the social and cultural factors that significantly impact the health of vulnerable groups like the Aboriginal community (Horrill et al., 2018; Lau et al., 2012). Culturally inappropriate services can arise from the recognised disconnect between the Western discourse about health and the Aboriginal discourse on determinants that affect health (Griffiths et al., 2016). The deficit model of health and the Western medical framing of health are poorly aligned with Aboriginal people's holistic health beliefs (Gatwiri et al., 2021; Maher, 1999). The Aboriginal worldview recognises good health as a complex system involving interconnectedness with the land, spiritual and ancestral recognition, and individual and community social, mental, physical and emotional wellbeing (Oliver, 2013). Inadequate access to culturally responsive PHC health care is recognised as a major barrier to Aboriginal people's PHC access (Gomersall et al., 2017).

Importantly, the literature cautions that much of the evidence on culturally appropriate PHC is based on the perceptions of healthcare providers rather than Aboriginal clients (Cook et al., 2005; Gozu et al., 2007). This finding marginalises Aboriginal people's experiences and emphasises the need to understand Aboriginal perceptions of cultural appropriateness in the services provided by health care providers.

Numerous studies identify a lack of cultural appropriateness of services in the primary healthcare sector as a barrier to Aboriginal people accessing health care (Aspin et al., 2012; Canuto et al., 2018, 2019; Durey et al., 2016; Hayman et al., 2009; Lau et al., 2012). These studies identify barriers and enablers, including the location and physical settings of services, provider experience and continuity of care, communication, prior experiences and racism. These factors are synthesised below.

4.4.2 Physical Health Care Setting

A contributing factor to their higher burden of disease is that Aboriginal people do not access PHC at the same rate as non-Aboriginal people (AIHW, 2018). There are many potential causes of failure to seek timely PHC, including anxiety or stress in waiting rooms, which can contribute to Aboriginal service users missing appointments or avoiding healthcare facilities until they are

severely ill (Duckett & Griffiths, 2016; Durey et al., 2016). The design of physical spaces in healthcare settings is another of the many interrelated factors that can create barriers to accessing health care. The impact of the physical environment on Aboriginal people's perceptions and experiences of health care cannot be isolated and quantified from other service delivery factors. It is likely influenced by various factors, including social and economic disadvantage and the lasting effects of colonisation, which include institutional racism (Bond et al., 2014; Paradies et al., 2008). Service delivery and access factors unrelated to physical space are discussed in the following sections.

The literature emphasises the importance of culturally appropriate design in healthcare spaces, particularly in waiting rooms and physical areas (Smith et al., 2017). Inappropriate design can hinder access to care by making attendees uncomfortable, feeling unwelcome or compromising privacy. Aboriginal people have suggested improving waiting areas by providing culturally appropriate signage and artwork, and arranging triage and reception areas to ensure privacy when discussing appointments and payments (Smith et al., 2017). Positive experiences in the physical environment were also noted when health services incorporated symbols, such as Aboriginal flags, or displayed information about local community events (Green et al., 2018; Jowsey et al., 2012; Smith et al., 2017). Engaging with Aboriginal artworks goes beyond aesthetic appreciation, especially when the art reflects cultural references tied to the local area (Fredericks, 2009). Other important aspects for Aboriginal people are views of the outdoors, space for family members to accompany the client and seating arrangements that provide sufficient room and areas for children to play and stay occupied while waiting (O'Rourke et al., 2020). Aboriginal participants also expressed sensitivity to the lack of physical and social spaces when everyone congregated in one waiting room (O'Rourke et al., 2020). The implications of these findings in relation to the physical aspects of health care point clearly to the need for healthcare providers to ensure the purposeful design of the physical and temporal aspects of their health services.

4.4.3 Continuity of Care

Continuity of care was raised as an important factor in supporting and enabling Aboriginal people to engage in health care in specialist and tertiary settings (B. Jones et al., 2020; Sivertsen et al., 2022). There are three facets to

continuity of care. The first is the traditional notion of continuity of care considered within the terms of the doctor-client relationship, known as relational continuity of care (Wright, 2018). The second is the availability of appropriate information to allow safe, coherent care, known as informational continuity, and the third is the consistency of care delivery, known as management continuity (Wright, 2018). Good relational continuity and ongoing consultations with the same provider were viewed positively by Aboriginal people, allowing for stronger relationships and better health outcomes (B. Jones et al., 2020).

Individuals with an ongoing relationship with a PHC provider were described as more likely to receive care based on guidelines, preventative care and better coordination of care with other providers to meet client needs (AIHW, 2020). Other benefits of having a continuous doctor-client relationship include improved diagnoses, better medication management, avoidance of repeat tests or other interventions and fewer hospitalisations, particularly for people with complex healthcare needs (AIHW, 2020). Having a usual PHC provider is associated with good communication between the client and provider, greater trust and satisfaction with providers and better health outcomes for clients (AIHW, 2020). Aspin et al. (2012) observed a long-term relationship with one healthcare provider as being beneficial in managing their chronic illness and positively impacting the participants.

4.4.4 Communication

The importance of communication was a major theme identified in the literature, with poor communication with healthcare professionals identified as a negative influence on Aboriginal people's health and wellbeing (Aspin et al., 2012; Durey et al., 2016; B. Jones et al., 2020). Examples of poor communication identified in the literature included health staff using medical terminology, failing to explain health concepts clearly and distributing health education material that lacked cultural relevance (B. Jones et al., 2020). Additional examples included communication being constrained by time limitations (B. Jones et al., 2020), health professionals not seeking family assistance in communicating information to family members with low literacy levels and excluding family from treatment decision-making (Ristevski et al., 2020).

Poor communication between healthcare providers and clients can have severe consequences. Not only does poor communication create a barrier to accessing health care for Aboriginal people, but it was also found to hinder effective self-management of chronic illnesses (Aspin et al., 2012; B. Jones et al., 2020). When communication is lacking, clients may struggle to understand their diagnosis and treatment options, preventing them from fully participating in their own health care (Aspin et al., 2012; B. Jones et al., 2020). Furthermore, poor communication can lead to incorrect diagnoses, delays in treatment and a failure to meet informed consent requirements for tests and procedures (B. Jones et al., 2020). This can result in a lack of awareness by Aboriginal people regarding their own health status, diagnoses and prognoses (Aspin et al., 2012; B. Jones et al., 2020).

Effective communication is critically important for Aboriginal people within healthcare interactions. It is critical in shaping their care experience, fostering trust, enhancing engagement and generating positive outcomes (Jennings et al., 2018). Moreover, it helps to minimise the power imbalance between Aboriginal clients and the health care system (Jennings et al., 2018). However, feelings of shame, embarrassment and being judged can significantly impede their ability to discuss health concerns (Canuto et al., 2018; B. Jones et al., 2020), leading to a sense of disempowerment. This situation, in turn, creates additional barriers to seeking health care in the future, emphasising the need for healthcare providers to consider these factors when treating Aboriginal service users.

Health literacy is an aspect of communication that is crucial in achieving positive health outcomes (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2014). While 59% of Australian adults have reported low health literacy and no national data is available specifically for Aboriginal people, it is acknowledged that health literacy is generally low among the Aboriginal population (Rheault et al., 2019). This situation is evident in the uncertainty expressed by Aboriginal people, who report not knowing which questions to ask their healthcare providers, leading to increased feelings of fear, powerlessness and intimidation (B. Jones et al., 2020).

In one study, communication between health professionals and Aboriginal clients was perceived differently by both parties. Aboriginal clients reported that

the information provided by PHC providers was inadequate and lacked coverage of all aspects of health care; however, PHC providers attributed communication gaps in explaining medicine to a perceived lack of interest or willingness to listen from Aboriginal people (Smith et al., 2017). No other research papers were found confirming the assertion that Aboriginal clients were unwilling to listen to their own treatment information.

4.4.5 Racism

The literature highlights the prevalence of racism experienced by Aboriginal people within the health system. Racism has been found to harm both mental and physical health (Paradies et al., 2015). The harmful effects of racism on physical health include diseases and conditions such as hypertension (Dolezsar et al., 2014), poor self-reported health (Paradies & Cunningham, 2012), obesity (Cozier et al., 2014), adult-onset asthma (Coogan et al., 2014) and cancer (Taylor et al., 2007). The harmful effects of racism on mental health have been shown to include conditions such as psychological distress, depression, anxiety, post-traumatic stress disorder, psychosis and substance abuse disorders (Berger & Sarnyai, 2015; Priest, Paradies, Gunthorpe et al., 2011; Temple et al., 2020). Frequent experiences of racism are associated with nearly five times higher odds of poor mental health and two and a half times higher odds of poor physical health among Victorian adults (Department of Health and Human Services, 2017). In 2018–19, 23% of Aboriginal people reported unfair treatment based on their Aboriginal identity, and approximately 2% reported avoiding health care due to previous unfair treatment (AIHW, 2022e). Racism and discrimination in the recent memories of participants and their families have been found to strongly deter Aboriginal people from accessing mainstream health services today (Lau et al., 2012).

Research provides increasing evidence of the harmful effects of racism in evoking emotional and physiological responses that are harmful to health (Kairuz et al., 2021). Individuals who feel shame in response to racism may internalise the experience, increasing the risk of mental health problems. The detrimental effects of racism on mental health include psychological distress, depression, anxiety, post-traumatic stress disorder, psychosis and substance abuse disorders (Berger & Sarnyai, 2015; Paradies et al., 2015; Priest, Paradies, Gunthorpe et al., 2011; Priest, Paradies, Stewart & Luke, 2011).

Aboriginal people in Victoria are almost three times more likely to experience high levels of psychological distress, partly due to exposure to racism (Markwick et al., 2015). Racism has also been reported to affect physical health, contributing to conditions such as hypertension, poor self-reported health, obesity, adult-onset asthma and cancer (Coogan et al., 2014; Cozier et al., 2014; Dolezsar et al., 2014; Paradies & Cunningham, 2012; Taylor et al., 2007).

Systemic racism within the healthcare sector was another theme prevalent in the literature. Decades of evidence show that interpersonal racism, institutional racism and prejudice within governance and health systems still serve as persistent and significant barriers to accessible health care for Aboriginal people (Gatwiri et al., 2021; Gracey & King, 2009; Hayter & King, 2019; B. Jones et al., 2020). Historically, health services have been absent or inappropriate for the Aboriginal community. For example, accommodation in the public hospital system was segregated until the 1960s due to colonist policies (Hayman et al., 2009, p. 604). Distrust and fear of health services caused by fear of racism and negative government interventions were also reported as barriers to Aboriginal people's access to mainstream health care services (Canuto et al., 2018; B. Jones et al., 2020).

4.4.6 Adverse Prior Experiences

The prior experience of Aboriginal people when accessing PHC is also described in the literature as impacting their health-seeking and health access decisions, with negative experiences reducing the likelihood of returning to that or other services (Canuto et al., 2018). Aboriginal people describe strong memories of experiencing discrimination, feeling patronised, receiving inadequate access to services and poor quality of care (Aspin et al., 2012). Aspin et al. (2012, p. 5) further reported that for several participants, the impact of these types of experiences was intensified by the knowledge that family members, friends and peers also experienced similar prejudicial treatment and that these experiences were 'strongly linked to feelings of frustration, sorrow, fear and distrust'. Aboriginal people who had negative healthcare experiences framed their negative treatment in relation to their Aboriginality and claimed they were treated differently by healthcare workers due to this (Aspin et al., 2012).

The prior experiences of others were reported as another factor influencing healthcare access choices. Community members' experiences and hearsay influenced many Aboriginal clients' perceptions of which health services or providers could be trusted (B. Jones et al., 2020). The mistrust resulting from hearing of other experiences manifested in several ways, from scepticism around the accuracy of staff explanations of diagnosis (Anderson et al., 2008) to a lack of trust in the transferring of their information and care plans between services (Corcoran et al., 2014), to a reluctance to share information with health care providers (Strong et al., 2015). This information is a pertinent reminder of the information spread and shared throughout the Aboriginal community via their strong communal and kinship bonds and that the experiences of others can be a strong factor in healthcare decision-making.

4.5 Personal Factors

Personal factors were identified in the literature review as impacting access to PHC for Aboriginal people, including the impact of shame and fear. These factors and their impacts are described below.

4.5.1 Shame and Fear

Shame, fear and embarrassment were emotions prominent in the literature in relation to Aboriginal people's experiences when accessing PHC (Canuto et al., 2018; B. Jones et al., 2020; Warwick et al., 2019). The combination of these stressors, trauma and disempowerment creates significant barriers to Aboriginal people successfully adopting and maintaining healthy lifestyles (Warwick et al., 2019.). Although shame is a universal emotion, it is experienced in a cultural milieu particular to the Aboriginal culture, which affects how it is indicated and displayed (Warwick et al., 2019). The concept of shame spoken of in Aboriginal communities reflects a low view of self related to intergenerational discrimination, marginalisation, poverty and disadvantage (Warwick et al., 2019).

A common fear identified in the literature was the association between hospitals and death. Several studies reported that some Aboriginal people associated hospitals with death (Baba et al., 2014; Fleming & Parker, 2020; Taylor et al., 2009). This view was more pronounced in rural and remote areas where tertiary hospitals and communication lines to communities may be weak,

causing a vicious cycle of reducing confidence in health care and delayed health-seeking behaviours, driving poorer outcomes (B. Jones et al., 2020).

The attitudes of Aboriginal men and their communities were found to influence their health-seeking behaviours, and shame, fear and stigma were commonly identified barriers (Canuto et al., 2018). Shame or embarrassment prevented Aboriginal men from talking about their health problems and, in some cases, from contacting or accessing health services (Canuto et al., 2018). Fear was associated with breaches of confidentiality, fear of hospital procedures, receiving bad health news and being labelled by others (Canuto et al., 2018). Stigma, in relation to sensitive health issues (mental health and sexual health), was also identified as a barrier to health-seeking behaviour. (Canuto et al., 2018). The findings identify the need for education and support for Aboriginal men seeking healthcare access and for their embarrassment and fears to be allayed by health professionals in a culturally appropriate and safe manner.

4.6 Environmental Factors

Several environmental factors were identified in the literature review as impacting access to PHC for Aboriginal people, which included the impact of reception staff on access choices, the availability of transport options to PHC and appointment availability.

4.6.1 Reception Staff

Among the barriers identified in the literature for Aboriginal people accessing PHC was non-supportive front desk staff (Hayman et al., 2009; Smith et al., 2017). Consumers expressed dissatisfaction when front desk staff failed to ask for their preferences regarding seeing a male or female doctor (Smith et al., 2017). Front desk staff must demonstrate respect and engage in culturally appropriate conversations, particularly when interacting with Elders (Smith et al., 2017). The literature also indicates instances where reception staff spoke condescendingly or rudely to clients, and their body language conveyed a lack of welcome or acceptance, as perceived by Aboriginal service users (Hayman et al., 2009).

Smith et al.'s (2017) research identified a significant disparity between the beliefs of front desk staff and Aboriginal service users. Most front desk staff (80%) reported satisfaction with the respect and support they provided to

Aboriginal clients; however, only slightly over one-third of Aboriginal participants (35.2%) felt the same way. These disparate perceptions highlight the need for significant efforts to ensure Aboriginal clients receive culturally appropriate services, as well as the need for improved training for front desk staff.

4.6.2 Transport

Transport is a significant barrier that affects Aboriginal people's access to mainstream health services, as highlighted in the literature (Durey et al., 2016; Lau et al., 2012; Warwick et al., 2019). Participants from remote communities specifically identified transport as a major obstacle to accessing care (Warwick et al., 2019). Various difficulties contribute to transport barriers, including the unavailability of a registered vehicle, lack of a valid driver's licence, inability to afford petrol, limited or no access to public transportation, challenges in securing rides with family or friends and difficulty finding parking (Canuto et al., 2018; Durey et al., 2016; Lau et al., 2012; Warwick et al., 2019). Transport barriers were reported to lead to Aboriginal people feeling as though they had failed to meet societal norms, such as keeping appointments or arriving on time, resulting in embarrassment and shame, further hindering their access to health care (Lau et al., 2012).

4.6.3 Appointment Availability

A further barrier to PHC access identified in the literature was the difficulty of obtaining an appointment or the long wait times for appointments (Canuto et al., 2018; Isaacs et al., 2012). The length of wait times for appointments was reported to vary significantly based on the geographic location of Aboriginal clients, with rural and remote areas facing longer wait times compared to metropolitan and urban centres.

4.7 International Literature

Further to the revised literature research question, international literature was selectively searched to determine if light could be shed on the experiences of Indigenous people when accessing primary health care during crises. Two articles were sourced which had relevance to this study.

First, Montesanti et al. (2021) researched the experiences of Indigenous people in Canada following the 2016 Horse River wildfire, including Indigenous perspectives of coping, individual and collective strengths that helped

Indigenous residents and communities to cope during and after the wildfire and intergenerational experiences of coping from stress. Montesanti et al.'s (2021) research highlighted Indigenous residents' experiences of disaster evacuation and displacement are impacted by past historical trauma and pre-existing social and economic inequities. Indigenous communities often experience poorer access to health care and significantly higher disease rates, further exacerbating vulnerabilities and their ability to cope during a disaster (Asfaw et al., 2019, 2020). Additionally, past experiences have shown that the impacts of disasters can have severe consequences for Indigenous communities' health, livelihood and economic wellbeing (Christianson, 2014; McGee et al., 2019). Conversely, Montesanti et al. (2021) found that disasters and emergencies also resulted in some positive coping experiences, including strengthened relationships and social networks.

Montesanti et al. (2019) note that it is imperative to situate the experience of Indigenous people and their ability to cope with a disaster event within a sociohistorical colonial context. This statement aligns with the argument of this thesis that the overarching impact of colonisation on Aboriginal people's PHC access is intensified during times of crisis. The research findings that support this argument are expounded in Chapter 9.

Second, a study from New Zealand (Imlach et al., 2021) researched access to primary health care for the general population during the COVID-19 lockdown period and found that 55% of respondents delayed seeking health care. The research found that factors that could influence delay were unclear national public service messages and poor service integration (Imlach et al., 2021). Influential factors at a primary care level included communication and outreach, gatekeeping and staff manner (Imlach et al., 2021). Although Imlach et al.'s (2021) study cohort was the general population, not specifically Indigenous people, the factors listed above from the study reflect factors that were identified from the relevant Australian literature. This indicates that some factors that impact the Indigenous community may have broader application to the general population as well; however, the overarching impact of colonisation would not be a factor for the general population.

4.8 Conclusion

The literature was reviewed to shed light on the experiences of Aboriginal people in relation to accessing PHC during usual times and times of crises. Scant literature was available on the experiences of Aboriginal people in regional and rural areas to access PHC during times of crisis. Due to the paucity of literature to answer this question, the review question was modified to remove the disaster and crisis elements. The new question asked how Aboriginal people in regional areas described their experiences of accessing PHC outside crises. Given that there was also little literature on this topic, the literature search further expanded to include what could be learned from PHC access experiences in urban and remote areas and for specialised interventions rather than holistic PHC. The identified gap in the Australian literature concerning PHC access during times of crisis for Aboriginal people provides a significant opportunity for future research into this topic.

Having provided background context in Chapters 1, 2 and 3 and discussed the literature review in Chapter 4, Chapter 5 now explains and justifies the research methodology and method chosen to address the research question.

Chapter 5 Methodology and Research Design

This chapter describes the methodology adopted for this study, including the paradigms that influenced the research design and methods used to answer the following research question: How do Aboriginal people in Lakes Entrance describe their experiences of accessing PHC during crises? The research design, the rationale for this study and the use of a qualitative, single within-case study method are also presented. The data-gathering method and data analysis are described. This chapter also engages with critical ethical questions about the research, which centre on my identity as a non-Aboriginal woman conducting research with an Aboriginal community.

5.1 Introduction

Chapters 2 and 3 of this research thesis described the past and continuing effects of colonialism on Aboriginal people. The following section presents the connection between colonialism and research, explaining why it is important in determining an appropriate methodology and research design.

From the earliest periods of colonisation, views about Aboriginal cultures and social organisation were based on ‘ill-informed perceptions and assumptions’ (NHMRC, 2018, para. 6). Colonists viewed Aboriginal people and societies through their own European cultural lenses and judged them accordingly (NHMRC, 2018). Through imperialism and colonisation, the West came to *see*, *name* and *know* Indigenous lands, people and resources (Tuhiwai Smith, 1999). Colonisers developed classification systems to manage these discoveries and help observers understand what they saw. For example, they described Aboriginal cultural practices and society in ways that reflected the colonisers’ values, beliefs and prejudices (Tuhiwai Smith, 1999). This approach was a misrepresentation of the lives, culture and society of Aboriginal people. These instruments or technologies of research were also instruments of knowledge that legitimatised various colonial practices (Tuhiwai Smith, 1999). In a colonial context, ‘this research was undeniably also about power and domination’ (Tuhiwai Smith, 1999, p. 60). These developments gave colonial researchers authorship and ownership of knowledge. As Tuhiwai Smith (1999, p. 42) stated:

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

Research in Aboriginal communities and with Aboriginal people has a long and problematic history. Research has long been used as an instrument of oppression, imperialism and colonialism (Held, 2019; NHMRC, 2018; Walter & Suina, 2019). The idea of categorising and ranking human beings into superior and inferior races is integral to Western thinking and spread through colonial expansion, justifying the discriminatory treatment of Indigenous people (NHMRC, 2018). In this way, research was an overt tool of colonial control, espousing and enacting racial pseudoscientific theories (Tuhiwai Smith, 1999). Racialised ideas and theories also informed social policies and legislation within Western countries and in the newly established colonial settlements (NHMRC, 2018), from social exclusion to structural injustice (Vivian & Halloran, 2022). For example, in 1819, the Crown Law Office determined that Australia had been taken possession of 'as desert and uninhabited' (Vivian & Halloran, 2022, p. 568). The legal elimination of Aboriginal people then permitted the Australian Constitution to be written without reference to Aboriginal people or their rights, based on the assumption that Australia would become a *white continent* (Deakin, 1903).

Further, Duke et al. (2021) suggest that the dominance of Western intellectual and moral epistemological and ontological approaches to Aboriginal health research has resulted in ineffective research outcomes at the expense of Aboriginal governance and knowledge systems. Aboriginal people have long been researched by non-Aboriginal people as subjects without understanding and consenting to the research and commonly without meaningful engagement or access to the results (Kennedy et al., 2022). It was, therefore, critically important to me that my research was designed in a way that met the ethical standards for research with Aboriginal people, as described by guidelines such as the Ethical Conduct in Research with Aboriginal and Torres Strait Islander People and Communities: Guidelines for Researchers and Stakeholders

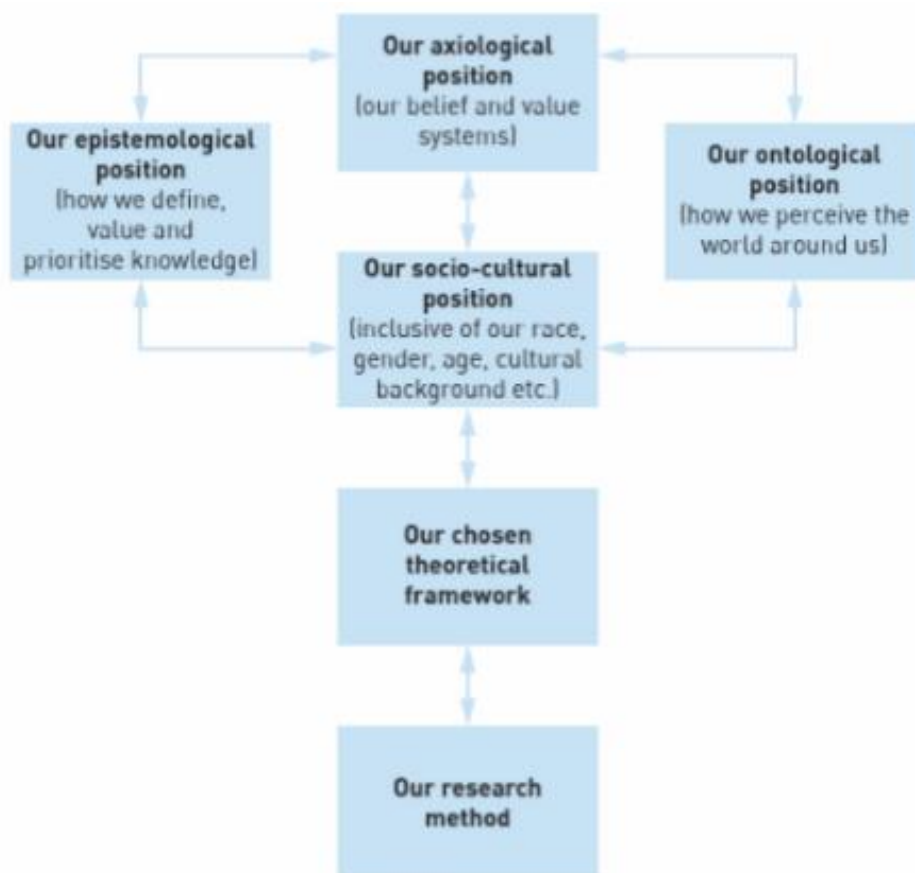
(NHMRC, 2018) and the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (AIATSIS, 2020). The ways these standards influenced this research design are explained in Section 5.2.3.

5.2 Methodology

The methodology is ‘the worldview influenced lens through which the research question and core concepts are understood, and translated into the research approach we take’ (Walter, 2019, p. 12). The methodology enables us to see where values, theories and worldviews interact with social research and why the methodology is appropriate to address the research question (Walter, 2019). The researcher’s methodology is influenced by certain epistemological and ontological assumptions and beliefs (Creswell, 2018). Figure 5.1 below shows how the elements of a methodology combine to produce the chosen theoretical framework (Walter, 2019), and these elements are discussed below.

Figure 5.1

Conceptualisation of a Methodology



Note: Walter, M. (2019). *Social research methods* (4th ed.). Oxford University Press.

5.3 Axiology

As explained above, research conducted in Aboriginal communities and with Aboriginal people has a long and problematic history (NHMRC, 2018; Tuhiwai Smith, 1999). Key criticisms have included, but are not limited to:

1. A focus on descriptive research that has done little more than document the extent of Aboriginal people's disadvantage and that has made minimal impact in improving health conditions for Aboriginal people (Bainbridge et al., 2015b; Kinchin et al., 2017).
2. Research that has been considered damaging and harmful, and insensitive, intrusive and exploitative (Bainbridge et al., 2015b).
3. Research practices that have perpetuated the exploitative history of colonialism and objectivisation of Indigenous people (Tuhiwai Smith, 1999).
4. Despite the identification of some clear research priorities for improving health outcomes, they have not been translated into action (NHMRC, 2018).
5. A failure to partner with Aboriginal people and organisations and thereby to meet Aboriginal people's real needs (Harfield et al., 2020).

According to Indigenist academics, an additional caution is to avoid qualitative findings, collection and interpretation as 'exoticism' (Tuhiwai Smith, 1999). Any research that primitivises Aboriginal people positions those people as *other* (Waite, 1999). This positioning reduces Aboriginal people to an *exotic stereotype* while exploiting and excluding Aboriginal people from non-Aboriginal society (Stasch, 2014, p. 192). The following approaches were taken in this research to embody the best ethical research practice with Aboriginal communities.

First, as a non-Aboriginal researcher conducting research in an Aboriginal community, it was important that all aspects of my research were informed by and approved by the local Aboriginal community. To ensure this occurred, I sought input from LEAHA and created a formal partnership agreement between myself and LEAHA to ensure local Aboriginal community input and oversight of the research proposal, methodology, analysis, dissemination and usage.

Second, as Martin (2008) notes, it is beholden to both Aboriginal and non-Aboriginal researchers to consider where they stand in relation to the protocols and beliefs of the Aboriginal people with whom they work and to be transparent about where they philosophically and intellectually situate themselves. In this research, I have been transparent about where I philosophically and intellectually situate myself, as discussed in the previous section. Whenever there was any doubt about safe cultural practice, I referred to the LEAHA CEO, Ms. Paula Morgan, who played multiple roles during this research process: that of critical friend and that of cultural adviser and reviewer of findings.

Third, informed by the National Statement on Ethical Conduct in Human Research (NHMRC, 2018), the Australian Code for the Responsible Conduct of Research (2018), and the AIATSIS (2020) Code of Ethics for Aboriginal and Torres Strait Islander Research, I aimed to establish a reciprocal relationship with Aboriginal organisations, in which the research provided a clear benefit to them. The research that has been undertaken in the Lakes Entrance community will be used by LEAHA to inform planning for future crisis management, be used as supporting material in grant applications for funding to support crisis planning, as well as funding applications for the improvement of PHC access in the Lakes Entrance region. Additionally, the research findings will be used by LEAHA to approach local healthcare providers to address PHC access issues uncovered in the research and work towards joint solutions.

Fourth, as noted above, my research and standpoint were framed by my experience. My education and training as a teacher and health services manager, and my previous work with the Aboriginal community influenced the choice of methods and the sociocultural frameworks engaged in this research. The formal and informal privileges of being a white, tertiary-educated, female health services manager operated consciously and unconsciously at the individual, communal and institutional levels. My values and identity are shaped by layers of family, work and life experiences. These factors combined to influence this research design, as described in Section 5.2.2.

Full engagement with this country's knowledge systems, entities and Aboriginal ancestors is not possible in the same way for a non-Aboriginal

researcher as it would be for a local Aboriginal researcher. Nevertheless, there remain responsibilities to demonstrate respect, reach out to Aboriginal custodians, Elders and leaders, and acknowledge their relatedness in the places where the study is located. These strategies have been explained in this section. Ethical approval for this research project was provided by the La Trobe University Human Research Ethics Committee (HEC20390), and the research was conducted according to the approval requirements.

5.4 Ontology

My ontological position, or how I perceive the world around me, aligns with an interpretivist paradigm. An interpretive approach to research embraces a view of reality as socially constructed, seeks to understand the perspectives and worldviews of those involved and has the capacity to provide detailed descriptions of everyday activities and interactions (Bloor, 2006).

To inform my worldview, I drew on the teachings and Indigenist methodologies of Tuhiwai Smith (1999) and Rigney (1999). Tuhiwai Smith (1999) argues that Western anthropology still constantly affirms the dominant culture's view of itself as the centre of legitimate knowledge and production. Tuhiwai Smith rejects positivism, seeing it as only valuing scientifically *proven* knowledge and argues that using a Western model meant that researched *truth* can only ever be defined by the imperialist researcher (1999, p. 35). While this research does not use Indigenist methodology, it has nevertheless been influenced by Indigenist writings. For example, Rigney (1999) says that the colonial history of Australia and its impact on Aboriginal people must be understood before commencing any research with Aboriginal people. I have described the impact of colonialism in Chapters 2 and 3 concerning health impacts while acknowledging that the social and cultural impacts go far beyond what is described in this research study. Rigney's (1999) principles of Indigenist research include privileging Aboriginal voices and amplifying the voices of Aboriginal people. This research has been conducted respectfully, and I have endeavoured to remain mindful of the role that colonisation has played and continues to play in the lives of the Aboriginal community.

Aboriginal people are diverse in language, culture and context. They are bound together by shared ontological viewpoints and knowledge that situate

their societies and relationships with all things (Blackstock et al., 2020). A shared tenet of Aboriginal worldviews is the interconnectedness of all living and non-living beings and things (Blackstock et al., 2020). The implications of this for my research is my acknowledgement that Aboriginal knowledge systems are holistic and relational, including Country, culture, spirituality, community and family as equal knowledge holders (Centre for Research Excellence - Strengthening Indigenous Health Care Equity, 2020). This research considers the connectedness and intersectionality of the elements of Aboriginal worldviews, and this is discussed in the findings in Chapters 6, 7 and 8.

5.5 Epistemology

A constructivist epistemology explores what it assumes to be a socially constructed dynamic reality through a framework that is value-laden, flexible, descriptive, holistic and context sensitive; that is, an in-depth description of the phenomenon from the perspectives of the people involved (Yilmaz, 2013). It is based on the epistemological assumption that social phenomena are so complex and interwoven that they cannot be reduced to isolated variables (Yilmaz, 2013). It tries to understand how social experience is created and given meaning. Therefore, the researcher aims to develop a close, empathic relationship with people to understand their experience (Creswell, 2018; Denzin & Lincoln, 2011).

5.6 Sociocultural Position

The researcher's sociocultural position is said by Aboriginal academic Walter (2019, p. 14) to be 'the defining element of our methodology', and the 'culmination of our axiological, ontological and epistemological positions'. In undertaking this research, I acknowledge my worldview, my sociocultural position, is comprised of numerous intersecting factors. I was born and raised and have lived in regional areas all my life. The beliefs and value systems I hold in relation to this research topic have been shaped by who and what I am. I was raised with politically left-leaning parents who had an active interest in social justice matters. I have lived in Lakes Entrance for 18 years, am a community member, and I work and socialise with members of the local Lakes Entrance Aboriginal community. As a 46-year-old white woman with secure full-time work and a home, and as a mother of three children, in good physical health, with an ongoing university education, I am aware of my privilege.

A researcher's positionality influences how the research is designed, conducted, outcomes and results (Holmes, 2020). Positionality, therefore, can be seen to affect the totality of the research process. It acknowledges and recognises that 'researchers are part of the social world they are researching and that this world has already been interpreted by existing social actors' (Holmes, 2020, p. 3). In this section, I have explained my position. I now add that I also position myself as an ally to the cause of improving Aboriginal health through supporting Aboriginal rights to cultural identity, beliefs, ancestry, lands and waters, and in equal measure, support the right of Aboriginal people to all the services and knowledge that modern Western health and Australian society have to offer its citizens.

In addition to the above, I acknowledge that I am an outsider to the cohort with whom I conduct research. Merton's (1972, p. 21) long-standing definition of insiders and outsiders is that 'insiders are the members of specified groups and collectives or occupants of specified social statuses: Outsiders are non-members'. I am not a member of the Lakes Entrance Aboriginal community. I know that I cannot fully understand the experiences described by the participants. I do not have their worldviews, have not had their lifetimes of cumulative experiences and do not exist within their social and cultural environment. What I have is the capacity to listen and a commitment to interpret their experiences with confirmation from Aboriginal Elders. I also have the ability to collate these experiences into themes, which can be analysed, checked and confirmed by people with cultural knowledge and used by the local community to plan for improvements to PHC access during times of crises.

5.7 Qualitative Research Design

The research design used to address the research question of 'How do the Aboriginal community of Lakes Entrance describe their PHC access during both usual times and times of crises?' utilises a qualitative research approach. Qualitative research aims to illuminate the contextual understanding of participants and their perspectives—exploring, describing and generating arguments and explanations for social phenomena. Yilmaz (2013, p. 312) defines qualitative research as 'an emergent, inductive, interpretive and naturalistic approach to the study of people, cases, phenomena, social situations and processes in their natural settings in order to reveal in descriptive

terms the meanings that people attach to their experiences of the world'. These factors made it an appropriate design to address the research question.

Qualitative researchers stress the socially constructed nature of reality, the intimate nature of the relationship between the researcher and what is being studied and the situational constraints that shape inquiry (Denzin & Lincoln, 2011). Qualitative research emphasises the meaning that people give to social interactions and sees the human world as a place of meaning in which our actions take place based on shared understandings (Walter, 2019).

5.8 Case Study

A case study research approach was chosen as a valuable way to answer *how* and *why* questions, topics that demand in-depth research using a holistic lens (Yin, 2014). It does not require control over actual behavioural events. I chose to pursue a research approach aligned with that of Stake (2010) because his approach to case study research is qualitative and closely aligned with constructivist and interpretivist orientations. It is underpinned by a strong motivation to discover meaning and understand experiences in context. In this approach, the role of the researcher in producing this knowledge is critical, and the researcher's interpretive role is essential (Stake, 1995). Again, this aligns with the interpretivist perspective underlying this research study, entailing the premise that multiple realities and meanings exist, which depend on and are co-created by the researcher (Stake, 1995).

The intrinsic single case study I used is underlined by a constructivist paradigm and focuses on a case because it is of interest in its own right; in other words, the case is *intrinsically* interesting (Stake, 1995). The case of the Lakes Entrance Aboriginal community accessing PHC during crises is interesting in and of itself. While the results of a case study are not generalisable in a way that quantitative researchers would recognise, it is argued that findings from a single case may be *transferred* (Guba & Lincoln, 1994) or *re-contextualised* (Morse, 1994) to other contexts.

Utilising case study research to address this research question enabled the examination of the data within the context of their use (Yin, 2014), that is, within the Lakes Entrance community. Attempting to understand the factors affecting how Aboriginal people in East Gippsland describe their experiences of

accessing PHC before and during natural disasters and pandemics would have been difficult without the contextual picture provided by the case study approach (Patton, 2002). The qualitative case study research design provided rich data and resulted in the highlighting of previously unstudied aspects of disaster health care for a minority and marginalised cohort.

5.8.1 Method and Phases of the Research

How data are gathered and analysed to respond to a research question or hypothesis comprises our research methods (Crotty, 1998). Many sources and methods of data collection and analysis can be used in case study research. However, interviews and observations are the preferred and dominant data collection methods (Stake, 2010). I used semi-structured interviews for my research, which allowed for collecting rich data from participants. In case study research, Stake (2010) recommends vignettes—episodes of storytelling—to illustrate aspects of the case and thick descriptions to convey findings. This approach also enables other researchers to make assessments of transferability. Consequently, vignettes demonstrate my research findings in Chapters 6, 7 and 8.

5.9 Phase 1: Literature Review

Chapter 4 described the literature review that was undertaken to address the research question and revealed that the research question was unable to be answered from the literature review alone.

5.10 Phase 2: Identification and Recruitment of Participants

This research had clearly defined criteria for inclusion: adults who self-identify as Aboriginal and are accepted as such by local Elders and the local Aboriginal community. Research participants must also have attempted to access PHC before or during a crisis and live in the Lakes Entrance region. Recruitment strategies included advertisements at both LEAHA and LTH&CS, and some participants were approached on advice from the CEO at LEAHA. Participants were also recruited via snowball sampling, which involves asking interviewees if they are aware of other people who might be relevant to approach about participation in the study (Flick, 2018).

Within an interpretivist framework, there are no fixed rules regarding the ideal number of participants. Travers (2001, p. 37) unhelpfully advises that

researchers need 'enough data to explore and document a range of themes'. In any qualitative study, the number of participants required to achieve findings saturation is much smaller than those used in quantitative studies because the point of diminishing returns to qualitative sampling means that further interviews do not add sufficient additional information to justify conducting them (Mason, 2010). A smaller sample size is sufficient, as qualitative research is concerned with understanding and making meaning rather than creating hypotheses (Crouch & McKenzie, 2006), and because of the labour-intensive nature of qualitative research, a large sample is impractical (Mason, 2010). Data saturation, or findings saturation, is 'the point at which no new information or themes are observed in the data' (Guest et al., 2006, p. 62). This point was reached at interview number 11; however, interviews continued to a total of 18 to meet the suggestions of the cultural adviser and ensure I had interviewed a representation of the community.

5.11 Phase 3: Data Collection

The principal method adopted for this research was in-depth interviewing. This is a form of qualitative interviewing that attempts 'to understand the world from the subjects' points of view, to unfold the meaning of people' [sic] experiences, to uncover their lived world' (Kvale, 1996, p. 1). Significantly, interviewing is a particularly efficient means of collecting data when the research design involves an analysis of people's motivations and opinions (Keats, 2000), as was the case in the present research study.

A total of 18 in-depth interviews were conducted throughout the data-gathering process, with participants ranging in age from their 20s to their 70s. Table 5.1 below details the interview participant details:

Table 5.1*Interview Participant Details*

Interview number	Pseudonym	Interview location	Age (years)	Gender
1	Anne	Lakes Entrance LEAHA	40–50	F
2	Bec	Lakes Entrance LEAHA	40–50	F
3	Carol	Lakes Entrance LEAHA	20–30	F
4	Dan	Lakes Entrance LEAHA	20–30	M
5	Elaine	Lakes Entrance LEAHA	20–30	F
6	Flora	Lakes Entrance LEAHA	70–80	F
7	Gwen	Lakes Entrance LEAHA (phone)	60–70	F
8	Holly	Lakes Entrance LEAHA (phone)	50–60	F
9	Ian	Lakes Entrance LEAHA	50–60	M
10	John	Lakes Entrance LEAHA	40–50	M
11	Karen	Lake Tyers Trust LTH&CS	50–60	F
12	Linda	Lake Tyers Trust LTH&CS	30–40	F
13 & 14	Molly & Nina	Lake Tyers Trust LTH&CS (group interview)	70–80 70–80	F
15 & 16	Orla & Penny	Lake Tyers Trust LTH&CS (group interview)	60–70 60–70	F
17	Quinn	Lake Tyers Trust LTH&CS	50–60	M
18	Rachel	Lake Tyers Trust LTH&CS	50–60	F

The semi-structured interviews were planned to be conducted face-to-face. Due to the government-mandated COVID-19 restrictions on meeting in person enforced in Victoria throughout 2020 and 2021, 14 interviews were conducted face-to-face and two via telephone. The face-to-face interviews were conducted at LEAHA and Lake Tyers Health and Children's Services (LTH&CS), the ACCHO's providing a familiar and comfortable venue for participants. There is no set time for an unstructured interview, and it is possible for an in-depth interview to take several hours; however, I planned that each interview would take approximately one hour. I based this duration on my estimation of the time participants would be willing to devote and the time deemed appropriate by Smith et al. (2009). In practice, interviews ranged in time from 40 minutes to

93 minutes, with 10 to 15 minutes of general conversation before the interviews commenced.

My aim to understand the participants' perspectives through semi-structured interviews meant entering the psychological and social world of the participants (Yin, 2014, p. 135). For this to occur, the participants needed to take part in guiding the interview, allowing me to probe emergent issues and follow up on the participants' interests or concerns. Open-ended questions are recommended by many researchers to 'understand and capture the points of view of other people without pre-determining those points of view' (Patton, 2002, p. 21). Although I acknowledge that interviews should flow naturally and set questions are to be avoided (Smith et al., 2009), the open-ended questions acted as a prompt for me as the researcher and to generate flowing conversation.

By signing the consent form (Appendix C), participants permitted interviews to be audio recorded and transcribed for textual analysis. Interviews were transcribed immediately following the interviews. I took hand notes following each interview to highlight topics to follow up later or to pursue in following participant interviews. After the transcription of each interview, I removed participants' details and identifying information from the textual data, replacing these with a code index. All interviewees were also offered a transcript of the interview; however, none of the 18 participants accepted this offer.

Although I conducted most semi-structured interviews individually, as Smith et al. (2009) recommended, two interviews involved interviewing two participants together. These took place at Lake Tyers Trust at LTH&CS, and both involved family members who were more comfortable speaking with me as a pair. Research participants were given a \$25 Coles Myer voucher for the time they spent being interviewed. I considered it essential to reimburse the participants for their time, given the problematic history of Aboriginal people being taken advantage of for research purposes.

5.11.1 Data Analysis

There is no singularly appropriate way to conduct qualitative data analysis. However, there is general agreement that analysis is 'an ongoing, iterative process that begins in the early stages of data collection and continues

throughout the study' (Bradley et al., 2007, p. 1760). The data analysis aims to rigorously and creatively organise, find patterns in and elicit themes from data (Houghton et al., 2015). There must be logic behind the analysis and, therefore, a framework (Yin, 2014). Morse (1994) provided an all-encompassing framework for analysis based on four stages: comprehending, synthesising, theorising and recontextualising. This framework provides a foundation for the four stages of analysis; however, Morse (1994) does not provide details about how to enact them, so strategies for analysis are also required. The data analysis strategies utilised in this research are those proposed by Miles and Huberman (1994). These processes involve broad coding, pattern coding or memoing, distilling and ordering and testing executive summary statements and developing propositions (Miles & Huberman, 1994), and have been acknowledged as influential in case study research (Evers, 2016; Yin, 2014). An overview of the framework analysis used in this research is provided in Table 5.2.

Table 5.2

Overview of Framework Analysis

Stages of analysis Morse (1994)	Analysis strategies (Miles & Huberman, 1994)
1. Comprehending	Broad coding
2. Synthesising	Pattern coding/memoing
3. Theorising	Distilling and ordering/testing executive summary statements
4. Recontextualising	Developing propositions

Note. Adapted from Morse's and Miles and Huberman's Stages of Analysis (Morse, 1994; Miles & Huberman, 1994).

5.12 Stages of Analysis

Each stage of Morse's (1994) analytical framework is described below, outlining how the analytical strategies of Miles and Huberman (1994) were enacted in this research.

5.12.1 Comprehending

The first stage of the analytic framework (Morse, 1994) is comprehending, which begins while collecting data. The aim is to gather sufficient data to write a complete, detailed, coherent and rich description (Morse, 1994). This step was actioned using the analytical strategies of Miles

and Huberman (1994), which involved initial coding named *broad coding*. A code is a descriptive or conceptual label assigned to raw data excerpts (Gale et al., 2013). Codes are tags (Miles & Huberman, 1994) or labels assigned to whole documents or paragraphs, sentences or words, which help catalogue key concepts while preserving the context in which these concepts occur. Codes can be identified in numerous ways and for different purposes concerning the research questions. Broad coding aims to uncover and develop concepts, and the text must be opened so that thoughts, ideas and meanings can be exposed (Miles & Huberman, 1994).

To assist with coding, I utilised a software program called NVIVO12. NVIVO12 is a tool for managing unstructured text, audio, image and video data. These codes were identified by single words with a description of each included in the NVIVO program. This initial coding related generally to the research questions and the interview, focus group and survey questions. At that initial stage, 46 codes were generated, which were merely descriptive and many more than were manageable. These initial broad codes related to the location of participants, either LEAHA or LTH&CS, the topics that were covered in the interview, such as COVID-19, bushfires and crises, participant identities, such as male or female, and codes, such as Question 1, Question 2.

As Creswell (2018) suggested, this initial coding was reduced during the second coding stage. The reduction process occurred in two stages: (a) by deleting codes that were redundant or where there was overlap and (b) by identifying or adjusting codes to address key issues as informed by the review of the literature. In this stage, more defined issues were beginning to emerge. This stage saw coding become more defined, and the use of codes such as reception staff, car availability and previous experience started to emerge.

Some experts (Janesick, 2003; Morse, 1994) argue that a single researcher conducting all the coding is sufficient and preferred. This approach is particularly true in studies where being embedded in ongoing relationships with research participants is critical for the quality of the data collected. In such cases, the researcher is the instrument; data collection and analysis are so intertwined that they should be integrated with a single person who is the *choreographer* (Janesick, 2003) of his/her own *dance*. Such an analysis may not

be possible to be repeated by others who have differing traditions and paradigms; therefore, disclosure of the researcher's biases and philosophical approaches is important. In contrast, other experts recommend that the coding process involve a team of researchers with differing backgrounds (Pope et al., 2000) to improve the breadth and depth of the analysis and subsequent findings. My research analysis follows Morse's (1994) stages, and given the interpretive paradigm of this research, it was appropriate that the coding was conducted by a single person—myself—in conjunction with LEAHA input.

5.12.2 Synthesising: Data Organising and Sorting

The next stage of the analysis framework is synthesising, which involves merging perceptions and cases to describe typical composite patterns (Morse, 1994). This step was achieved by organising and coding the data via pattern coding and involved explanatory, inferential codes to create a more meaningful analysis (Miles & Huberman, 1994). The pattern coding results were discussed and refined with an Aboriginal adviser from LEAHA.

Another synthesising strategy used was writing memos, also known as executive summary statements. From the pattern codes, memos were formulated. Memos are summaries of key information derived from the coding system; they lay the foundation for further development of propositions regarding the data (Miles & Huberman, 1994). These were drafted against each theme.

Through this reduction process, I gradually developed a sense of the main themes emerging from this research. The data interpretation, coding and thematising were iterative processes, including checking the original data and revisiting the research question at each stage. At this stage, some themes were beginning to emerge prominently, such as the importance of the location and type of service provider to the overall experience, while other themes were still unclear.

5.12.3 Theorising

The third stage of Morse's (1994) analysis framework is theorising. Despite the title, this stage does not necessarily focus on developing theory but rather examining relationships among the data. Concerning the strategies proposed by Miles and Huberman (Lawrence et al., 2013, p.33), this involves

‘building towards a more integrated understanding of events, processes and interactions in the case’. It is an active, continuous, and rigorous process of viewing and challenging the data (Morse, 1994). This stage was particularly important for making comparisons and contrasts among participants’ views. It provided a clearer picture of the participants’ perceptions and how these formed into the overall identifiable research themes. At this stage, the overall umbrella factor of colonisation became very clear as being an influencing factor on the sub-themes that had emerged.

5.12.4 Recontextualising: Displaying, Verifying and Drawing Conclusions

The final stage of Morse’s (1994) framework is developing propositions. This stage involves the formalising and systemising of data into a coherent set of explanations (Miles & Huberman, 1994). It is the displaying, verifying and drawing of conclusions from the data. The data management and organisation processes described in stages 1–3 of the analysis were straightforward and described in the literature (Walker et al., 2008). The fourth step of analysis, meaning making from the abstract and development of themes, presented the greatest challenge for me and for which Morse (1994) provided the most significant direction. Morse (1994, p. 33) described this process as one ‘of speculation and conjecture, of falsification and verification, of selecting, revising and discarding’.

I was able to identify the commonalities and differences emerging from the analysed data and present them as themes. Themes can be defined as ‘general propositions that emerge from diverse and detail-rich experiences of participants, and provide recurrent and unifying ideas regarding the subject of inquiry’ (Bradley et al., 2007, p. 1762). Themed qualitative data analysis is used to characterise the experiences of individual participants by general insights from the whole of the data. The emerging themes could all be categorised under an umbrella theme of colonisation and were then divided into three further themes. As discussed in Chapter 1, Andersen et al.’s (2013) BMHSU was adapted, and his three determinant categories, predisposing, enabling and need factors, are replaced in this study by three themes: (a) service delivery factors, (b) personal experiences and (c) environmental factors, and their sub-themes. Further sub-themes were identified and confirmed from these three categories

with my cultural adviser. These are all discussed in detail in the research findings in Chapters 6, 7 and 8.

5.13 Communication of Research Outcomes

This research was co-designed with a cultural advisory panel, and findings and implications were also designed with the co-creators.

5.14 Conclusion

This chapter has described the methodological considerations of this research project, including a detailed description of the methodology and the considerations of research being undertaken within an Aboriginal community by a non-Aboriginal researcher. It also described the strategies used to ensure that the research was conducted ethically and culturally appropriately. The use of a case study research method as appropriate for conducting this research was explained and justified, and the method and phases of research were described in detail. The strategies for data analysis and how they were used in this project were explained. An explanation of the four criteria for ensuring quality research as proposed by Lincoln and Guba (1985) and how these have been incorporated into this research design concluded the chapter. The next chapter describes the first theme of the research findings—service delivery factors.

Chapter 6 The Impact of Service Delivery Factors on the Healthcare Experience for the Lakes Entrance Aboriginal Community

6.1 Introduction

This thesis now turns to the research findings presented in Chapters 6, 7 and 8. The research findings were categorised into three themes under the overarching theme of colonialism: service delivery and personal and environmental factors. These three themes were then further broken down into three sub-themes, all of which were found to have impacted the experiences of Aboriginal people accessing PHC during both crisis and normal times. These are reflected in Table 6.1 below.

Table 6.1

Graphic Depiction of Research Themes

Overarching theme		Colonisation	
Themes	Service delivery factors that were found to impact the healthcare experience	Personal experiences that were found to impact the healthcare experience	Environmental factors that were found to impact the healthcare experience
Sub-themes	• Type of service provider • Continuity of care • Communication	• Shame and fear • Intergenerational trauma • Prior experience or racism	• Transport • Medical bureaucracy and infrastructure • Priorities other than health

The present chapter, Chapter 6, presents the first theme, that of service delivery factors impacting health care experiences. Chapter 7 discusses the second theme, the impact of personal experiences on the healthcare experience and Chapter 8 discusses the third theme, the impact of environmental factors. The factors identified in the research are all described and analysed in relation to the participants' lived experiences when accessing PHC both during usual times and during the crises of the 2019–2020 bushfires and the COVID-19

lockdown restriction period. It is important at this point to acknowledge that the above themes and sub-themes are not discrete. They both overlap and run in parallel, with more than one theme or sub-theme often in evidence in the participants' responses.

6.2 Service Delivery Factors

6.2.1 Lakes Entrance Community Medical Options

The Lakes Entrance Aboriginal community have several medical healthcare options. These include attending a private GP clinic, a community health care medical clinic and the two ACCHOs. The private and community health care medical clinics are located in Lakes Entrance.

The first ACCHO is LEAHA, which is in Lakes Entrance and is co-located with Gippsland Lakes Complete Health, the local community health centre. LEAHA does not have doctors onsite; it has nurses available to perform consultations and support LEAHA clients' health needs. If a medical consultation is required, the LEAHA staff arrange for their client to be seen at the local community health organisation, Gippsland Lakes Complete Health, where many doctors work. LEAHA currently serves 468 Aboriginal clients in the Lakes Entrance area, providing a range of PHC services, including chronic care, allied health workers and nursing and GP services (LEAHA, 2023). Over the past year, LEAHA has delivered 8,300 instances of care (LEAHA, 2023).

The second ACCHO is Lake Tyers Health and Children's Centre (LTH&CS), which is located onsite at the Lake Tyers Trust and is staffed by two nurses, one full-time and one part-time, by a doctor who attends on Tuesday mornings from a local community health centre and by various other visiting health care professionals.

6.2.2 The Impacts of the Type of Healthcare Service on the Participants' Healthcare Experience

The interviews revealed that the type of PHC service offered played an important role in the client's experiences. The research participants highlighted the role of ACCHOs in the provision of health care services as being of critical importance. When accessing health care during regular times, participants strongly preferred to seek PHC via the two ACCHOs, LTH&CS and LEAHA, rather than via what they termed *mainstream* healthcare providers. This theme

was one of two predominant themes that concerned the impact of the type of health care service on the health care experience, the other being the comfort level participants had liaised with the ACCHO staff.

The first sub-theme identified, the preference for attending their local ACCHO, was evident from participant interviews, irrespective of whether they lived at Lakes Entrance or Lake Tyers Trust. Multiple reasons were provided for this. Appointments are not made to see the doctor at LTH&CS. Residents can come and wait in the waiting room; if too many people are waiting, they can leave and come back later. LTH&CS residents view the centre as a warm and welcoming place where residents feel comfortable attending, as evidenced by John's comment, 'I know them and they know me, and I just drop in when I need to see someone, and they sort me out'. Residents' artwork is displayed alongside community notices. Community lunches and meetings are held in the health centre, and the residents are known and acknowledged by name.

When appointments are made by LEAHA staff to see the GP at Gippsland Lakes Complete Health, participants can wait at LEAHA in their waiting room and be called over to the Gippsland Lakes Complete Health mainstream waiting area when the doctor is ready. Participants expressed a clear preference for waiting at LEAHA rather than in the mainstream medical clinic waiting room, as illustrated by Elaine's reflection that she 'just feels more comfortable waiting at LEAHA, have a chat and a cuppa here'. Various reasons were given for this, including not liking to sit in the Gippsland Lakes Complete Health waiting room where they felt uncomfortable, judged by other service users and not seeing other Aboriginal people in the waiting room. This element of the participants' responses is covered in Chapter 7.

The second sub-theme identified was that of respect for the ACCHO staff. Participants who attended LTH&CS explained that they see the nurses for many of their health concerns. The full-time nurse has worked at the Trust for the past 20 years, and the relationship that she has built with residents is evident in their stories. Participants told of feeling comfortable with the nurses, which was demonstrated in observations, such as 'she (the nurse) sits in with me and explains stuff if I don't know' (Nina) and 'I don't mind if the doctor ain't there, 'cause the nurses know all about me medication and stuff anyways' (Quinn).

Nurses also perform consultations and advise the residents if they need urgent medical care and their issue cannot wait until the following Tuesday morning for the doctor's visit. If this is the case, the nurses will call the community health clinic or private medical clinic in the local town of Lakes Entrance and make an appointment on behalf of the resident. Overwhelmingly, when referred to Lakes Entrance for follow-up appointments, residents strongly preferred seeing the doctor who usually sees them at the Trust. This preference causes issues when the doctor is booked for the day and has no available appointments. This situation is evident in Penny's remark that she 'would rather see no one, than have to see someone I don't know'.

Participants who attend LEAHA also spoke of the support provided by their ACCHO staff, with their views reflecting those of the LTH&CS attendees. It was common for participants to speak of how knowledgeable and supportive the ACCHO staff were and how they were 'community'. Comments including 'they know me and me family and chat with me when I come in' (Elaine), and 'I like coming to LEAHA because they've got everything I need here, and they know our mob – they just gets us' (Holly) appear to reflect the importance of these relationships to Aboriginal people's health care access.

ACCHOs are PHC services that are initiated and operated by the local Aboriginal community to deliver holistic, comprehensive and culturally appropriate health care to the community that controls it through a locally elected Board of Management (Pearson et al., 2020). As Khoury (2015, p. 472) points out, ACCHOs 'transcend the concept of a specialised medical clinic and function as community spaces through which Indigenous people attempt to deal with their immediate health needs and the underlying structural causes that produce very poor health outcomes'.

The finding that participants preferred to access PHC via their local ACCHO was unsurprising and is consistent with the literature reviewed in Chapter 4, for example (Panaretto et al., 2014; Pearson et al., 2020). Aboriginal people intimately understand that health is a complex integration and balance of physical, environmental, emotional, social, spiritual and cultural wellbeing (Pearson et al., 2020), and this complexity is not reflected within the mainstream Australian healthcare system. Therefore, to deliver health services that provide

holistic health care and embody Aboriginal culture, Aboriginal people developed an alternate model of PHC in ACCHOs.

The ACCHO sector is recognised for its provision of holistic and comprehensive PHC. Part of their success is attributed to the trust that Aboriginal people place in them, primarily due to their culturally appropriate service delivery (Pearson et al., 2020). The Aboriginal community knows how best to administer specialised health care, health promotion and health interventions to its members (Naren et al., 2021). LEAHA and LTH&CS utilise such strategies in their communities, and the community's trust in them is evident in the preferences of their communities to access health care via their service. Indeed, in a study comparing outcomes and indicators between ACCHOs and mainstream services, ACCHOs performed better in terms of best practice care, monitoring clinical performance, increasing engagement of Aboriginal community members and better leadership in training non-Aboriginal staff in Aboriginal health matters (Panaretto et al., 2014). This finding is reflective of the participants' responses.

6.2.3 Experiences of Access During Crises

During times of crisis, the usual delivery of healthcare services is disrupted. Services are often unable to be delivered in the same location, with the same staff or in the same mode as usual.

During the 2019–2020 bushfires, participants reported that many factors impacted the delivery of health care services to the Lakes Entrance Aboriginal community. These included the physical location of the participants themselves, as participants evacuated to either the local evacuation centre at Bairnsdale or to relatives or friends in areas not affected by bushfires. A shortage of local GP appointments due to GPs themselves being affected by the bushfires was another critical factor affecting service delivery. Participants recounted a reluctance to seek any health care support from medical providers that they did not know and said they preferred to wait and see their usual provider once they could get an appointment. John told me:

It were bad enough, having to get moved out... and then I brung me medicines with me, and so I had them. I were supposed to have a check-up, but I couldn't get there anyway, and I just didn't worry about it. I were

more thinkin' about when could I get home, and what were happenin' to me family and that.

During both the 2019–2020 bushfires and the COVID-19 pandemic, LEAHA created a list of all their clients with chronic illnesses and divided it into four main categories: respiratory, cardiac, renal and diabetes. They then rang all their clients twice weekly to check in on them and offered support with accessing medical services and medications. If the client needed prescriptions renewed, the LEAHA staff would arrange a telephone consultation and arrange for the script to be filled and delivered to the client. LEAHA also delivered hampers with essential goods and fresh fruit and vegetables to their clients during this time. Participants mentioned their appreciation of having a yarn with the LEAHA staff and feeling connected to others, particularly during COVID-19 restrictions. Yarning, or having a yarn, are Aboriginal terms that describe informal conversation or storytelling in a culturally safe environment (Burke et al., 2022). Quinn's statement supports this approach: 'the staff ask how you're going, and things like that'.

During the COVID-19 pandemic, most PHC consultations could not be delivered in person. Face-to-face consultations were replaced with telehealth consultations, delivered via video and phone. People displaying any COVID-19 symptoms could not physically access PHC via medical centres and were instead asked to stay in their cars and be treated outside. Testing for COVID-19 took place in cars through drive-through testing centres.

The disruption to usual healthcare practices appeared to confuse research participants. Participants spoke of their strong preference for face-to-face consultation options with their known provider and their dislike of telehealth. Gwen contrasts her experiences of accessing during the bushfires to those during the COVID-19 lockdown:

I think that's about the COVID testing which was so utterly confusing. The bushfires I was okay. I had supplies of medication, but COVID was a different thing altogether, it was frustrating. I know that they had to keep their commandments of, you know, stick to the rules of not being inundated with a flood of people who might have even spread it. But I think to me it was frustrating because it was just going through the

difficulties of accessing if you needed to get in there to be tested, and even see a doctor, if you have the symptoms. One thing media saying get tested, and the other thing is it wasn't quite as accessible as the media were saying. But then personally, it just wasn't right.

Being tested from cars in a drive-through setting caused numerous issues for participants. Not having a car was raised as a barrier to accessing COVID-19 testing via the drive-through clinic, as participants spoke of being reliant on others to borrow their car or be driven to appointments. In the COVID-19 context, this meant interacting with others not from their household and breaking the COVID-19 restrictions. This position was too hard for some participants, who decided not to be tested despite having symptoms. Some participants were not happy about how the testing was delivered, as confirmed by Flora's words:

I got put out by the fact that they were treating us from our cars, where they should have really and truly found a building, and then tested us. I know that there's a few houses there that could have been made like a bit of a COVID clinic for people to access and be tested, and then not feel so intimidated about the process of how it was done.

Later, during the COVID-19 pandemic, when vaccinations became available, LEAHA and LTH&CS offered immunisation at their premises. This response led to a strong uptake in vaccination of the local Aboriginal population. In the East Gippsland local government area, 84.9% of Aboriginal residents had received their first COVID-19 vaccination dose by 17 November 2021, in contrast with the Latrobe local government area in Gippsland, with a lower Aboriginal population and a COVID-19 vaccination rate of 79.7% at the same time (DOHAC, 2021b). Research participants felt comfortable attending both LEAHA and LTH&CS in person to receive information, support and vaccination from familiar and trusted health professionals.

Second, the findings show that drive-through, point-of-care, health testing and treatment during a crisis can be a barrier and disincentive to healthcare participation. Overlooking the lack of car ownership within the Aboriginal community when crisis planning meant that many Lakes Entrance Aboriginal community members could not drive to access healthcare testing or diagnosis and treatment during COVID-19 restrictions. The utilisation of car testing and

treatment resulted in excluding a cohort of Australians already suffering disproportionately from chronic and acute health conditions.

6.3 The Impacts of Continuity of Care on the Healthcare Experience

6.3.1 Continuity of Care During Usual Times

I now direct attention to the sub-theme of continuity of care. This research shows how the health access inequities experienced by Aboriginal people during usual times appear to be exacerbated during times of crisis. Continuity of care significantly impacted the experiences of the Lakes Entrance Aboriginal community when accessing health care, with two main reasons for this identified through the interviews. Continuity of care can be defined as the service user's experience of a continuous caring relationship with an identified health professional or, for providers in vertically integrated systems of care, the delivery of a seamless service through integration, coordination and the sharing of information between different providers (Gulliford et al., 2006). Continuity of care is acknowledged as important to the healthcare experience, with demonstrated benefits including a reduction in mortality (Pereira Gray et al., 2016), lower rates of presentations to emergency departments (Gill et al., 2000), better clinical outcomes for a range of conditions (Palmer et al., 2018), better adherence to medications (C. C. Chen et al., 2013) and better overall experience of care (Hofer & McDonald, 2019). All participants in the research noted that they felt most comfortable seeing the same doctor at each healthcare visit.

The first reason provided by most participants for preferring to see the same doctor related to repeating their story to each different provider. This situation concerned participants for several reasons, including their uncertainty about the doctor fully understanding their health needs and the participants not understanding when treatments or medications were changed. Changing treatments and medications were explained by the participants as the likely outcome when attending a doctor unfamiliar with the participant's care. The issue of changing medications and the confusion this caused was raised by most respondents and illustrated by Molly's comment, delivered with intensity:

We like to stick to the one doctor, cause you go to all different doctors they give you all sorts of pills...and you have to keep telling your

story...and they're killing us, you know we've got liver and kidney troubles...Yeah, you should just stick to the one doctor, not different doctors.

The second commonly raised reason identified in the continuity of care sub-theme was the importance to the participants of knowing how their healthcare provider would treat them. Most participants recounted poor prior experiences with doctors, which had resulted in wariness regarding how they would be treated and concern about whether the treatment they received would be culturally appropriate and sensitive to their needs. Participants knew that by seeing their 'usual' doctor, there was no cause for worry prior to the appointment. They spoke of knowing that the doctor would not talk down to them and would explain their health matters to them in a way they could understand. As Rachel said, 'I know he'll tell me what's going on, and tell me what I have to do, and I'll know what he's going on about'.

Conversely, they spoke of the fear of being booked to see a doctor other than their usual provider and the increased likelihood that they would not attend the appointment. The comfort of having continuity of PHC with the same GP was expressed, which made it clear that there is overlapping and intersectionality with other factors, including racism, prior experience and communication. These are discussed further in the following sections.

Maintaining care continuity was the focus of various PHC components, and research has shown that Aboriginal people experience better overall health outcomes when care is not compartmentalised (Fraser et al., 2017). Intersectoral service coordination is also critical for ensuring a continuum of care across PHC and secondary care.

6.3.2 Continuity of Care During Crises

Two main themes were identified in the research findings in relation to how participants experienced care continuity during times of crisis. The first related to reluctance to seek health care if their usual health care provider was unavailable, and the second was the role played by the local ACCHOs, LEAHA and LTH&CS, in supporting clients during crises. These crises appeared to exacerbate existing factors affecting continuity of care and the health conditions of Aboriginal people.

Participants spoke of the impact on their health in the weeks following the bushfires when they had returned to their homes after evacuating during the immediate threat of fire. They described experiencing ongoing breathing difficulties, attributed to ash and soot in the air, on the ground and covering homes and structures. Several participants were frustrated at not being able to access their usual doctor and described how, rather than seeing an unfamiliar doctor, they decided not to access health care. Karen's comment illustrates this: 'I'll just wait and see what happens... Dr (redacted) will be back soon and I'll just wait and see him'. Critically, as a result of not accessing health care, one participant described their condition deteriorating to a point where an ambulance had to be called to take them to the emergency department at the Bairnsdale Regional Health Service.

Next, most participants spoke appreciatively of the support they received from LTH&CS and LEAHA during times of crisis. Many participants spoke of how supportive the known nurses at the LTH&CS were, how they felt comfortable speaking to them about their healthcare needs and how the nurses acted as liaisons to arrange the required healthcare. This local support from LTH&CS and LEAHA provided continuity of care via a familiar and trusted contact point for participants during the instability caused by the crisis.

The experiences described in this section clearly illustrate the importance of care continuity to Aboriginal people and how disruptions to the status quo during disasters can have serious consequences for the health of an already marginalised group. Further, on one level, experiences related to the continuity of care from the health provider are also related to intersecting factors such as racism, the impact of prior experience, health literacy issues and communication factors. They illustrate that none of these factors can be viewed in isolation, as they are interrelated. These are discussed further in this chapter and in Chapters 7 and 8.

6.4 The Impacts of Communication on the Healthcare Experience

6.4.1 Communication

Communication was raised by all participants as an important influencing factor on the health care experience. The ways in which medical staff, nurses

and reception staff communicated with participants influenced their experiences and choices with health care. The three commonalities in the participants' experiences related to the use of verbal and written communication in the health sector, feeling unheard by their medical provider and the role of ACCHO staff in supporting their understanding of their health care conditions and treatment.

First, terminology and language use was a major factor impacting participants' health care experiences. Participants explained that doctors use complex vocabulary and do not explain diagnoses or treatment options in a way they could understand. As participant Orla earnestly told me, 'They use them jawbreakers; you know, them big words'. The use of medical terminology and complex language resulted in participants feeling uncertain about their understanding of, and participation in, their own health management. Several participants also reported resultant feelings of shame and of feeling 'dumb'. One participant, Holly, spoke of her experience working in a hospital as a liaison officer. Holly said, 'you'd go in and the doctor would be talking to one of them, a patient, and I'd think, God, now I have to go and find out what that means because the patient still don't know what that means'. When I asked why service users did not ask the doctor to explain further, Holly answered readily:

Oh, shame. Like, they feel stupid, or I don't know. They just don't speak up. I think it's because of the scary side, too, 'if I don't ask then I won't know'. Just ask for understanding terms and references. The language is really a barrier with the doctors.

Written material was another issue raised by participants under the theme of communication. Being provided with printouts or handouts explaining their condition, diagnosis or treatment by health care professionals, in lieu of what they considered to be an adequate verbal explanation, was not appreciated by participants. Participants spoke of their reluctance to query doctors for explanations and explained that they often left appointments without an adequate understanding of their diagnosis, condition or treatment plan.

Second, feeling unheard by medical professionals was another common experience raised by participants. Most participants reported feeling they were not listened to or taken seriously, when raising their health concerns and attempting to explain symptoms to their doctor. One participant summed up her

experience of not being heard while attempting to support her family member during a doctor's consultation by saying:

They think they know better. I argued with (redacted) that (redacted)'s knee was getting worse, and they kept saying no, she needs this, she needs this, her knee is fine. I said I want a second opinion, and got her down to Traralgon, and you know what it was? The pin had come out (of her knee) and the plate had moved, and that's why she was in so much pain. And nobody would listen to me. So they need to listen. Black fellas know their own body. (Rachel)

Third, many participants mentioned the support provided by ACCHO staff in supporting them with health care communication needs. As described by a LEAHA staff member, Susan:

We check and ask to see if they understand and if they are on top of things. If they're not, that's when we will have a talk and see how they understand and what they don't understand. Just let them know that we're there for them, doesn't matter... And no question is a silly question. So then they know they don't feel silly asking it. They feel comfortable in asking. They don't feel silly or anything.

Participants appreciated the opportunity to have an ACCHO staff member either with them in their consultation for support, or available to speak with them afterwards and go over what had occurred in the consultation.

6.4.2 Health Care Communication Experiences During Times of Crises

Clear communication during a crisis is important for the community to understand what is occurring, what they need to do, and where they can access support. Usual communication channels can be disrupted, and the community can be confused about the appropriate action. Participants shared stories of their communication experiences during the COVID-19 pandemic and the 2019–2020 bushfires. Their stories consistently reflected the positive role that LEAHA and LTH&CS took in communicating clearly and constantly during these times, particularly in relation to correcting misinformation and providing advice and support about what to do and where to access support.

During the bushfires, the local Aboriginal community relied on LTH&CS and LEAHA for communication in relation to what was occurring in the community, what protective health care measures could be taken, and where health care could be accessed. LEAHA quickly communicated to the Aboriginal community about mask wearing and supplied masks to assist with the ongoing impact of smoke in the air.

During the COVID-19 pandemic restrictions, misinformation circulated in the local Aboriginal community, predominantly via social media, relating to symptoms, personal protection, testing and lockdown rules. As Betty said, 'There were heaps of stuff on facey [Facebook], and some said it were all made up by the gov'ment, and some said masks didn't work to protect ya, and it would hurt ya breathin' to be wearin' the masks anyway, and ya shouldn't do it'. During the early days of COVID-19, the local Aboriginal community shared various memes and posts via social media, which stated that COVID-19 was a hoax from the government and that the pandemic was deliberately orchestrated to gain more control over the population. This information was shared repeatedly and was taken as fact among a community where mistrust of government and authorities was already strongly evident.

Another topic of misinformation was related to COVID-19 vaccinations. Misinformation included that the vaccination was made from aborted fetuses, developed too quickly, unsafe and had multiple nasty side effects. 'Didn't wanna get no vax', said Gwen, 'Dunno what it is, the stuff in there, ya know? Don't think they're tellin' us the truth about it'. LEAHA and LTH&CS staff supported their community by providing clear and accurate communication on all healthcare aspects via social media, in person, flyers and letters. The healthcare information and advice given by the staff at LEAHA and LTH&CS was listened to as a trusted source by the Aboriginal community.

LEAHA and LTH&CS also compiled lists of community members affected by morbidities and comorbidities. Each of these community members was allocated to a LEAHA staff member. The LEAHA staff member was then responsible for contacting and following up with each community member. As Anne explained:

Yeah, and obviously um mail outs, so we hand deliver our mail to our community, like we drop it off, the health care workers drop it off to their home, so that had flyer in it of where to go and what to do if they needed support, and the same, those weekly phone calls were great, so each staff member had I say, think, 15 households that were theirs during the bushfires and then that just went onto COVID, so they rang them weekly or fortnightly depending on where we were at. And that was really good, 'cause then community could say you know, I need a script, or I'm struggling with food, it was really good. A lot of community said yeah that was amazing, they felt like they weren't forgotten.

In addition to the LEAHA staff delivering mail and information to their community, they also delivered care packages of fresh fruit, vegetables and other essential goods throughout the pandemic. This gave the LEAHA staff an opportunity to deliver pharmacy medicine and provide informal health check-ins and further information, as illustrated by Anne's comment: 'we're [LEAHA] very connected, like because most of our staff are Aboriginal, we know who's who in the zoo and who needs a bit of extra food or support'.

6.4.3 Discussion of Communication During Times of Crisis and the Impact on the Healthcare Experience

The experiences of the participants concerning communication during crises support the literature recommendations that effective crisis communication needs to be timely, clear, concise and appropriate to the target audience (S. C. Jones et al., 2010; Vaughan & Tinker, 2009). Despite the overwhelming evidence that health promotion messages need to be tailored for Aboriginal people (Smith & Judd, 2020; Vallesi et al., 2018), there was little communication specifically tailored for the Aboriginal community from the government during the COVID-19 pandemic (Finlay & Wenitong, 2020). To fill this gap, ACCHOs demonstrated their capacity to deliver scientifically valid, evidence-based and culturally translated COVID-19 prevention messages (Finlay & Wenitong, 2020).

The ACCHO sector's understanding of population health has led to a strong history of culturally centred health promotion and social marketing materials (Vallesi et al., 2018). Before the World Health Assembly declared

COVID-19 a global pandemic, ACCHOs and their peak bodies had developed messages for their communities (Finlay & Wenitong, 2020). ACCHOs took a leading role in health communication to the respective communities they served to best distribute the relevant information about COVID-19 in a culturally safe and appropriate manner (Markham et al., 2020; Naren et al., 2021). The success of their work, evident in the low numbers of Aboriginal reported cases of COVID-19, can be attributed to the early response and leadership of the ACCHO sector (P. Dudgeon et al., 2021). The experiences of the participants attending ACCHOs at Lake Tyers Trust and Lakes Entrance reflect these literature findings, and the communication provided in relation to COVID-19 and bushfire support and advice was accepted and appreciated by their local community.

Health literacy is another factor that must be considered when communicating with the public during crises. The messaging must be understood, accepted and applied (Smith & Judd, 2020). If the message is not understood, it cannot be actioned. Research on health literacy has shown that more than a third of people worldwide have difficulties finding, understanding, evaluating and using information necessary to manage their health (Van den Broucke, 2020). That means that crisis communication should be planned through an equity lens (Smith & Judd, 2020), with attention to the most vulnerable and at risk of misunderstanding the communication. Information needs to be provided in an understandable way, and different formats, such as animations, may assist in transmitting messages clearly (Okan et al., 2020).

6.5 Conclusion

This chapter described the lived experiences of the Lakes Entrance Aboriginal community accessing health care during times of crisis, focusing on the theme of service delivery factors. The chapter shows the impact of different types of healthcare services and highlights the community's preference for accessing PHC through their local ACCHO rather than through mainstream health providers, both in normal times and during crises. The significance of continuity of care to the participants and their preference for engaging with familiar PHC providers is emphasised. Furthermore, the importance of effective communication is highlighted, encompassing both the participant-practitioner

communication and the efficacy of general healthcare messaging during times of crisis.

The type of health care services available to the Lakes Entrance Aboriginal community played a pivotal role in shaping their health care experiences during times of crisis. The research findings demonstrate a strong preference among the participants for accessing PHC services from their local ACCHO rather than mainstream providers. This preference is rooted in the cultural safety and holistic care ACCHOs provide, which aligns with the community's values, beliefs and needs, particularly those relating to continuity of care and communication. ACCHOs are seen as trusted spaces where Aboriginal individuals feel more comfortable, understood and respected. They offer culturally appropriate care that acknowledges and incorporates Aboriginal culture, spirituality and community connections. This sense of familiarity and cultural continuity is particularly crucial when individuals seek solace and support during crises.

Existing continuity of care issues were intensified during times of crisis. Continuity of care emerged as a significant factor in the participants' experiences. They expressed a strong preference for engaging with known PHC providers who were familiar with their health history, cultural background and specific needs. Participants reported feeling more comfortable sharing personal information and discussing their health concerns with practitioners who understood their individual circumstances. Moreover, consistent engagement with the same healthcare provider allowed for personalised care plans, ongoing monitoring and follow up, leading to better management of chronic conditions and overall health promotion.

Effective communication was highlighted as another critical factor impacting the healthcare experiences of the community during times of crisis, and existing communication issues were intensified. Participants emphasised the importance of clear and respectful communication between themselves and their healthcare practitioners. Open dialogue, active listening and mutual understanding were key elements that facilitated trust and positive healthcare encounters.

Furthermore, the efficacy of general healthcare messaging during times of crisis was a crucial consideration. Participants highlighted the need for culturally appropriate and accessible messaging that effectively reached the Aboriginal community. They emphasised the efficacy of utilising multiple communication channels to disseminate vital health care information.

In summary, this chapter has shed light on the experiences of the Lakes Entrance Aboriginal community in relation to accessing health care during times of crisis, focusing on the theme of service delivery factors. The findings underscore the importance of ACCHOs to the local Aboriginal community. Continuity of care and effective communication were also identified as key factors in ensuring positive healthcare experiences.

Chapter 7 The Influence of Personal Experience on the Healthcare Experiences of the Lakes Entrance Aboriginal Community

7.1 Introduction

Chapter 7 continues the research findings chapters, exploring the theme of past personal experiences that impacted the healthcare experience of Aboriginal people in the Lakes Entrance community. The sub-themes of personal factors, including shame and fear, the influence of intergenerational trauma and prior experiences, including racism, are all described.

The experiences described by participants in this chapter were painful for them to recount, and hearing them was upsetting. In their responses, participants described the ongoing impact these experiences had on their lives, not solely related to healthcare access and experiences.

7.2 The Influence of Shame and Fear on Participants' Experiences of Healthcare Access

7.2.1 Shame

Shame was spoken of by most participants in relation to their experiences when accessing health care. For Aboriginal communities, the term *shame* has a particular meaning that is distinct from Western conceptualisations of shame. For the Aboriginal community, shame may be experienced when a person behaves in a way that violates collectivist, cultural or spiritual norms or is singled out positively or negatively (Whop et al., 2022).

Several participants described their shame when waiting in mainstream doctors' waiting rooms with predominantly or all-white clients. These participants believed other people waiting were looking at them and wondering why they were there and for what issues they were seeing the doctor. No evidence was provided to substantiate these perceptions; however, they were clearly deeply held beliefs and were spoken of often. Anne's comments illustrate this:

I think they feel shame, walking into an organisation with so many white faces. Lots of our community members don't feel that, but the older ones

and the younger ones, a lot of the younger generation, not so much the middle generation, feel a little bit like they're being looked at when they walk in the door or, I don't know. I just feel like they think that they won't get the same treatment.

This distinction between the attitudes of the middle generation as opposed to the older and younger generations is discussed in detail later in this chapter. Conversely, multiple participants conveyed the comfort they felt when entering a healthcare space and seeing a face they recognised or a member of the Aboriginal community was present. As Karen said, 'and seeing mob when I go in, just makes me feel better, ya know, like it's ok to be there, another Black face'.

Shame was also spoken of in relation to money and payment for healthcare services. Several participants relayed how the Aboriginal community accessed health care through the local mainstream community health medical clinic. When this occurs, LEAHA provides funds directly to the clinic to pay for the local community to access nursing consultations when required. Participants described feeling judged by reception staff for not having the money to pay for their care and utilising the LEAHA funds available. Participants reported that being distinguished from other service users who could pay for their care was shameful to them. This is illustrated by a LEAHA staff member's comment:

You know, if they go to the front counter, and they're questioned about something, especially if it's with the monetary items, a lot of them don't have, whereas, you know, we've got something set up over the other side so they don't have to pay for their Nurse consults and, just all that's a bit of a shame job.

7.2.2 The Influence of Fear on the Participants' Healthcare Experiences

Fear was another prominent theme in the participants' interviews that impacted their healthcare experience. Fear was stated explicitly in terms such as 'scared' (Anne, Carol, Gwen, Linda and Orla) and 'nervous' (Anne, Dan, Karen, Rachel and Quinn) and implicitly in participants' answers. Participants stated many reasons for their fear, including fear of mainstream healthcare provider facilities, breaches of their confidentiality, receiving bad news, the unknown and hospitals.

Fear of mainstream healthcare provider facilities was identified by several participants. One participant told me that in a local mainstream clinic, the police were called if you were aggressive. I asked if this had happened to them, and they replied 'no'. I then asked if this had happened to their family or someone else they knew. They again replied that it had not. I asked them to clarify what they meant, and they told me there was a sign in the clinic that said, 'Poor behaviour will not be tolerated'. The participant interpreted this as stating the police would be called if they questioned the wait length or requested a different doctor than the one they had been allocated. The fear of perceived authority figures was clear, indicating how fear and historical trauma intersect.

Fear was also mentioned by participants in relation to their fear of breaches of their confidentiality. Participant Linda spoke of having to make an appointment in a mainstream clinic; the receptionist first refused to make an appointment for her with her chosen doctor, then asked for what exactly Linda wanted to see the doctor. Linda responded, 'no, you're only reception', and refused to tell the receptionist what her medical issue was. She said she felt embarrassed when asked to share her private medical issues in the reception area where waiting clients could hear. She also wondered if all clients were asked this and if she had been singled out due to her Aboriginality.

Fear of breaches of confidentiality was conveyed by two participants in relation to LEAHA and LTH&CS. Their concerns centred on the strong familial relationships in the community and the possibility of Aboriginal staff at the ACCHOs repeating their private health information to their relatives in the community. No incidents of breaches were provided; however, the participants were both earnest in communicating their fear. As Linda said, 'big mouth, ya know? Knows everythin' what's goin' on, and yappin about other people's business, and ya dunno what they're sayin' about you and your stuff'.

Fear of receiving bad health news was a concern for over one-third of participants. Participants were of the consensus that it was better not to know bad news and that if something were going to happen to you, it would happen anyway. This was illustrated by participant Bec's comment, 'I don't want to be told something I don't want to hear. You know what I mean? I'd rather not know and live in denial'.

Fear of the unknown was another fear described by multiple participants. The uncertainty as to who would treat them, what would happen to them, what tests might be needed, what that would entail and what might be found were all areas of concern for participants. This fear was evident in Orla's statement, 'Yes, the unknown is huge for our mob. If we don't know what to expect, then it can get quite scary'. Mob is a colloquial term that many Aboriginal people use to identify their people or communities and can represent a family group, clan group or wider Aboriginal community group (Deadly Story, 2022).

Multiple participants mentioned fear of hospitals as a factor influencing their healthcare access decisions. As Quinn said:

Aboriginal people, a lot of people in the community won't go to the doctor until it's too late. I suppose it's the worry, because so many generations have done the same thing and died, and when they go to doctors and get put into hospital, they don't think they're going to come out. A lot of our middle aged and older ones go into hospital and don't come out because they haven't sought that medical, they haven't seen a doctor early enough.

Interestingly, the fear of hospitals was spoken of by older participants but was not identified by middle-aged and younger respondents. This observation could be attributed to earlier experiences of systemic racism in hospitals or fear of their mortality. The comments from Quinn also support the previously described fear, that of fear of receiving bad health news and, therefore, the denial of health issues.

7.3 The Influence of Fear on the Participants' Healthcare Experiences During Crises

Participants recounted how their fears of accessing healthcare manifested and impacted their healthcare access during the 2019–2020 bushfires. Participants all described the role that LTH&CS or LEAHA played in providing them with support and assistance during the 2019–2020 bushfires and COVID-19 outbreak and subsequent restrictions. Participants stated that during the crises, they could ask for information, advice and support at their ACCHO, and they felt comfortable and safe to do so. This sentiment is captured in Flora's

statement, 'I wouldn't ask anyone else, I'd just go to LEAHA, they know what's goin' on'.

Participants reiterated how comforting they found the familiarity of their ACCHO and their staff during the bushfires, particularly when many outside and unfamiliar government bodies and groups were also present locally, attempting to support the local community. Fear and mistrust of government authorities and bodies are prevalent in the local Aboriginal community for reasons described and explained in Chapters 2 and 3. This fear made community members reluctant to seek assistance or support from unfamiliar government authorities and other groups. As one participant, John, bluntly explained, 'we don't know them, we don't trust them. We'll stick with our mob'.

The same issue of fear of outside bodies was encountered during the COVID-19 pandemic. This was illustrated by Ian's comment about the Public Health Network bus, which travelled around Gippsland during the pandemic, delivering vaccinations from the bus to different towns. Ian said he was not sure if the bus was 'for Blackfellas, or for everyone like'. Ian said he would not attend something if it was not specifically for Aboriginal people and staffed by known Aboriginal staff. Ian chose to wait until vaccinations were offered at LEAHA, and he was vaccinated there in a familiar and trusted environment.

Several participants spoke of their reluctance to seek healthcare support during the COVID-19 pandemic period due to fear of whether they would be able to see their preferred doctor. They also told of their uncertainty about which COVID-19 government-mandated restrictions applied at different times, whether they were allowed to physically present for healthcare treatment and their fear of exposing themselves or others to the virus through their potential actions. Participants' fear and mistrust of government rules and regulations and authorities were also evident in their responses, as was their implicit trust in accessing both LEAHA and LTH&CS for information and support. The escalation of existing fears during the 2019–2020 bushfire period and the periods of the COVID-19 lockdown were evident.

7.4 The Influence of Intergenerational Trauma on Healthcare Access and Experiences

The impact of intergenerational trauma was a sub-theme strongly identifiable from the participants' interviews. As with many other sub-themes, there was significant overlap and intersectionality with other themes, and it was difficult to separate some examples into a particular category. The attitudes of older and younger participants varied in their perspectives on generational trauma, and these are discussed below.

7.4.1 Intergenerational Trauma

Multiple examples of intergenerational trauma were recounted by older participants, which affected their attitudes and behaviours towards accessing health care. Stories recounted by participants included those of their parents or grandparents living at Lake Tyers Beach and having to hide either themselves or their siblings in the bush when government officials came for fear of being taken away from their families. A clear causal connection can be established between these stories and attitudes of government mistrust, as well as participants explicitly speaking of not wanting to access health care due to mistrust of doctors, officials and the government.

The main concerns relayed by older participants related to government interference in their autonomy, as evidenced by Quinn's comment, 'what if they say I'm too sick to stay at home, and they make me go to hospital or somethin', or they wanna come lookin' around my place to see what's going on'. Several participants spoke of Centrelink (now Services Australia) and the constant compliance requirements for updated information. Services Australia is an Australian federal agency that manages government services and payments to Australians. The participants said they were wary of accessing health care and their health or personal information provided by the doctor or health care service to Centrelink, which may impact their pension payments. As Molly said, 'It's all forms, forms, forms, and fillin' in this one and that one, and then another one, and then they say nah, ya gotta go back and get a letter from ya doctor'. Older participants voiced concerns relating to Services Australia.

Multiple participants provided another example of generational trauma influencing health care decisions and experiences. Multiple older participants

told me that in the past, Aboriginal women had not been allowed into the local hospital and had been made to give birth outside on the verandah. Although participants could not recount specific examples or which period this referred to, the collective memory and ongoing impact of this was still keenly felt. Gwen said, 'and back then, the hospital, we weren't allowed in there, and we had to have babies outside, like we were animals'. The fear and wariness of seeking health care at the local hospital was still evident in the health care choices of some older members of the Aboriginal community.

7.4.2 The Influence of Intergenerational Trauma on the Healthcare Experiences of Younger Participants

Intergenerational trauma was described differently by younger participants under 50 years of age. Carol said that she had been told plenty of stories from her grandparents, and while she felt sorry for her grandparents and what they experienced, 'to me, that's really sad, but it's not my life today'. Carol went on to explain that she did not take the stories on personally:

No. That happened back then, the people that did that, it's not the people here today. This is our history. It's not just our history, it's your history too. And all I can say is really that we just learn and live from it and move forwards and don't make the same mistakes what happened back then. And that's the way I see it. It's not just ours. It's all of our history as well. And I don't look at like, just say, I have a friend and their grandfather did some things back in the day, but I'm not going to hold her accountable for that.

Carol's words exemplified the predominant younger participant attitude of feeling empathy for those who had experienced trauma in the past but did not want to take on that emotional burden themselves. Not wanting to let generational trauma and racist attitudes affect their lives was also exemplified in these words from Elaine:

You do feel really bad. Yeah. It does hurt you. Yeah. It does. And like it does affect you in ways, but I try not to let it affect me with my life. And try to teach my kids different, as well. Like yes, it did happen, but we don't do that now. That doesn't happen anymore. And if it does, I always tell my kids, 'Don't react on it.' And just deep breaths, and move on for the rest of

the day, because when you do come across them people, they ain't going to change. It's better off just to move on and don't have an argument about that.

Conversely, participant Anne, who was also under 50, felt the generational trauma of her ancestors and recognised how this trauma was transmitted through the generations. Anne said:

I know some of my Elders here in Lakes, like the trauma they have gone through, some of them are in their 70's now you know. And they used to walk from Metung to come in here (Lakes Entrance) and go to the movies, you know, and then they'd be made to sit outside the fence, they wouldn't be allowed to go in. You know, and that's in our lifetime – you just think, and that's in our lifetime, and it's awful. But they're still really traumatized by that obviously, and it's really fed through their children and grandchildren and you know. It's a really strong message, and you know the grandchildren, they really feel that and then they follow through with it, they have those feelings when they go to certain places too.

The above examples show no uniform response from participants to intergenerational trauma and demonstrate the ongoing impact of trauma.

7.4.3 The Impact of Intergenerational Trauma on Participants' Healthcare Experiences During Times of Crisis

The influence of intergenerational trauma on healthcare experiences during a crisis was evident in the participants' interview responses. Participants were impacted in various ways, including being triggered or experiencing an intense negative emotional reaction (Atkinson, 2019) from crisis events, all described below.

Firstly, several participants explained how, during the 2019–2020 bushfires, the evacuation from their homes to evacuation centres heightened their concerns of becoming homeless. This fear was particularly evident in the interview responses of the older respondents. Participants feared their homes and land being burned, resulting in the destruction of their communities. They were also worried about whether they would be able to return to the Lake Tyers Trust or if 'the government would put us somewhere else, not let us go back'

(Penny). This fear of government intervention in their lives can be linked to past government policies, as outlined in Chapter 2.

Concerning the COVID-19 pandemic, many participants described struggling during the periods of COVID-19 lockdown restrictions. The heightening of existing trauma was evident in participants' responses. They expressed how they found the lockdown restrictions, in many ways, not restricted only to their ability to access health care. Several participants spoke of how being locked down during COVID-19 was like being, in the words of Nina, 'locked down on the mish'. This statement referred to the Lake Tyers Trust, previously named the Lake Tyers Mission, and sometimes still referred to as 'the mish' by older local Aboriginal residents. Residents at the Lake Tyers Trust, until the 1970s, needed permission to leave the Trust by the Trust Manager and did not have freedom of movement, as explained and discussed in Chapter 2. The likening of COVID-19 government-enforced restrictions to the government-enforced measures of the past was explicitly stated. Participants recounted being triggered by this, wondering how long it would last and if it was a return to the 'bad old days' (Molly).

Within Australia, Aboriginal people have a history of being confined to designated areas such as missions and reserves, which was government policy from approximately the 1890s to 1970s (AIATSIS, 2020). The lockdown of Victorians during the COVID-19 pandemic for containment purposes included the inability of people to leave their homes except to obtain food or access medical treatment at different stages. This approach has triggered episodes of post-traumatic stress for those older Aboriginal people who still live on the missions and reserves (Power et al., 2020), and this is reflective of the experiences spoken of by the residents of the Lake Tyers Trust.

Third, participants also talked of their holistic health concerning the COVID-19 lockdown restrictions, which restricted people leaving their homes unless they could obtain food or access health care. Orla spoke of being unable to travel for Sorry Business, which was 'like in old days, when you had to get permission, and they could say no to you'. *Sorry Business* is the Aboriginal English term used by the Aboriginal community to describe the mourning period when a family member dies and all responsibilities that follow under traditional

lore and custom (CCQ, 2019). Many Aboriginal people in Australia travel frequently between communities to attend Sorry Business (Nolan-Isles et al., 2021). Participants described feeling upset and guilty that they were unable to travel for Sorry Business and, therefore, meet their collective cultural obligations.

Fourth, participants described being treated outside during the COVID-19 pandemic, specifically being tested in their cars and being treated in their cars in the car park when they displayed COVID-19-like symptoms. One participant, Gwen, likened this outdoor treatment to the old days when Aboriginal people were not allowed in hospitals to give birth. She described shaking with fear and anger in response to being treated in a car park. Other participants also described similar concerns, which were discussed in Chapter 6.

Fifth, the racist treatment of one participant at the evacuation centre after the 2019–2020 bushfires, as described in Chapter 6, was shared within the community, and numerous participants spoke of how this reminded them of their own prior racist experiences and reinforced their concerns about accessing health care from unknown providers.

The above concerns combine to illustrate the importance of considering all factors when planning and implementing communication, public health measures, treatment options and more during crises. Without understanding these cultural and other factors, government measures can disproportionately negatively affect Aboriginal communities. The intensification of trauma for Aboriginal participants during these times of crisis was evident, as were the physical and emotional impacts of this. Again, this speaks to the need for the involvement of local organisations such as ACCHOs during crises, as they understand their local communities, the local context and how to best engage and support their communities through hardship.

7.5 The Impact of Prior Experience and Racism on the Participants' Healthcare Experience

7.5.1 The Influence of Prior Experience and Racism

The next theme sub-theme identified in the research findings under personal experiences was the impact of prior experiences and racism on the participants' healthcare experiences. Participants spoke of experiencing racism in four main ways: (a) being provided with what they perceived as low levels of

care, (b) having their symptoms and pain dismissed, (c) being treated poorly and with a lack of respect and (d) feeling powerless in their health care interactions.

First, many participants recounted being treated with what they perceived and described as low levels of care. Elaine narrated that when she attended a medical centre with a sore wrist, the doctor did not even touch her; just looked at her wrist and told her she would be fine, to put some ice on it, rest it and take paracetamol if required. Elaine went home and put up with her painful wrist until after a week of pain, she went back to the medical centre, saw another doctor and was sent for x-rays, which revealed a broken wrist. Elaine angrily summed up her experience by saying of her poor initial treatment, 'don't treat me that way 'cause I'm Black. I like to be treated the way as whitefellas - treat us the same'.

Second, participants narrated having their symptoms and pain dismissed and their belief that this was due to their Aboriginality. Carol described telling an unfamiliar doctor about her crippling stomach pain. The doctor did not complete any diagnostic tests, either blood or imaging, and told Carol that her pain was normal period pain, despite Carol repeating that her pain had been constant for three weeks and was becoming worse. The doctor told Carol that he would not prescribe her any painkillers (despite Carol not asking for them) and that Carol could take over-the-counter painkillers if required. Carol recounted that the doctor dismissed her as if she were only pretending to be ill to obtain prescription drugs: 'It was like I was just Black, and trying to get drugs, and there wasn't anything wrong with me. He just spoke to me like I was pretending, and just a nuisance'. After another week of pain, Carol ended up in the emergency department of the local hospital, where she was diagnosed with diverticulitis, an inflammation and infection of her colon.

Third, an experience recounted by a resident of Lakes Tyers Trust, Karen, highlights how a single experience of being treated poorly and with a lack of respect in the healthcare system can impact future health decisions. Karen's GP had referred her to a specialist doctor in Melbourne, 340 kilometres away. Karen explained that arranging to travel to Melbourne, the stress of leaving the Trust, worrying about her medical condition, organising accommodation and the unfamiliar and confusing experience of navigating the city and a metropolitan hospital meant that accessing health care was an overwhelming experience for

her. Although LTH&CS assisted with these arrangements, she still found the experience confronting. When Karen and her mother finally arrived at the metropolitan hospital, they were misdirected by reception staff and took some time to find the actual appointment location. After Karen was called to see the doctor, she extended her hand to shake hands and introduce herself. Karen recalls that the doctor looked at her outstretched hand, looked away and then told her to take a seat. The doctor then asked Karen about her alcohol intake and was openly sceptical when Karen described it as minimal. Karen was highly distressed by this experience. She said that while she understood hand hygiene procedures, the doctor could have shaken her hand and washed their own. She felt a lack of respect shown to her by the doctor. She felt the doctor doubted her word about her alcohol consumption because she was Aboriginal, so the doctor assumed she was lying. That interaction has impacted Karen's medical interactions since she now suffers from worries and concerns about being treated by unfamiliar doctors. As Karen said:

He wouldn't shake our hands or nothin. He accused me of being a alcoholic, and ... I had to get Mum outta there, I had to be strong for Mum.... and then I went home to my own house, and I sat on the couch, and I just cried.

As a result of this experience, Karen stated that she would not see that doctor again unless a Koorie (Aboriginal) Liaison Officer was present. She also said she was so anxious before any medical consultation that she often did not sleep the night before. Karen said she did not always listen properly or understand what was being said during a consultation, as she was so worried about how the doctor would behave towards her and what the doctor was thinking of her. Karen's story illustrates the ongoing impact a single racist experience can have on future health encounters and choices.

Fourth, participants commonly described feeling powerless in healthcare interactions and treatment in their interviews. Not understanding their diagnosis, not being given options for treatment or having treatment risks explained to them and not understanding what they needed to do to manage their healthcare conditions were all experiences described by participants. These have been

analysed under the sub-themes of continuity of care and communication in Chapter 6.

Additionally, many participants spoke of overhearing racist remarks made about them by staff in healthcare settings. One Aboriginal participant indicated her disgust at hearing derogatory comments and conversations about Aboriginal people in healthcare settings. Due to her fair hair and skin, she thought people assumed she was Caucasian and, therefore, felt free to make racist remarks in front of her. She recalls overhearing many racist comments about healthcare experiences—too many to quantify. She said:

It's sad. Yep. They're just judging. And you still hear that stuff, 'oh you know Blackfella's, they get everything they need' and 'everything's handed to them for nothing' and 'they don't work', you know there's still that mentality, and that a lot of our mob have to live with, and it's really sad. (Anne)

The stories that participants recounted about racist healthcare experiences were raw and heartfelt. Participants spoke of the ongoing impacts that these encounters had on their healthcare experiences. Some participants were still distressed by their experiences. Some participants described their reluctance to seek health care treatment unless necessary, which was summed up in Nina's comment that she'd 'rather not go through the hassle of the whole thing, and then end up feelin' like shit anyway'.

Participants strongly preferred to attend health care via the local ACCHOs in LEAHA and LTH&CS with known doctors. Interestingly, participants spoke of discussion within the Aboriginal community about which medical professionals to avoid due to what the community perceived as their racist behaviour and attitudes. Participants who recounted racist experiences also mentioned being more cautious and watchful in their future healthcare encounters with unknown health professionals and in unfamiliar environments. As Rachel said, 'it just takes that one bad experience. You pretty much only get one shot with Black fellas. And, if you ruin that shot, it takes a lot of work to get that back'. That wariness and caution were also described clearly by Anne:

you know, we do, we automatically think people are looking at us and talking about us because they know I'm an Aboriginal person, one of

‘those’ people. But I feel quite sad that us people feel like that. But it’s just, I suppose, generations and generations of racism and people looking at you funny or not accepting you.

The findings above are congruent with the literature on this topic, which agrees that racialised minorities can perceive their experiences of racism as consisting of inadequate care and a dismissal of their symptoms and suffering, a lack of respect and a lack of power to negotiate in health care interactions (Hamed et al., 2022). Further, they report a loss of trust in health care and higher unmet needs (Quigley et al., 2021) and subsequently delaying seeking health care (Hamed et al., 2022). Prior healthcare experiences impacted the choices made by participants concerning their future healthcare access choices. Sadly, all research participants spoke of encountering racism in varying contexts when accessing PHC, highlighting factors such as culturally inappropriate services, communication factors and the type of service provider. The interactions of these factors cannot be isolated or separated as they combined to influence the participants’ experiences when accessing PHC.

7.5.2 The Influence of Prior and Racist Experiences on the Participants’ Healthcare Experiences During Times of Crisis

Many participants described their unease at consulting unfamiliar healthcare providers during crises. The preference for participants to have continuity of care from a trusted provider has been discussed in Chapter 6, as has participants’ preference for their usual location of services. During times of crisis, however, usual healthcare arrangements are not always possible. This was evident for the local Lakes Entrance Aboriginal population during the 2019–2020 bushfires and the COVID-19 pandemic. Many participants described their unease at consulting unfamiliar healthcare providers during crises. Some of the participants chose not to engage with a health provider at all.

Most participants spoke of racism when describing how and why they did or did not access health care during these crises. A story relating to the 2019–2020 bushfires was recounted to me by 12 of the 18 participants. A resident of the Lake Tyers Trust was evacuated and moved to the Bairnsdale Oval evacuation centre. They had gone over to the evacuation centre control area to ask how they would access prescription medication left at home at the Trust.

The worker at the centre cut him off and told them they would not be giving them anything, as they had already given out enough 'to you people today'. The resident was devastated and refused to return to the control area and went without their medication instead. The racism displayed by the worker towards the evacuated person seeking assistance was soon shared among the Aboriginal community, and knowledge of the incident became so widespread that it was reported in the national news (Moore, 2020; Williamson et al., 2020). The worker ultimately apologised to the Lake Tyers community member.

The experience recounted above illustrates several themes identified in this research. First, the experience resulted in the person forgoing medical treatment due to the racism they encountered. Second, it exemplifies the point made by several research participants that the Aboriginal community talk to each other about their bad experiences and where and who to avoid in health care circles. Interestingly, none of the participants mentioned sharing positive experiences within the community in their responses. Third, the racist experience was shared among the community, reinforcing their scepticism and anxiety about unfamiliar health providers and the reception they would receive. Fourth, the bureaucratic nature of the evacuation centre set-up was a trigger for some participants who were already wary of both government bodies and the reception they would receive. The racist response from the worker acted to confirm previously held concerns.

This section has described participants' experiences with racism when accessing health care. While this chapter has utilised one participant's story to highlight the theme of racism identified throughout the interviews, many more could have been utilised. The intersectionality of racism with other sub-themes, such as the type of provider, continuity of care, communication, shame and other factors, cannot be separated.

Many participants spoke of how experiencing racism made them feel. Phrases and adjectives such as 'not good enough' (Quinn) and 'shithouse' (Linda) were used. The impact of experiencing racism on participant's mental health and self-esteem was evident in their words, tone of voice and body language as they shared their stories. This observation reflects the substantial body of interdisciplinary research that has documented the damaging effects of

racism on the historical and contemporary lives of Aboriginal people, including that racism affects both mental and physical health (Jakubowicz et al., 2017; Paradies et al., 2015). The literature also documents the experience of interpersonal racism in health settings being associated with increased psychological distress over and above what would be expected in other settings (Kelaher et al., 2014). This finding was reflected in the participants' recounting of events and is evident in Quinn's rhetorical question: 'Wouldn't ya think they'd be better than that at a doctor's?'

In relation to racism, the stories of the participants in the Lakes Entrance Aboriginal community have illuminated the community's collective memory. Of the 18 research participants, 12 told me the story of the Lake Tyers Trust resident who was turned away from accessing support at the evacuation centre, and each of the 12 recounted the story in the context of how wary they were accessing services from unknown providers, due to the potential for racist treatment.

The stories of racist treatment experienced during a crisis are supported by the NACCHO, which indicated that it had received anecdotal evidence suggesting a lack of support for Aboriginal people during and after the 2019–2020 bushfires (CoA, 2020). The NACCHO had heard evidence of 'experiences of racism and discrimination when evacuating and accessing emergency support and supplies [including at evacuation centres]' (CoA, 2020, pp. 4–5). This finding speaks to the experiences of the Lakes Entrance community and the role played by the local ACCHO's in supporting participants during the 2019–2020 bushfires and the COVID-19 pandemic.

7.6 Conclusion

This chapter has provided a comprehensive exploration of the personal factors that significantly influenced the healthcare encounters of the Lakes Entrance Aboriginal community. The research findings shed light on several key sub-themes that emerged throughout the study: shame and fear, the influences of intergenerational trauma and prior experiences encompassing racist interactions. Through in-depth interviews and narratives shared by the participants, the profound impact of these sub-themes on their lived experiences has been carefully examined and analysed.

The sub-theme of shame and fear emerged as a powerful force affecting the healthcare experiences of the Lakes Entrance Aboriginal community. Many participants expressed feelings of shame when accessing health care services, stemming from historical and ongoing marginalisation, discrimination and stigma. This sense of shame often leads to reluctance to seek medical assistance, leading to delayed or inadequate care. Additionally, fear played a significant role, with individuals expressing apprehension about the potential judgement, mistreatment or dismissal they might encounter within healthcare settings. These emotions profoundly influenced their healthcare experiences, leading to a lack of trust and a strained client-provider relationship.

Intergenerational trauma was another critical sub-theme that surfaced in the research. Participants shared personal stories of the long-lasting effects of historical injustices, such as forced removal and cultural suppression, passed down through generations. The trauma experienced by their ancestors continued to impact their present healthcare encounters and intensified during the crises under study. It shapes their perceptions, attitudes and interactions within healthcare settings, often manifesting as heightened vigilance, mistrust and a reluctance to engage with mainstream healthcare systems. Understanding and addressing intergenerational trauma is crucial for providing culturally sensitive and appropriate care to the Lakes Entrance Aboriginal community.

The sub-theme of prior experiences, specifically racist interactions within healthcare settings, also played a significant role in shaping the healthcare experiences of the community members. All participants recounted encountering racial discrimination, stereotypes and biased treatment when seeking medical care. These negative encounters left lasting impressions and created a deep-seated mistrust towards health care providers and institutions. Such experiences hindered their willingness to engage with health care services, resulting in decreased access to necessary treatments, preventative care and health promotion initiatives. These past personal experiences intensified during crises, and the resultant impact on participants' physical and emotional health was evident.

Through presenting the participants' lived experiences, this chapter offered valuable insights into the complex dynamics between the influence of

personal factors and healthcare encounters for the Lakes Entrance Aboriginal community.

Chapter 8 The Influence of Environmental Factors on the Healthcare Experiences of the Lakes Entrance Aboriginal Community

8.1 Introduction

This chapter continues the research findings chapters, exploring the theme of environment factors which impacted the healthcare experience of Aboriginal people in the Lakes Entrance community. The sub-themes of competing priorities, transport issues, and the influence of medical bureaucracy and the physical environment of health care settings, are all described.

This chapter is presented in the form of a journal article, which has been accepted for publication by the Australian Journal of Rural Health as of 31/10/2023 (Appendix E).

8.2 Journal Article

The Experiences Of A Regional Aboriginal Community Accessing Primary Health Care During Times Of Crisis

Abstract

Objective

The importance of primary health care (PHC) to Aboriginal Australians is widely acknowledged, as is the underservicing of the Aboriginal Australian population. This study identifies environmental factors (beyond personal and service delivery) that functioned as barriers and enablers to Aboriginal Australians' experiences accessing PHC during crises, and recommends approaches during future events.

Setting

The study was set in Lakes Entrance, a regional Victorian locality with a sizable Aboriginal community which was affected by bushfires during 2019/2020 and COVID-19 restrictions during 2020-2021.

Participants

Participants were 18 Aboriginal People over the age of 18 living in the locality during either bushfires or COVID-19.

Design

This research utilised a case study approach. Data were collected through in-depth interviews and analysed using thematic analysis.

Results

The barriers identified included the impact on PHC access of priorities other than health, including housing; financial constraints; difficulties with transport; medical bureaucracy and the physical environment of the health care setting, including appointment-making processes; interactions with medical reception staff; and waiting room environments. Enablers identified included the supportive role of the local Aboriginal Community Controlled Health Organisations (ACCHO) and their staff, which was highlighted in participant responses. The preference of many Aboriginal people to access PHC via their local ACCHO, rather than mainstream health care services, appears even more salient during crises than in normal times.

Conclusion

Results may help direct interventions to improve PHC access and experiences for regional Aboriginal communities both during and outside of periods of crisis.

Keywords

Health access; Primary health care; Barriers and enablers; Aboriginal and Torres Strait Islander health;

'What is already known on this subject.'

- Aboriginal and Torres Strait Islander People suffer disproportionately from poor health outcomes and chronic disease compared to the broader Australian population.
- Access to general practitioners and other PHC providers is acknowledged as essential to improving Aboriginal people's health outcomes.

'What this paper adds'

- This paper identifies environmental factors that impacted the experience of regional Aboriginal community members when accessing PHC during crises.
- This paper highlights the positive role Aboriginal Community Controlled Health Organisations (ACCHOs) played in supporting the community with PHC access during crises.

Background/Introduction

Aboriginal People's health status

A gap in the life expectancy and health outcomes of Aboriginal and Torres Strait Islander People (hereafter respectfully referred to as Aboriginal) compared to non-Indigenous Australians is widely acknowledged (Commonwealth of Australia, 2022). Against virtually all health and social status markers across the lifespan, Aboriginal Australians are the most marginalized and disadvantaged in Australian society (Canuto et al., 2018). These disparities are a result of the ongoing devastating impact of colonisation expressed as racism, discrimination, and for many, loss of identity, language, culture, and land, all of which result in trauma and directly impact health care outcomes (Nolan-Isles et al., 2021).

Further, Aboriginal People continue to face significant obstacles when accessing and using health care services and this exacerbates poorer health outcomes (AIHW, 2011). As a result, Aboriginal people tend to access the health care system late in the disease process and in emergency situations, and are less likely to engage in PHC prevention services (Commonwealth of Australia, 2022; AIHW, 2022c). This exacerbates poorer health outcomes.

Aboriginal People and access to PHC

Aboriginal People often cannot access appropriate mainstream PHC to effectively meet their needs, for myriad reasons (Davy et al., 2016; Harfield et al., 2018). Identified barriers include high costs of health care; experiences of racial discrimination; distance/ travel time, and availability of transport; lack of availability of culturally appropriate services and culturally sensitive health care professionals (Aspin et al., 2018; McBain et al., 2011; AIHW, 2011).

Ensuring access to PHC is widely accepted as key to improving health outcomes (Grad, 2002; WHO, 2008). Access to high-quality primary care can help to address social determinants of health and redress health inequities (Fitzpatrick et al., 2021). ACCHO service provision is associated with positive health outcomes (Gwynne et al., 2019; State Government of Victoria, 2022) for Aboriginal Australians, through intersectoral action which supports improving health literacy, improving screening and treatment, and managing acute and chronic illnesses (AIHW, 2022c).

PHC during crises

Equitable, reliable, and consistent access to PHC is a critical foundation of health and well-being at every stage of life, and is crucially important during public health crises (WHO, 1978). When disaster strikes, the impact on Aboriginal people is disproportionate to that of the general population (Williamson et al., 2022). Crises shift how PHC is delivered, and regular care is often postponed (Williamson et al., 2022). When health systems are overwhelmed during crises, deaths caused by lapses in routine care can increase dramatically (Williamson et al., 2022).

Crises during the study period

The crises referred to in this paper are the active period of the 2019/2020 bushfires, henceforth referred to as the bushfires, and the restrictions associated with the COVID-19 pandemic in 2020/2021.

The bushfires in East Gippsland resulted in loss of life, displacement of thousands of people, and the temporary isolation of numerous communities (State Government of Victoria, 2022). By the time all significant fires across Victoria were contained in February 2020, over 1.5 million hectares was burnt, including over 1000 registered Aboriginal heritage places (State Government of Victoria, 2022). In Eastern Victoria, the fires impacted 248 Aboriginal people, with 42 homes destroyed or made unliveable (State Government of Victoria, 2022). Further, businesses, community facilities, and thousands of kilometres of roads and fences were damaged or destroyed. Key regional industries such as agriculture, tourism, forestry, and retail were severely affected (Williamson et al., 2022).

Barely a month after bushfire containment, the first COVID-19 restrictions came into effect in Victoria, Australia. The state of emergency, declared in March 2020, led to mandatory directions to stay at home and isolate when diagnosed with COVID-19.

Direct impacts of crises can include injuries and death from extreme events; indirect impacts can affect human systems, including mental health, productivity, and damage to housing and health care facilities (Lansbury Hall & Crosby, 2022). Due to their isolated locations, infrastructure, economic resources, limited transport, and existing health vulnerabilities, regional and remote Aboriginal communities are additionally vulnerable to the impacts of disasters and the associated health effects (State Government of Victoria, 2022). Crises are projected to increase due to the impacts of climate change (United Nations, 2023), thus making crisis planning increasingly essential.

Environmental factors comprise the physical and social environmental conditions impacting health, including housing conditions and the physical

environment in which health care is delivered. Conceptualising environmental health factors this way, as encompassing a range of human made physical or social features, contrasts with traditional environmental health approaches which focused primarily on toxic substances in air, water and soil (National Research Council, 2013). In this research, the environmental themes addressed included priorities other than health; transport; and medical bureaucracy and the physical environment.

The literature has little to say about experiences of regionally located Aboriginal People accessing PHC during crises. The only two articles addressing this topic describe the acceptability to a rural Victorian Aboriginal community of a primary health care mobile clinic for Aboriginal People during the COVID-19 restrictions (Beks et al., 2022b); and a grounded theory study of the success of a locally-led, holistic, comprehensive and culturally safe response by an ACCHO to the COVID-19 pandemic in an Aboriginal community, Yarrabah (McCalman et al., 2021). We have chosen to address environmental factors in this paper because they emerged in our analysis as critical to PHC access during the periods of crisis under study. Additionally, some of these factors (such as transport access) are more amenable to change than factors pertaining to individual histories and professional cultures, offering potential to improve the service response.

Methods

As a study led by a non-Aboriginal researcher conducting research in an Aboriginal community, it was important all aspects were informed and approved by the local Aboriginal community. A formal partnership was created between the lead author and Lakes Entrance Aboriginal Health Association (LEAHA), to ensure local Aboriginal community input and oversight of the research proposal, methodology, analysis and dissemination, and usage. The second author is a Gunai woman who provided critical input and was the project cultural advisor.

Setting

The Lakes Entrance community is in far East Gippsland, Victoria, Australia, the traditional land of the Gunaikurnai people. The population of Lakes

Entrance is 8,524, including residents of Lakes Entrance, Lake Tyers, and the Lake Tyers Trust (Informed Decisions, 2022). East Gippsland's Aboriginal and Torres Strait Islander population is 1683, or 3.5% of the total population (Australian Bureau of Statistics, 2021). PHC services are provided by two ACCHOs, LEAHA and Lake Tyers Health and Children's Services (LTHCS), and a community health clinic and private medical clinic in Lakes Entrance.

Design and methods

The research design entailed a qualitative case study approach aligned with that outlined by Stake (1995). In Stake's (1995, p.23) approach, "...knowledge is constructed rather than discovered". Consequently, case study researchers are interpreters who report their constructions of the knowledge they gather. The qualitative case study research design provided rich data and highlighted previously unstudied aspects of disaster health care for a minority and marginalised cohort.

Eligibility and Recruitment

Inclusion criteria for participants were adults aged over 18, who identified as Aboriginal. Research participants were required to have accessed or attempted to access PHC during the crises specified above. Recruitment was through advertisements at LEAHA and LTHCS, with some participants approached on advice from the project cultural advisor.

Participants

Fifteen participants were female, and three were male, as described in Table 1. Four participants were ACCHO employees and community members, and the remaining fourteen were community members and users of PHC. Some participants had a community connection relationship with the second author, who facilitated some interviews, but not with the primary author.

Pseudonym	Location of interview	Age	Gender
Anne	Lakes Entrance, LEAHA	40-50	F
Betty	Lakes Entrance, LEAHA	40-50	F
Carol	Lakes Entrance, LEAHA	20-30	F
Dolly	Lakes Entrance, LEAHA	20-30	F

Elaine	Lakes Entrance, LEAHA	20-30	F
Flora	Lakes Entrance, LEAHA	70-80	F
Gwen	Lakes Entrance, LEAHA (phone)	60-70	F
Holly	Lakes Entrance, LEAHA (phone)	50-60	F
Ian	Lakes Entrance, LEAHA	50-60	M
John	Lakes Entrance, LEAHA	40-50	M
Karen	Lake Tyers Trust, LTHCS	40-50	F
Linda	Lake Tyers Trust, LTHCS	30-40	F
Molly and Nina	Lake Tyers Trust, LTHCS, (group interview)	70-80 70-80	F F
Orla and Penny	Lake Tyers Trust, LTHCS, (group interview)	60-70 60-70	F F
Quinn	Lake Tyers Trust, LTHCS	50-60	M
Rachel	Lake Tyers Trust, LTHCS	50-60	F

Table 1: Participant Table: Aboriginal People's Perspectives on Accessing Primary Health Care During Crises: A Case Study of the Lakes Entrance Community. Woodland, R. (2023).

Data Collection

All interviews were conducted by the first author. Sixteen interviews were conducted face-to-face at the local ACCHOs, with two interviews conducted in pairs at the request of the interviewees. Two interviews were conducted by telephone. Only participants and researcher were present during interviews. Interviewees were difficult to source after conducting 18.

Interviews were semi-structured, and were recorded and transcribed, with participants offered the opportunity to review their transcripts. Interviews ranged in length from 40 to 93 minutes, and a \$25 Coles/Myer voucher was provided to participants in acknowledgement of their time.

Analysis

Data analysis strategies utilised in this research were those proposed by Miles and Huberman (1994), which involve broad coding; pattern coding or memoing; distilling and ordering and testing executive summary statements; and

developing propositions. Analysis was performed throughout the data collection process to inform further interviews.

NVivo 12 was used as a data management tool and data was coded by the first author. The cultural advisor and second author reviewed identified themes. Participant anonymity was ensured through use of pseudonyms. Participants' quotes have been used verbatim to prioritise their voice, and support claims made (Lincoln & Guba, 1985; Corden and Sainsbury, 2006).

Ethics

La Trobe University (HEC20390) provided ethics approval for this research project, and the NHMRC Guidelines on Ethical Conduct in Research with Aboriginal and Torres Strait Islander People and Communities: Guidelines for researchers and stakeholders (NMHRC, 2018) were followed.

Results

We identified the following themes as environmental factors in PHC access; competing priorities; transport issues; and the influence of medical bureaucracy and physical environment of health care settings. Although there was considerable overlap between themes, for ease of presentation they are discussed separately below.

The influences of competing priorities on PHC access during times of crises

Participants indicated that accessing health care and focusing on their health needs during the 2019/2020 bushfires and COVID-19 restrictions were simply not priorities for many community members. Meeting basic needs such as shelter and food took higher priority, as Anne explained:

...the plain old thing that health's not a priority...I think the thing because obviously a lot of them have got shit going on in their lives, whether its...god knows what it is...whether it's trauma, or elder abuse, or there's just so much going on in their lives, so the main thing is to keep a roof over their heads and make sure they've got a meal, got lunch and tea tonight so their health is like way down the list.

Some participants named housing as a priority above health care during crises. Following the 2019/2020 bushfires, there was greater competition for the already limited supply of local housing. The high demand led to increased rental prices, and as a result private rental options became even more unobtainable for Aboriginal community members, many of whom have comparatively low incomes. Several participants described couch surfing, or moving from couch to couch, instead of stable, permanent accommodation, as the reality for family members and friends. John said, "I stay with 'em till they kick me out, then I stay with 'nother one, and I'm thinkin' about who I can crash with next". Further, participants spoke of the problems arising from COVID-19 social distancing requirements, within houses occupied by extended families.

Several participants described prioritising their own health needs below those of others during crises. Karen explained : "Priorities are a big thing, cause our mob are all about looking after everyone else, and it's like a mum thing isn't it, looking after everyone else and you're last". Several participants described how during the 2019/2020 bushfires, their concern for family and community members who had been evacuated outweighed thoughts of their own health needs.

Further, participants privileged concern for the health of family and community members, particularly Elders and older family members over their own, during COVID-19 isolation periods. Participants also expressed concern for other matters they were prioritising above personal health needs, such as having to home-school children, an inability to travel for sorry business [bereavement] due to lockdown, and concerns relating to finances.

Participants described a lack of financial resources as a major factor influencing health care access choices and health care experience. Betty described :

That would be one of our biggest barriers, cause nowadays it's \$5 for the nurse, um, and they don't know whether they're going to be bulk-billed [fully funded by the federal health scheme] or not when they see the GP, and that sort of thing. So, they won't go.

Participants incurred extra expenses when they evacuated from their homes during the 2019/2020 bushfires. This meant they had less money for health care. These experiences were echoed later when participants' usual health care arrangements with ACCHOs were interrupted due to government-mandated COVID-19 lockdowns and staff shortages. This uncertainty led to concern and fear of whether people would be bulk-billed or charged at mainstream medical clinics. Rather than have these uncomfortable conversations, participants chose to wait until health care was available via the ACCHO.

The influence of transport issues on PHC access during times of crisis

Many participants identified lack of transport as a barrier to accessing PHC. During the 2019/2020 bushfires, the public transport bus did not travel its regular route due to road closures, and unacceptable risks of fire and falling trees. The lack of public transport hindered participants' capacity to travel. Participants also reported limited medical transport services during the bushfires and immediate aftermath. Some ACCHO staff had evacuated, and the medical transport service could not be staffed. However, this was a short-term scenario and both ACCHOs had medical transport services running as usual soon after.

Participants explained how during the COVID-19 restrictions, low car ownership rates among the Aboriginal community acted as a barrier to accessing health care. The Department of Health organised COVID-19 testing for the public, delivered via drive-through clinics. Such service delivery presented difficulties for many of the Lakes Entrance Aboriginal community who did not own or have access to a car. Consequently, some of the Lakes Entrance Aboriginal community, who were also among the most disadvantaged due to their pre-existing health conditions, were excluded from accessing much-needed testing. COVID-19 restrictions also prohibited people from being physically close to others who were not from their households. As a result, Aboriginal community members could not share cars with other community members to access health care, obtain a COVID test, or access treatment.

For participants who were car owners, the high costs of petrol, insurance, registration, and car maintenance were raised as additional barriers. Holly explained:

Most of our mob don't have cars, or reliable cars, and then the same deal, if they have got an appointment in Bairnsdale say, they might have a car, but they haven't got the money for petrol to get there.

A strategy local ACCHOs LEAHA and LTHCS used to overcome these transport barriers, was using a medical driver service as soon as they were able to. This service drove Aboriginal clients to health care appointments in Lakes Entrance, throughout Gippsland, and to Melbourne. Participants appreciated medical transport services, and acknowledged the critical role they played in health service access during difficult times.

The influence of medical bureaucracy and the physical environment of health care settings on the health care experience during times of crisis

Participants described issues with medical bureaucracy and processes when accessing health care being exacerbated during the 2019/2020 bushfires and the COVID-19 restrictions. First, managing referral letters and imaging or pathology slips appeared to impact participants' health care experience. As explained by Karen, difficulties associated with arrangement of imaging and testing acted as barriers to accessing health care:

...it's too hard, too much, too much stuffing around, you've gotta get the appointments like, and then get there, and then get home, and you dunno how much it's gunna cost, and is it worth it even? And then you've gotta go back to the doctor again....

Participants expressed gratitude for both LEAHA and LTHCS's support in managing medical referrals, testing, and imaging. ACCHO staff kept track of medical appointments and arranged medical transport for clients, sent referral letters, arranged appointments, and assisted with booking and accessing medical imaging and testing. In this way, ACCHOs were a key enabler of health

care access for the participants, yet participants constructed mainstream health services differently.

Participants' concerns and issues about interacting with mainstream medical reception staff were exacerbated during the bushfires and COVID-19 restrictions. During times when ACCHOs were not open and fully staffed, due to working-from-home restrictions during COVID-19, and staff shortages due to the impact of bushfire, some participants could not access their usual health care arrangements via their ACCHOs, so were forced to engage with mainstream health care providers.

Participants spoke of their experiences at mainstream PHC clinics during this period, particularly medical reception staff's behaviour and attitudes. Many participants described receiving poor treatment from reception staff at medical clinics, which were variously described as "rude" and "unhelpful". Karen explained, "...they was uppity, you know? Just like they was better than us, and we was nothin'." Ian explained how the reception staff's behaviour impacted participants:

You just feel like, unwanted. You just feel like they don't want to treat you, it just becomes... I don't know if those are the right words, but it just feels so like - is racism playing its part again in that? Intimidation was the word, but you just feel like you know, you're not worthy of going in to see a doctor, which puts a lot of people off.

Some participants offered a different perspective on the medical reception staff's attitudes. They posited that it could be challenging to distinguish racist behaviour from poor customer service, as stated by Anne, "...some of those staff are like that whether it's you or I or someone that's Black or white – you know what I mean?". Another participant agreed and added, "...but it just means that the intimidation's more felt by us because we've always had these knock-backs, if you know where I'm coming from". Some participants recounted that they preferred to forego health care, rather than engage with medical reception staff at mainstream services.

As noted above, during the 2019/2020 bushfires and COVID-19 restrictions, issues with appointment-making processes at mainstream services were heightened because usual health care arrangements via the ACCHOs were compromised. Participants explained how usual appointment-making processes at their local ACCHOs met their needs. At LTHCS appointments are not made, and the clinic works on a 'come and wait' system. At LEAHA, clients can make appointments to see the doctor at the community health clinic through LEAHA, rather than directly calling the community health clinic.

In contrast, participants described their difficulties with mainstream health care appointment making, and seeing their preferred doctor. Participants recounted explaining to reception staff they were happy to wait for a medical appointment with their preferred doctor, as continuity of care was important to them. Participants advised that receptionists could have been much more helpful in working with them to make an appointment with their preferred doctor. Molly summarised her experiences: "They just make ya feel like ya troublin' them, and they don't care".

Mainstream health services waiting rooms were described by participants as deterrents to accessing PHC via mainstream services. The lack of Aboriginal reception staff, and the lack of Aboriginal people in the waiting room, including being "...the only Black face in the place...", as Elaine said, meant that participants weren't comfortable in that environment.

Discussion

This study identified the barriers and enablers described by a regional Aboriginal community accessing PHC during crises, a topic largely ignored in the literature to date.

Diverse environmental factors that impacted Aboriginal community residents' access to health care during crises were identified, including: the influence of priorities other than health on the health care experience, including housing and other priorities; transport issues; and the influence of medical bureaucracy including managing medical documentation, medical reception

staff, managing the appointment making process and physical health spaces such as medical waiting rooms.

First, PHC access and experiences were found to be impacted by factors other than health, including housing needs, prioritising others above themselves, and financial constraints. These findings reflect the findings of a growing body of literature (Nolan-Isles et al., 2021; Wenitong et al., 2014), however have not been researched in the context of a crisis. The research findings indicate that during times of crisis, support mechanisms are required to facilitate the Aboriginal community's access to housing and finances, therefore enabling primary health issues to be addressed. Participants clearly communicated their preference for accessing support through the local ACCHOs, with whom they shared strong pre-existing relationships. Therefore, housing, and financial services support could be delivered through local ACCHOs.

Second, transport issues played a significant role in impacting participants' experiences. Communities in regional areas face transport barriers due to greater geographic distances to travel (Nolan-Isles et al., 2021; Harfield et al., 2018); limited PHC options nearby (Harfield et al., 2018); minimal public transport options (Nolan-Isles et al., 2021; Harfield et al., 2018); and higher travel costs such as petrol (Nolan-Isles et al., 2021; Harfield et al., 2018). Findings concerning participants' exclusion from COVID-19 testing due to lack of vehicle ownership, strongly suggest that car access and car ownership is even more important than usual to access PHC during crises, and that testing options for people without cars should be available.

Third, findings show that unhelpful medical bureaucracy in the form of medical documentation, medical reception staff, making appointments, and physical spaces such as medical waiting rooms impacted health care access during crises. Thus, there are implications for future crisis planning relating to the provision of culturally appropriate and acceptable care for the Aboriginal community.

While acknowledging the importance of identifying barriers to accessing care in the context of participants' experiences, in writing this study we did not want to contribute to the deficit discourse characterising much research on Aboriginal health (Fogarty et al., 2018). Consequently, we highlight the critical

role ACCHOs have played as enablers of health care access both during usual conditions and crises.

The key role ACCHO staff play in supporting communities is recognised in the literature (Jayakumar et al., 2023; Reeve et al., 2015), however no research to date has focused on the role of ACCHOs during crises. This research found ACCHO staff appeared to be a critical enabler, assisting Aboriginal participants to manage medical bureaucracy issues by providing support with making medical appointments, arranging medical imaging and testing, and providing transport. During crises, therefore, it is critically important for ACCHOs to be supported to continue service provision to communities.

Overall, participants clearly preferred to access PHC via the local ACCHOs rather than mainstream health providers during crises. Several characteristics define Aboriginal PHC service delivery models, including accessible health services, community involvement, culturally appropriate and skilled workforce, holistic health care and wellness, self-determination and empowerment, connection to culture, and coordination of intersectoral and multidisciplinary collaboration (Grad, 2002). A substantial body of evidence demonstrates the better performance and outcomes of ACCHOs compared to mainstream general practice (Campbell et al., 2018; Munns et al., 2018; Panaretto et al., 2014).

ACCHOs are ideally placed to promote and protect the health of Aboriginal communities during times of crisis due to their unique characteristics, as demonstrated by participant responses. ACCHOs pre-existing links and proximity to communities and networks mean they are well-placed to understand the environmental, social, and cultural elements affecting health, and deliver context-appropriate care and effective risk communication (Colbran et al., 2021).ⁱ Due to their relationship with the community and their ongoing presence, ACCHOs can continue PHC delivery and support throughout crises and into the recovery phase.

Findings also demonstrate the considerable efforts of the ACCHO sector, as a PHC provider, to address both the social determinants of health and health inequity factors experienced by Aboriginal communities during crises. The enablers promoted and supported by ACCHOs during crises included financial

assistance with medical appointments; providing transportation options; supporting interagency communication and coordination for medical referrals, imaging, and testing; continuity and consistency of care as far as possible during unprecedented times; in-depth knowledge of community members and the local context and family dynamics; and respect for, and understanding of, factors competing with health care access. Here, the community's strong relationships with ACCHO staff, and the appreciation for the support and care the ACCHO staff provided were evident.

Strengths and limitations

Strengths of this study include the codesign process with the local ACCHO and cultural advisor and the use of a cultural advisory panel to identify and verify the themes arising from the participants' experiences. An additional strength of this study is that it amplifies Aboriginal participants' experiences and voices.

Limitations of this study are that only three men were interviewed from 18 interviews, which may discount the male voice and experience. Additionally, there were few young adult participants in the study. Research into the perspectives/experiences of young adults accessing health services during periods of crisis would also provide valuable insights.

To address the issues that Aboriginal communities face when accessing PHC during a crisis, further, larger scale studies could be undertaken, and the results synthesised for government and policymakers to utilise for future crisis planning.

Conclusions

The conclusions drawn from the present study are as follows. The preference of many Aboriginal people to access PHC via their local ACCHO rather than mainstream health care services appears even more salient during crises than in normal times. Accessing services from unfamiliar providers was not an acceptable option for the Aboriginal community.

The enablers the ACCHOs provide to their local communities during crises built and expanded on the positive experiences of cultural safety they

provided during usual times; the trust participants displayed in the ACCHOs; addressing distance and travel barriers through the provision of medical transport drivers; supporting the community with assistance managing medical bureaucracy such as appointment making, managing referrals, and support with medical testing and imaging; and the cultural safety provided during uncertainty and the chaos of crises.; that addressed distance and travel barriers.

Interventions could both build on the supportive environment and comprehensive care already provided by ACCHOs, and address some of the barriers to access that people experience when using mainstream health services – for example through provision of cultural safety training for all PHC staff, including reception staff in private clinics and government health centres, and by building stronger links between different health care providers in the region.

Identifying the above barriers and enablers and the role played by the ACCHOs, assists in identifying strategic options to improve PHC accessibility during crises. Findings from this study highlighted the potential of ACCHOs to mobilise and meet the needs of clients and the local community during crises. ACCHOs' response during the 2019/2020 bushfires and the COVID-19 restrictions period has demonstrated that knowledge of Indigenous communities via pre-existing relationships is an essential foundation for primary health delivery during crises, and is worthy of future research and government investment.

This study provides a compelling case for further research to describe emerging innovations within Indigenous PHC contexts in response to public health crises and disasters. This knowledge has the potential to inform and support ACCHO health systems to be more resilient to future crises, such as public health emergencies and disasters, and also to meet the challenges faced by Indigenous populations. For this to occur, governments must reinforce financial commitments and responsibilities toward equitable PHC service infrastructure for Indigenous communities, particularly during public health crises or emergencies (Williamson, 2022).

8.3 Conclusion

This chapter described the experiences of the Lakes Entrance Aboriginal community accessing health care during times of crisis, focusing on the theme

of environmental factors. The chapter discusses the impact of competing priorities on PHC access, including priorities such as shelter, housing, food, trauma, elder abuse, looking after family members, and lack of money. It highlighted the inability of community members to focus on their own health needs when competing priorities took precedence, and emphasised the exacerbation of these competing priorities during crises.

Pre-existing transport issues were also exacerbated during crises. The impact of these was explained by community members, as was the appreciation the community had for the support provided by their local ACCHOs. The medical driver services provided by LEAHA and LTHCS were acknowledged by the community members as playing a critically important role in facilitating their healthcare access.

The chapter also covered the issues participants described with medical bureaucracy and processes when accessing health care, being exacerbated during the 2019/2020 bushfires and the COVID-19 restrictions. Participants described these issues as being management of health care referral letters and imaging or pathology slips; dealing with changed appointment making processes during the crises; and interactions with reception staff and uncomfortable waiting room environments at mainstream PHC clinics.

In summary, this chapter has shed light on the experiences of the Lakes Entrance Aboriginal community in relation to accessing health care during times of crisis, focusing on the theme of environmental factors. The findings emphasise the importance of ACCHOs to the local Aboriginal community in PHC delivery and health care access.

Chapter 9 Discussion and Implications for Practice

9.1 Introduction

This chapter presents a discussion of the research findings concerning their implications for practice. Policy implications are covered in Chapter 10. The research findings were categorised into three themes and broken down into sub-themes. Chapter 6 described the experiences of the Lakes Entrance Aboriginal community in relation to service delivery factors, which included the type of PHC service provider, continuity of care and communication. Chapter 7 described the influence of personal factors on the healthcare experience, including those of shame and fear, intergenerational trauma, racism and prior experiences in the healthcare sector. Chapter 8 was presented as a journal article submitted for publication in the *Australian Journal of Rural Health*. Chapter 8 described the impact of environmental factors, including transport factors, medical bureaucracy and processes and the influence of priorities other than health on the healthcare experiences of the Aboriginal community.

The discussion in this chapter draws on Australian and international literature to inform the implications for practice in PHC settings arising from this research. As identified in Chapter 5, scant literature is available in Australia that specifically focuses on the experiences of regional (or otherwise) Aboriginal people accessing PHC during times of crisis. Further, this chapter demonstrates that the impacts of colonisation on Aboriginal people's healthcare access are heightened during times of crisis.

9.2 The Impact of Service Delivery Factors on the Healthcare Experience and Implications for Practice

The research findings demonstrated the importance to the Aboriginal community of the type of health care provider they access, the continuity of holistic care provided and the importance of appropriate communication. These factors align with the four primary health core functions: first contact, comprehensiveness, continuity and coordination (Prates et al., 2017). In the context of primary health care, there is general agreement that the achievement of these well-known core primary care functions is associated with better quality

services, lower costs, less inequality in health care and better population health (Baicker & Chandra, 2004; Lewin et al., 2008; Starfield et al., 2005).

First, despite a few concerns about confidentiality in this close-knit Aboriginal community, this study's participants strongly preferred to access PHC via their local ACCHOs, LEAHA and LTH&CS, rather than at mainstream local health providers. This preference existed during normal times and crises. Since the first ACCHO was established in 1971 in response to 'experiences of racism in mainstream health services, and an unmet need for culturally safe and accessible health care', they have provided health care to Aboriginal communities (NACCHO, 2022).

Aboriginal PHC service delivery models are defined by several characteristics, including community involvement, culturally appropriate and skilled workforce, holistic health care and wellness, self-determination and empowerment, connection to culture and coordination of intersectoral and multidisciplinary collaboration (Harfield et al., 2018; Pearson et al., 2020). These unique characteristics explain why the Aboriginal community in this study find PHC offered via their local ACCHO to be culturally appropriate, acceptable and better suited to meeting their needs than that provided by mainstream health care providers. ACCHOs have been reported to be 23% better at attracting and retaining Aboriginal clients than mainstream providers (AHMAC, 2017).

Evidence at a population and sector level, as well as from the social and cultural determinants of health, all testify to the effectiveness of ACCHOs in supporting the Aboriginal community. This finding includes strong population-level evidence for the effectiveness of ACCHOs in supporting Aboriginal communities. In the decade from 2009–2010 to 2018–2019, there was a fourfold increase in the rate of Aboriginal-specific health checks for Aboriginal people, from 68 checks per 1,000 population in 2009–10 to 297 per 1,000 in 2018–19 (AIHW, 2023). Data suggest that GPs at ACCHOs conducted nearly half of all Aboriginal-specific health checks despite only making up about 1.8% of full-time-equivalent GPs (AIHW, 2022c).

Sector-level evidence shows ACCHOs are proven to be clinically effective and more effective than other health services at improving Aboriginal health outcomes (M. A. Campbell et al., 2018). They also contribute to health policy

through advocacy for their communities and reducing barriers to accessing health care (Nolan-Isles et al., 2021). Evidence shows how the ACCHO sector effectively addresses the social and cultural determinants of health (Pearson et al., 2020). It is estimated that between one-third and one-half of the health gap between Aboriginal and non-Aboriginal people is the result of the social determinants of health, particularly regarding socio-economic status (AHMAC, 2017). The ACCHO sector addresses the social determinants of health in ways that other sectors are unable to do, including going beyond the treatment of individual clients for discrete medical conditions to include a focus on cultural security; client transport; client advocacy; population health programs, including health promotion and prevention; public health advocacy and inter-sectoral collaboration; participation in health planning processes; structures for community engagement and control; and significant employment of Aboriginal people (Davy et al., 2016; Pearson et al., 2020).

Findings from this research have reiterated the importance of ACCHOs and the Aboriginal PHC model to the Aboriginal community. The culturally safe and appropriate care and information ACCHOs provide are even more important during times of crisis. The Australian Red Cross (2023) pointed out the disruptive and stressful nature of crises and people's need to access support from people close to them. This need speaks to the implications for practice from the findings from the present study, namely, the need for familiar and trusted health care provided by ACCHOs with whom the local community has pre-existing relationships during times of crisis.

9.3 Continuity of Care

The importance of continuity of care for the Lakes Entrance Aboriginal community during times of crisis was described in Chapter 6. The continuity of care enabled by local ACCHOs took several forms.

Medical continuity of care for the community was provided by ACCHO staff, who supported their service users with teleconference support while accessing medical appointments and filling prescriptions for clients who were unable to leave their homes. Literature from overseas indicates that PHC services have a strong capacity to maintain care continuity during a pandemic, continuing access to other health services and supports (Laupacis, 2020).

Recent international literature also highlights the importance of equitable, reliable and consistent access to regular health services for Indigenous people and communities during a public health crisis (Imlach et al., 2021; Montesanti et al., 2019).

The adoption of virtual care by some Aboriginal health services was also reported to support continued access to services and support during the COVID-19 pandemic (Danila Dilba Health Service, 2020; Fitts et al., 2020). This research indicates that telehealth was acceptable to the community when offered by a known provider, facilitating continuity of care. This finding has implications for practice for healthcare providers who wish to use telehealth as a delivery method to utilise known medical professionals with the support of known ACCHO staff. This need is particularly relevant during crises when the uncertainty of the situation makes known and trusted relationships even more important. The National Aboriginal and Torres Strait Islander Health and Wellbeing Plan (2021) states that telehealth and other emerging technologies must be culturally safe and responsive. It specifies that this means they must consider the importance of establishing relationships with Aboriginal people as key to enabling effective health service delivery. They must also include implementing localised responses supporting strong provider and client relationships. This approach aligns with the findings from this research.

This research found that some participants chose not to engage with health care rather than see an unfamiliar doctor. This finding has implications for overall health outcomes due to the prevalence of chronic conditions that Aboriginal people experience disproportionately, contributing to Aboriginal people having an estimated life expectancy 10 years shorter than non-Aboriginal Australians (CTG, 2019). Chronic diseases are the leading cause of illness, disability and death among Aboriginal people (AIHW, 2022f). The effective management of chronic disease can delay disease progression, improve quality of life, increase life expectancy and decrease the need for high-cost interventions, leading to net savings (Thomas et al., 2014; Zhao et al., 2014).

Interestingly, this finding about continuity of care was in marked contrast to that of Liu et al.'s (2017) study of Chinese healthcare consumers' preferences regarding continuity of care. Liu et al. (2017) found that while consumers

preferred relational continuity with specialists, they did not place the same importance on continuity of care with primary care providers. Study authors noted that the quality of primary care was low in China and that consumers' preferences may also have indicated their lack of confidence in primary care (Liu et al., 2017). However, these results highlight the importance of culture and context as factors concerning healthcare consumers' preferences.

9.3.1 Implications for Practice: Continuity of Care Findings

Considering the findings in relation to continuity of care, health services may benefit from ensuring that during a crisis, existing healthcare relationships and practices are sustained and supported as much as possible. In a practical sense, this can be achieved through healthcare organisations reflecting on the adequacy of their business continuity plans and planning contingencies to ensure they can continue services. This initiative would need to be supported by government and funding bodies, which is discussed further in Chapter 10, which addresses the findings' policy implications.

The findings on this topic have relevance to both ACCHOs and mainstream health organisations during usual times, in that facilitating continuity of care depends on having the resources to maintain market-rate pay and conditions of health care professionals, who are in short supply and high demand in regional areas (National Skills Commission, 2022). If ACCHOs cannot maintain the continuity of health care professional staff, they risk relying on a parade of short-term locum appointments. ACCHOs staffed by short-term health care staff will not meet community needs and, as described in Chapter 7, will further exacerbate health conditions for Aboriginal community members who prefer to go without health care rather than see unknown providers.

The research findings also highlighted that Aboriginal participants preferred continuity of health care providers due to a consistent PHC provider supporting a consistent medication treatment regimen. Participants described their confusion when medication treatments changed and the impact on their ability to maintain adherence to medication regimens. Considering this, both mainstream and ACCHO PHC providers may investigate more widespread use of client record sharing to enable all healthcare providers to fully understand the client's diagnosis, tests and treatment plans. My Health Record is an Australian

government initiative to store and share medical health information among health professionals electronically. The benefits of using My Health Record for continuity of care for clients have been espoused by the GP community (Yates, 2019). Given the mistrust that Aboriginal service users displayed in government organisations and lower levels of health literacy in the Aboriginal community, this could be difficult to enact and would require significant resourcing.

9.4 Communication

This section describes the findings and implications for practice in relation to communication, in terms of both communication to the community, and communication between the health care provider and the client.

9.4.1 Communication and the Community

The findings described in Chapter 6 suggest the importance of two forms of health-related communication to the Lakes Entrance Aboriginal community during times of crisis: (a) communication to the community in general about the crisis, including addressing misinformation, and (b) communication between community members and their health care providers.

First, communication to the community from LEAHA and LTH&CS took various forms, including via social media, multiple weekly phone calls and personal visits whereby essentials, such as medication and groceries, were delivered. The research findings demonstrated that communication from the local ACCHOs was trusted and regarded as more valid than that from other official channels, such as the Victorian Government and local Public Health Network.

The literature indicates that effective health-related communication has many factors. The messaging must be understood, accepted and applied (Smith & Judd, 2020). If the message is not understood, it cannot be actioned. Research on health literacy has shown that more than a third of the population worldwide has difficulty finding, understanding, evaluating and using information necessary to manage their health (Van den Broucke, 2020). Health information must be tailored to different population groups and acknowledge the social and cultural context surrounding their health (Finlay & Wenitong, 2020; Van den Broucke, 2020; Vraga & Jacobsen, 2020).

Literature on effective communication among Aboriginal people states that mutual trust should exist between the communicator and the audience (Finlay & Wenitong, 2020; Vaughan & Tinker, 2009). This study indicated the high level of trust the Aboriginal community has in the local ACCHOs, which may explain why the community trusts and accepts the validity of information coming from this source and why it is so effective. The acceptance by the Aboriginal community of information communicated by the ACCHO is in direct contrast to the acceptability of information from other government organisations due to a long history of distrust of government and medical institutions by the Aboriginal community (Graham et al., 2022; Topp et al., 2021).

Communication during crises should be provided through a 'health equity lens' (Smith & Judd, 2020, p. 159), with attention to those most vulnerable to the crisis and most at risk of misunderstanding the communication. This view is supported by a local Lakes Entrance Aboriginal organisation, GLAWAC, which provided a submission to the Royal Commission into the Australian Bushfire Season 2019–2020 about their experiences (CoA, 2020, p. 2). The submission stated that many Aboriginal communities and individuals were unsure of crisis messaging and suggested, 'how these messages and targeted preparation initiatives are developed to be more appropriate and better received by Aboriginal people in the community should be an area for all to improve'. (CoA, 2020, p. 2).

9.4.2 Implications for Practice: Communication to the Community

The experiences of the Lakes Entrance Aboriginal community have shed light on the implications for practice regarding public health communication during crises. Organisations can learn from the successful use of various communication modes and methods by LEAHA and LTH&CS during the 2019–2020 bushfires and the COVID-19 restrictions period.

The use of social media, predominantly Facebook, using groups that were popular with the local Aboriginal community was particularly successful; the groups included the official LEAHA and LTH&CS Facebook pages. Information about healthcare access and other crisis-related information was provided to the community using social media and posting to address and correct misinformation circulating online. Information was also communicated to

the Aboriginal community through short videos featuring local Elders and via handouts and flyers, which were physically delivered to community members' houses.

The National Aboriginal and Torres Strait Islander Health and Wellbeing Plan (2021, p. 41) states that 'communication materials must also be culturally and linguistically accessible for Aboriginal and Torres Strait Islander populations'. As described above, the communication methods LEAHA and LTH&CS used were culturally and linguistically accessible. This approach may explain their success in reaching their local community. As evidenced in Chapter 6, this study's participants trusted messaging featuring local Elders.

9.4.3 Communication Between Health Care Providers and Aboriginal People

Second, the importance of communication between participants and their healthcare providers was a salient finding of this research. This issue is even more relevant during crises when community members are disrupted and stressed. In a crisis, people take in information, process it and act on it differently than they would in non-crisis times (Covello et al., 2001; Seeger et al., 2005). Missing critical details in information, believing the first messages encountered and looking for additional information to confirm information are common information processing problems encountered during a crisis (Covello et al., 2001). At these times, reverting to the familiar and trusted, in the form of their health care provider, is what research participants want.

The issue of poor healthcare provider communication is recognised in the literature, including service users receiving health education material that was not culturally relevant (Artuso et al., 2013; B. Jones et al., 2020), clients being subjected to the use of medical jargon by staff members which impacted them negatively (B. Jones et al., 2020; Mbuzi et al., 2017; Meiklejohn et al., 2017), clients having communication restricted by time constraints (B. Jones et al., 2020), clients not having family assistance sought when low literacy levels were present (Ristevski et al., 2020), a dominance of biomedical knowledge and marginalisation of Aboriginal knowledge (Cass et al., 2002) and differing modes of discourse between clients and providers (Cass et al., 2002). These negative effects were resolved or reversed when culturally relevant and competent

interactions occurred, such as those provided by ACCHO staff (Gomersall et al., 2017).

Communication between health professionals and Aboriginal service users must be understood within a broader sociocultural and political context. Communication sits within the context of a broader health system and government system, which can be viewed as mechanisms of colonisation and, therefore, controlling Aboriginal people (Eckermann et al., 2010). For instance, the taking of children, refusal of care, and racially segregated wards are documented health system examples of oppression occurring within many clients' lifetimes (Forsyth, 2007). This contextual knowledge assists in explaining why communication between health professionals and Aboriginal service users is loaded with meaning beyond what is being communicated.

9.4.4 Implications for Practice: Communication Between Healthcare Providers and Aboriginal People

The research findings have significant implications for practice during crises, particularly highlighting that Aboriginal community members tend to prefer accessing PHC from familiar and trusted providers with whom they have established relationships. There are three main implications for practice: enabling continuity of care from healthcare providers, communication between Aboriginal people and their healthcare providers and better cultural awareness from healthcare providers to inform their communication.

First, enabling continuity of care during times of crisis is critically important for healthcare providers working with Aboriginal community members. This point has been addressed earlier in the chapter.

Second, communication between Aboriginal people and their healthcare providers has been identified in the research findings as an area that can constitute a barrier to PHC access. This element from the health care provider's perspective was addressed earlier in the chapter under continuity of care. The research finding that healthcare provider communication is often problematic for the Aboriginal community implies that mainstream PHC providers need to reflect on their own skills in providing their clients with appropriate verbal and written communication and upskill themselves in how this can be done to meet the needs of their local community and local clients.

From the perspective of the Aboriginal service users, there may be benefit in the ACCHOs and PHC providers educating and supporting service users to obtain the confidence to clarify issues, ask questions and discuss options with their provider. This issue is tied to health literacy, which can be fostered and improved both by ACCHOs and mainstream PHC providers. This implication is recognised and reflected in Objective 4.1 of the National Aboriginal and Torres Strait Islander Health Plan 2021–2031 (DOHAC, 2021c, p. 41), which states that ACCHOs must be prioritised as best placed to develop and deliver literacy information and programs that are tailored to benefit individuals, families and communities, to enable ‘self-management and decision-making in health and wellbeing’. It is important to acknowledge that this implication for practice does not imply that Aboriginal people are responsible for the communication difficulties they encounter within the health care system. As the following research explains, systemic and structural racism are forms of racism that are pervasively and deeply embedded in and throughout systems, laws, written or unwritten policies, entrenched practices and established beliefs and attitudes that produce, condone and perpetuate widespread unfair treatment of people of colour (Kairuz et al., 2021).

A third implication for practice flowing from the research findings is the need for health professionals to understand and reflect on their position within a health system, which many Aboriginal people see as a representation of inequality and control over Aboriginal people. This implication for practice aligns with Objective 3.2 of the National Aboriginal and Torres Strait Islander Health Plan 2021–2031 (DOHAC, 2021c, p. 38), which aims for improved cultural safety in workplaces across health and calls for action across the health system to address this.

Cultural competence has been identified as one strategy to address racial and ethnic health disparities by providing culturally tailored healthcare services (Betancourt et al., 2003). The concept of cultural competence originated in the late 1980s to overcome cultural and linguistic barriers between health care practitioners and clients, improving access and delivery of health care services (Saha et al., 2008). It emphasises the need for practitioners to be effective in cross-cultural contexts and develop awareness of cultural differences (Saha et al., 2008). Cultural competency is a key strategy for reducing inequality in

healthcare access and improving the quality and effectiveness of care for Aboriginal people (AIHW, 2015b). Cultural competence at an interpersonal level is important. However, Watego et al. (2021) remind us that greater reflexivity by practitioners about their own culture and location does not necessarily result in adjustments to their health practice. Cultural competence, however, expands beyond individual interactions to encompass health systems and organisational policies (Saha et al., 2008).

Therefore, healthcare organisations, not just individual practitioners, are responsible for being culturally competent (Hosking, 2011). A systems approach is necessary because clinicians alone cannot ensure culturally appropriate care (Dreachslin & Myers, 2007). Healthcare organisations are interconnected systems, and there is a need to integrate attitudes, practices, policies and structures throughout the organisation to effectively serve culturally diverse populations (Peters et al., 2013). To enhance cultural competence, organisations must adapt their systems and subsystems to accommodate the needs of both their workforce and clients (Hosking, 2011).

9.5 The Impact of Personal Factors on the Healthcare Experience and Implications for Practice

9.6 Shame and Fear

This research project revealed the community's experiences of shame and fear when accessing PHC during crises. The feelings of shame and fear included feeling shame at being the only Aboriginal person in a room of white faces, fear of being asked to pay for services and being unable to do so, fear when facing the unknown with service providers, fear of treatment, fear of breaches of their confidentiality and fear of mainstream health services. The impact of these emotions was a reluctance to engage in health care unless the provider and environment were known to the person.

The experiences recounted by the Lakes Entrance Aboriginal community concerning shame, fear and feelings of powerlessness were congruent with the literature on the topic of healthcare experiences during usual times (Anderson et al., 2008; Artuso et al., 2013; Canuto et al., 2018; Devitt et al., 2017). However, no literature addressed this topic of shame and fear in relation to healthcare experiences, specifically during times of crisis. This study extends the literature

by showing that barriers to PHC access in usual times appear to be intensified and rendered more complex to address during times of crisis, such as during bushfires and pandemics.

The literature identified many possible causes for feelings of shame, including being singled out for attention, losing the security and anonymity of their immediate social group, not knowing the correct way to behave or being forced to act in a way that does not conform to their social and spiritual obligations (Maher, 1999). Additionally, shame could be caused by a perception of being talked down to and harsh judgements of different expectations and practices (Scrimgeour & Scrimgeour, 2008), as well as low levels of literacy and numeracy (NCAHS, 2009). The causes described above can lead to poor self-esteem and a lack of confidence in accessing services (Hayman et al., 2009). Shame is arguably a chief reason many Aboriginal people do not attend non-Aboriginal-specific health services (Maher, 1999).

Fear of racism, disrespect, judgement and negative government interventions were reported in the literature as barriers to Aboriginal people accessing some mainstream healthcare services (Nolan-Isles et al., 2021). During crises, external government organisations' presence on the ground to address crisis impacts can cause problems for the Aboriginal community. The research demonstrates the Aboriginal community's distrust of governments and medical institutions (Graham et al., 2022) due to the negative impacts of a long history of colonial-influenced policies and services. Conversely, the research demonstrated that messaging from trusted local Elders was well received, and an implication for practice is using this method to communicate messages to local communities.

9.6.1 Implications for Practice: Shame and Fear Findings

The implications of the research findings on shame and fear for supporting the Aboriginal community to access PHC during times of crisis are clear. Accessing care from trusted providers with whom community members have a pre-existing relationship is essential for them to feel comfortable and confident addressing their health needs. Aboriginal health and education workers facilitate trust between healthcare workers and clients, thereby enabling Aboriginal people better access to healthcare services (Nolan-Isles et al., 2021).

Findings from this study contribute to the current literature by extending what is known by indicating that known workers are critically important to health care provision for the Aboriginal community during times of crisis.

9.7 Trauma: Intergenerational and Collective

The findings from this project indicated that prior intergenerational and collective trauma impacted the healthcare experience, and these effects were intensified during times of crisis. The research project participants described how their experiences and decisions were impacted by prior trauma.

The literature indicates that health and wellbeing are interrelated, and many factors contributing to the burden of disease for Aboriginal Australians have a social basis rather than a specific physical cause (Marmot, 2016; Menzies, 2019). The social determinants of health include collective, historical and intergenerational trauma (Menzies, 2019). Disproportionality and disparity exist between the health and wellbeing of Aboriginal people and non-Aboriginal people due to direct social determinants that are associated with 'colonisation, marginalisation, [and] intergenerational trauma' (Griffiths et al., 2016). Several comprehensive studies demonstrate an association between trauma and impaired health (Felitti & Anda, 2010; Schnurr et al., 2014). Experiencing trauma, regardless of its impact on subsequent mental health, leads to an increased risk of poor physical health outcomes.

Conceptually, historical trauma is animated by the 4Cs: colonial injury, collective experience, cumulative effects and cross-generational impacts of such injuries (Kirmayer et al., 2014). Historic trauma describes the impact of cultural genocide, geographic displacement or forced removal as a 'dehistoricisation of experience' (Davoine & Gaudilliere, 2004, p. 47). Aboriginal people survived despite genocide, introduced diseases, forced removal from their lands, prohibition of spiritual and cultural practices and forced removal of their children by the state (Atkinson, 2013; Menzies, 2019). The forcible separation of Aboriginal children over several generations until 1969 (known as the Stolen Generations) is, arguably, the practice that has left the most traumatic legacy, which continues to have a profound impact on Aboriginal people today (AIATSIS, 2022).

Typical symptoms of collective and intergenerational trauma include deep mistrust of self and others, including family, fear and anticipation of betrayal, shame and humiliation, losing traditional values, desecrating land and institutions, self-directed violence, suicide, risk-taking behaviour, substance abuse, unremitting grief, intergenerational conflict-role diffusion, sexual abuse, other boundary violations, dependency—hostile or pathological, a conspiracy of silence and an overall attitude of secrecy (Atkinson, 2002; Tilbury, 2009).

This research project found that COVID-19 restrictions resulted in unprecedented disruption to the usual relational and collective practices of the Aboriginal community. This event has been extremely detrimental, as it has been empirically proven that the cultural determinants of health have an overwhelmingly positive impact on the health of Aboriginal people (Bourke et al., 2018). In addition to post-traumatic stress, pre-existing trauma and stress are also triggered during disasters, so according to Macauley (2020, as cited in Power et al., 2020) there may also be a corresponding rise in harmful alcohol and substance abuse. The implications for practice are the evident requirement for the holistic needs of the Aboriginal people to be considered when planning and implementing crisis responses.

Rural communities are acknowledged to face unique challenges, including collective trauma due to the disruption and damage to the social connectedness of a community (Smith & Burkle, 2020). The experiences the Lakes Entrance Aboriginal community recounted in relation to historic and collective trauma reflected the literature on the topic described above.

The frequency of disasters in Victoria also points to increased incidences of those affected having to cope with the cumulative impacts of overlapping disasters in the same places (Brady et al., 2021). For example, the East Gippsland community experienced a drought from 2016 to 2019, the impact and aftermath of the 2019–2020 bushfires and the COVID-19 pandemic restrictions (Bureau of Meteorology, 2022). This accumulation of trauma and the associated health effects strongly suggests the need for those affected to receive culturally safe and appropriate care that attends to trauma and acute and chronic health conditions.

9.7.1 Implications for Practice: Trauma

Implications for practice include the requirement for practitioners to recognise the exacerbation of pre-existing trauma conditions and the need for these to be addressed sensitively and appropriately. The community of Lakes Entrance have strongly indicated that their known relationships with health care providers, who are locally situated and understand their history and context, are critically important to their PHC access.

Mainstream PHC providers and providers working with Aboriginal people during crises or disasters may benefit from a stronger understanding of the trauma affecting Aboriginal people. The National Aboriginal and Torres Strait Islander Health Plan 2021–2031 (DOHAC, 2021c, p. 40) states that ‘trauma-aware and healing-informed approaches must be utilised to restore wellbeing and enable people to self-manage and control health decisions’. The plan (DOHAC, 2021c) advises that such approaches must occur in stages, meaning that PHC providers must first understand the complex experiences of intergenerational trauma for Aboriginal people. This approach requires culturally safe and responsive care that considers the impact of programs and services on clients. Trauma-aware, healing-informed and culturally safe support must also extend to the workers themselves (DOHAC, 2021c). This approach is important to avoid triggering or worsening trauma experienced by Aboriginal health professionals, who work with people with complex issues.

9.8 The Impact of Environmental Factors on the Healthcare Experience and Implications for Practice

Diverse environmental factors that impacted Aboriginal community residents’ access to health care during crises were identified in this research project, including the influence of priorities other than health on the health care experience, such as housing and other priorities, transport issues and the influence of medical bureaucracy, including managing medical documentation, medical reception staff, managing the appointment-making process and physical health spaces such as medical waiting rooms. First contact, continuity, comprehensiveness and coordination reflect the four primary healthcare functions as described in Chapter 3 (Prates et al., 2017), which are acknowledged to be associated with better quality services, lower costs, less

inequality in health care and better population health (Baicker & Chandra, 2004; Lewin et al., 2008; Starfield et al., 2005).

9.9 Priorities Other Than Health

The research project findings revealed that priorities other than health, including the social determinants of health, specifically poverty and reliable and secure housing, can impact the accessibility of PHC care during a crisis.

Relevant literature described the effectiveness of ACCHO community health workers addressing social determinants of health such as housing and food security (Fitzpatrick et al., 2022; Hernandez et al., 2020). In addition to providing surface-level care during the pandemic, these workers were also found to provide sustainable interventions tailored to the community's needs (Dyer, 2020; Fitzpatrick et al., 2022). Examples of successful interventions included virtual care and virtual health promotion, mobile testing and vaccine centres and innovative programs, all of which provide better access to PHC services for Aboriginal people (Hostetter & Klein, 2020).

9.9.1 Implications for Practice: Priorities Other Than Health

The implications of the research findings for practice are the requirement for addressing determinants such as housing and poverty before healthcare needs can become a focus and a priority. Specifically, findings from this research indicate that during times of crisis, support mechanisms are required to facilitate the Aboriginal community's access to housing and money, enabling PHC issues to be addressed. Transport was another issue raised by participants as a priority other than health, impacting their service access options and opportunities. As observed previously, participants communicated their preference for accessing support through their local ACCHO and the importance of those strong pre-existing relationships with Aboriginal community members. Therefore, housing and financial services support could be delivered through local ACCHOs. This finding is discussed further in the implications for policy in Chapter 10.

9.10 Transport Barriers

The research findings exposed transport barriers' impact on the Lakes Entrance Aboriginal community when accessing health care during a crisis. The combined impacts of geographic distance limited regional public transport and

low rates of car ownership all affected the ability of community members to access PHC, which was magnified during times of crisis.

The available literature recognises that transport is a widespread issue for Aboriginal communities throughout regional and remote Australia, not just the Lakes Entrance community. Transport was another barrier identified in Chapter 8 that influences Aboriginal people's access to mainstream health services (Durey et al., 2016; Lau et al., 2012; Warwick et al., 2019). Participants from remote communities found transport a major barrier to accessing care (Warwick et al., 2019). Transport barriers materialised in various ways. Difficulties included the unavailability of a registered vehicle, the lack of a current driver's licence, inability to pay for petrol, poor or no public transport, difficulty accessing a ride with family or friends and difficulty finding parking (Canuto et al., 2018; Durey et al., 2016; Lau et al., 2012; Warwick et al., 2019). Transport barriers often result in Aboriginal people's perceived failure to abide by society's norms, such as keeping appointments or getting to appointments on time, which in turn results in feelings of embarrassment and shame from Aboriginal people, adding to the barriers to accessing health care (Lau et al., 2012).

Further, transport issues played a significant role in impacting participants' experiences. Communities in regional areas face transport barriers due to greater geographic distances to travel (Harfield et al., 2018; Nolan-Isles et al., 2021), limited PHC options nearby (Harfield et al., 2018), minimal public transport options (Harfield et al., 2018; Nolan-Isles et al., 2021) and higher travel costs such as petrol (Harfield et al., 2018; Nolan-Isles et al., 2021). This literature, as listed, reflects the situation with transport in usual times. Apart from the work of Beks et al. (2022b), as described in Chapter 4, there has been no previous literature on transport to PHC during times of crisis for Aboriginal people. The findings from this study, concerning participants' exclusion from COVID-19 testing due to lack of vehicle ownership, extend the literature by strongly indicating that car access and car ownership become even more critical to PHC access during times of crisis.

9.10.1 Implications for Practice: Transport

The National Aboriginal and Torres Strait Islander Health and Wellbeing Plan 2021–2031 identifies transport as a barrier to access, which must be

addressed (DOHAC, 2021c). Implications for practice from this study include the requirement for crisis planning strategies to consider transport barriers when planning or implementing crisis management strategies. Modes and methods of service delivery must be responsive to the difficulty of physically accessing services due to transport restrictions.

Participants spoke of the importance of the transport options the ACCHOs provided them during crises, highlighting that this was their only option to access PHC. ACCHOs preparing contingency plans for transportation during crises is a way to ensure that transport does not become a barrier to PHC access. However, the preparation and action of contingency plans would require adequate resourcing. Contingency plans could include staff backup options or partnerships with other local organisations to offer transportation. Alternatively, the feasibility of service delivery being brought to the clients via a mobile clinic could be investigated.

An additional practical implication evident from the research findings is the consideration of point-of-care testing during crises. Testing for COVID-19, for example, via cars in an outside carline, was a barrier for the research participants. Consequently, testing in future crises should be planned and implemented to allow for walk-in or in-home testing for people who do not have cars.

9.11 Medical Bureaucracy and Processes

The research findings showed that participants felt uncomfortable accessing mainstream health organisations for PHC for many reasons, including perceived rudeness and unhelpfulness from reception staff, difficulty making appointments and managing medical documentation, and waiting rooms and the physical environment. Consequently, there are implications for future crisis planning concerning providing culturally appropriate and acceptable care for the Aboriginal community.

The research project identified enablers to PHC access promoted and supported by ACCHOs during crises, including paying for medical appointments, providing transportation, supporting interagency communication and coordination for medical referrals, imaging, testing, continuity and consistency of care as far as possible during unprecedented times, in-depth knowledge of

community members and the local context and family dynamics and respect for and understanding of factors competing with health care access. Here, the community's strong relationships with ACCHO staff and the appreciation for the support and care the ACCHO staff provided were evident.

The literature indicated that non-supportive front desk staff were among the barriers affecting delivering culturally appropriate PHC services (Hayman et al., 2009; Smith et al., 2017). Many clients reported feeling shamed and judged by staff members in mainstream health services (Aspin et al., 2012; Canuto et al., 2018; B. Jones et al., 2020; Shahid et al., 2016). Consumers were unhappy when the front desk staff did not ask for their preference for seeing a male or female doctor (Smith et al., 2017). Reception staff talking down to clients, being rude, being unable to hold a culturally appropriate conversation and their body language being perceived by Aboriginal clients as unwelcoming were also highlighted in the literature (Hayman et al., 2009; Smith, 2017).

This study extends the above literature by highlighting that research participants mentioned waiting rooms and the physical environment as factors impacting their healthcare experiences. The literature speaks to many Aboriginal clients feeling more welcome in environments where their culture is featured (Green et al., 2018; B. Jones et al., 2020; Smith et al., 2017). These features may be implemented through the design of waiting areas, including outdoor spaces, or designs that allow for the opportunity to perform smoking ceremonies (Smith et al., 2017). Extended periods of waiting, in some cases, led to people feeling shame and helplessness, leading them to leave the service without being seen (Jowsey et al., 2012).

9.11.1 Implications for Practice: Medical Bureaucracy and Processes

There are several implications of the research project findings for practice. First, front-facing staff, such as receptionists and administrative staff's skills, may be enhanced through training in culturally appropriate communication and ensure they understand the barriers Aboriginal people may face in accessing PHC. Second, in times of crisis, existing PHC access arrangements that the Aboriginal community feel comfortable with should be maintained and supported as far as possible. Third, the research findings have implications for waiting rooms and physical treatment spaces.

First, given the research findings, mainstream front-facing staff, such as receptionists and administrative staff, may benefit from training in culturally safe and appropriate communication with Aboriginal community members and all culturally and linguistically diverse community members. Frontline staff could also take from the research findings the need for flexibility in appointment-making processes with Aboriginal community members, particularly during crises when continuity of care from health care providers is even more important. Reception staff learning the names of clients and greeting and addressing them by name is another implication for practice that would improve the person-centred care that clients receive. The research finding that finance and costs are a barrier for the Aboriginal community in accessing mainstream PHC indicates that mainstream healthcare providers could do more to remove financial obstacles. Such issues could be addressed via the use and promotion of bulk-billing, the use of upfront and transparent information to members of the Aboriginal community about any potential costs at the time of appointment booking and customer service staff being aware of the sensitivities and using an understanding and tactful approach towards any financial discussions.

Second, existing PHC access arrangements that the Aboriginal community feel comfortable with should be maintained. This approach includes the critical role that ACCHO staff played in supporting Aboriginal community members with appointment and documentation management, which was evident in the research participants' comments. While this topic has been explored in the literature, it remains under-researched in the context of crisis. The implications for practice are the importance of the support ACCHOs and their staff play in supporting their communities with accessing PHC and appointment and document management, and the need for this to be maintained and supported as possible during times of crisis.

Third, considering the research findings, mainstream PHC providers may benefit from being additionally aware of the physical environment in which they provide health care. Physical spaces were discussed by participants and the need for these to be culturally appropriate and acceptable to the local Aboriginal community. Mechanisms should be in place for mainstream PHC providers to consult with their local Aboriginal community and discuss how the physical waiting spaces could be more welcoming and culturally safe. There is no single

catch-all solution; rather, the local Aboriginal community needs to be consulted to identify the issues and ensure solutions have local contextual relevance and acceptability from the community.

9.12 Racism

The research findings revealed that experiences of racism were prevalent among the Lakes Entrance community and that these experiences impacted the likelihood and comfort levels of Aboriginal community members accessing PHC.

Extant literature points to the high incidence of racism in health care, with nearly one-third of Aboriginal participants reporting experiencing racism, including exclusion and hearing racist names and comments based on stereotypes (Kelaheer et al., 2014). The ramifications of this racism have received attention in the literature, with racism found to be damaging to both physical and mental health (Baba et al., 2014; Elias & Paradies, 2021; Paradies et al., 2015; Shahid et al., 2016; Worrall-Carter et al., 2016).

The harmful effects of racism on physical health were highlighted in Chapter 4. A clear link has been demonstrated between experiences of racism and avoidance, with psychological distress resulting (Temple et al., 2020). Temple et al. (2020), for example, found that people who reported experiencing racism always had a higher risk of presenting psychological distress.

The research showed that all participants had experienced racism in a healthcare setting. Therefore, participants were wary of accessing health care from unknown providers due to fear of how they would be treated and of the unknown. Compared to non-Aboriginal clients with the same medical needs, Aboriginal clients were about one-third less likely to receive appropriate medical care across all conditions (Paradies et al., 2008). In a crisis, people are under stress from the crisis itself. Findings strongly suggested that receiving health care from a known and trusted provider during times of crisis was a practical option, enabling participants to feel more confident that they would not be subjected to racism, thus increasing the likelihood of them accessing PHC and meeting their health care needs.

The health care and services ACCHOs offer are acceptable to the Aboriginal community. The ACCHO staff at LEAHA and LTH&CS are local and possess knowledge and understanding of local history, culture, community and

spirituality, which may help maintain trust with community members. Building and maintaining trust within communities is invaluable to combat the effects of racism, both at institutional and individual levels, where the health care system has led to a lack of trust in the health care system for many Aboriginal individuals and communities (Fitzpatrick et al., 2022). Thus, ACCHOs represent a proven strategy for improving access to health services during a public health crisis (Fitzpatrick et al., 2022).

9.12.1 Implications for Practice: Racism Findings

Firstly, it is important to acknowledge that there are no silver bullets to address the issue of racism in the health sector at individual, institutional or system levels. Individual or interpersonal racism is ‘an attitude or theory that some human groups, socially defined by biological descent and physical appearance, were superior or inferior to other groups in physical, intellectual, cultural, or moral properties’ (Van den Berghe, 2007). Institutional racism is the collective failure of an organisation to provide appropriate and professional services to people based on their colour, culture or ethnic origin (Watego et al., 2021). Systemic racism operates across political, legal, economic and social systems and is the pre-determinant of institutional racism (Watego et al., 2021). Experiences of racism outside the health sector also impact people’s willingness to access PHC, as evidenced in Chapter 7, which shows findings that concern some participants’ fear of child removal and the removal of their government benefits.

Racism is an acknowledged issue in the health sector. It is so prevalent that the ambitious Priority 8 of the National Aboriginal and Torres Strait Islander Plan 2021–2031 (DOHAC, 2021c, p. 8) is to ‘Identify and eliminate racism’ in the health sector. Watego et al. (2021, p. 1) note that the previous National Aboriginal and Torres Strait Islander Health Plan included an aim of ‘a health system free of racism’; however, the plan did not provide an explicit analysis of the operations of race and racism in the Australian healthcare system and limited detail was included as to how the goal of a health system free of racism was to be achieved. This goal was clearly not achieved, as it is again included as a priority in the current plan. Further, Watego et al. (2021) critique the previous plan for identifying the relationship between racism and health as fundamentally involving individualist health behaviour, which fails to

acknowledge the ongoing impact of colonisation and dispossession and the impact of discriminatory government policies and practices on racism in the health sector.

Aboriginal people have a right to effective and responsive health care, with access to services that are prevention-focused, culturally safe, responsive, equitable and free of racism. The research participants spoke of experiencing racism in four main ways: (a) being provided with what they perceived as low levels of care, (b) having their symptoms and pain dismissed, (c) being treated poorly and with a lack of respect and (d) feeling powerless in their health care interactions. These findings have implications for practice for mainstream PHC providers, particularly during times of crisis.

Interpersonal racism can be addressed by PHC practitioners being aware of the existence of racism and their role in providing culturally safe and appropriate care. Education for PHC providers on appropriate cultural practice with Aboriginal people, effective communication skills and trauma-informed care are important considerations. Such training may enable an understanding of why power dynamics may feel uneven to the service user in interactions. This model relies on developing practitioner expertise in and appreciation for the differences in beliefs, customs and needs of members of other cultures (Watego et al., 2021).

Furthermore, cultural safety training and reflective practice for practitioners can also improve practice. Cultural safety, as distinct from cultural competence, is the responsibility of a health practitioner but is judged by the client (Watego et al., 2021). Cultural safety requires practitioners to identify ways their cultural, professional and institutional location shapes the care they provide (Brascoupé & Waters, 2009; Papps & Ramsden, 1996; Ramsden, 2002; Williams, 1999). Through this focus on identifying, acknowledging and addressing power differentials, cultural safety by necessity involves questions about race and racism (Papps & Ramsden, 1996, p. 495; Ramsden, 2002).

Recommending cultural competence and cultural safety training for practitioners, however, does assume that the root causes of racism are practitioner ignorance or attitudes, and this assumption discounts both the institutional and systemic aspects of health racism. As these recommendations

are for practice implications based on the research findings, there are no practice recommendations provided for institutional racism or systemic racism. However, there are policy recommendations, which are addressed in the next chapter. Given the ongoing effects of colonisation on health systems, it is important to state that broader efforts to undo some of the harms of colonisation are required. While it is outside the scope of this research project to determine what these should be, reforming PHC on its own will not redress disadvantage, either in usual times or in times of crisis.

9.13 Conclusion

This chapter has summarised and discussed the research findings from Chapters 6, 7 and 8 in relation to their implications for practice. It considered the impacts of colonisation on Aboriginal people's access to PHC and how this is intensified during times of crisis. This finding offers many opportunities for service and practice improvements, which have been described above.

The study found that the overarching implication for practice during times of crisis was the importance of understanding the critical role ACCHOs and their PHC delivery models play in the Aboriginal community. Further, this leads to the need to maintain ACCHO service delivery during a crisis, provide culturally appropriate care, mitigate the influence of shame and fear on PHC access, maintain continuity of care and be in the best position to understand pre-existing trauma and the need to address these sensitively and appropriately.

Crisis planning and management strategies must also consider transport barriers. Research findings indicate that modes and methods of service delivery during a crisis must consider the Aboriginal community's difficulty physically accessing services due to transport restrictions. Healthcare organisations also need to be aware that front-facing staff, such as receptionists and administrative staff, may benefit from training in culturally appropriate communication to ensure they understand the range of barriers Aboriginal people may face in accessing PHC.

The next chapter discusses the implications of the research findings for policy and research, as well as the overall strengths and limitations of the research and provides a conclusion to the research project.

Chapter 10 Implications for Policy and the Conclusion

10.1 Introduction

Through the experiences of the research participants, this research has revealed the barriers and enablers for the Lakes Entrance Aboriginal community when accessing PHC during times of crisis. The research findings have highlighted the impact of colonisation on Aboriginal people's PHC access and demonstrated how this is intensified during times of crisis. The research has also offered opportunities to identify service improvements. Aboriginal people must be able to receive primary health care when and where they need it. This finding means ensuring PHC services are available, accessible, culturally safe and responsive, including during times of crisis and emergency.

PHC is critical to improving the health status of Aboriginal Australians (Canuto et al., 2018; Griew et al., 2008). During crises, when access to PHC can be compromised, the Aboriginal community are impacted disproportionately due to their high levels of health disadvantage (AIHW, 2022c). Decreased healthcare access for Aboriginal people through missed, delayed or avoided healthcare may lead to further adverse health outcomes and inequities (Crooks et al., 2020; Power et al., 2020). This sentiment was evident when Karen spoke of how she would 'just wait and see what happens' after her preferred doctor was unavailable during a crisis. As a result of not accessing health care, her existing condition deteriorated to the point where an ambulance had to be called to take her to the local hospital. As such, it is incumbent upon the relevant government to ensure that planning and funding for the health sector is appropriate and effective to ensure continuity of care during times of crisis.

PHC is key to strengthening the resilience of health systems to prepare for, respond to and recover from shocks and crises (WHO, 2023). The strength of emergency preparedness in any society depends on organisational systems, including laws, regulations, policies and the appropriate allocation of resources through these systems (WHO, 2017). Those who plan for emergency response on a societal level require a sound knowledge of the factors that can affect society, including knowledge of the sections of society that are vulnerable or likely to be disproportionately affected by the emergency or crisis. Therefore, the

findings of this research have implications for policymakers and those who are funding, planning and implementing crises preparation and implementation.

10.2 Australian Centre for Disease Control

Disaster and pandemic planning, preparedness and recovery must embed mechanisms for the leadership of Aboriginal communities, including advice and guidance on culturally specific responses and communication strategies. This approach requires strong partnerships between all levels of government, led by community organisations (such as ACCHOs), to embed community planning, preparedness and recovery processes and principles at the local level and to enable these organisations to deliver inclusive and culturally safe responses to support and protect communities. This strategy includes surge capacity support for ACCHOs during disasters or crises. National planning must also consider the increasing adverse health effects of a changing climate on Aboriginal people.

While there has been an acknowledged lack of national coordination and oversight concerning health crisis management in Australia (CoA, 2020), this lack may be rectified by the establishment of an Australian Centre for Disease Control (CDC), as proposed by the Australian federal government (DOHAC, 2023a). The CDC's purpose will be the improvement of Australia's preparedness for the next pandemic and other health emergencies, the boosting of response capacity, the strengthening of prevention, communication and national coordination and enhancement of collaboration across all levels of government, and, importantly, the prevention of both non-communicable (chronic) and communicable diseases (DOHAC, 2023a, p. 1). While the Australian CDC is still in the planning phase, a paper on the roles and functions of the CDC was released in late 2022, and stakeholder responses have been gathered and compiled (Wunsch, 2022). The consultation paper (DOHAC, 2023a, p. 21) notes that included in the CDC's proposed remit is addressing social determinants of health to reduce the burden of disease and support better health equity and improved outcomes for at-risk populations, including safe and affordable housing. This priority aligns with outcomes from this study, indicating that social determinants of health and priorities other than health need to be addressed with the Aboriginal community before health issues can be prioritised.

Several stakeholders in the CDC consultation identified that national responses were often less effective at the local community level, given language and cultural barriers (Wunsch, 2022, p. 9). This point reflects the present research findings that local and contextualised communication was more trusted and actionable for Aboriginal participants than national, mainstream communication. A key learning here for the CDC will be to ensure that it leverages community organisations that understand their local communities, such as ACCHOs, and can facilitate greater engagement, understanding and uptake of required protective behaviours from their community.

The critical importance of ensuring appropriate engagement with Aboriginal people and ensuring that Aboriginal people are represented across all levels of the CDC governance structure was also noted by stakeholders (Wunsch, 2022, p. 20). This requirement aligns with priority reform three in the National Agreement on Closing the Gap (CoA, 2022), which speaks to the importance of ensuring government organisations are adequately equipped to respond to the needs of Aboriginal people. Further, stakeholders noted that well-established and strong local Aboriginal health networks and services are trusted by their local communities, as highlighted by this research study (Wunsch, 2022, p. 20). Findings from this study also highlighted the importance of adequate engagement with Aboriginal people and appropriate resourcing for Aboriginal health networks and ACCHOs. A priority for the CDC will be to engage and leverage them appropriately. A mechanism for doing so via the ACCHOs is described in the following sections.

Australia's health response to the pandemic was described as 'attracting a thesaurus of negative adjectives' (Duckett, 2022, p. 10400), with both federal and state coordination and arrangements poorly managed throughout the COVID-19 pandemic in 2020 and 2021. The weaknesses exposed during the pandemic should provide the basis for better planning and responses in the future, and the proposed Australian CDC, as outlined above, may provide for comprehensive coordination and better oversight of planning for future crises.

10.3 The Role of the Aboriginal Community Controlled Health Sector

There are 32 ACCHOs in Victoria, supporting more than 65,000 Aboriginal people across the state (Victorian Aboriginal Community Controlled Health Organisation [VACCHO], 2022). They are supported by their peak representative, VACCHO. The ACCHO sectors' funding model with the government has been characterised by short-term, piecemeal grants for 'body parts' and 'disease' (VACCHO, 2022). *Body parts* refer to the practice of the government funding interventions for a specific body part, for example, eye health. VACCHO argues that this approach to funding has not adequately resourced the culturally responsive, wrap-around model of care that VACCHO and the ACCHO sector champion and aim to deliver to the community (VACCHO, 2022). The ACCHO sector has been calling for much-needed funding reform that would enable ACCHO's authority to identify outcomes, develop solutions and track performance in self-determined ways with access to pooled, flexible and sustainable funding to do so. In practice, this would mean ACCHOs could identify and respond to their local priorities rather than priorities identified at a state or national level.

The local Lakes Entrance context reflects overall sector concerns, with the 2023 LEAHA Annual Report stating that only five of their service programs are funded recurrently: the Koori Youth Justice Program, the Medical Transport Program, the Local Justice Worker Program, the Aboriginal Health Promotion and Chronic Care Program and the Alcohol and Drug Service, to a total of \$572,856 per annum (LEAHA, 2023). Other programs and services delivered by LEAHA are funded as one-off programs or programs dependent on year-to-year funding.

The National Aboriginal and Torres Strait Islander Health and Wellbeing Plan 2021–2031 (DOHAC, 2021c, pg. 56) identifies, in Priority 7, the requirement for communities to be prepared and have the necessary infrastructure to respond to natural and other disasters. The plan states:

Aboriginal and Torres Strait Islander people's perspectives, ways of living and culture must be at the centre of actions for healthy environments, sustainability, and preparedness. This means that all development,

design, and implementation must happen in partnership, with shared decision making, led by Aboriginal and Torres Strait Islander people.

Disaster and pandemic planning, preparedness and recovery must embed mechanisms for the leadership of Aboriginal communities, including advice and guidance on culturally specific responses and communication strategies. This approach requires strong partnerships between all levels of government led by community organisations (such as ACCHOs) to embed community planning, preparedness and recovery processes and principles at the local level and to enable these organisations to deliver inclusive and culturally safe responses to support and protect communities. This initiative includes surge capacity support for ACCHOs during disasters or crises. National planning must also consider the increasing adverse health effects of a changing climate on Aboriginal people.

10.3.1 Impacts of Natural Disasters

Natural disasters and a changing climate threaten Aboriginal people's physical and cultural wellbeing. Aboriginal cultural knowledge and understanding of natural environments are key to preparing for and avoiding disasters. This knowledge has been emphasised in the findings of the Royal Commission into National Natural Disaster Arrangements (DOHAC, 2020a), which states that all governments should explore further opportunities to leverage Aboriginal land and fire management insights when developing, planning and executing public land management across Australia.

10.4 Implications of Findings for Policy

The findings from this study have several implications for emergency management and health system policy. Critically, findings strongly suggest a need for the state of Victoria to consider the projected likelihood of more severe, frequent, and longer-lasting natural disasters due to climate change (Fitzgerald et al., 2019). If global temperatures continue to rise to 2 °C above pre-industrial levels, bushfires in Australia, like those of 2019–2020 will be about eight times more likely (van Oldenborgh et al., 2021). To effectively address these challenges, governments will need to plan appropriately.

However, there are further policy implications arising from this doctoral research that relate specifically to Aboriginal people's PHC access during times of crises, all of which are related to ACCHOs:

1. Health communication during crises: the use of ACCHOs to provide locally informed and contextualised information to their community during times of crises.
2. Culturally safe and appropriate health care: the provision of culturally safe and appropriate care by ACCHOs to the community during crises.
3. Appropriate funding and resourcing: the need for ACCHOs to be appropriately funded and resourced to deliver care, support and services during crises.
4. Aboriginal community involvement in crisis planning: Aboriginal voices and perspectives are prioritised and included in the preparation for crises and crisis governance.

10.4.1 Health Communication in a Crisis

First, PHC plays a role in public health communication during crises. As stated in the Alma-Ata declaration, PHC 'includes education concerning sanitation, immunization, prevention and control of endemic disease' and 'addresses the main health problems in the community, providing promotive, preventative, curative and rehabilitative services accordingly' (WHO, 1978, p. 1). Based on these declaration components, public health messaging, health promotion and infectious disease communication and education play an important role for PHC.

Participants in this research found communication from their local ACCHOs to be informative and effective during crises. Specifically, ACCHO's provision of locally contextualised information using communication modes such as social media, in-person communication, newspapers and flyers was an important response to misinformation circulating in communities.

The international literature suggested the benefit of Indigenous health service organisations mobilising in the early stages of the COVID-19 pandemic and promoting culturally relevant and safe communication and education about the virus to their communities (Fitzpatrick et al., 2022). Some (e.g., Crooks et al.,

2020; Finlay & Wenitong, 2020; Kerrigan et al., 2021) pointed to the efficacy of the reliable and culturally appropriate communication provided by Indigenous health services around vaccinations, infection prevention and safety within PHC settings to address their community's needs during a public health crisis. Emphasis was placed on delivering culturally safe and culturally relevant communication that went beyond translation to Indigenous languages; instead, services used modes of communication they knew would reach their clients and provided customised information resources that were based on localised Indigenous histories, cultures and worldviews (Kerrigan et al., 2021).

In the Australian context, COVID-19 has shown how effectively ACCHOs have managed a deadly pandemic among a vulnerable population group. However, it is argued that there is a lack of recognition by the government of the intricacy and complexity of the communication being provided by ACCHOs (Naren et al., 2021). The literature strongly suggests a need for effective crisis communication to be timely, clear, concise and appropriate to the target audience (Finlay & Wenitong, 2020; S. C. Jones et al., 2010; Vaughan & Tinker, 2009). This research has extended previous discussions by showing how effective research participants found locally contextualised and trusted communication from their local ACCHOs. Thus, a real commitment to supporting ACCHOs to deliver timely, clear, culturally appropriate messaging to communities is required.

10.4.2 Culturally Safe and Appropriate Healthcare Provided by Aboriginal Community Controlled Health Organisations

Culturally safe and culturally responsive care, along with the inclusion of Aboriginal values in the design and delivery of health care services, are important domains of responsiveness to consider during public health emergencies (Fitzpatrick et al., 2022). Cultural safety is also essential to ensure the suitability of PHC strategies or interventions.

Aboriginal ACCHO staff possess knowledge and understanding of local history, culture, community and spirituality (Pearson et al., 2020), all factors that maintain trust with community members. The building and maintenance of trust in communities is an invaluable component of the overall ACCHO model, as the effects of colonialism and racism, both at institutional and systemic levels, within

the healthcare system have led to a lack of trust in the mainstream healthcare system for many Aboriginal individuals and communities.

National and government organisations do not necessarily have pre-existing relationships with members of Aboriginal communities, which means Aboriginal people are unlikely to reach out to these charities and services for support or accept support when it is offered. In some cases, a cultural stigma may be attached to reaching outside the Aboriginal network for help (Kairuz et al., 2021). This stigma may discourage Aboriginal people from requesting evacuation and recovery support from any organisation besides their local community-controlled services.

A 2020 report from the Grattan Institute (Duckett et al., 2020, p. 37) suggested that ‘crisis contingency plans should include escalation protocols that quickly mobilise additional health care workers from outside an affected region’. However, bringing external healthcare workers into crises, where uncertainty and stress levels are high, does not consider the cultural requirements of the varying Aboriginal communities across Victoria. Enacting Duckett et al.’s (2020) suggestion may also lead to further marginalisation of an already disadvantaged cohort.

This research project found that participants preferred to access PHC via their local ACCHO rather than mainstream health organisations due to the provision of culturally safe care from known and trusted providers, where continuity of care was critical. This finding supports a case for policy to establish ACCHOs as the main organisations to liaise with Aboriginal communities during crises.

In May 2023, LEAHA received a federal grant of over 2.2 million dollars from the Indigenous Australians’ Health Programme (IAHP) – Closing the Gap Major Capital Works Program Grant Opportunity GO5504 (Major Capital Works Program). The grant will support the construction of a comprehensive PHC clinic in Lakes Entrance, Victoria, to accommodate service needs and enhance the LEAHA culturally appropriate delivery model. The project aligns with the National Closing the Gap Agreement and signifies a critical step towards building the reach and impact of Aboriginal community-controlled organisations in the area. Further, the findings of this research will be provided by LEAHA,

VACCHO and NACCHO to advocate for policy change concerning the role of LEAHA and LTH&CS during times of crisis. Specifically, the advocacy is for policy to expand the remit of ACCHOs by defining the role of the ACCHOs during crises and to ensure ACCHOs are the lead organisation for their local Aboriginal communities during times of crisis that impact health.

10.4.3 Appropriate Funding and Resourcing

If Aboriginal PHC models are to be enacted and ramped up during a public health crisis or emergency, governments must reinforce financial commitments and responsibilities towards equitable PHC service infrastructure for Aboriginal communities (Fitzpatrick et al., 2022). Such arrangements must be formalised in policy and planning documentation and allocated in state budgets. This approach aligns with the argument that health equity will not be achieved without dramatic redistribution of power and resources (Bump et al., 2021).

The role that local ACCHOs in Lakes Entrance and Lake Tyers played during the 2019–2020 bushfires and COVID-19 has been explained in Chapters 6, 7 and 8 from the participants' perspectives. The ACCHO staff delivered a range of services above and beyond those that are funded by the state and federal governments. Additional services included, but were not limited to, supporting community members with housing, conducting extensive advocacy for their clients and their own organisations, childcare responsibilities and responding to community-identified priorities such as dental or oral health (The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange, 2020).

Taking on these extra roles and supporting their communities in unplanned ways places an additional and unexpected burden on Aboriginal community-controlled services as they provide emergency and recovery support they are not funded or resourced to do (CoA, 2020). Repercussions for taking on additional roles impact the organisational capabilities of ACCHOs themselves, encompassing challenges in leadership, staffing, financial capacity, community engagement and healthcare service delivery (McCalman et al., 2021a).

For ACCHOs to continue to play an important role in supporting their communities with PHC and social needs throughout crises, policy needs to formally recognise roles that ACCHOs are likely to fulfil in crisis planning and

resource them appropriately. Resourcing issues challenged the capacity of ACCHOs to make responsive decisions as the pandemic continued to impact Aboriginal communities, both directly and indirectly (McCalman et al., 2021a). Strengthening systems at the community and peripheral health facility level contributes to building resilience, which is critical for withstanding shocks to the health system (WHO, 2021).

10.4.4 Aboriginal Community Involvement in Crisis Planning

Finally, meaningful community input and appropriate governance enable preparedness strategies to be suited to the community's needs, increasing their likelihood of being appropriate and effective. The findings from this research suggested that the Aboriginal community of Lakes Entrance displayed low levels of trust in mainstream health services and organisations. Lack of adequate community engagement has been shown to contribute to low levels of community trust, which in turn hampers PHC implementation for critical emergency services (Bitton et al., 2019).

Governance is a key factor in effective health emergency preparedness. The World Health Organization (2019) reports that government engagement with community-based organisations is a key enabler of emergency preparedness. Direct involvement of community members in crisis healthcare planning strengthens public accountability in health systems. It enables preparedness strategies to be suited to individual communities' needs, increasing their likelihood of being appropriate and effective (Edelman et al., 2021).

The findings of this study that local Aboriginal ownership and control was critical to the effective response to COVID-19, support and extend broader evidence for Aboriginal community ownership of governance and improvement processes (Tsey et al., 2012a, 2012b). Provisions must be made to allow for evolving governance processes, relationships, institutions and structures to support tailored, place-based approaches to crises, including pandemics and other health issues (Hunt, 2008).

Objective 7.4 of the National Aboriginal and Torres Strait Islander Health and Wellbeing Plan 2021–2031 (DOHAC, 2021c, p. 58) states that disaster and pandemic planning, preparedness and recovery must embed mechanisms for

leadership by Aboriginal communities, including the provision of advice and guidance on culturally specific responses and communication strategies. The plan (p. 58) specifically mentions the requirement for disaster and crisis planning to 'include surge capacity support for ACCHOs during disasters or crises'. The results of the research support and highlight this recommendation, though it has not yet been implemented, and as previously discussed, ACCHOs in Victoria are not funded for disaster, crisis or surge capacity planning.

Findings from this project indicated the lack of trust participants had in government systems and organisations. Including Aboriginal voices and perspectives in crisis policymaking and planning processes may increase the likelihood of better relationship creation and trust promotion, as well as policy and plans better suited to local contexts. The research findings indicate that plans should include a requirement for local Aboriginal participation to ensure the local Aboriginal voices are heard concerning the local context and environment, thus ensuring plans are culturally appropriate and consider all relevant factors.

Australia's disaster management sector has had little systematic engagement with the diverse situations and needs of communities experiencing disadvantage (Rogers et al., 2021). Aboriginal people are also at risk of being overlooked in many aspects of disaster response and recovery efforts without a seat at the table alongside other agencies or community members (Rogers et al., 2021). This issue has been highlighted in the recent Royal Commission into National Natural Disaster Arrangements, which recommended that governments engage with Traditional Owners on Aboriginal land and fire management (Duckett et al., 2020).

At a policy level, the National Aboriginal and Torres Strait Islander Health and Wellbeing Plan (2021, p. 57) states that 'Aboriginal and Torres Strait Islander cultural knowledge and understanding of natural environments are key to preparing for and avoiding disasters'. It has been recommended that governments should explore further opportunities to leverage Aboriginal and Torres Strait Islander land and fire management insights when developing, planning, and executing public land management across Australia (CoA, 2020).

10.5 Implications of Findings for Future Research

There are many implications of these findings for future research. First, the current research design could be repeated on a larger scale with more cases to confirm findings (Creswell, 2018). This approach may also assist in identifying contextual differences between Aboriginal communities' experiences and, therefore, the identification of their needs so they can be adequately addressed at a policy and practice level. Further studies of Aboriginal people's access to PHC in a crisis would contribute to the limited literature on a much needed and important topic. These opportunities must include the Aboriginal community in prioritising, planning and conducting research priorities.

Second, these research findings lend themselves to translation into an action plan for improvements in mainstream PHC organisations in the Lakes Entrance community. Future research could plan, implement and evaluate specific initiatives. Research could focus on participants' perspectives, mainstream healthcare providers and clinicians as they implement recommendations to improve their cultural safety and healthcare access. Specific initiatives to address the health access issues described in the research findings could be planned, implemented and evaluated, with the results used to inform how other mainstream health organisations can improve their cultural safety and become more welcoming and supportive of their local Aboriginal community.

Third, research could be planned and conducted with regional ACCHOs on a widespread scale to examine the strategies they used to support their local communities with PHC access during crises and assess the efficacy of those strategies from the perspectives of both ACCHO staff and clients. A mixed-methods research design could be used to collect and analyse participants' perceptions and quantitative evidence regarding service delivery comparisons between usual times and crises and differences in clinically defined and measured outcomes. Research into this area would address a previously uninvestigated topic, and findings could inform government policy and planning for disaster and crisis mitigation strategies.

Fourth, research on PHC access for Aboriginal people could be planned and ready to implement in the event of new crises, including a component of evaluation of initiatives. Montesanti et al. (2022, p. 106) stated:

In order to facilitate rapid, responsive, and relevant disaster research, we need rapid-learning research systems that integrate researchers, funders, health and social systems, frontline workers, and community partners asking relevant research questions, using innovative research designs and methods, and leveraging rich, longitudinal data across a range of population groups and communities affected.

These systems need to be established prior to a disaster and be ready for rapid mobilisation (Montesanti et al., 2022). This approach would support the contemporaneous data collection and, with a pre-planned evaluation component, would be ready to commence for the next crisis or disaster. It is important to acknowledge that disasters are important in the policy process because they can open windows of opportunity for elevating issues onto the government agenda (Montesanti et al., 2022). Therefore, generating timely and up-to-date evidence is crucial to accelerate the emergence of opportunities for policy reform and effective responses.

Fifth, an exploration of responses related to PHC access during crises for Aboriginal people in other colonised nations could be undertaken. Such research could shed light on international responses to the issue of PHC access for Aboriginal people during a crisis. Those international responses may inform the development of action and implementation plans for the National Aboriginal and Torres Strait Islander Health and Wellbeing Plan 2021–2031 (DOHAC, 2021c), particularly Objective 7.4 concerning disaster planning and similar plans in other countries.

The results of this research project, coupled with the scarcity of available research data and backed by the acknowledgment of the limitations of support services by NACCHO (2022), provide compelling evidence to advocate for additional research and inquiry into the role of ACCHO in providing PHC support to their communities during times of crises.

10.6 Implications of Findings for Theory

Contributions to theory development were also revealed through this research project. As described in Chapter 1, just as others have adapted Andersen et al.'s (2013) BHMSU for research with distinct populations, I adapted the model to suit the context of my research with the Aboriginal community of Lakes Entrance. This adaptation had the approval of the research project's cultural adviser. My adaptation provided for the overarching and all-pervasive impact of colonisation to be prominently identified and acknowledged. Andersen et al.'s (2013) three determinant categories, predisposing, enabling and need factors, are replaced in this model by three themes: (a) service delivery factors, (b) personal experiences and (c) environmental factors. Sub-themes are then categorised under these three factors. Elements of the BMHSU (Andersen et al., 2013) that were outside this research's scope, such as health behaviours, feedback loops and health outcomes, were excluded from this adaptation. The benefits of this adapted model may be suited to other Aboriginal research contexts. They may also prove helpful to future researchers attempting to identify health service usage factors that are affected by a common overarching factor.

10.7 Strengths and Limitations of this Research

There are strengths and weaknesses inherent in every research project. Presenting research strengths and limitations is crucial for transparency, critical evaluation, contextualisation, methodological rigour and intellectual honesty (Levitt et al., 2021). It contributes to the overall trustworthiness and quality of qualitative research and supports the advancement of knowledge collaboratively and constructively. The strengths and limitations of this research project are described below.

10.7.1 Strengths: Methodology

This research has several strengths in its methodology. A research partnership arrangement was signed between the author and LEAHA in relation to formulating the research methodology. Co-designing the methodology with the ACCHO is a significant strength (Beks et al., 2022a).

The processes used to establish a research partnership with an ACCHO were key to setting the research agenda, including identifying ethical issues, the

needs of local Aboriginal people, and expectations from the research. The participation of Aboriginal community members throughout the entire research process, as subjects and, importantly, as cultural advisers and reviewers of findings, was methodologically important and ethically appropriate (NHMRC, 2018). The case study method and use of semi-structured interviews allowed Aboriginal community members to share their perspectives and experiences directly.

The use of a cultural adviser in this research is another significant strength (NHMRC, 2018). It ensured that the research was culturally appropriate, that the findings accurately reflected community perceptions and that the participants' world views and cultural values, beliefs and practices were accurately represented. Credibility was achieved through data triangulation between the researcher and the cultural adviser (Creswell, 2018).

10.7.2 Strengths: Prioritisation of Aboriginal Voices

Furthermore, one of the strengths of this research lies in its emphasis on prioritising Aboriginal experiences and voices. It is widely recognised that meaningful partnerships between researchers and Aboriginal people are essential to achieving significant benefits for Aboriginal communities (Harfield et al., 2020). To uphold ethical standards in research conducted with the Aboriginal community, it is of utmost importance to prioritise and give prominence to the voices and lived experiences of Aboriginal people throughout the entire research process (Anderson et al., 2022).

By centring Aboriginal perspectives, this research amplifies Aboriginal people's voices and acknowledges their invaluable knowledge and expertise. It recognises that the experiences, insights and cultural understandings of Aboriginal people are essential for generating comprehensive and meaningful findings.

10.7.3 Limitations: Sample Size

Interviews were conducted with 18 PHC users from the Lakes Entrance community. This is a small sample of the wider Victorian and Australian Aboriginal population. However, the number of participants was within the resource and time constraints of the study and provided an in-depth rather than a broad examination of the issues.

The case study was of one regional Victorian Aboriginal community. The selection of the study site and the geographical location met several criteria for selecting case study sites as described by Yin (2014), namely, answering a *how* question, not manipulating the behaviour of those involved in the study and being able to cover contextual conditions because they are relevant to the study. Furthermore, it is recognised that each Aboriginal community in Victoria and Australia is characterised by unique social, economic, geographical and demographic environments and conditions, but that the overarching impact of colonisation applies to the entire Australian Aboriginal people. As Lincoln and Guba (1985) suggested, providing a rich description of this study's context enables researchers considering application in other sites to make assessments of transferability.

Studies on future crises could benefit from using more case study sites emphasising rural, regional and metropolitan Victoria. This research would allow a broader analysis of the issues and a comparison of community barriers and enablers in diverse locations. However, as Yin (2014) and Gerring (2004) argue, the value of case study research is in the depth of the material that can be explored rather than its breadth.

10.7.4 Limitations: Sample Composition

The sample of 18 participants comprised 15 men and three women. Having limited experiences recounted by men may be a limitation of this research. This research examined the experiences of the adult Aboriginal community when accessing PHC in general rather than in relation to specific health concerns or priorities or from certain demographics. Researching specific demographic sectors, such as mothers aged between 18 and 28 or men between the ages of 40 and 60 could provide for a deeper and more contained examination of local responses to local PHC access.

10.7.5 Limitations: Research into Different Perspectives

This research primarily focused on capturing the experiences of the Aboriginal community from their own perspective, emphasising the importance of their voices. It would be valuable to include interviews with key stakeholders from the state government to gain a comprehensive understanding of the state government's approach and policy directions concerning public health and crisis

planning. This approach may include stakeholders such as the Department of Health and the Department of Families, Fairness and Housing, which would provide valuable insights into the state government's role in shaping policy context, funding regulations and priorities that directly impact Aboriginal communities. This additional perspective would enable a thorough examination of the state government's strategies and decision-making processes.

This aspect holds significance since, as emphasised in this thesis, state governments play a crucial role in local public health planning and funding. Policies and strategic directions can vary based on political ideologies and economic constraints. Nonetheless, taking action to foster social capital and empower local people by decentralising power and funding is crucial for successful crisis planning and implementation.

10.7.6 Limitations: Research Timing

Another limitation of this research may include the timing, as interviews were conducted in 2021 and 2022, up to three years after the bushfires and two years after the COVID-19 restriction periods. Respondents' memories of their experiences during the 2019–2020 bushfires may have been overshadowed by the more recent memories of the COVID-19 lockdown. A recent study into the reliability of recall in primary health service settings (Khare et al., 2019) found that regardless of the mode of data collection, reliance on participant recall of past utilisation events results in data that are prone to recall error—inaccurate or incomplete recollection—which can lead to recall bias and threaten the reliability of results.

10.8 Conclusion

This research project has demonstrated that colonisation's impact on Aboriginal people's PHC access is intensified and exacerbated during times of crisis, offering opportunities to identify service improvements. The preference of many Aboriginal people to access PHC via their local ACCHO rather than mainstream health care services has been reiterated. This sentiment appears even more salient during crises than in normal times.

The enablers the ACCHOs provide to their local communities during crises built and expanded on the positive experiences of cultural safety they provided during usual times, including the trust participants displayed in their

ACCHOs, addressing distance and travel barriers through the provision of medical transport drivers, supporting the community with assistance managing medical bureaucracy, such as appointment making, managing referrals and support with medical testing and imaging, the cultural safety they provided during uncertainty and the chaos of crises and the addressing of distance and travel barriers through the provision of medical transport drivers.

The enablers identified in this study, including the role played by the ACCHOs, assist in identifying strategic options to improve PHC accessibility during crises. Findings from this study highlighted the potential of ACCHOs to mobilise and meet the needs of clients and the local community during crises. ACCHOs' response during the 2019–2020 bushfires and the COVID-19 restrictions period has demonstrated that knowledge of Aboriginal communities via pre-existing relationships is essential for PHC delivery during crises and is worthy of future research and government investment.

While acknowledging the importance of identifying barriers to accessing care in the context of participants' experiences, I did not want to contribute to the deficit discourse characterising much research on Aboriginal health in writing this study. Strengths-based researchers do not ask, 'What is the problem and how can it be fixed?' Instead, they ask, 'What is working, despite the challenges, and how can we enable these effective elements to generate change and new growth?' (Tsey, 2019, p. 77). Consequently, this research highlights the critical role ACCHOs have played as enablers of healthcare access during usual conditions and crises.

This study provides a compelling case for further research to describe emerging innovations within ACCHOs in response to public health crises and disasters. This knowledge has the potential to inform and support ACCHO health systems to be more resilient to future crises, such as public health emergencies and disasters, and to meet the challenges faced by Aboriginal communities. For this to occur, governments should enable ACCHOs to provide locally informed and contextualised information to their community during times of crises, utilise ACCHOs to provide culturally safe and appropriate care during crises, include Aboriginal community members in crisis planning and

preparation, and provide appropriate funding and resourcing to ACCHOs to deliver care, support and services during crises.

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Appendix A: Ethics Approval

Date: 12/10/2020

Subject: Notification of Ethics Review Outcome - Approved

Ethics Application Number: [HEC20390](#)

Ethics Application Title: Primary Health Care Access During a Disaster:
What are the experiences of an Indigenous Australian community in rural
Victoria?

Approval Period: 12/10/2020 to 12/10/2025

Approved Documents:

HEC20390 Application Form dated 01.09.2020

HEC 20390 Semi Structured Interview Questions dated 01.09.2020

HEC20390 Research Agreement dated 12.08.20 SIGNED FINAL

Participant Informed Consent Form 05_10_2020 V2_Clean

Project Advertisement 05_10_2020 V2_Clean

Project-Description 05_10_2020 V2_Clean

I am pleased to advise you that the Human Research Ethics Committee (HREC) has granted ethical approval of the project listed above, subject to the following conditions being met:

Conditions of Approval specific to this project

N/A

Appendix B: Research Partnership Agreement

1



LAKES ENTRANCE ABORIGINAL
HEALTH ASSOCIATION INC

RESEARCH AGREEMENT

The aim of this research project, as discussed with and understood by Paula Morgan, LEAHA CEO, is:

To understand how access to primary health care during and post disaster is described by Indigenous Australians in East Gippsland, to determine if the needs of this community were met effectively during the 2019/2020 bushfires, and the 2020 COVID19 pandemic.

Names of researchers and research institution/s

Primary Researcher: Rebecca Woodland (D.Ph. student)
Supervising Researcher: Dr Sarah MacLean, La Trobe University
Supervising Researcher: Dr Heather Downey, La Trobe University

Funding details

N/A

Benefit to the participants and broader Aboriginal and/or Torres Strait Islander population

Society: The benefits of this research to society will be to better inform disaster preparedness and planning by understanding the cultural perspectives of the Indigenous population. The results will also be published in order to share them with a wider audience, and potentially inform other communities.

The participants: Understanding the experiences of Indigenous Australians when accessing primary health care during and post disaster will allow for better future disaster planning which prioritises the Indigenous experience and voice. Primary health care is essential for the management of non-communicable diseases, and access to primary health care during and post disasters is of critical importance to sectors of society which suffer disproportionately from non-communicable diseases, i.e. Indigenous Australians. While we do not expect direct benefits to the participants, they may benefit from improved disaster planning in health care for future disasters.

Commitment of the researchers and the participating organisations and communities

Participant Demands: Read about and consent to the research. It is expected to take up to 15 minutes to explain the project, allow the participant to read the consent form, ask questions, and then provide verbal consent. Participants are also asked to

Negotiated Research Agreement: Rebecca Woodland and Lakes Entrance Aboriginal Health Association (LEAHA) July 2020

complete an in-depth interview: It is expected that interviews will take between 60 – 120 minutes, depending whether there are one, two or three participants in each interview in a session.

Lakes Entrance Aboriginal Health Association (LEAHA) Demands: To advertise the project to prospective participants, to provide input and support to the project and the primary researcher and participants, and to advise on cultural matters.

Clarification of roles and responsibilities of researchers and participating organisations and communities

Primary Researcher: Rebecca Woodland

Supervising Researcher: Dr Sarah McLean, Latrobe University

Supervising Researcher: Dr Heather Downey, Latrobe University

LEAHA:

- Advertisement of the research project to prospective participants
- Support for the researchers and participants,
- Advice and Support to the Primary Researcher on cultural matters
- Input into the research project to their satisfaction

Informed consent process

Once the participant has expressed interest in participation, and after a discussion has been had about what the project entails, the participant will provide verbal consent to participate.

Data collection, ownership, analysis and storage

The data collection method used will be in-depth interviews with up to 30 participants, either by phone, Zoom, or in person, depending on the current pandemic guidelines and the interviewee's preferences. Interviews will be conducted either singly, in pairs or triads, depending on the preferences of the interviewee, in order to cater for their comfort and support.

The in-depth interviews will be semi-structured. An interview guide will be used, which will include a list of questions and topics that will need to be covered during the conversation. A semi-structured format, however, will allow for the researcher to follow topical trajectories in the conversation to that may stray from the guide if and when they are deemed appropriate. This also provides the participants with a level of input and control to raise any points which are of particular relevance to their experiences, and empowers them during the interview.

The data collected will be stored securely for 7 years, then destroyed. The data and thesis are owned by Rebecca Woodland. The data will not be made publically available, and the thesis will only be made publically available with the prior approval of LEAHA.

LEAHA will participate in the analysis of the data once collected.

Strengthening capacity strategy

Negotiated Research Agreement: Rebecca Woodland and Lakes Entrance Aboriginal Health Association (LEAHA) July 2020

Depending on the results of the project, the findings may be used by LEAHA to support proposals or submissions for disaster preparedness plans, strategies and projects in the future.

Communication and media strategy

The student will submit a thesis to La Trobe University in partial fulfilment of the requirements of the Doctorate of Public Health. This thesis will only be made publically available with the agreement of LEAHA.

Communication will be to the Lakes Entrance Aboriginal Community via LEAHA channels including the LEAHA centre, Facebook, Elders groups, TIS group, etc, and any other channels that LEAHA deems suitable.

Copyright and intellectual property management

The copyright for all material produced from this project will be owned by the primary researcher, Rebecca Woodland. The thesis will only be made available publically with the approval of LEAHA.

Dissemination process, including to communities and key stakeholders

The final research thesis in its entirety will also be made available to the local ACCHO's, so that they can distribute via their communication channels to the local Indigenous community and stakeholders.

A one-page summary will also be made available at LEAHA for any interested parties to access.

The research may also be disseminated via conference presentations and journal articles.

Signed:

Paula Morgan, CEO, Lakes Entrance Aboriginal Health Association:



Date: 12.8.2020.

Signed:

Rebecca Woodland, La Trobe University D.Ph.Student



Date: 29th July 2020

Negotiated Research Agreement: Rebecca Woodland and Lakes Entrance Aboriginal Health Association (LEAHA) July 2020

Appendix C: Consent Form and Participant Information Sheet



Participant Information Statement and Consent Form

The research is being carried out by the following researchers: Rebecca Woodland The research is being carried out in partial fulfilment of Doctor of Public Health under the supervision of Dr Sarah MacLean and Dr Heather Downey. The following researchers will be conducting the study:		
Role	Name	Organisation
Student	Rebecca Woodland	School of Psychology and Public Health
Research funder	This research receives in kind support from La Trobe University.	

1. What is the study about?

You are invited to participate in a study of the experiences of Aboriginal Australians in East Gippsland who accessed primary health care during or after the bushfires in 2019/2020 or during the COVID19 pandemic 2020. We hope to learn what your experiences were, what worked for you and what didn't, to assist with planning for healthcare services for future disasters. Your contact details were obtained from Lakes Entrance Aboriginal Health Association.

2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. Who is being asked to participate?

You have been asked to participate because:

- You are an Aboriginal Australian living in East Gippsland. You are eligible to participate if you accessed, or tried to access, healthcare during or after the 2019/2020 bushfires, or during the COVID19 pandemic.

4. What will I be asked to do?

If you want to take part in this study, we will ask you to participate in an interview, either face-to-face, via videoconference, or phone-call. It will take approximately 40-90 minutes of your time to be part of this study.

5. What are the benefits?

There are no benefit to you personally in taking part in this study, however the expected benefit to society and the Indigenous community is that there will be a better understanding of the needs of the community when planning for healthcare access during and post disaster.

6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Rebecca Woodland	Researcher	██████████	19303944@students.ltu.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- There may be a risk that if you accessed healthcare and had an upsetting experience, you may become upset talking about it. If this occurs, you are able to cease the interview immediately.

7. What will happen to information about me?

We will **collect** information about you in ways that will not reveal who you are.

We will **store** information about you in ways that will not reveal who you are.

We will **publish** information about you in ways that will not be identified in any type of publication from this study.

We will **keep** your information for 7 years after the project is completed. After this time we will destroy all of your data.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/)
<https://policies.latrobe.edu.au/document/view.php?id=106/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

8. Will I hear about the results of the study?

We will provide a one page summary of the study at LEAHA for you to access, and also provide the entire thesis to LEAHA as well.

9. What if I change my mind?

You can choose to no longer be part of the study at any time until [four weeks] following the collection of your data. You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us; or
3. Emailing us

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

When you withdraw we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed we can only withdraw information, such as your name and contact details. If results haven't been analysed you can choose if we use those results or not.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
--------------------------	-----------------	------------------	--------------

Rebecca Woodland Researcher 0429483008 19303944@ltu.students.edu.au

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC20390	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time until [four weeks] following the collection of my data. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:

- ☐ Only used for this specific study;
- ☐ I agree to have my interview audio and/or video recorded

Participant Signature

☐ I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

- ☐ I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;
- ☐ I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University or any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been analysed.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group

I would like my already collected and unanalysed data

- ☐ Destroyed and not used for any analysis
- ☐ Used for analysis

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

CI Name	Rebecca Woodland
Email	19303944@ltu.students.edu.au
Phone	██████████
Postal Address	Rebecca Woodland C/O- LEAHA, Jemmeson St, Lakes Entrance 3909

Appendix D: Semi-structured Interview Questions

Semi Structured Interview Questions

Issue	Question	Probe
Access to Primary Health Care	When you're feeling sick, what do you usually do to get looked after?	Can you tell me about what you usually do to take care of your health needs?
		Where do you usually access healthcare?
	If you're a bit off colour, or you have a medical condition that's playing up, what would you usually do?	What things help you to get help?
		What things stop you from getting help?
		Can you tell me about any ongoing medical conditions you have that you have to have treatment for?
Access to Primary Health Care during disaster	During the bushfires, or during COVID19, have you needed to see someone about your health?	<u>Got Help</u>
		How did you know to go there for help?
		How did you organise your appointment?

Was it the Bushfires or
COVID19, and what
happened?

Can you tell me about any
problems you had trying to get in to
see a (insert health professional)?

What were you feeling at this time?

Couldn't Get Help

If you couldn't get help, what did
you try?

Why do you think you couldn't get
the help you needed?

How did you feel about not being
able to access help?

Didn't Try

If you thought you needed help but
didn't try to get any, why didn't you
try?

What can you tell me about why
you made that decision?

did this make you feel?

Were there any other
times during the
Bushfires or COVID19
where you needed
healthcare?

As above

What happened on that
occasion?

How did the
Bushfires/COVID19
impact on your ability to
seek healthcare?

What was different from usual?

Why do you think it was different
from usual?

How did you know what to do and
where to go?

How did you know what was
operating and was open, and
what wasn't?

Where were you getting information
about the situation (Bushfires and
COVID19) from?

Opinion on
whether the
Health Care
provided
during the

So when you saw (x),
what happened then?

Can you tell me about the care they
gave you?

disaster met
their health
care needs

Were you seeing the (insert
healthcare professional) for an
ongoing health concern you have,
or was it for something new or one
off?

Were your problems solved after
seeing the (insert health care
professional), or is it an ongoing
issue?

How would you describe the care
the (insert healthcare professional)
gave you?

How would describe the way the
(insert healthcare professional)
communicated with you?

Can you tell me about how you felt
after the consultation?

Did you have to have any follow up
treatment, and were you able to
organise that?

Is there anything else you'd like to
tell me about your health care
experience?

Improvements for access to health care in future disasters	Based on your experiences, what do you think should be done to improve access to health care for Aboriginal during disasters?	What things could be put in place to help you to access healthcare? What do you wish you'd known about healthcare during the Bushfires or COVID19? What would be the best way of communicating to the community about their health during disasters? What should health care providers know, that they don't know?
Other	What haven't we covered today, that you think I should know about health care and access during a disaster?	

Were there any differences in the way that the Bushfires and Covid affected you in relation to healthcare access?

Appendix E: Australian Journal of Rural Health Publication Acceptance

AJRH-05-2023-0097.R1



Pim Kuipers <pim.kuipers@jcu.edu.au>
To: Rebecca Woodland



Tue 31/10/2023 9:55 AM

Follow up. Start by Tuesday, 31 October 2023. Due by Tuesday, 31 October 2023.
You forwarded this message on 31/10/2023 10:50 AM.

Dear Ms Woodland,
Sincere apologies that your manuscript was caught up in an administrative backlog.
I can confirm that this has now been actioned by the Associate Editor, the manuscript is accepted for publication and can be cited as such.
Best wishes
Pim

Associate Professor Pim Kuipers

Principal Research Fellow, CQ Centre for Rural & Remote Health, James Cook University, Emerald.

Editor in Chief, Australian Journal of Rural Health.

M 0437 384810 | E pim.kuipers@jcu.edu.au | W cqcrh.jcu.edu.au



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CENTRE FOR RURAL
& REMOTE HEALTH

We acknowledge the Australian Aboriginal and Torres Strait Islander peoples as the traditional owners of the lands and waters where we live and work.

Your feedback is appreciated and can be submitted to: feedback@jcu.edu.au

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