Developing an mHealth program and respiratory measures with and for Aboriginal and Torres Strait Islander women caring for young children

By

Sarah Jane Perkes

BAppSc (OT) (Hons 1st), MPH

Thesis submitted to Flinders University
for the Degree of Doctor of Philosophy
College of Medicine and Public Health
Flinders University
March 2024

Contents

Thesis summary

Aboriginal and Torres Strait Islander women have great strength and influence in their communities. Health promotion programs targeting women's health inevitably have important positive impacts for children and other community members. Mobile health (mHealth) programs are an opportunity to improve access to culturally appropriate health information in real time. The aim of this thesis was to use co-design approaches to develop an mHealth program (Growin' Up Healthy Jarjums) and robust culturally sensitive measures for a research trial with Aboriginal and Torres Strait Islander mothers of young children.

As many co-design research projects do, this research changed direction substantially from beginning to end. Initially this thesis was focused child respiratory health, including the development of an mHealth tool to capture respiratory health outcomes of infants participating in a research trial. However, once we got talking to women it became clear that they wanted a tool that provided them with knowledge and support on a wide range of health topics. The focus of this thesis then shifted to co-designing an mHealth program with multiple health topics.

This thesis includes four linked studies: a cross-sectional survey to determine access to and interest in mHealth among Aboriginal and Torres Strait Islander women (Chapter 8); a co-design study to develop a prototype mHealth program for women's and children's health (Chapter 9); a pilot study to examine acceptability and engagement of a prototype mHealth program (Chapter 10); and a Delphi study to gain consensus on the most relevant and acceptable respiratory and birth measures for Aboriginal and Torres Strait Islander infants participating in a research trial (Chapter 11).

The cross-sectional survey (Chapter 8) confirmed that Aboriginal and Torres Strait Islander women were high users of smart phones and have a strong interest in mHealth. In the co-design study (Chapter 9) an mHealth prototype was developed covering 12 health topics. A 4-week pilot study (Chapter 10) identified that the program was perceived as useful and culturally appropriate, SMS had the highest engagement, and areas for technical and engagement-related improvements to the app were identified. In the final study (Chapter 11), relevant and acceptable measures for child respiratory health for use in a research trial were identified including 15 measures for birth, 17 measures from 1 to 6 months of age and 3 questionnaires for use at 6 months of age.

This thesis has generated knowledge on the access to, interest in and preferences for mHealth among Aboriginal and Torres Strait Islander women of reproductive age, an area where there has been limited data to date. Furthermore, a co-designed mHealth program that aimed to improve health knowledge and health behaviours among Aboriginal and Torres Strait Islander mothers has been developed and pilot tested. This work provides a solid foundation to further develop this mHealth program, and test it for effectiveness. The measures identified and developed in Chapter 11 may be used to measure respiratory health outcomes of the Growin’ Up Healthy Jarjums mHealth program, though additional outcome measures will need to be identified to capture other outcomes. If effective, the Growin’ Up Healthy Jarjums mHealth program would be provided to the same communities that co-designed it.

Declaration

I certify that this thesis:

1. does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university;

2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

16/06/2023

Statement of the contribution of others

This thesis has been made possible through the support of many people, including those as follows:

Supervisors
Professor Billie Bonevski
Dr Kerry Hall
Professor Joerg Mattes

Contributing authors
Jessica Bennett
Professor Billie Bonevski
Professor Catherine Chamberlain
Dr Rosie Dobson
Professor Gillian Gould
Dr Kerry Hall
Belinda Huntriss
Dr Michelle Kennedy
David Lambkin
Bernise Leece
Professor Joerg Mattes
Kerrin Palazzi
Noelene Skinner
Professor Robyn Whittaker

Research visit
National Institute for Health Innovation (NIHI), University of Auckland

Study participants
Mothers, health professionals and academics

Participating organisations
Aboriginal Maternal Infant Health Service, Mid North Coast Local Health District, NSW Health
Armajun Aboriginal Health Service
Awabakal Aboriginal Medical Service and Preschool
Birra-Li Aboriginal Maternal and Child Health Services, Hunter New England Local Health District, NSW Health
Galambila Aboriginal Health Service
Inverell Aboriginal Maternal and Infant Health Service, Hunter New England Local Health District, NSW Health
Kulai Preschool Aboriginal Corporation
Muloobinba Aboriginal Corporation

Funders
Australian Government Research Training Program Scholarship
Agency for Clinical Innovation, NSW Health
Clinical Excellence Commission (CEC)
Commonwealth Scientific and Industrial Research Organisation (CSIRO)
Hunter Medical Research Institute (HMRI)
Mid North Coast Local Health District
Society for Research on Nicotine and Tobacco

Copyediting and formatting of this thesis has been carried out by professional editor Donna Armstrong, in accordance with the Institute of Professional Editors' *Guidelines for editing research theses* (2019).

Acknowledgements

To start, a sincere thanks to my supervisors, Professor Billie Bonevski, Dr Kerry Hall and Professor Joerg Mattes. Billie, thank you for your rapid and expert feedback, unwavering support through all the ups and downs, and your strong leadership on aspects beyond this PhD. Kerry, since we first met for coffee back in 2017 you have been a great support. I admire your knowledge and wisdom, and your down-to-earth way of explaining things. Joerg, I have appreciated your quality input, and your genuine interest and support during my candidature. You have a knack for using few words to convey complex ideas. Together you have been a great team to introduce me to research. Thank you for your supervision.

An important acknowledgement in memory of Guyinbaraay woman Associate Professor Maree Gruppetta. Maree supervised me for the first 2 years of my PhD. Maree was down to earth, warm, intelligent, funny and had grit. Thank you Maree for all your guidance. May you rest in peace.

A special thanks to Noelz, Bez and Bernii – strong, intelligent and funny women. I've learnt so much from each of you and had a ball. I admire your knowledge of and dedication to your communities. Thank you for sharing it all; this thesis would not have been possible without you.

Thanks to Rosie and Robyn for your generosity in sharing your mHealth expertise. I learnt a lot from you both. This work is better for your contributions.

Mum, thank you for teaching me your strong moral compass and determination. Dad, thank you for being dependable and caring. Thank you to you both for helping care for the girls. Thanks to Iain, Pat and Danielle for your interest, encouragement and advice, on all things. Dan, thank you for prioritising my PhD and taking such good care of our girls. Rosie and Maggie, my babies, I love you dearly and can't wait to play more now that this is done.

Publications

Perkes SJ, Bonevski B, Hall K, Mattes J, Chamberlain C, Bennett J, Whittaker R, Palazzi K, Lambkin D, Kennedy M. Aboriginal and Torres Strait Islander women's access to and interest in mHealth: national web-based cross-sectional survey. Journal of Medical Internet Research. 2023;25:e42660. https://doi.org/10.2196/42660

Perkes SJ, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B. Development of a maternal and child mHealth intervention with Aboriginal and Torres Strait Islander mothers: co-design approach. JMIR Formative Research. 2022;6(7):e33541. https://doi.org/10.2196/33541

Perkes SJ, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B. Evaluation of an mHealth intervention (Growin' Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: engagement and acceptability study. JMIR Pediatrics and Parenting. 2023;6:e43673. https://doi.org/10.2196/43673

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Presentations

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. *The views of Aboriginal women on health supports: a mixed methods study*, Health Innovation and Research Symposium Mid North Coast Local Health District, Port Macquarie, Australia, June 2018

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. *The views of Aboriginal women on health supports: a mixed methods study*, Centre for Brain and Mental Health Research Postgraduate and Postdoctoral Conference, Newcastle, Australia, August 2018

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. T*he views of Aboriginal women on health supports: a mixed methods study*, Australian Public Health Conference, Cairns, Australia, September 2018

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. *Surfing the online wave: the MAMAS and BUB EMPOWER apps*, Aboriginal and Torres Strait Islander Women's Health Meeting, Adelaide, Australia, September 2018

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. *The views of Aboriginal women on health supports: a mixed methods study*, 7th Rural Health and Research Congress, Tamworth, Australia, September 2018

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. S*ocial media and app preferences among Aboriginal women for health and well-being*, E-Mental Health International Conference, Newcastle, Australia, November 2018

Perkes S, Skinner N, Mattes J, Gruppetta M, Bonevski B. *Mothers Aunties Maternal Aboriginal Smokefree (MAMAS) Study*, Hunter Cancer Research Alliance Symposium, Newcastle, Australia, November 2018

Perkes S, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B. *The co-design of a smartphone application with Aboriginal women*, Society for Research on Nicotine and Tobacco (SRNT) Oceania Conference, Sydney, Australia, October 2019

Awards

University of Newcastle Research Training Program Scholarship (RTPS), 2017, $26,682 per annum for 3.5 years

MAMAS (Mothers Aunties Maternal Aboriginal Smokefree) and Bringing up Bubs (BUBS) Apps, ON Prime, Commonwealth Scientific and Industrial Research Organisation (CSIRO), 2018, $3000

The preferences of Aboriginal women on health supports: a mixed methods study, Mid North Coast Local Health District Innovation Challenge Grant, 2018, $5000

Best Early Career Poster, Society for Research on Nicotine and Tobacco Oceania Conference, 2019, $500

Greaves Family Postgraduate Scholarship, Hunter Medical Research Institute (HMRI), 2019, $12,500

Ian O'Rourke Scholarship in Patient Safety, Clinical Excellence Commission (CEC), NSW Health, 2019, $9594

Development of a mobile health app for Aboriginal women and children post birth to five years, including smoking cessation, Agency for Clinical Innovation Grant, NSW Health, 2020, $29,959.43

Intermissions and disruptions to candidature

Intermission/Disruption	**Dates**	**Total number of working days**
Initial commencement date	1 July 2017	NA
Change of supervisors and change of PhD studies	27 March 2019	NA
Parental leave	24 July 2020 to 15 October 2020	60 working days
Carer responsibilities due to COVID-19 restrictions	10 August 2021 to 7 September 2021	20 working days
Carer responsibilities due to COVID-19 restrictions	29 September 2021 to 29 November 2021	45 working days
Financial and carer responsibilities due to COVID-19 restrictions	30 November 2021 to 27 May 2022	125 working days
Parental leave	10 October 2022 to 1 August 2023	240 working days

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Abbreviations

ACCHO	Aboriginal Community Controlled Health Organisation
AH&MRC	Aboriginal Health and Medical Research Council
AMS	Aboriginal Medical Service
apps	applications
ASQ	Ages and Stages Questionnaire
GP	general practitioner
HDR	Higher Degree Research
mHealth	mobile health
MMS	multimedia messaging service
NICU	neonatal intensive care unit
NSW	New South Wales
OR	odds ratio
REDCap	Research Electronic Data Capture
SMS	short messaging service

Section A – Introduction

Section A provides an introduction to the content and context of this thesis. A substantial part of the introduction is dedicated to the impacts of colonisation and the subsequent social and economic inequalities impacting the health of Aboriginal and Torres Strait Islander Australians. It is important to provide this context as the ongoing impacts on health outcomes for Aboriginal and Torres Strait Islander people are profound and must be addressed during the development of health programs. Chapters 3 and 4 then introduce the more focused topics of this thesis: mobile health (mHealth) programs and co-design methodologies.

Section A comprises the following chapters:

Chapter 1. Aboriginal and Torres Strait Islander health and health inequities

Chapter 2. Aboriginal and Torres Strait Islander concepts of health, health care utilisation, and factors impacting access to health care

Chapter 3. Mobile health (mHealth)

Chapter 4. Approaches for developing mHealth programs

Chapter 5. Thesis aims and research questions

Note: ‘Aboriginal and Torres Strait Islander people’ is used throughout this thesis to refer to Indigenous people in Australia. ‘First Nations people’ is used when referring to indigenous people internationally.

Chapter 1 – Aboriginal and Torres Strait Islander health and health inequities

Content

1.1 Chapter overview

Understanding a population's history, culture and demographics is an important first step to developing a health program. This chapter begins with a brief introduction to the Aboriginal and Torres Strait Islander peoples of Australia, followed by an outline of the health status of Aboriginal and Torres Strait Islander peoples, then more specifically women and children. A summary of the causes of health inequities experienced by Aboriginal and Torres Strait Islander people, including the historical, social and political determinants of health, is provided.

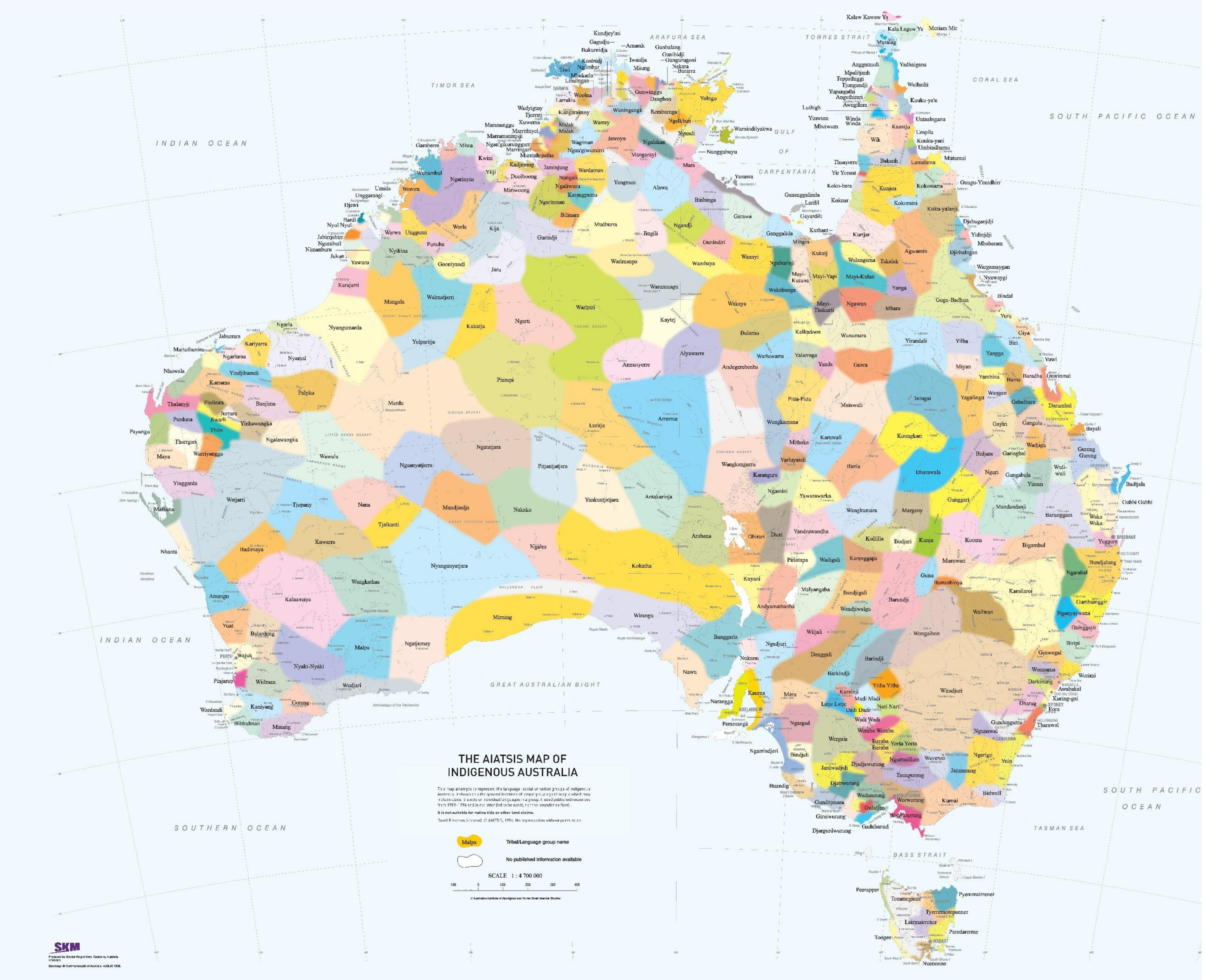
1.2 An overview of Aboriginal and Torres Strait Islander communities and health outcomes

> *"I bin thinkin' this bin Gurindji country. We bin here longa time before them Vestey mob."*
>
> Vincent Lingiari

1.2.1 Aboriginal and Torres Strait Islander people in Australia

Aboriginal and Torres Strait Islander people are the longest-surviving culture in the world (1). They consist of many diverse cultural groups (Figure 1.1), with over 250 languages and 800 dialects (1). In the 2021 census, 812,728 people identified as being of Aboriginal or Torres Strait Islander origin, representing 3.2% of the total population (2). The Aboriginal and Torres Strait Islander population is much younger than the non-Indigenous population, with more than half (51%) of the Aboriginal and Torres Strait Islander population under 25 years of age (3). The largest proportion of Aboriginal and Torres Strait Islander people live in the state of New South Wales (NSW) (34.2%; 3.4% of all people in NSW), followed by Queensland (29.2%; 4.6% of people in Queensland), Western Australia (10.9%; 3.3% of people in Western Australia), Victoria (8.1%; 1% of people in Victoria), the Northern Territory (7.5%; 26.3% of people in the Northern Territory), South Australia (5.2%; 2.4% of people in South Australia), Tasmania (3.7%; 5.4% of people in Tasmania) and the Australian Capital Territory (1.1%; 2% of all people in the Australian Capital Territory) (3). Aboriginal and Torres Strait Islander people are more likely to live in urban (38%) or inner and outer regional areas (44%) compared with remote or very remote areas (17%) (4).

Figure 1.1. The AIATSIS map of Indigenous Australia



Source: AIATSIS, 1996 (5). Reproduced with permission.

This map attempts to represent the language, social or nation groups of Aboriginal Australia. It shows only the general locations of larger groupings of people which may include clans, dialects or individual languages in a group. It used published resources from the eighteenth century – 1994 and is not intended to be exact, nor the boundaries fixed. It is not suitable for native title or other land claims. David R Horton (creator), © AIATSIS, 1996. No reproduction without permission. To purchase a print version visit: https://shop.aiatsis.gov.au/

1.2.2 Overall health outcomes

A number of health outcomes for Aboriginal and Torres Strait Islander people have remained steady or worsened over the past decade (6), including rates of mental illness (7), psychological distress (7), asthma (8), diabetes (9), cardiovascular disease (7) and chronic obstructive pulmonary disease (7). Gains have been made in some areas, such as decreased smoking during pregnancy (10), antenatal visits (10, 11), Year 12 completion (3) and university attendance (3). Aboriginal and Torres Strait Islander people experience high levels of distress (12). A majority (73%) of Aboriginal and Torres Strait Islander people report that they have experienced high levels of stress in the previous 12 months; the death of a family member or close friend is the most common stress. This level of stress is 1.4 times the rate for non-Indigenous people (13).

1.2.3 Women's health outcomes

Aboriginal and Torres Strait Islander women have great strength and influence in their communities. They are "healers, storytellers, keepers of our kids and truth-seekers" (14) (para. 3). They have been instrumental in driving change for Aboriginal and Torres Strait Islander people, including leading the mandate for the Uluru Statement from the Heart (14). Aboriginal and Torres Strait Islander women look after not only their own health, but the health of the collective: their community, grandchildren, parents, grandparents, children and other family members (15). The positive experiences and role modelling by Aboriginal and Torres Strait Islander women to their children and others influence development and behaviour, and often lead to better health outcomes for all of their community (16). Health promotion programs targeting women's health inevitably have important positive impacts for children and other community members.

The life expectancy for Aboriginal land Torres Strait Islander women is 7.6 years less than non-Indigenous women (17). The leading cause of death for Aboriginal and Torres Strait Islander women is coronary heart disease, followed by chronic lower respiratory disease (18). The majority of Aboriginal and Torres Strait Islander women aged 15 years and over are not meeting guidelines for physical activity, vegetable intake or fruit intake, 36% report they smoke tobacco daily, and 35% report they experience high or very high levels of psychological distress (12). Aboriginal and Torres Strait Islander women are more than four times as likely as non-Indigenous women to give birth as teenagers, and maternal death is more than two times higher than in other Australian women (18).

1.2.4 Children's health outcomes

The health of Aboriginal and Torres Strait Islander children remains significantly poorer than that of non-Indigenous children. For some, the poor health trajectory starts *in utero* or at birth. Among babies born to Aboriginal and Torres Strait Islander women in 2015-2016, 14% were born preterm and 12% low birth weight (18). Low birth weight is associated with developmental delays in childhood and a number of morbidities in adulthood, including increased risk of coronary heart disease, diabetes, hypertension and stroke (19). Aboriginal and Torres Strait Islander infant mortality (less than 1 year old) is almost twice as high as for non-Indigenous infants (6.2 compared with 3.2 per 1000 births) (18). Aboriginal and Torres Strait Islander children experience morbidity at high rates throughout childhood (20). Morbidities are particularly high in remote communities where overcrowding and poor access to health care are major factors; for example, 23% of infants living in remote communities in the Northern Territory experience scabies, which can lead to kidney disease and rheumatic heart disease (13). Aboriginal and Torres Strait Islander children also experience poor respiratory health, with Aboriginal and Torres Strait Islander children aged 0–4 years old experiencing hospitalisation rates for respiratory disease of 78 per 1000 population, compared with 48 per 1000 population for non-Indigenous children (20).

1.3 The causes of health inequities experienced by Aboriginal and Torres Strait Islander peoples

“Then they took the children away
Took the children away
The children away
Snatched from their mother’s breast
Said this is for the best
Took them away”

Archie Roach

1.3.1 Historical and political causes

The health and wellbeing of Aboriginal and Torres Strait Islander people has been significantly impacted by dispossession, interruption of culture and intergenerational trauma since the colonisation of Australia (21). Aboriginal and Torres Strait Islander women face more challenges to achieve good health than most other Australian women, and Aboriginal and Torres Strait Islander infants face more illness than most other Australian infants. To understand why these challenges and gross inequalities exist, a brief introduction to the historical and socioeconomic context of Aboriginal and Torres Strait Islander health is described here.

The health of Aboriginal and Torres Strait Islander people changed dramatically and abruptly upon the invasion by Europeans. Prior to the invasion, Aboriginal and Torres Strait Islander people enjoyed generally ‘good’ health. People lived on a diet of ‘bush’ foods, had an active lifestyle, enjoyed strong culture and language, and had an emphasis on family and kinship (22). Upon the European invasion, people were massacred, disease was spread and land was stolen. The arrival of the First Fleet brought tobacco and alcohol, which were offered to Aboriginal and Torres Strait Islander people in exchange for labour and land (23). The damage since the invasion has been sustained by numerous poor policy decisions, such as displacement of people from their land to reserves and the Stolen Generations. The Stolen Generations refers to a period in Australia’s history in which Aboriginal children were removed from their families through government policies from the mid-1800s to the 1970s (24). Almost half of Aboriginal and Torres Strait Islander adults report that either they or a relative have been removed from their family (25), causing significant intergenerational trauma. The ramifications have led to Aboriginal and Torres Strait Islander people having the worst health of any population group in Australia today.

In periods after the invasion, government policy was geared towards control and segregation, such as reserves, as it was widely assumed that Aboriginal and Torres Strait Islander people would die out. When it became apparent that this was not going to happen, throughout the 1950s and 1960s policy was redirected towards assimilation (defined at the 1961 Native Welfare Conference of Federal and State Ministers) (26). The effects of these policies have been long-lasting. The overall lack of autonomy over simple daily decisions and poor living conditions resulted in cyclic poverty and gross disempowerment. People became dependent on the government for their most basic needs, including food, housing, money (welfare handouts), education, employment and child rearing (26). Housing was inadequate, diet was insufficient (e.g. tea, sugar, flour), health care was limited, and rations included tobacco and alcohol. Tobacco rations initiated and reinforced nicotine addiction (26).

In the 1970s, there was a shift in Aboriginal and Torres Strait Islander policy towards self-determination (in response to the Aboriginal Tent Embassy established in 1972). It was the goal of the government to reach health equality between Aboriginal and Torres Strait Islander people and non-Indigenous people; however, no real plan was developed (26). In recent decades, promising gains have been made, with an increase of Aboriginal and Torres Strait Islander community-controlled health organisations (27). However, due to inefficient funding arrangements, inappropriate mainstream services, a lack of partnership and poor planning, Aboriginal and Torres Strait Islander people have continued to experience significantly poorer health than other Australians (27, 28).

1.3.2 Determinants of health

The multiple determinants of health are illustrated in Figure 1.2: level 1 is the overarching structural environment; level 2 is the material and social conditions in which people live and work; level 3 is the support from family and community; and level 4 is the actions and choices taken by individuals (29). It is the complex interplay of these social and environmental factors that contributes to Aboriginal and Torres Strait Islander peoples experiencing significantly poorer health (30). Examples include structural racism (31); lower educational attainment, employment and income (32); inadequate and overcrowded housing (3); high incarceration rates (27% of the adult prison population is Aboriginal and Torres Strait Islander) (3); and high-risk health behaviours (7). The Whitehall studies, which show the 'social gradient' of disease (i.e. the lower a person's socioeconomic status, the poorer health they experience), first established that social and economic disadvantage is one of the leading causes of poor health (33-35). Improving social and economic conditions is as important for the health of a population as medical care (36).

Figure 1.2. Dahlgren and Whitehead model of the main determinants of health

This image has been removed due to copyright restriction. Available online from Dahlgren G, Whitehead M. Policies and strategies to promote social equity in health. Stockholm: Institute for Future Studies; 1991.

Source: Dahlgren and Whitehead, 1991 (29)

Other important determinants of health particularly relevant to this thesis are cultural determinants. For Aboriginal and Torres Strait Islander people, cultural determinants are protective factors that can promote good health and wellbeing. They include:

- family/community
- Country and place
- cultural identity
- self-determination (37).

Aboriginal and Torres Strait Islander people have been connected to culture for over 65,000 years (38), including cultural knowledge, expression, Country and caring for Country, language, family, kinship and community (39). Aboriginal and Torres Strait Islander communities have kept their culture alive by passing on knowledge from one generation to the next (40). When the passing down of connection to culture was disrupted (following colonisation), Aboriginal and Torres Strait Islander ways of health and wellbeing were impacted. It is becoming well recognised that connection to culture is a health program in itself for Aboriginal and Torres Strait Islander people (37, 41, 42). The importance of connection to culture for wellbeing was reported recently in the Mayi Kuwayu study (the National Study of Aboriginal and Torres Strait Islander Wellbeing), which found Ranger participation (e.g. using traditional knowledge with conservation training to protect and manage their land, sea and culture including activities such as bushfire mitigation, protection of threatened species, and biosecurity compliance (43)) was associated with very high life satisfaction and family wellbeing (compared with non-rangers (44)). In examining mediating variables, it was found that current cultural practices, spending time on Country and speaking an Aboriginal language partially mediated the associations between Ranger status and high life satisfaction, and between Ranger status and high family wellbeing (44).

Health programs can be aimed at all levels represented in the model of determinants of health; for example, with the goal of reducing smoking prevalence, interventions include taxation on tobacco (level 1), smoke-free public places (level 2), community-specific health promotion programs (level 3) and targeted smoking cessation programs for groups and individuals at high risk (level 4) (29). It is now recognised that a multi-level approach with Aboriginal and Torres Strait Islander perspectives and control is needed to close the gap in the inequities that persist (21, 27, 45)

1.4 Chapter summary

Aboriginal and Torres Strait Islander peoples are the oldest living culture in the world and the first peoples of Australia. Approximately 250 years ago, Australia was invaded and colonised, involving frontier wars and Aboriginal and Torres Strait Islander people being removed from their land. Since this time, Aboriginal and Torres Strait Islander people have experienced disadvantage across all levels of the determinants of health. It is well recognised that the social, cultural and political determinants of health are the biggest influence on Aboriginal and Torres Strait Islander health outcomes (46). We know that large-scale systemic health reforms that position Aboriginal and Torres Strait Islander peoples as the decision-makers for Aboriginal and Torres Strait Islander peoples are required (46). At the same time as working towards big systemic changes, access to culturally safe health care services and health programs to support individuals and communities to improve their health is also needed.

Chapter 2 – Aboriginal and Torres Strait Islander concepts of health, health care utilisation, and factors impacting access to health care

Content

2.1 Chapter overview

Access to high-quality health care is an important element for good health. Aboriginal and Torres Strait Islander peoples experience a range of barriers to accessing appropriate health care related to the determinants of health, including culturally inappropriate care. This chapter firstly describes Aboriginal and Torres Strait Islander concepts of health and wellbeing to understand what concepts should underpin health programs for Aboriginal and Torres Strait Islander peoples. This is followed by a description of the health services available to Aboriginal and Torres Strait Islander peoples and health service utilisation, followed by a nuanced review of barriers and enablers to Aboriginal and Torres Strait Islander families accessing health care.

2.2 Aboriginal and Torres Strait Islander concepts of health and wellbeing

> *"To us, health is about so much more than simply not being sick. It's about getting a balance between physical, mental, emotional, cultural and spiritual health. Health and healing are interwoven, which means that one can't be separated from the other."*
>
> Dr Tamara Mackean

2.2.1 Social and emotional wellbeing

The term social and emotional wellbeing is a broad term that represents a holistic concept of health that includes physical, spiritual and emotional aspects, as well as the wellbeing and connectedness of family, community and culture, as the underpinnings of health, as shown in Figure 2.1 (48). Social and emotional wellbeing is generally used by Aboriginal Community Controlled Health Organisations (ACCHOs) as a definition for what the service aims to provide and achieve for the community, though different cultures and services may interpret the term slightly differently (48). To understand the domains of social and emotional wellbeing represented in Figure 2.1, the National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing (49) developed a table with descriptions of each (Table 2.1).

Figure 2.1. Social and emotional wellbeing from an Aboriginal and Torres Strait Islander perspective

This image has been removed due to copyright restriction. Available online from Gee G, Dudgeon P, Schultz C, Hart A, Kelly K. Aboriginal and Torres Strait Islander social and emotional wellbeing. In: Dudgeon P, Milroy H, Walker R, editors. Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice. Canberra: Australian Government Department of the Prime Minister and Cabinet; 2014. p. 55-68.

Source: Gee, Dudgeon, Schultz, Hart and Kelly 2013 (48)

Table 2.1. The domains of social and emotional wellbeing with risk and protective factors

Domain	Description	Examples of risk factors	Examples of protective factors
Connection to body	Physical health – feeling strong and healthy and able to physically participate as fully as possible in life.	• Chronic and communicable diseases • Poor diet • Smoking	• Access to good healthy food • Exercise • Access to culturally safe, culturally competent and effective health services and professionals
Connection to mind and emotions	Mental health – ability to manage thoughts and feelings.	• Developmental/ cognitive impairments and disability • Racism • Mental illness • Unemployment • Trauma, including childhood trauma	• Education • Agency: assertiveness, confidence and control over life • Strong identity
Connection to family and kinship	Connections to family and kinship systems are central to the functioning of Aboriginal and Torres Strait Islander societies.	• Absence of family members • Family violence • Child neglect and abuse • Children in out-of-home care	• Loving, stable, accepting and supportive family • Adequate income • Culturally appropriate family-focused programs and services
Connection to community	Community can take many forms. A connection to community provides opportunities for individuals and families to connect with each other, support each other and work together.	• Family feuding • Lateral violence • Lack of local services • Isolation • Disengagement from community • Lack of opportunities for employment in community settings	• Support networks • Community-controlled services • Self-governance

Domain	Description	Examples of risk factors	Examples of protective factors
Connection to culture	A connection to a culture provides a sense of continuity with the past and helps underpin a strong identity.	• Elders passing on without full opportunities to transmit culture • Services that are not culturally safe • Languages under threat	• Contemporary expressions of culture • Attending national and local cultural events • Cultural institutions • Cultural education • Cultural involvement and participation
Connection to Country	Connection to Country helps underpin identity and a sense of belonging.	• Restrictions on access to Country	• Time spent on Country
Connection to spirituality and ancestors	Spirituality provides a sense of purpose and meaning.	• No connection to the spiritual dimension of life	• Opportunities to attend cultural events and ceremonies • Contemporary expressions of spirituality

Source: Commonwealth of Australia, 2017 (49)

2.2.2 Self-determination and empowerment

Self-determination is essential and foundational and is core to health program development. Self-determination is the right to “freely determine political status and freely pursue economic, social and cultural development” (50). As discussed in the previous chapter, it is the social and political determinants of health that are the main drivers of health generally; therefore, any health program aiming to improve health equity for Aboriginal and Torres Strait Islander peoples should consider self-determination (51). Self-determination strategies can be implemented at various levels. At a national level, the Australian public will be asked in late 2023 to vote on a Voice to Parliament to be enshrined in the Constitution, which would enable Aboriginal and Torres Strait Islander peoples to provide advice to the Australian Parliament on policies and projects that impact their lives (52). At a community level, ACCHOs are governed by Aboriginal and Torres Strait Islander peoples to deliver culturally appropriate health services. At an individual level, using co- development methodologies to create health programs aims to centre the voices of the individuals they are designed for (53), and ultimately support individuals to exercise the right to make decisions about their own health.

The term empowerment aligns closely with self-determination and is often used in Aboriginal and Torres Strait Islander health (54-56). Empowerment is defined as a multi-level construct that involves people gaining control and purpose over their lives in the context of their social and political environment, with the understanding that powerlessness and chronic stress are key underlying causes of ill health and risky health behaviours (57). Basing health programs on the theory of empowerment is viewed as key for both health research and frontline services (55).

2.3 Health services

"Unless the approaches to Aboriginal health are broadened to include greater attention to the health problems of adults, and are matched by broad ranging strategies aimed at redressing Aboriginal social and economic disadvantages, it is likely that overall mortality will remain high."

Dr Charles Perkins

2.3.1 General public health services

Public health services in Australia include tertiary, secondary and primary health services. Tertiary health care is specialised health care that is largely provided in hospitals, and may include emergencies, complex medical care and surgery (58). Secondary health care is accessed following a referral from a primary health care provider and includes medical specialists (58). Primary health care is usually the first point of care for a patient and includes general practitioners (GPs), Aboriginal health workers, Aboriginal health practitioners, allied health, community nurses and dentistry. This thesis is focused on primary health care. The mHealth program developed as part of this thesis was intended to be an adjunct to face-to-face primary health care, including encouraging users to access their GP or other primary health care professional.

Health care in Australia is provided free or at low cost for all Australians via Medicare (federally funded universal health care) and state governments, although out-of-pocket costs have risen in the past 10 years, with an estimated 20–40% of GP appointments requiring an out-of-pocket cost (average cost is $40.25 per 15-minute appointment) (59). Waiting times for GP appointments (and specialist services) have also increased over the last several years, with one in five patients reporting that they waited longer than acceptable to get an appointment with a GP, and one in 10 reporting that they did not see a GP when they needed to. This number is higher in areas with socioeconomic deprivation (60).

2.3.2 Private health services

Despite free universal health care, more than half of the Australian population (13.6 million) have private health insurance (61). Private health insurance can cover both private hospital stays and ‘extras’ such as allied health and dentistry, which are often not covered by Medicare. Care in a private hospital is usually associated with shorter waiting times, choice of specialist, and single rooms during hospital stay (62). In 2018–2019, in non-remote areas, 21% of Aboriginal and Torres Strait Islander people aged 15 and over were covered by private health insurance, compared with 58% of non-Indigenous Australians (63).

2.3.3 Aboriginal Community Controlled Health Organisations

An ACCHO is a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive and culturally appropriate health care to the community through a locally elected Board of Management (64). ACCHOs were established for local Aboriginal and Torres Strait Islander communities in response to experiences of racism in mainstream health services and an unmet need for culturally safe and accessible primary health care (64). There are now more than 140 ACCHOs across Australia (64). ACCHOs have been shown to improve health outcomes across a range of areas including sexual health, maternal and child health, smoking cessation, and cardiovascular health (65). Additionally, people attending ACCHOs tend to report higher satisfaction with care and more accessible health care than those attending other primary health services (66). The success of ACCHOs can be partly attributed to the broad range of services they provide that address the social determinants of health, including supporting (or connecting) people with education, employment, income, food subsidies; managing behavioural risk factors (exercise, diet, smoking); and providing culturally safe care medical care and psychosocial support (67).

Aboriginal and Torres Strait Islander women and children can seek health care from ACCHOs or a general primary health care service. Specific services for Aboriginal and Torres Strait Islander women’s and children’s health exist in both ACCHOs and general primary health care services. Locally developed programs are achieving positive health outcomes for Aboriginal and Torres Strait Islander women (68). One such exemplar of a women’s and children’s health promotion program developed by an ACCHO is the Waminda Dead or Deadly program (69) (see Box 2.1).

Box 2.1. Waminda Dead or Deadly program (69)

The Dead or Deadly program has been running for over 10 years on the South Coast of New South Wales and aims to enhance cultural connection and health and wellbeing through a range of activities, including cooking groups with local ingredients, exercise groups (pre- and postnatal), yarning groups and lifestyle medicine. The program was designed by and for local Aboriginal and Torres Strait Islander women and therefore operates in a flexible way to meet local women's needs.

2.3.4 Utilisation of primary health care services

According to Medicare data, Aboriginal and Torres Strait Islander people access GP services only slightly more than non-Indigenous Australians, which is considered to be low use of health care given that the burden of disease among Aboriginal and Torres Strait Islander peoples is more than double that of non-Indigenous Australians (63). About 30% of Aboriginal and Torres Strait Islander people report that they needed to but did not see a health care provider in the 12 months prior (63). About one-third (33%) of those who did not see a health care provider when they needed to reported a reason related to service availability or transport/distance, the waiting time being too long, or the service not being available (63). The main service gaps reported by Aboriginal and Torres Strait Islander primary health care organisations include mental health or social and emotional health and wellbeing, youth services, and alcohol, tobacco and other drug services (63).

2.4 Barriers and enablers for Aboriginal and Torres Strait Islander families accessing primary health care services

> *"The access to health care for Indigenous people has always been so deprived and poor and if someone was sick, they would rather see my mum than go to a hospital, where there were no Aboriginal health workers."*
>
> Dr Kelvin Kong

2.4.1 Summary of barriers and enablers for Aboriginal and Torres Strait Islander people accessing primary health care services

Access to primary health care represents dynamic interactions of individuals in their social context interfacing with health care services that operate in a variety of constrained structures and environments (70). Poor access to primary health care for First Nations people is a global phenomenon, and a national challenge (20). Critical for the health of Aboriginal and Torres Strait Islander families is access to health care that is of high quality, appropriate, affordable, acceptable and comprehensive (20, 71-73). It is important to have a thorough understanding of barriers and enablers to accessing health care in order to drive change and develop effective health programs (74). Key features of enablers and barriers to accessing health care include:

- they are not fixed concepts but can be positively or negatively influenced;
- the degree to which an intervention can influence an enabler or barrier varies; and
- 3) they are inter-related, whereby a change in one may effect a change in another (74).

A number of barriers and enablers are associated with a person’s ability to access health care in Australia. Factors include wait times, cost (75, 76), service availability, understanding the urgency of care, and other life stresses (77). Aboriginal and Torres Strait Islander people experience additional disparity. Barriers experienced by Aboriginal and Torres Strait Islander people include fear, low health literacy (78), rural location, poor communication from health providers, low socioeconomic status (79), low quality of care, and racist treatment (70, 80). Reviews on First Nations people internationally report similar findings, with barriers including lack of services in rural locations, poor communication by health providers and low socioeconomic status (79), while enablers identified include competent and compassionate program delivery, flexible access, continuity and integration of health care, and culturally supportive care (81). A review conducted on enablers and barriers to the implementation of primary health care programs for First Nations peoples identified design attributes, workforce, patient and provider partnership, clinical care pathways, and access as factors that enable or inhibit implementation (74).

2.4.2 Literature review of barriers and enablers for Aboriginal and Torres Strait Islander families accessing primary health care for their children

Given a focus of this thesis is on developing an mHealth program for women’s and children’s health, it is necessary to understand the barriers and enablers for this population to accessing health care. The reviews mentioned above are focused on adults. We therefore have reviewed the literature to understand barriers and enablers for Aboriginal and Torres Strait Islander families accessing primary health care for their children. Enablers and barriers have been analysed and reported on within a framework (82) of determinants of health including culturally distinct factors. The characteristics of studies are presented in Table 2.2, and barriers and enablers in Table 2.3.

Twenty-four articles were identified and coded for barriers and enablers. Studies were conducted in a range of locations covering all Australian states and territories, including 11 urban, 6 regional and 4 remote locations, and 3 studies in multiple locations. In total, 35 barriers and 42 enablers were identified. The barriers were fairly evenly spread across the five levels of determinants, although slightly fewer barriers were identified in the overarching levels (societal and culturally distinct factors). This may be because we focused on family-perceived barriers, of which individual- and relationship-level barriers may be more tangible. Barriers identified included 9 individual-level barriers, 8 relationship-level barriers, 9 community and organisational–level barriers, 5 society-level barriers, and 4 culturally distinct–level barriers. Enablers were less evenly spread than barriers, with most enablers positioned at the relationship level and community and organisational level. Enablers identified included 2 individual-level enablers, 13 relationship-level enablers, 21 community and organisational–level enablers, 1 society-level enabler, and 5 culturally distinct–level enablers.

As described in the previous section, barriers and enablers are inter-related, whereby a change in one may impact another. For example, if structural racism was address at the culturally distinct level, it would likely impact barriers at other levels, including factors at the individual level such as shame, mistrust and feeling judged, and at the relationship level such as poor quality of care and lack of rapport. The mHealth program described in this thesis is focused on providing culturally appropriate health information at the organisational level. Other knock-on impacts of the program may include improving confidence and sense of belonging at the individual level, empowerment of mothers to optimise child development at the relationship level, and strengthening children's connection to culture at the culturally distinct level.

Table 2.2. Study characteristics of studies on family-perceived barriers and enablers to accessing primary health care for Aboriginal and Torres Strait Islander children

Author and year	Geographic location	Population (n)	Age of child	Method	Aim
Campbell (83) 2018	Queensland (Regional)	Family members (4)	Babies (age not specified)	Interviews	To determine how the Baby One Program was implemented, enablers, strategies used and formative implementation outcomes.
Chando (84) 2022	New South Wales (Urban)	Carers (19)	Age not reported	Interviews	To describe the aspects of delivering child health programs that are important to carers and staff from two Aboriginal Community Controlled Health Organisations who are partners in the Study of Environment on Aboriginal Resilience and Child Health (SEARCH).
Clapham (85) 2018	New South Wales (Urban)	Family members (9 mothers)	Birth to 5	Interviews	To determine the effectiveness of the home visiting model as an injury prevention program.
Coombes (86) 2020	New South Wales, Northern Territory, Queensland, South Australia (Urban, remote, very remote)	Mothers, fathers, Aunties, cousins, grandparents and siblings (59)	Birth to 16	Interviews	To identify barriers and enablers to culturally safe and appropriate burn aftercare for Aboriginal and Torres Strait Islander families.
DiGiacomo (87) 2017	New South Wales (Urban)	Women (19)	5 months to 13 years	Interviews	To better understand the experiences and needs of parents/carers/families of Aboriginal children with a disability.
DiGiacomo (88) 2013	New South Wales (Urban)	Carers (5)	Author confirmed children under 5	Focus groups	To ascertain the factors involved in accessing services and support for Aboriginal children with a disability.
D’Sylva (89) 2019	Western Australia (Regional)	Community members, a majority of parents (40)	Ages not reported	Interviews and focus groups	To identify the barriers to, and enablers for, seeking medical help for chronic wet cough in Aboriginal children.

Author and year	Geographic location	Population (n)	Age of child	Method	Aim
Durey (90) 2017	Western Australia (Urban)	Parents (52)	Young children	Focus groups	To explore perceptions and experiences as they relate to the oral health – responses analysed to identify barriers and enablers to children's oral health.
Foley (91) 2013	Queensland (Urban)	Mothers (20)	3 to 12 months	Interviews	To examine urban Aboriginal and Torres Strait Islander mothers' breastfeeding experiences to inform support for mothers and their families.
Graham (92) 2017	New South Wales (Urban)	Parents (10)	Preschool age and school age	Interviews	To identify factors that assisted Aboriginal families to attend and engage with a speech pathology service.
Green (93) 2016	Eastern Australia (Urban)	Parents and carers (19)	0–8 years	Interviews	To describe the carer journey of accessing support and services.
Greenstein (94) 2016	Northern Australia (Regional)	Carers (9)	Birth to 21 years	Interviews	To compare the outcomes of two cycles of continuous quality improvement at a paediatric physiotherapy service with findings from interviews with clients and their carers using the service.
Greenstein (95) 2016	Northern Australia (Regional)	Parents and foster carers (9)	Birth to 21 years	Interviews	To explore the experiences of Aboriginal and Torres Strait Islander children with physical disability and their carers of their community-based physiotherapy service, factors that influence their experiences of the physiotherapy service, and how the service could be improved.
Hendrickx (96) 2020	Western Australia (Remote)	Parents and carers (16)	Ages not reported	Interviews and focus groups	To explore community knowledge, attitudes and practices in relation to skin infections, specifically findings pertaining to barriers and enablers of health service utilisation.
Jeffries-Stokes (97) 2004	Western Australia (Regional)	Key informants (56); mothers (22)	Birth to 12 months	Focus groups	To explore perceptions, knowledge and experience of otitis media and barriers to compliance with treatment among Aboriginal people of the Kalgoorlie-Boulder area.
Jones (98) 2018	Northern Territory (Remote)	Carers (9)	0 to 3 years	Interviews	To explore carers' views about an inclusive, parent-implemented early childhood program for children aged 0–3 years in an Aboriginal community health context.

Author and year	**Geographic location**	**Population (n)**	**Age of child**	**Method**	**Aim**
Kruske (99) 2012	Northern Territory (Remote)	Mothers and other family members (15)	Birth to 12 months	Observation and interviews	To explore the experiences and beliefs of Aboriginal families as they cared for their children in the first year of life, through collection of family stories concerning child rearing, development, behaviour, health and wellbeing between each infant's birth and first birthday.
Middleton (100) 2017	South Australia (Urban, regional)	Mothers (20)	*In utero* to 8 weeks	Interviews	To evaluate implementation and outcomes of the Aboriginal Family Birthing Program.
Minniecon (101) 2003	Queensland (Urban)	Mothers (5)	Up to 6 weeks	Interviews	To identify barriers that exist for Aboriginal and Torres Strait Islander women accessing mainstream antenatal and postnatal services, as well as existing barriers with hospital staff.
Ou (102) 2011	Australia (Urban, regional)	Parents (152)	6 to 18 months	Questionnaire and interviews	To evaluate parents' perceived unmet needs in early childhood health care services among Aboriginal and Torres Strait Islander, non-English-speaking background and English-speaking background children, and the related barriers.
Smith (103) 2017	Queensland (Remote)	Community members (54) (32/54 had children)	Ages not reported	Survey	To explore the views of key stakeholders on cultural appropriateness of primary health care services for Aboriginal people.
Thomas (104) 2022	New South Wales (Regional)	Parents and carers (12) (7 identified as Aboriginal)	Young children	Interviews and focus groups	To gain a deeper understanding of the reasons why children in Lismore were overdue for their vaccinations, and the potential strategies that may be effective in reducing the number of overdue children.
Ussher (105) 2016	Australia (Urban)	Mothers (10)	Birth to 5 years	Observation, interviews, focus group	To examine women's experiences and constructions of motherhood in the context of early intervention programs.

Author and year	**Geographic location**	**Population (n)**	**Age of child**	**Method**	**Aim**
Young (106) 2017	Australia (Urban)	Carers (16)	Ages not reported	Interviews (phone)	To describe the perspectives of health professionals and communities on an innovative health service delivery project, Hearing EAr health Language and Speech services (HEALS).

Table 2.3. Family-perceived barriers and enablers to accessing primary health care for Aboriginal and Torres Strait Islander children, within a social determinant framework

Determinants	Barriers	Enablers
Individual-level factors include biological and personal history factors such as age, socioeconomic status, health and psychosocial factors	• Low health literacy • Type of health condition • Time-poor/competing commitments • Unable to attend due to work • Feeling judged • Mistrust • Lack of confidence • Shame	• Sense of belonging • Acceptability of treatment
Relationship-level factors include relationships with health professionals	• Poor communication • Poor quality of care • Lack of assistance • Lack of follow-up • Judgement • Blame • Lack of rapport • Not respectful • Negative past experiences with clinic	• Trusting relationship with health professional • Continuity of health professional • Expertise of health professional • Caring health professional • Good communication (clear, family-centred, respectful) • Long-established relationships • Comprehensive health instructions • Quality of care • Reassurance • Thorough assessments • No judgement • Empowered to optimise child's development • Engaging with the child to allay fears

Determinants	Barriers	Enablers
Community and organisational – level factors include the geographical location of health service, transport, service availability	• Financial barriers • Lack of available appointments • Not open after hours • No transport • Long waitlists • Poor physical accessibility • Time of program or appointment not suitable • No service • Lack of culturally appropriate information	• Ease of access • After-hours care • Free or low-cost care • Transport provided • Holistic lens (broad range of personal and environmental factors) • One-stop-shop • Team-based approach • Support services • Referrals completed • Child-friendly waiting rooms • Health worker helps book and attend appointment • Family approach • Baby bundles • Home visits • Timely service • Safe and accepting environment • Ensuring adequate medical supplies • Financial support (providing essentials if required, e.g. formula) • Waiting time not too long • Comfortable, inviting clinic facility • Outreach activities
Society-level factors include social norms, social policy	• Society lack of awareness around disability • Social exclusion • Poverty • Transient between health services • Normalisation of illness/poor health	• Ongoing funding of programs and services

Determinants	Barriers	Enablers
Culturally distinct–level factors include historical contexts, languages, cultural practices, spirituality, values	• Discrimination • Child reporting/removal • Culturally inappropriate care • Racism	• Aboriginal women caring for Aboriginal women • Aboriginal and Torres Strait Islander approaches to interacting and communicating • Strengthening child's connection to culture • Aboriginal health workers and liaisons important for effective communication and accessing care • Engaging and culturally secure staff and practices

This literature review on factors impacting Aboriginal and Torres Strait Islander families' access to health care for their children identified 77 factors overall. Two common threads amongst the identified barriers identified to accessing health care were racism and economic deprivation. Of the 35 barriers identified, 16 could be attributed to racism (feeling judged, mistrust, lack of confidence, shame, poor quality of care, judgement, blame, lack of rapport, not respectful, negative past experiences with clinic, lack of culturally appropriate information, social exclusion, discrimination, child reporting/removal, culturally inappropriate care, and racism) and 6 to economic deprivation (low health literacy, competing commitments [to health care], financial barriers, no transport, poverty, and normalisation of poor health). This review further points to the need for structural reform to end racism in health care provision, including the need for a redistribution of wealth and power. At an individual level, the findings reinforce the requirement to centre cultural safety, and provide practical, cost-effective solutions for individuals to have the opportunity to improve health behaviours. More research is needed to understand how each factor influences health care access and utilisation amongst Aboriginal and Torres Strait Islander families, and how health programs can address barriers and optimise enablers.

2.5 Chapter summary

Aboriginal and Torres Strait Islander knowledge of health and wellbeing includes the whole self as well as connectedness and wellbeing of Country and the community. Aboriginal-owned and -operated health services cater to Aboriginal and Torres Strait Islander perspectives of health and wellbeing, offering more culturally appropriate services. The evidence is building that Aboriginal and Torres Strait Islander services achieve better health outcomes than general health services (67).

Enablers and barriers at all levels of the determinants of health can impact health care access and utilisation by Aboriginal and Torres Strait Islander people. Carefully designed health programs have the potential to impact these barriers and enablers and improve access to health care at all levels of determinants.

Chapter 3 – Mobile health (mHealth)

Content

3.1 Chapter overview

mHealth has potential to address barriers and optimise enablers of health service use by Aboriginal and Torres Strait Islander people, to ensure that access to health information is culturally safe, accessible and affordable. In this chapter, an overview of mHealth is provided, followed by an overview of access to and acceptability of mHealth among Aboriginal and Torres Strait Islander people, and existing mHealth programs for Aboriginal and Torres Strait Islander mothers.

3.2 mHealth

> *"Our country has unforgivable gaps in the life outcomes of Aboriginal and Torres Strait Islander people and other Australians in all aspects of life, including mortality, chronic disease, disability rates, housing security, education, employment and wealth."*
>
> Pat Turner AM

3.2.1 Overview

mHealth is the use of mobile technology to improve health. An abundance and ever-growing range of new mobile technology is available to find, share and generate health information (107). Types of mHealth include telehealth, health websites, social media campaigns, online patient portals, health applications (apps), SMS (short messaging service) text message programs, wearable devices, and software apps, which range in complexity. The major benefits of mHealth are the low cost and ability to reach large numbers of consumers, including those who experience barriers to face-to-face health care such as in regional and remote parts of Australia. mHealth is used for a range of purposes including health education, health behaviour change, sensors and point-of-care diagnostics, registries and vital events tracking, and data collection (108).

3.2.2 The potential of mHealth for promoting health and wellbeing in general is significant, with low cost, wide reach and high acceptability; it can also be equitable if digital inclusion is considered carefully. mHealth is being used increasingly for health promotion because of its reach, with over 7 billion mobile phone subscriptions globally (109). The Be He@lthy, Be Mobile initiative by the World Health Organization has reached over 3.5 million people (110). The COVID-19 telehealth experience has reinforced how important it is to have alternatives to face-to-face health care. Global evidence suggests mHealth is effective and acceptable to populations underserved by traditional primary health and public health campaigns (111, 112). In this thesis, we focus on SMS text messages, social media and apps for delivery of mHealth.SMS text messages

SMS has the advantage of being accessible on all phones and not requiring access to 'mobile data'. There are few technical barriers to SMS and high acceptability of the modality among new mothers (112, 113). In a meta-review (23 systematic reviews, 371 studies, 79,665 participants) on the impact of mHealth on a range of outcomes, including clinical outcomes, adherence to treatment and care, health behaviour change, disease management and attendance rates, SMS was the most frequently examined function and reported to be most successful overall (114). SMS appears to be particularly effective at increasing smoking cessation rates (in adult smokers from mostly high-income countries) (115). The evidence for SMS to improve nutrition and physical activity is not as strong; however, SMS used in conjunction with other mHealth functionality has shown significant positive effects for healthy eating (114). Some studies have found SMS to have high acceptability among mothers (112, 113).

3.2.3 Social media

Social media is another form of mHealth with potential to support health. A recent Cochrane review on behavioural programs delivered through social media for health behaviour change, health outcomes and health equity (88 studies; n=871,378) reported varied effects. Overall, mHealth programs delivered through social media was found to improve physical activity, weight loss and general wellbeing, but had small to no effect for other outcomes (116). No studies focusing on Aboriginal and Torres Strait Islander people were included in the review. A report on Australian women's use of digital health found that women caring for infants and young children were more likely than other women to use social media and online forums to share and create health information (107).

3.2.4 Applications (apps)

Health apps continue to be popular, though the evidence suggests apps have limited effectiveness on changing health behaviours long term (114, 117-119). Some studies have found that apps can be effective at changing behaviour among some clinical groups, such as those receiving cardiac rehabilitation (114). A co-designed mHealth app developed in New Zealand with Māori and Pacific Islander people was tested in a cluster randomised controlled trial in 2019 (n=1451) (120). Adherence to health-related behaviour guidelines increased at 12 weeks in both groups, with no difference between groups. Engagement with the app overall was low, although those that did engage with the app as it was designed saw greater benefit. Content that centres culture and frames positive health messages has greater acceptability (121-123). Additionally, there are serious concerns about the types of data being collected by health apps, the use of individuals' data and privacy conduct (124).

3.3 Aboriginal and Torres Strait Islander use of mHealth

"The first step to improving outcomes for Indigenous Australians is the recognition and privileging of an Aboriginal world view; in effect moving to a position of decolonisation. Knowledge and respect for culture and acknowledging our true history deepens respect and appreciation of an Aboriginal world view."

Associate Professor Michael Wright

3.3.1 Access

mHealth may be particularly beneficial for Aboriginal and Torres Strait Islander communities, given their high rate of mobile phone use (125, 126) and barriers to accessing mainstream primary health care (127). The latest data available suggests Aboriginal and Torres Strait Islander people have high ownership of smartphones; a survey with 400 Aboriginal and Torres Strait Islander people in 2014 reported 70% of Aboriginal and Torres Strait Islander people owned a smartphone (125). It is likely that access to smartphones is much higher now. In addition, Aboriginal and Torres Strait Islander people are more likely to exclusively use a mobile phone to access the internet than are the rest of the population (35% compared with 19.9%) (128). Although it is important to note there are also barriers to Aboriginal and Torres Strait Islander people accessing mHealth including access to consistent, fast and large amounts of data, and more likely to use prepaid data. More updated data on access to smartphones among Aboriginal and Torres Strait Islander people would be beneficial to ensure digital inclusion of mHealth programs.

3.3.2 Acceptability

Studies focused on Aboriginal and Torres Strait Islander people using SMS to improve health show high acceptability (129-131). Apps also appear to have high acceptability, but low engagement (132), as is often the case universally (133). In the few trials focused on Indigenous populations, app usage has been reported to be low (120, 132). A recent pilot randomised controlled trial of a smoking cessation app with 49 Aboriginal people in Australia reported low to moderate level of app usage, and at 6-month follow-up only one participant was abstinent from smoking (132). The authors concluded that while there was broad acceptability for the app, mHealth programs should be designed with functions that are commonly used, such as social media platforms (132). Evidence to date shows that Aboriginal and Torres Strait Islander people are frequent users of Facebook (121, 122, 126, 134). The latest data available from 2014 suggests that 69% of Aboriginal and Torres Strait Islander people used Facebook, compared with 40% of non-Indigenous Australians (125). The Aboriginal and Torres Strait Islander health sector were early adopters of social media networks to promote health (121, 135); social media campaigns on COVID-19 by Aboriginal and Torres Strait Islander health organisations is a recent example (136). Deadly Choices, an Aboriginal-led social marketing campaign for health promotion, is another good example illustrating high acceptability of using social media for health promotion among Aboriginal and Torres Strait Islander people, with 94,035 Facebook followers, 19,300 Instagram followers and 9000 TikTok followers (137).

3.3.3 Existing mHealth programs for Aboriginal and Torres Strait Islander mothers

Available mHealth programs for Aboriginal and Torres Strait Islander mothers and their children are limited but growing. Examples include an app, website and SMS text message program on infant feeding (138); SMS, videos and MMS (multimedia messaging service) for otitis media in children (130); SMS, phone call, Facebook or email for postpartum blood glucose screening (129); a prototype app for social and emotional wellbeing during pregnancy (139); a mindfulness app for women and children of all ages (140); an interactive website on child development, Deadly Tots (141); and Facebook pages such as the 'Stay Strong and Healthy' page for health during pregnancy (142), and 'Yarn and Heal – Our Way' for Aboriginal women of all ages to connect and yarn (143). While these studies suggest mHealth has high acceptability among Aboriginal and Torres Strait Islander mothers, further research is needed to evaluate its effectiveness.

3.4 Chapter summary

mHealth programs continue to develop at high speed. mHealth may be an important solution to address barriers faced by Aboriginal and Torres Strait Islander mothers seeking health care for themselves or their children. It is important that we seek to advance mHealth solutions developed by and for Aboriginal and Torres Strait Islander women, to promote digital inclusion and access to health information. Careful consideration should be given to user preferences and privacy to ensure user safety and long-term use of any newly developed mHealth programs.

Chapter 4 – Approaches for developing mHealth programs

"At the heart of every solution to grievance is yarning. Our voice."

Professor Megan Davis

Content

4.1 Chapter overview

In this chapter, frameworks and theories drawn upon in this PhD are described. Of particular importance to this PhD are the co-design approaches used for the development of the Growin' Up Healthy Jarjums mHealth program. Lastly, steps for developing and evaluating mHealth are described.

4.2 Behaviour change theory

"I can feel the restlessness throughout our sisterhood, through all of society that enough is enough. The time has come for change."

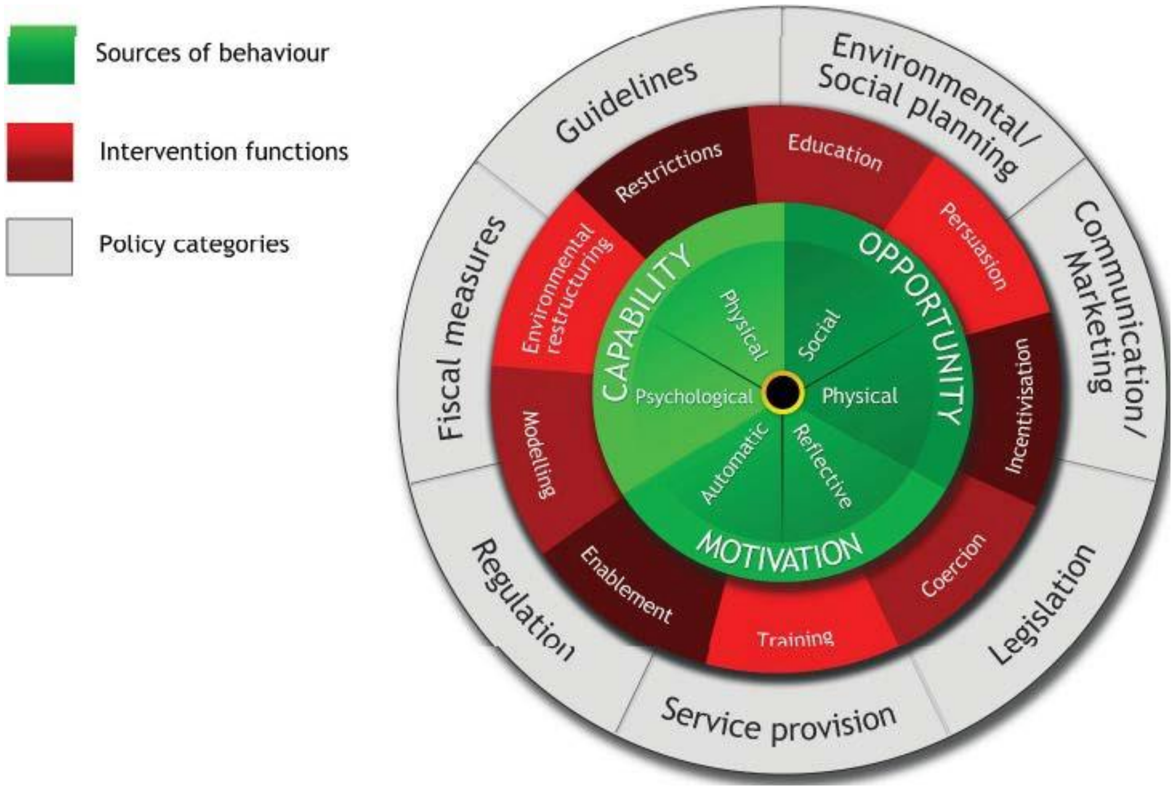
June Oscar AO

4.2.1 Behaviour Change Wheel

Theories provide a solid foundation to the understanding of health behaviours and, therefore, how changes in health behaviours might be encouraged and made. As a result, it is important that the development of effective digital health programs is based on behaviour change theory (144). The

Behaviour Change Wheel (Figure 4.1) is one of many behaviour change frameworks. It was developed to be more comprehensive than and overcome the limitations of other frameworks (145). The Behaviour Change Wheel includes nine intervention functions: education, persuasion, incentivisation, coercion, training, enablement, modelling, environmental restructuring, and restrictions. The mHealth program described in this thesis includes four overarching intervention functions from the Behaviour Change Wheel: education, persuasion, training and modelling (examples are shown in Table 4.1). Behaviour change techniques (146) were then used to deliver these functions (144). The methods outlined by Michie and colleagues were used (147).

Figure 4.1. Behaviour Change Wheel (Reproduced with a Creative Commons Attribution licence).



Source: Michie et al, 2011 (145)

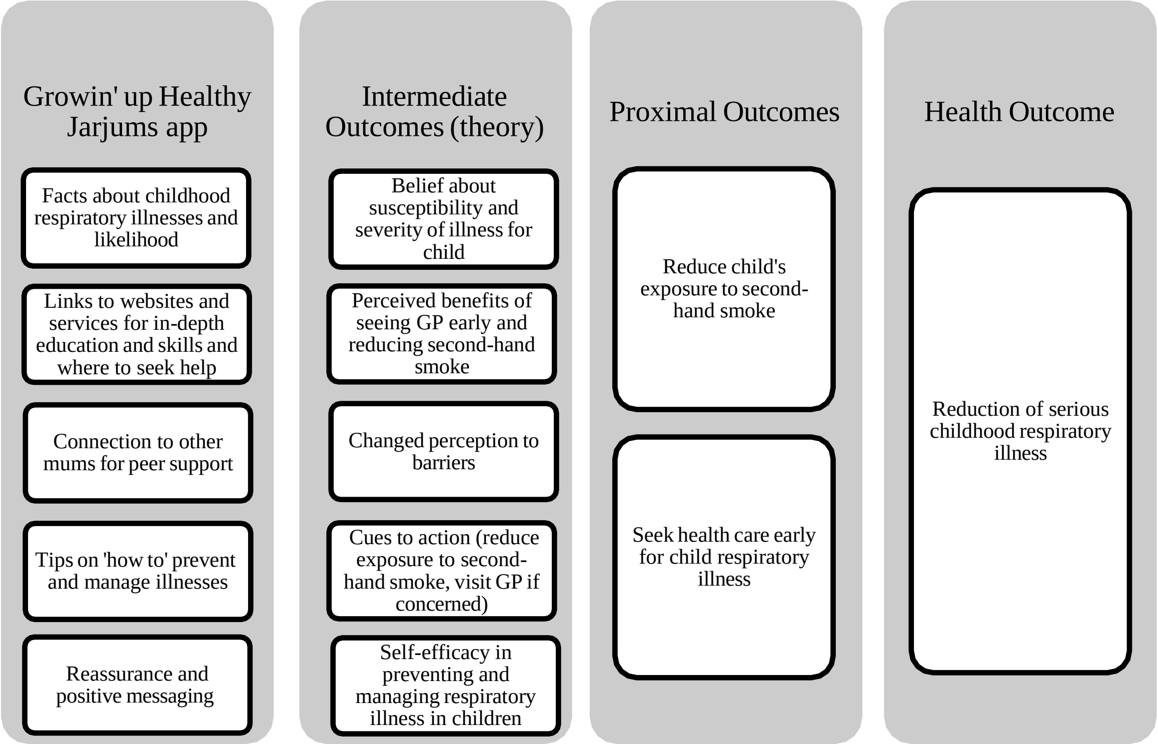
Table 4.1. Definitions and examples of the Behaviour Change Wheel intervention functions used in the Growin' Up Healthy Jarjums program

Program functions	Definition	Example from Growin' Up Healthy Jarjums
Education	Increasing knowledge or understanding	Information provided in text messages, app and Facebook page on 12 health topics for mothers and children
Persuasion	Using communication to induce positive or negative feelings or stimulate action	Using positive and affirming images and statements about Aboriginal women and mothers to motivate health behaviour change
Training	Imparting skills	Videos and links to videos of professionals and community members performing skills needed for healthy behaviours, including exercise regimes, cooking, using smoking cessation medication, and reading and playing with children
Modelling	Providing an example for people to aspire to or imitate	Using images and videos of Aboriginal women and children performing healthy activities to increase healthy activities among mothers and children

4.2.2 Health Belief Model

The Health Belief Model has been used since the early 1950s as a guiding framework for developing health programs (148). The basic constructs are perceived threat of illness, perceived benefits of health behaviour change, perceived barriers to change, cues to action, and self-efficacy (148). The Health Belief Model is considered to be well suited to mHealth programs with use of the cues to action component (149). The Health Belief Model was used to underpin the app portion of the program described in this thesis. A logic model is shown below (Figure 4.2) on one topic (child respiratory health) that is included in the app as an example of how the constructs of the Health Belief Model were used to underpin the app.

Figure 4.2. Logic model for Growin' Up Healthy Jarjums mHealth program based on Health Belief Model



Source: Adapted from Abroms et al, 2015 (150)

4.3 Developing and evaluating mHealth programs

> *"We seek constitutional reforms to empower our people and take* a rightful place *in our own country. When we have power over our destiny our children will flourish. They will walk in two worlds and their culture will be a gift to their country."*
>
> Uluru Statement from the Heart

4.3.1 Co-design approaches

Co-designing mHealth centres mutual learning, where both users and researchers learn about potential mHealth technologies and designs that may be of most benefit to the end user (53). It is a partnership approach where end users are actively involved in all steps (151). The co-design approaches and activities used in this thesis were learnt from a research team in New Zealand. As part of this PhD, the PhD student and Aboriginal research assistants were successful in receiving a travel scholarship to visit the National Institute of Health Innovation (NIHI) in New Zealand to receive co-design mentoring. The aim of the visit was to receive mentoring from Professor Cliona Ni Mhurchu and colleagues on co-design methodologies and processes used to develop and test mHealth programs in a culturally safe way. Mhurchu and colleagues used an extensive co-design process to develop a health app with Māori and Pacific communities (151). The 2-week visit included a series of meetings with NIHI academics, a project manager, app developer, and staff from The Fono (Pacific health organisation) and Toi Tangata (Māori health organisation). The learnings from the research visit were used in this PhD for the co-design and pilot test of the Growin' Up Healthy Jarjums mHealth program.

The co-design framework used for the development of the mHealth program in New Zealand (120) was based on the work by Bratteteig (53) and was used to guide methods of this thesis The framework involves a series of steps: 1) opportunity identification; 2) knowledge generation; 3) elucidation of needs and desires; 4) description of the mHealth requirements; 5) envisaging the mHealth tool; and 6) prototype development, testing and evaluation. Using this framework in the New Zealand context took 2 years excluding relationship building prior to starting. In this thesis, a more condensed process took place due to the timing of a PhD and resources. An overview of how this co-design framework was used in this thesis is shown in Table 4.2.

Table 4.2. Co-design steps used in this thesis

Co-design steps	Examples in this thesis
Opportunity identification (real-life problem)	Women reported a lack of culturally safe digital health programs (identified during the modified Delphi study and in previous unpublished qualitative research by the PhD student and team in the communities in which studies for this thesis took place).
Knowledge generation (understanding practice)	The concept of developing an app to improve child health was discussed with organisations and a small number of mothers informally. These early discussions led to the possibility of expanding the program to include a range of health topics to increase interest and engagement. We reviewed the literature for theory, evidence and existing resources. We approached research groups in Australia and New Zealand that had developed mHealth programs with Indigenous and minority communities, including the Deadly Tots, My Baby Now, iBobbly, OL@-OR@, and TextMatch apps. Discussions with research teams provided insight into timelines, methods to consult, technical barriers and usability considerations.
Identification of needs and desires	We conducted focus groups with 42 participants: 31 women and 11 health professionals. Co-design activities included discussions, card sorting, storyboarding, design activities, survey, guidance from expert groups, and an iterative design phase with the research team.
Description of mHealth requirements	The same focus groups were used to identify women's existing patterns of phone and app use, and to generate ideas for design, content and features for the mHealth program.
Envisaging the mHealth tool	A triangulation of data collected in focus groups, survey, theory and evidence was used to develop the mHealth program. Focus group data was coded to identify: 1) design characteristics; 2) content modules; and 3) features and functions.
Prototype development, testing and evaluation	The Growin' Up Healthy Jarjums mHealth program was developed using rapid iteration cycles. A 4-week pilot test with 47 participants was completed to examine feasability and acceptability.

4.3.2 Processes for developing and evaluating mHealth programs

There are a number of frameworks and guides for developing digital health programs. In this thesis, the steps presented in Table 4.3 were used (152). The formative work included a national cross-sectional survey to determine access to and interest in mHealth among Aboriginal and Torres Strait Islander women, as well as focus groups to understand end user patterns of phone use and preferences for a new mHealth program. Next, a pilot study was completed to assess acceptability, engagement and technical processes. Lastly, a Delphi study was completed to identify culturally safe objective measures suitable for a randomised controlled trial.

Table 4.3. Summary of the research and evaluation steps in the development of an mHealth program

Research steps	Description of methods used	Purpose	Examples of measures or questions
Formative research	• Focus groups • Online surveys	• To inform the development of the program content and regimen	• How do target audience use their phones? • How does evidence and theory behind program fit with mobile phone usage? • What would attract target audience to program?
Pretesting	• Online surveys • Focus groups • Individual interviews	• To determine acceptability of proposed program to target audience • To improve and refine program on the basis of feedback	• What styles/content/language do they prefer? • Who should be role models? • Are messages useful and understandable?
Pilot study	• Small and non-randomised	• To test content and regimen of Program • To test processes (e.g. recruitment, registration, data collection)	• Is program acceptable? • Are there any technical or process issues? • Baseline measures for sample size calculations if necessary
Randomised controlled trial	• Pragmatic community-based randomised controlled trial	• To test the effect of the program in comparison with a control group	• Health-related outcomes • Objective measures • Participant satisfaction • Adverse/unintended effects
Qualitative research	• Semi-structured interviews	• To improve the program further • To determine implementation issues and methods	• How can we improve the program? • What aspects were un/helpful? • Was theory conveyed? • Were messages acted upon? • What are the best methods for rollout and promotion?
Evaluation of implementation impact	• Phone/online surveys • Semi-structured interviews	• To determine the effect of the program once scaled up	• Reach, utilisation, health-related outcomes, flow-on effects on health/other services, unintended consequences, effect of different promotional methods

Source: Adapted from Whittaker et al, 2012 (152)

4.3.3 APEASE (Acceptability, Practicability, Effectiveness, Affordability, Safety, Equity)

The APEASE criteria is one mechanism to evaluate behaviour change programs (Table 4.4) (145). It is therefore a useful tool to reflect on during the development of health programs (144). The APEASE criteria were used as a guide during the development of the Growin' Up Healthy Jarjums mHealth program and are reflected on in more detail in the discussion section of this thesis (Chapter 12).

Table 4.4. The APEASE (Acceptability, Practicability, Effectiveness, Affordability, Safety, Equity) criteria for evaluating behaviour change programs

Criterion	Definition
Acceptability	To what extent is the program likely to be acceptable to key stakeholders, including users, funders and those charged with implementing it?
Practicability	To what extent can the program be implemented as designed to the intended users at scale?
Effectiveness	To what extent is the program likely to achieve or exceed a desired level of effectiveness for a given target behaviour and how cost-effective is it likely to be in relation to a desired outcome?
Affordability	Can the program be implemented at the desired scale to the intended users within a realistic budget?
Safety	To what extent is the program likely to have unwanted side effects?
Equity	To what extent is the program likely to increase or decrease economic, social or health inequalities?

Source: Michie et al, 2011 (145)

4.4 Chapter summary

Frameworks, models and theories are fundamental to developing high-quality health programs. Equally important is learning from those that have developed similar programs before you, team members, as well as the intended users of the program. Novel ideas and problem-solving is best done through discussion and thinking together with a diverse set of minds. The knowledge drawn upon for this thesis has been a combination of theory and lived experience.

Chapter 5 – Thesis aims and research questions

Thesis aim: To use co-design approaches to develop an mHealth program and robust culturally sensitive respiratory measures for a research trial with Aboriginal and Torres Strait Islander mothers of young children (under 5 years of age) in NSW, Australia.

Table 5.1 shows the methods and research questions specific to each thesis study/chapter.

Table 5.1. Thesis research questions

Chapter 8 (Study 1): Aboriginal and Torres Strait Islander women's access to and interest in mHealth: national web-based cross-sectional survey	**Chapter 9 (Study 2):** Development of a maternal and child mHealth program with Aboriginal and Torres Strait Islander mothers: co-design approach	**Chapter 10 (Study 3):** Evaluation of an mHealth program (Growin' Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: engagement and acceptability study	**Chapter 11 (Study 4):** Respiratory, birth and health economic measures for use with Aboriginal and Torres Strait Islander infants in a research trial: A modified Delphi with an Aboriginal and Torres Strait Islander panel
Methods: Cross-sectional survey	**Methods:** Co-design focus groups	**Methods:** Pilot study	**Methods:** Modified Delphi
Research questions: 1. What is the rate of digital device ownership, and access to the internet among Aboriginal and Torres Strait Islander women? 2. How frequently do Aboriginal and Torres Strait Islander women use social media and the internet? 3. How do Aboriginal and Torres Strait Islander women currently use mobile phones to improve health? 4. What mHealth modalities and topics are of interest to Aboriginal and Torres Strait Islander women for future mHealth programs?	**Research questions:** 7. What mHealth design characteristics are preferred by Aboriginal and Torres Strait Islander women? 8. What mHealth topics are preferred by Aboriginal and Torres Strait Islander women? 9. What mHealth features and functions are of interest to Aboriginal and Torres Strait Islander women?	**Research questions:** 10. Is a prototype mHealth program (to improve health knowledge, health behaviours and access to health services) engaging to Aboriginal and Torres Strait Islander women? 11. Is a prototype mHealth program acceptable to Aboriginal and Torres Strait Islander women? 12. What changes to the mHealth program will improve engagement and acceptability?	**Research questions:** 13. What are the most relevant and acceptable respiratory, birth and health economic measures for use with Aboriginal and Torres Strait Islander infants participating in a research trial? 14. Is using a mobile phone to collect data in a research trial acceptable to Aboriginal and Torres Strait Islander women?

5. Are Aboriginal and Torres Strait Islander women more likely to use mHealth for health topics that they are less confident to talk to a doctor/health worker about in person? 6. What factors (age, remoteness, caring for a child under 5 years, level of education) are associated with ownership of digital devices, access to the internet, and interest in using a mobile phone to improve health?			

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Section B – Conducting research in collaboration with Aboriginal and Torres Strait Islander peoples

Section B is an important section of this thesis; it outlines the PhD candidate's positional standpoint, including their limitations in doing health research with Aboriginal and Torres Strait Islander peoples as a European-Australian. This section includes a brief summary of First Nations research methodologies, the research governance for the four studies included in this thesis, and the application of the Aboriginal Health and Medical Research Council (AH&MRC) ethical guidelines.

Section B comprises the following chapters:

Chapter 6 – Positional standpoint and First Nations research methodologies

Content

6.1 Chapter overview

The purpose of this chapter is to recognise Aboriginal and Torres Strait Islander peoples' knowledge and ways of doing research. I also acknowledge my positional standpoint and biases as a European-Australian researcher doing a PhD in Aboriginal and Torres Strait Islander health.

6.2 Positional standpoint

I approach this research as a European-Australian trained as an occupational therapist. As a non-Indigenous person, self-awareness of beliefs, attitudes and behaviours and how these impact my ability, or inability, to work in Aboriginal health research is essential to conducting ethical research (1). By declaring my standpoint, I recognise my biases, and how my world views can be in contrast and at times damaging to the people being researched. More importantly, I acknowledge that Aboriginal knowledge, and ways of knowing, doing and being, are of the most importance and value to this research.

A researcher's declared standpoint is a written reflection of their sociocultural, epistemological, axiological and ontological position (2). I grew up in Western Sydney, Australia, in a white middle-class suburb with three older brothers and a mother and father. I had a good start to life. My earliest memory of learning about Aboriginal people was from my mum. Mum worked on Palm Island as a registered nurse for a couple of years in the mid-1970s. The most common stories she told centred on the women's humour, and their joy for each other. Mum also spoke about the systemic racism.

During my childhood, Mum and Dad were respite foster carers. We had hundreds of kids stay at our house over the years. Some had unimaginable abuse and neglect as their start to life. My family often had discussions around the dinner table about injustices in Australia, for both Aboriginal and Torres Strait Islander peoples, and migrants and refugees. I became aware early that discourse in

Australia often blamed individuals for their situation rather than acknowledge the root cause of inequities, such as systemic racism. On reflection, this early education at home – that we all have a very different start to life and ongoing opportunities – planted the seed for an interest in public health and health equity.

I am an occupational therapist trained in a Western biomedical paradigm. I have worked mainly in government positions in community health in a variety of locations in NSW including Western Sydney, Eastern Sydney, Southwest Sydney and Newcastle. I also worked in Katherine in the Northern Territory, and I currently work for an Aboriginal Community Controlled Health Organisation in NSW.

My upbringing, education and professional experience have together provided a foundation of interest and early understanding of public health. I continue to become more self-aware of my limitations, biases and place as a European-Australian working in Aboriginal health research.
I continue to learn and practice towards working in a culturally safe and respectful way. It is clear from the literature (3-5)that Aboriginal health research is successful when Aboriginal and Torres Strait Islander people lead and have meaningful engagement throughout the research.

6.3 First Nations research methodologies

European-Australians have an abhorrent history of doing research *on* Aboriginal and Torres Strait Islander peoples. The most vile perhaps was the measuring of Aboriginal and Torres Strait Islander peoples' skull sizes in an attempt by Europeans to prove their superior intellectual capacity (5). Less abhorrent, though nonetheless damaging, has been the routine exclusion of Aboriginal and Torres Strait Islander peoples from leading or meaningfully contributing to health research that is focused on themselves (5). Unethical research practices have resulted in many Aboriginal and Torres Strait Islander people retreating at the word 'research', with the word stirring silence, distrust and offence (5).

In contemporary research practice with Aboriginal and Torres Strait Islander peoples, it is expected that Aboriginal and Torres Strait Islander people lead or co-lead research, communities have meaningful engagement throughout, and Aboriginal and Torres Strait Islander peoples are a part of the research at all levels (4). There are numerous renowned First Nations scholars who have documented First Nations methodologies, knowledges and important principles for conducting research with First Nations peoples.

One of the most well-regarded scholars on First Nations research methodologies is Distinguished Professor Linda Tuhiwai Smith who authored *Decolonizing methodologies* (6). Tuhiwai Smith is a Māori scholar who privileges First Nations perspectives, knowledges and ways of doing research (6). She critically appraises the ways in which ‘the West’ has collected and classified information on First Nations peoples over centuries, and then disseminated the ‘knowledge’ back to First Nations peoples, and caused damage in a multitude of ways (6). She does not prescribe a set way of doing research, but rather provides a set of principles and examples, and refers to Kaupapa Māori: “Kathy Irwin characterises Kaupapa Māori as research that is ‘culturally safe’; that involves the ‘mentorship’ of elders; that is culturally relevant and appropriate while satisfying the rigour of research; and that is undertaken by a Māori researcher, not a researcher who happens to be Māori” (6) (p. 240). Tuhiwai Smith suggests that a non-Indigenous person can be involved in Kaupapa Māori research, but not on their own; and if they are involved in such research, they must position themselves as a non-Indigenous person, though she recognises that some would say that, by definition, Kaupapa Māori research is Māori research exclusively (6).

Another renowned First Nations scholar is Distinguished Professor Maggie Walter who is an Aboriginal (Palawa) quantitative researcher. Walter suggests that statistics are not neutral entities but based on the researcher’s social, racial and cultural standpoint (7). She writes that non-Indigenous researchers typically focus on difference, disparity, disadvantage, dysfunction and deprivation, and omit Aboriginal and Torres Strait Islander worldviews, perspectives, values and lived experience (7). Walter and other First Nations scholars (7-9) have called for data that “disrupt deficit narratives, data that are disaggregated, data that reflect the embodied social, political, historical, and cultural realities of Indigenous people’s lives, as Indigenous peoples, and data that address Indigenous nation rebuilding agendas” (7) (p. 236). Anything less results in data that continues the deficit narrative, which blames Aboriginal and Torres Strait Islander peoples for their worse health outcomes (10).

An important concept to change the deficit narrative is data sovereignty, which many First Nations scholars have written about (6, 7, 11). Data sovereignty is broad, though can be summarised as the right of Indigenous peoples to determine legal and ethical dimensions around data storage, ownership, access and consent; intellectual property rights; and practical considerations about how data are used in the context of research, policy and practice (11). Data sovereignty can be practised through data governance, ensuring there is Indigenous decision-making from start to finish – from data conception to use of data (7).

Chapter 7 – Research governance and ethics

Content

7.1 Chapter overview

In this chapter, an overview of the research governance and adherence to ethical guidelines is provided. The research team, communities and participating organisations have worked together in some way since 2017. We continued to build on these solid working relationships throughout the studies in this PhD.

7.2 Research governance

As many co-design research projects do, this research changed direction substantially from beginning to end. Initially this thesis was focused on child respiratory health, including the development of an mHealth tool to capture respiratory health outcomes of infants participating in the SISTAQUIT trial. Once we got talking to women it became clear that they wanted a tool that provided them with knowledge and support on a wide range of health topics for mother and baby. The focus of this thesis then shifted to co-designing an mHealth program with multiple health topics and became the Growin' Up Healthy Jarjums mHealth program. At the same time as co-designing an mHealth tool with three NSW communities, we wanted to understand the access to and interest in mHealth among Aboriginal and Torres Strait Islander women nationally, an area where there has been limited data to date. To do this we collaborated with the Which Way study. There are three different Governance models discussed in this section aligning with the three different umbrella projects in this thesis; Which Way? (Chapter 8), Growin' Up Healthy Jarjums (Chapter 9, and 10) and SISTAQUIT (Chapter 11).

The research governance for the study in Chapter 8, 'Aboriginal and Torres Strait Islander women's access to and interest in mHealth: national web-based cross-sectional survey', is described in detail in the protocol for the larger Which Way? study of which it is a part (12):

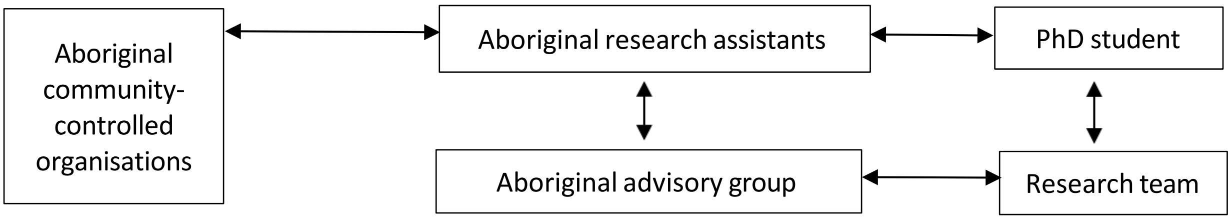
> "In acknowledgement of the importance of Aboriginal oversight guided by local

Aboriginal knowledges and wisdom, we developed an Aboriginal Research Governance Committee with partnering communities to strengthen our research and transparency processes. Each partnering Aboriginal Health Service is a full partner and co-owner of the research. Each service has supplied formal letters of community support and hold a seat on the Aboriginal Research Governance Committee (ARGC). The ARGC is established to oversee the research process including research design, implementation, analysis and reporting. The ARGC was established as each partnering community service offered a letter of support and confirmed their long-term commitment to the project. The ARGC, with the research team, developed a Terms of Reference for the group, which is a drafted, shared document that can change over time, as the project changes, staff changes, or competing demands and priorities change. The Terms of Reference

> offers a tool for transparency of the reciprocal relationship between the research team and the partnering communities. The Terms of Reference outlines the function of the committee as well as both the community’s requests of the Research Team and the Research Team’s requests from community. The research governance committee meets monthly via Zoom and are provided with brief written reports on project progress for staff to share with their service staff and community. The ARGC is chaired by the lead investigator (MB), an Aboriginal researcher. The ARGC consult, design and direct all of the research conduct. The ARGC act as a community representative, ensuring that research processes, plans and reports are shared with relevant community and offer feedback and direction to the research team. The ARGC support directing and coordinating further community consultations, reporting back to community and methods of research dissemination that is appropriate and meaningful to each community. Ongoing, informal dialogue occurs throughout the project with members of the ARGC on community needs or interest in other research areas, updates on other projects or developments within the community or upcoming events. This is an organic and reciprocal relationship process that goes beyond the research project or even research itself. Rather, it is a representation of Indigenous epistemology (knowing), ontology (being), and axiology (doing).”

An overview of the governance for the studies in Chapter 9 (‘Development of a maternal and child mHealth program with Aboriginal and Torres Strait Islander mothers: co-design approach’) and Chapter 10 (‘Evaluation of an mHealth program (Growin’ Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: Engagement and acceptability study’) is provided in Figure 7.1.

Figure 7.1. Research governance for Growin’ Up Healthy Jarjums



For the study in Chapter 9, Aboriginal research assistants on the team led the Aboriginal advisory process, guided by participating Aboriginal community-controlled organisations. Aboriginal research assistants led communications with organisations and community members, and provided advice to the research team on local protocols. This informal process worked well by allowing flexibility of involvement among organisations, with some organisations having a desire to be more involved, and others less involved. For the study in Chapter 8, we continued to build on the processes and the solid working relationships by developing an advisory group. An Aboriginal advisory group helped to formalise and solidify the process and add greater transparency and accountability in line with the '8 steps in the research journey' from *Keeping research on track II* (13).

The objective of the Aboriginal advisory group was to acknowledge that Aboriginal and Torres Strait Islander peoples have the right to make decisions about research that is affecting them. It is paramount that the research conducted ensures Aboriginal and Torres Strait Islander communities are fully informed about, and agree with, the purposes and conduct of the project. The role of the Aboriginal advisory group was to provide cultural consultation, advice and direction to ensure that the Growin' Up Healthy Jarjums research (including development and implementation) was appropriate and meaningful to the communities involved.

The Aboriginal advisory group provided guidance on:

- Research design and methodologies
- Research plan implementation and conduct
- Analysis of findings ensuring appropriate reflection of community and ways of doing in the organisations
- Guidance of future research
- Knowledge translation strategy.

The advisory group included Aboriginal researchers on the research team (Noelene Skinner, Belinda Huntriss and Bernise Leece) and an Aboriginal investigator (Dr Kerry Hall). Representatives from participating organisations were invited to be members of the advisory group; however, they decided that they preferred to communicate ad hoc with the Aboriginal research assistant from their community, who would then discuss relevant issues with the advisory group or with the PhD student. The advisory group met every 3 months during the study period. Full details of the advisory group can be found in Appendix 1.

The research governance for the study in Chapter 11, 'Respiratory, birth and health economic measures for use with Aboriginal and Torres Strait Islander infants: a modified Delphi with an Aboriginal and Torres Strait Islander panel', is stated in the protocol for the larger Supporting Indigenous Smokers To Assist Quitting (SISTAQUIT) study of which it is a part (14):

> "An Aboriginal advisory panel including members of Aboriginal Community Controlled Health Services, Aboriginal Medical Services, and Indigenous experts is monitoring the conduct of the study and providing cultural advice, and will also monitor the dissemination of its findings. An independent data safety and monitoring board will oversee the integrity and safety of data collection, storage, and sharing."

7.3 Adhering to the AH&MRC *Ethical guidelines: key principles (2020) V2.0*

In NSW, the AH&MRC guidelines for ethical research with Aboriginal and Torres Strait Islander peoples define five key principles (4):

1. Net benefits for Aboriginal people and communities
2. Aboriginal community control of research
3. Cultural sensitivity
4. Reimbursement of costs
5. Enhancing Aboriginal skills and knowledge.

Detailed below is how the Growin' Up Healthy Jarjums research adhered to these principles as stated in the AH&MRC guidelines (in bold) (4):

1. Net benefits for Aboriginal people and communities

The benefits of the research may be for Aboriginal health in general or specifically for the health of Aboriginal people and communities participating in the project.

1.1 Co-designing a research project with Aboriginal people and communities will help ensure that it is determined as a priority, a need and is of benefit to the Aboriginal people and communities affected.

This study used a co-design methodology. The co-design methods used included focus group and interview discussions, card sorting, storyboarding, design activities, survey, guidance from expert groups, and an iterative design phase with the research team.

1.2 The research addresses and overcomes an identified issue.

Like all people, Aboriginal and Torres Strait Islander women want good health for themselves and their children. For many Aboriginal and Torres Strait Islander women and children, accessing reliable and culturally responsive health support is difficult. Online health supports can be empowering community-development tools to promote health in Aboriginal communities (15). Online supports are increasingly popular ways to disseminate health information, with good reach and acceptability (16-18). The number of smartphone apps continue to grow at a rapid pace, with little guidance on which apps are effective. A number of recent studies using co-design principles to develop mHealth programs with Indigenous populations have reported high acceptability and feasibility (17, 19, 20). The aim of this research was to co-develop and pilot an mHealth program on Aboriginal and Torres Strait Islander women's and children's health (ages 0 to 5 years). Novel approaches that are localised, culturally meaningful and women-centred may offer a promising resource to improve the health of Aboriginal and Torres Strait Islander women and children (21).

1.3 The risks have been identified, assessed, and mitigated.

We identified during the design of the study that some women (and others in their communities) may have become distressed by information in the mHealth program, specifically information on social and emotional wellbeing, smoking, and alcohol and other drugs. We anticipated that using a co-design methodology would increase cultural safety. All content for the mHealth program was developed with Aboriginal research assistants who are from the communities in which the mHealth program was co-designed and piloted. Women reported they did not feel distressed by participating in the co-design or pilot.

1.4 There will be a net benefit after considering known negatives and potential risks.

Based on the results of the study, we believe that there was a benefit to women and health professionals that participated in the study. Women and health professionals that participated had the opportunity to learn new health information, and to engage with and comment on the use of new technologies to support and promote health. The benefit may also extend to the families and communities of the women who participated. Ultimately, the Growin' Up Healthy Jarjums mHealth program aims to reduce the rates and inequities of non-communicable diseases experienced by Aboriginal communities by directly contributing to improving modifiable health behaviours among Aboriginal and Torres Strait Islander people'.

2. Aboriginal community control of research

Aboriginal Community Control must be a key focus of all projects affecting Aboriginal people. This means that at all stages of the research project, Aboriginal people and communities participating in or affected by the research will be fully informed about and agree with the purposes and conduct of the project.

2.1 It is acknowledged that Aboriginal people have a right to make decisions about research affecting them.

We acknowledge that Aboriginal people have the right to make decisions about health research affecting them. The knowledge (including lived experience, connections, community, and health and research knowledge) shared by Aboriginal team members, organisations and participants is the focus of this work.

2.2 Aboriginal community involvement, support and consent has been sought.

Five Aboriginal organisations (two Aboriginal health services, two Aboriginal preschools, and an Aboriginal family and parenting corporation) and three NSW Health sites participated. Alongside with the PhD candidate two Aboriginal researchers were involved in recruitment, consent, interviews and communication with participants and services.

2.3 There is Aboriginal oversight and meaningful engagement at all stages of the project.

The Growin' Up Healthy Jarjums research is co-led by a Kuku Yalanji, Lama Lama investigator Dr Kerry Hall. Three team members are Aboriginal women from (or connected to) the communities where the research took place: a Gumbaynggirr woman (Noelene Skinner), a Gomeroi woman in the Kamilaroi Nation (Bernise Leece), and a Worimi woman working in the Awabakal community (Belinda Huntriss). Aboriginal researchers from participating communities (NS, BL and BH) led the implementation of the project to support cultural safety.

2.4 Formal agreements have been developed with the people and communities affected.

Written support and agreements were sought from all participating organisations.

2.5 There is appropriate Aboriginal Governance of all stages of the project.

This research was governed by an Aboriginal advisory group in partnership with Aboriginal organisations (Armajun Aboriginal Medical Service [AMS], Galambila AMS, Awabakal AMS and preschool, Kulai Aboriginal preschool Corporation, and Muloobinba Aboriginal Corporation) as detailed in Section 7.2.

2.6 Provide communities with all the relevant information and explanations on the intent, process and methodology, evaluation, and potential value of any research proposal.

We met with organisations to initially discuss the research process, design, objectives and potential benefits. We liaised over the phone and by email with any questions or thoughts throughout the research.

2.7 Comply with requests for further information from relevant community-controlled organisations associated with the research proposal.

The community-controlled organisations contacted Aboriginal research assistants or the PhD student with any questions, to which we provided all available information.

3. Cultural sensitivity

Cultural protocols and community decision-making processes will vary between Aboriginal communities, researchers should consider this when designing a project.

3.1 Varying community protocols and processes have been considered and adhered to.

Three Aboriginal research assistants led consultations with their respective communities, and thus carried out and advised on community protocols and processes appropriate for each community and organisation.

3.2 Aboriginal community involvement, support and consent has been sought.

Aboriginal researchers obtained verbal and written support from Aboriginal organisations and participants.

3.3 Members of the community affected by the research have been properly consulted with and are informed of the purposes and conduct of the research.

Aboriginal research assistants provided organisations and participants with written information sheets with detailed information about the study, as well as having various conversations with them prior to the research starting and throughout the study.

3.4 Outline your Aboriginal consultation and engagement to date.

The consultation for the Growin' Up Healthy Jarjums research began during a study that the PhD student and two Aboriginal research assistants worked on in 2017. Noelene Skinner, a Gumbaynggirr woman, and Bernise Leece, a Kamilaroi woman, led consultations in their communities in both the co-design and pilot studies. A third Aboriginal researcher, Belinda Huntriss, joined Growin' Up Healthy Jarjums at the start of the research. Belinda is a Worimi woman and had worked previously in the Awabakal community, thus she led community consultation with the Awabakal community. Due to the trusted and long-standing connections of these three researchers in their communities, a number of Aboriginal organisations supported or participated in Growin' Up Healthy Jarjums (including Armajun AMS, Galambila AMS, Awabakal AMS and preschool, Kulai Aboriginal preschool and Muloobinba Aboriginal Corporation)as well as NSW Health Aboriginal Maternal and Infant Health Services located in Inverell, Coffs Harbour, and Newcastle The Aboriginal researchers led consultation, including contacting women and organisations that participated in the 2017 study who expressed interest in further research, as well as contacting additional organisations and mothers to promote and invite them to the Growin' Up Healthy Jarjums study. Further evidence of their reach and connection in their respective communities was the high number of mothers that participated and were followed up. Noelene, Bernise and Belinda communicated with participants and organisations throughout the study (ad hoc emails, phone calls and visits) and responded to any queries as they arose. An ad hoc arrangement was preferred by organisations (rather than set meetings).

3.5 Questionnaires, surveys, and other documents must be determined culturally appropriate by the Aboriginal people and communities affected.

All questionnaires and program content were either co-developed, or reviewed and modified by the Aboriginal researchers on the team.

3.6 History, colonisation and its ongoing impacts is addressed.

A key driver for this study was the understanding that mainstream health promotion material is not always culturally appropriate and safe for Aboriginal and Torres Strait Islander people, for a multitude of reasons. As a team, we acknowledge the devastating impact of colonisation by Europeans to Aboriginal and Torres Strait Islander peoples, and the ongoing impact. To prevent doing further harm, we adhered to the AH&MRC guidelines for ethical guidance, including having Aboriginal team members at all levels of the research team, and Aboriginal team members leading all engagement with organisations and participants.

4. Reimbursement of costs

There must not be any imposition upon Aboriginal people and communities to be involved in the research project.

4.1 Reimbursements may be financial or non-financial; but should be considerate of costs, time and travel incurred by Aboriginal people involved in the project. Knowledge and experience sharing must also be considered as a valuable resource.

In both the co-design and pilot phases of the research, participants were reimbursed with gift cards for their time, travel, knowledge and lived experience. In the co-design phase, participants were reimbursed with a shopping voucher worth A$30 for attending focus groups and interviews, and were provided with refreshments. In the pilot phase, participants were reimbursed with a A$20 shopping voucher at baseline, a A$10 shopping voucher per week for the 4-week pilot study (total A$40) to cover data use, and a A$20 shopping voucher for participating in the follow-up interview.

4.2 Must be appropriate to the scale of the research project but must not coerce participants to be involved.

The amount that participants were reimbursed was agreed upon by the research team and organisations as reasonable. Three separate ethics boards approved the amount participants were reimbursed.

5. Enhancing Aboriginal skills and knowledge

Build the capacity of Aboriginal people to participate in and lead research projects. Individuals may be from an Aboriginal Community Organisation, Aboriginal Reference Group, participants or researchers on the project team.

5.1 Ensure that there is a process in place to disseminate information back to the Aboriginal people or communities affected by the research.

At the end of each stage of research we emailed and posted a summary of the results to participants and organisations as well as posted on Facebook. Further, the Aboriginal research assistants on the team had many formal and informal conversations with people and communities affected at a variety of community events and places.

5.2 Aboriginal people should be employed on research projects, wherever possible there should be training and development opportunities. There should be an emphasis on employing local Aboriginal people in line with cultural protocols.

The research team is a mixture of Aboriginal researchers and non-Indigenous researchers. As described above, three Aboriginal research assistants are from (or connected to) the communities where the research took place and the research is co-led by Kuku Yalanji, Lama Lama woman Kerry

Hall. The cultural identities of the remaining team members are Macedonian-Australian (Billie Bonevski), German-Australian (Joerg Mattes), Pakeha or European New Zealand (Rosie Dobson) and European-Australian (Sarah Perkes).

> ***5.3 Aboriginal people should be listed investigators on research projects that affect Aboriginal communities. Aboriginal people in the project team should be offered authorship opportunities where possible.***

A Kuku Yalanji, Lama Lama academic (KH) as well as two non-Indigenous academics (BB, JM) are listed as investigators. All of the research team are authors of the co-design and pilot papers.

7.4 Ethics documents

Ethics documents for the studies in Chapters 8 and 11 are stored as per protocol for the larger studies that they are a part of. Ethics documents for the studies in Chapters 9 and 10 are listed below and can be found in the Appendices:

Appendix 2 – Co-design interview guide: women

Appendix 3 – Co-design interview guide: staff

Appendix 4 – Pilot interview guide: women

Appendix 5 – Pilot interview guide: staff

Appendix 6 – Survey: women

Appendix 7 – Survey: staff

Appendix 8 – Information sheet: women

Appendix 9 – Information sheet: organisations

Appendix 10 – Ethics approval: AH&MRC

Appendix 11 – Ethics approval: The University of Newcastle

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Section C – Studies and thesis discussion

Section C comprises four independent linked studies, followed by a discussion on the overall findings and future direction of the research presented in this thesis.

Section C comprises the following chapters:

> Chapter 8. Aboriginal and Torres Strait Islander women's access to and interest in mHealth: national web-based cross-sectional survey (Study 1)
>
> Chapter 9. Development of a maternal and child mHealth program with Aboriginal and Torres Strait Islander mothers: co-design approach (Study 2)
>
> Chapter 10. Evaluation of an mHealth program (Growin' Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: engagement and acceptability study (Study 3)
>
> Chapter 11. Respiratory, birth and health economic measures for use with Aboriginal and Torres Strait Islander infants: a modified Delphi with an Aboriginal and Torres Strait Islander panel (Study 4)
>
> Chapter 12. Discussion

Chapter 8 – Aboriginal and Torres Strait Islander women's access to and interest in mHealth: National web-based cross-sectional survey (Study 1)

Content

8.1 Chapter overview

Formative research is the first step to develop mHealth programs, as outlined in the introduction section of this thesis (Chapter 4). Formative research can include surveys or focus groups. The study described in this chapter is the first part of the formative research of this thesis. This chapter describes the methods, results and findings from a national cross-sectional survey on Aboriginal and Torres Strait Islander women's access and preferences for mHealth.

8.2 Publication details

Perkes SJ, Bonevski B, Hall K, Mattes J, Chamberlain C, Bennett J, Whittaker R, Palazzi K, Lambkin D, Kennedy M. Aboriginal and Torres Strait Islander women's access to and interest in mHealth: national web-based cross-sectional survey. Journal of Medical Internet Research. 2023;25:e42660. https://doi.org/10.2196/42660

A copy of the manuscript can be found in Appendix 12.

Student's contribution to the publication:

70% Research design

50% Data collection and analysis

90% Writing and editing

Co-authors:

Professor Billie Bonevski

Dr Kerry Hall

Professor Joerg Mattes

Professor Catherine Chamberlain

Jessica Bennett

Robyn Whittaker

Kerrin Palazzi

David Lambkin

Michelle Kennedy

Authors' contributions to the publication:

MK led the conceptualisation of the larger study, acquired funding, designed the methodology, and reviewed and edited the manuscript. SP, BB, KH, JM, CC, JB and RW contributed to the conceptualisation of the study and/or design of the survey instrument. SP led the design of the survey items for mHealth, contributed to data analysis, and led the writing of drafts and final manuscript. BB, KH, JM, CC, JB, RW, KP, DL and MK reviewed the manuscript. KP and DL completed the statistical analysis. Co-authorship approval for Higher Degree Research (HDR) publication of the Chapter 8 manuscript can be found in Appendix 13.

8.3 Abstract

Background: Health programs delivered through digital devices such as mobile phones (mHealth) have become an increasingly important component of the health care tool kit. Aboriginal and Torres Strait Islander women of reproductive age are likely to be caring for children and family members and needing health care, but little is known about their access to and interest in mHealth.

Objective: The objectives of this study were to investigate Aboriginal and Torres Strait Islander women's ownership of digital devices, access to the internet, current mHealth use, and interest and preferences for future mHealth. We examined the factors (age, remoteness, caring for a child younger than 5 years, and level of education) associated with the ownership of digital devices, use of internet, and interest in using a mobile phone to improve health. This study also examines if women are more likely to use mHealth for topics that they are less confident to talk about face-to-face with a health professional.

Methods: A national web-based cross-sectional survey targeting Aboriginal and Torres Strait Islander women of reproductive age (16–49 years) was performed. Descriptive statistics were reported, and logistic regressions were used to examine the associations.

Results: In total, 379 women completed the survey; 89.2% (338/379) owned a smartphone, 53.5% (203/379) a laptop or home computer, 35.6% (135/379) a tablet, and 93.1% (353/379) had access to the internet at home. Most women used social media (337/379, 88.9%) or the internet (285/379, 75.2%) every day. The most common modality used on the mobile phone for health was Google (232/379, 61.2%), followed by social media (195/379, 51.5%). The most preferred modality for future programs was SMS text messaging (211/379, 55.7%) and social media (195/379, 51.4%). The most preferred topics for future mHealth programs were healthy eating (210/379, 55.4%) and cultural engagement (205/379, 54.1%). Women who were younger had greater odds of owning a smartphone, and women with tertiary education were more likely to own a tablet or laptop. Older age was associated with interest to use telehealth, and higher educational attainment was associated with interest for videoconferencing. Most women (269/379, 70.9%) used an Aboriginal medical service and overall reported high rates of confidence to discuss health topics with a health professional. Overall, women showed a similar likelihood of selecting a topic in mHealth whether they were or were not confident to talk to a health professional about that.

Conclusions: Our study found that Aboriginal and Torres Strait Islander women were avid users of the internet and had strong interest in mHealth. Future mHealth programs for these women should consider utilising SMS text messaging and social media modalities and including content on nutrition and culture. A noteworthy limitation of this study was that participant recruitment was web-based (due to COVID-19 restrictions).

8.4 Introduction

Aboriginal and Torres Strait Islander people experience inequitable health burden due to the continuing impacts of colonisation, intergenerational trauma and systemic racism experienced in Australia (1). A number of health outcomes for Aboriginal and Torres Strait Islander people have remained steady or worsened over the past decade (2) including rates of mental illness (3), psychological distress (3), asthma (4), diabetes (5), cardiovascular disease (3) and chronic obstructive pulmonary disease (3), although gains have been made in other areas, such as decreased smoking during pregnancy (6), antenatal visits (6, 7), Year 12 completion (8) and university attendance (8).

The life expectancy gap between Aboriginal and Torres Strait Islander women and non-Indigenous women is 7.6 years. Although the life expectancy of Aboriginal and Torres Strait Islander women has improved in recent decades, the gap still remains (9). Addressing the social, cultural and political determinants of health will lead to the greatest improvements in Aboriginal and Torres Strait Islander health outcomes (10). A large-scale systemic reform that positions Aboriginal and Torres Strait Islander people as the decision-makers for Aboriginal and Torres Strait Islander people is required (10).

Aboriginal and Torres Strait Islander women are "healers, storytellers, keepers of our kids and truth-seekers" (11) (para. 3). Aboriginal and Torres Strait Islander women have been instrumental in driving change for Aboriginal and Torres Strait Islander people, including leading the mandate for the Uluru Statement from the Heart (11). Aboriginal and Torres Strait Islander women not only look after their own health, but the health of the collective: their community, grandchildren, parents, grandparents, children and other family members (12). The positive experiences and role modelling by Aboriginal and Torres Strait Islander women to their children and others influence development and behaviour, and often lead to better health outcomes for all of their community (13). Health promotion programs targeting women's health inevitably have important positive impacts for children and other community members.

There is strong evidence that health promotion programs developed by and for Aboriginal and Torres Strait Islander women are most successful (10, 14, 15). Aboriginal and Torres Strait Islander women can seek health care from an ACCHO or a mainstream public health service. Specific services for Aboriginal and Torres Strait Islander women's and children's health exist in both ACCHOs and mainstream services, though ACCHOs tend to outperform mainstream services in health and wellbeing outcomes (16). One such exemplar of a women's and children's health promotion program developed by an ACCHO is the Waminda Dead or Deadly program (17). This program has been running for over 10 years, and aims to enhance cultural connection and health and wellbeing through a range of activities including cooking groups with local ingredients, exercise groups (pre- and postnatal), yarning groups and lifestyle medicine. The program was designed by and for local Aboriginal and Torres Strait Islander women and therefore operates in a flexible way to meet local women's needs (16). Locally developed programs are achieving positive health outcomes for Aboriginal and Torres Strait Islander women (16). To supplement these programs, and to reach women who may not have access, alternative modes of delivery could be beneficial.

The potential of technology for promoting health and wellbeing in general is significant, with low cost and wide reach, high acceptability, and equitability if digital inclusion is considered carefully.

Telehealth, health websites, social media campaigns, online patient portals, health apps, SMS text message programs and wearable devices are becoming important daily tools for health care nationally and internationally. The COVID-19 experience has reinforced how important it is to have alternatives to face-to-face health care. Global evidence suggests mHealth to be effective and acceptable to populations underserved by traditional primary health and public health campaigns (18, 19). mHealth may be particularly important for Aboriginal and Torres Strait Islander communities given the high rate of mobile phone use (20, 21) and barriers to accessing mainstream primary health care (22). An important first step to developing and delivering effective mHealth programs is gathering information about the population, including context, digital access and interest in mHealth (23). This information is critical to designing programs that have sustained engagement (23), which many mHealth solutions fall short of (24). To date, there is little information on access to, interest in and preferences for mHealth among Aboriginal and Torres Strait Islander women.

The aims of this study were to:

1. Describe Aboriginal and Torres Strait Islander women's ownership of digital devices and access to the internet.
2. Describe Aboriginal and Torres Strait Islander women's current use of, interest in and preferences for future mHealth programs.
3. Examine factors (age, remoteness, caring for a child under 5 years, and level of education) associated with Aboriginal and Torres Strait Islander women's access to digital devices and the internet, and interest in using a mobile phone to improve health.
4. Examine if Aboriginal and Torres Strait Islander women are likely to be interested in using mHealth for health topics that they are not confident talking to a health professional about.

8.5 Methods

8.5.1 Design

A web-based cross-sectional survey design was selected, as we were interested in the experiences and views of a large sample of women at one point in time and to compare different variables at that point in time. We had planned to complete a portion of the surveys face to face; however, due to COVID-19 restrictions, web-based data collection was the most feasible approach. This study is reported according to the Checklist for Reporting Results of Internet E-Surveys (25).

8.5.2 The Which Way? study

This study is part of a larger study, the Which Way? study, a co-designed and co-owned research study with urban and regional Aboriginal and Torres Strait Islander communities(26-31). The Which Way? study aims to improve care relating to smoking cessation by developing an Indigenous-led evidence base for smoking cessation to support Aboriginal and Torres Strait Islander women to be smoke-free during pregnancy and beyond. Detailed information on the larger study research prioritisations, governance, relationships and methodologies can be found in the protocol paper (30).

8.5.3 Study participants

Aboriginal and Torres Strait Islander women of reproductive age (16–49 years) who were smokers or ex-smokers (any level of consumption) were invited to participate in this study. Smokers and ex-smokers were the eligibility criteria, as this study is a substudy of a large study on Aboriginal and Torres Strait Islander women's preference for non-pharmacological approaches to smoking cessation.

8.5.4 Procedures

Consent was obtained via a digital consent sheet using a tick box at the beginning of the survey. A copy of the participant information sheet was provided via a hyperlink; progression through the survey was not granted until consent was provided. Participants were also informed of the approximate time required to complete the survey in the opening page of the survey. The survey was hosted on REDCap (Research Electronic Data Capture; Vanderbilt University) (32). The database was accessible by authorised team members only. On completion of the survey, women were eligible to go in a draw for a chance to win an iPad. Women were recruited over a 3-month period between July 10, 2020, and October 10, 2020, inclusive. Participants were recruited via snowballing and targeted Facebook and Instagram paid advertising. The survey was promoted through social media by using both organic and paid advertisements. A Facebook page and an Instagram account were developed for the Which Way? study. The survey link was shared by the research team through professional contacts and by Aboriginal partner organisations via organisational social media pages and accounts. Paid advertising was used to increase reach on social media accounts. Advertising was specified for 'location: Australia' and 'Aboriginal peoples' television network-Aboriginal title-smoking'. It was an open survey; all participants who accessed the link to the website were able to participate in the survey.

Survey instrument

The survey included 36 items, of which 17 items are reported on here. Branching logic was used to present questions that were relevant for each participant based on their previous responses. Generally, there was one survey item per page. The full survey took 10 minutes to complete. Women were required to complete each response to progress through the survey and were unable to return to their responses. Survey items and questions were developed in partnership with the partnering services. A draft survey was discussed among the research team and partners, then pretested with 15 Aboriginal and Torres Strait Islander women and community members known to the research team.

Participant characteristics (9 items)

The characteristics that were analysed were 1) Aboriginal and Torres Strait Islander status; 2) age; 3) smoking status; 4) rurality (Accessibility and Remoteness Index of Australia); 5) use of Aboriginal Health Services; 6) education; 7) pregnancy status; 8) number of children living in the household; and 9) number of children younger than 5 years.

Access to digital devices and the internet (4 items)

1. Device ownership was determined by asking "What device(s) do you own?" (Response options: iPad/tablet; laptop or home computer; smartphone (iPhone or Android); mobile phone (calls/text only); I do not have access to any of these) (33).
2. Internet access was determined by asking "Where do you have internet access?" (Response options: home; workplace; commuting/travel; community centre; I don't have internet access anywhere; somewhere else) (33).
3. Frequency of social media use was determined by asking "In the last 12 months, how often have you accessed social media?" (Response options: not at all; about once a week; a few times per week; every day) (34).
4. Frequency of internet use was determined by asking "In the last 12 months, how often have you accessed the internet for other things?" (Response options: not at all; less than once a week; about once a week; a few times per week; every day) (35).

Using your phone to improve health (4 items)

1. Women were asked to indicate how they currently used their mobile phone for their health by responding to: "Do you currently use your mobile phone for anything to do with your health?" (Multiple selections allowed; response options: I use Google to find health information; I read posts or watch videos about health on social media; I use a health

tracker; I use health apps; I use telehealth, e.g. talk to a health worker on the phone for advice or treatment; I use text messages to communicate with health workers or have used a text messaging service for health; other; no, I don't use my phone for health) (34).

2. Women were asked to indicate what mHealth modalities they would be interested in using in the future by responding to: "What type of mobile health would you like to use in the future if available?" (Multiple selections allowed; response options: text messaging service, e.g. to help quit smoking or exercise or remind me to do something for my health; social media; health apps; health tracker; phone calls to talk to a health worker; videoconferencing to video call with a health worker; other; no, I wouldn't use my phone for health in the future) (34).
3. Women were asked to indicate which three health topics they would be most interested in by responding to: "Pick 3 health topics that would be of most interest to you if using a mobile phone for your health" (Response options: help me improve what I eat; engage with Aboriginal and Torres Strait Islander culture; show/teach me exercises; improve my mental health; help me to stop smoking; women's health; help me limit or quit cannabis or other drugs; children's health; help with family violence; help me limit drinking) (34).
4. To determine participants' confidence to talk to a health professional about different health topics in person, women were asked to respond to: "Do you feel confident to talk with a doctor/health worker about the following health topics (women's health, eating/diet, exercise, children's health, mental health, quitting smoking, reducing alcohol, family violence, cannabis or other drug use)?" (Response options: yes; no; not relevant).

8.5.5 Exclusion criteria

Women were excluded from all analyses if they did not meet the inclusion criteria (self-identifying as an Aboriginal and/or Torres Strait Islander woman, aged 16–49 years, and a current or ex-smoker) or if their survey was incomplete.

8.5.6 Ethics

Ethics approvals were granted by AH&MRC NSW (#14541662), University of Newcastle (H-2020-0092) and the Local Health District ethics committee (2020/ETH02095).

8.5.7 Analyses

The data were analysed in SAS v9.4 (SAS Institute). Descriptive statistics are presented as count (%), mean (standard deviation; SD) and median (range). Age was categorised as <21, 21–34 and >34 for descriptive statistics. Logistical regressions were used to examine the associations between age, remoteness, caring for a child younger than 5 years, and level of education with device ownership, mHealth modalities of interest, and mHealth topics of interest (top three selections only). A chi-square test was used to examine the relationship between women's interest in using mHealth for a health topic they were not confident to discuss in person with a health professional. An alpha level of 0.05 was specified for all tests and confidence intervals (CIs).

Logistic regressions are presented as odds ratios (ORs, with 95% CI). For the logistic regressions, age was treated as continuous, and ORs reported for increments of 5 years. Rurality was dichotomised into 'major city', 'regional' and 'remote' Australia. 'Caring for a child younger than 5 years of age' was recoded as a binary response for the purposes of analysis. Level of education was collapsed into three categories and is presented as an overall Wald type-3 p-value and pairwise ORs (95% CI) and p-values for each level comparison with the reference ('completed high school'). 'Education' was recoded into 'Did not complete high school', 'Completed high school' and 'Competed tertiary education' for the purposes of analysis. Complete case analysis was used for this study, given the relatively low number of participants being excluded due to missing data.

8.6 Results

Data were collected for 865 women. Of these, 607 were eligible; 228 were excluded due to incomplete surveys, leaving 379 women included in the analyses.

8.6.1 Participant characteristics

Participant demographics are presented in Table 8.1. The mean age of the women was 31 years. More than half (194/379, 51.2%) of the women lived in cities, 42.7% (162/379) in a regional area and 6.1% (23/379) in a remote area. Most (269/379, 70.9%) women used an Aboriginal health service.

Table 8.1. Demographic characteristics of Aboriginal and Torres Strait Islander women who were included in the survey (N=379)

Characteristic	**n (%)**
Total	**379 (100)**
Age	
<21	43 (11.3)
21–34	196 (51.7)
>34	140 (36.9)
Mean (SD)	31.0 (7.7)
Median (min, max)	32 (16, 49)
Remoteness	
Major city	194 (51.2)
Regional	162 (42.7)
Remote	23 (6.1)
Level of education	
Up to Year 9	37 (9.8)
Year 10–11	102 (26.4)
Year 12	73 (19.3)
Current student at university/TAFE/apprentice	77 (20.3)
Trade certificate	40 (10.6)
University degree	50 (13.2)
Aboriginal and Torres Strait Islander status	
Aboriginal	357 (94.2)
Torres Strait Islander	7 (1.8)
Aboriginal and Torres Strait Islander	15 (3.9)
Use of Aboriginal health service	
Yes	269 (70.9)
No	110 (29.0)
Children living in household	
1–2	159 (42.0)
3 or more	129 (34.0)
None	91 (24.0)
Children under 5 years living in household	
None	237 (63.5)
1 or more	142 (37.5)

TAFE = Technical and Further Education

8.6.2 Access to digital devices and the internet

Rates of device ownership, internet access, and frequency of social media and internet use

Approximately 89.2% (338/379) of the women owned a smartphone, 53.6% (203/379) a laptop, 35.6% (135/379) a tablet, and 16.4% (62/379) a mobile phone (calls and text only) (Table 8.2). Approximately 93.1% (353/379) of the women had access to the internet at home, and 88.9% (337/379) of the women used social media every day.

Table 8.2. Device and internet access and frequency of social media and internet use (N=379)

Characteristic	n (%)
Total	**379 (100)**
Device ownership	
Smartphone (iPhone or Android)	338 (89.2)
Laptop or home computer	203 (53.6)
iPad/tablet	135 (35.6)
Mobile phone (calls/text only)	62 (16.4)
I do not have access to any of these	2 (0.5)
Access to the internet	
Home	353 (93.1)
Workplace	165 (43.5)
Commuting/travel	90 (23.7)
Community centre	48 (12.7)
Somewhere else	17 (4.5)
I don’t have internet access anywhere	8 (2.1)
Use of social media in the last 12 months	
Every day	337 (89.0)
A few times per week	33 (8.7)
Not at all	5 (1.3)
About once a week	4 (1.1)
Use of internet for other things in the last 12 months	
Every day	285 (75.2)
A few times per week	70 (18.5)
About once a week	16 (4.2)
Less than once a week	7 (1.8)
Not at all	1 (0.3)

8.6.3 'Using your phone to improve health'

Current mHealth modalities used

The most common function used on the mobile phone for health was Google (232/379, 61.2%), followed by social media (182/379, 48%), health trackers (130/379, 34.3%), health apps (124/379, 32.7%), telehealth (116/379, 30.6%) and text messages (69/379, 18.2%) (Table 8.3).

Future mHealth modalities of interest

The most preferred mHealth modality for future health care was text messages (211/379, 55.7%), followed by social media (195/379, 51.5%), health apps (124/379, 48.5%), health trackers (164/379, 43.3%), telehealth (152/379, 40.1%) and videos (100/379, 26.4%) (Table 8.3).

mHealth topics of interest

The most preferred topic for future mHealth programs was healthy eating (210/379, 55.4%), followed by cultural engagement (205/379, 54.1%), exercise (162/379, 42.7%), mental health (155/379, 40.9%), stop smoking (122/379, 32.2%), women's health (61/379, 16.1%), limit or quit cannabis or other drugs (48/379, 12.7%), children's health (45/379, 11.9%), family violence (28/379, 7.4%) and limit unsafe drinking (23/379, 6.1%) (Table 8.3).

Table 8.3. Mobile phone use, and preferences for mobile health topics and functions (N=379)

	n (%)
Total	**379**
Current mobile health modalities used	
I use Google to find health information	232 (61.2)
I read posts or watch videos about health on social media	182 (48.0)
I use a health tracker	130 (34.3)
I use health apps	124 (32.7)
I use telehealth	116 (30.6)
I use text messages	69 (18.2)
Other	8 (2.1)
No, I don't use my phone for health	51 (13.5)
Future mobile health modalities of interest	
A text messaging service	211 (55.7)
Social media	195 (51.5)
Health apps	184 (48.5)
Health tracker	164 (43.3)
Phone calls to talk to a health worker	152 (40.1)
Videoconferencing to video call with a health worker	100 (26.4)
Other	5 (1.3)
No, I wouldn't use my phone for health in the future	20 (5.3)
Mobile health topics of interest	
Help me improve what I eat	210 (55.4)
Engage with Aboriginal and Torres Strait Islander culture	205 (54.1)
Show/teach me exercises	162 (42.7)
Improve my mental health	155 (40.9)
Help me to stop smoking	122 (32.2)
Women's health	61 (16.1)
Help me limit or quit cannabis or other drugs	48 (12.7)
Children's health	45 (11.9)
Help with family violence	28 (7.4)
Help me limit drinking	23 (6.1)
Other	9 (2.4)
None of these topics interest me	5 (1.3)

Confidence to talk with a health professional about different health topics

Women reported high rates of confidence to discuss all health topics with a health professional (Table 8.4).

Table 8.4. Confidence talking with a doctor/health worker about different health topics (N=379)

Health topic	Yes n (%)	No n (%)	Not relevant n (%)
Women's health	328 (86.6)	36 (9.5)	15 (4.0)
Eating/diet	314 (82.8)	51 (13.5)	14 (3.7)
Exercise	307 (81.0)	51 (13.5)	21 (5.5)
Children's health	305 (80.5)	12 (3.2)	62 (16.4)
Mental health	285 (75.2)	50 (13)	44 (12.0)
Quitting smoking	265 (70.0)	49 (13.2)	65 (17.2)
Reducing alcohol	162 (42.7)	47 (12.4)	170 (44.9)
Family violence	135 (35.6)	79 (20.8)	165 (43.5)
Cannabis or other drug use	111 (29.0)	68 (17.9)	200 (52.7)

8.6.4 Association between participant characteristics and device ownership

For every 5-year increase in age, the odds of owning a smartphone decreased by 35% (OR=0.723; 95% CI 0.509, 0.834; p<0.001). Of those aged 16–21 years, 100% (43/43) owned a smartphone; of those aged 21–34 years, ownership was 90.8% (178/196); and of those aged 34–49 years, ownership was 83.6% (117/140). There was no association between owning a smartphone and level of education attainment or caring for a child younger than 5 years (Supplementary Tables S1 and S2).

Women who had completed tertiary education were almost twice as likely (OR=1.916; 95% CI 1.095, 3.354; p=0.02) to own an iPad or tablet compared to those whose highest education was high school completion. No other characteristics (age, remoteness, caring for a child under 5) were associated with ownership of an iPad or tablet (Supplementary Tables S3 and S4).

There was a statistically significant overall association with the level of education and ownership of a laptop or computer. Individuals who had completed tertiary education were more than twice as likely (OR=2.176; 95% CI 1.180, 4.012; p=0.01) to own a laptop or home computer compared to those who had completed high school. Those who had not completed high school were 69% less likely to own a laptop or computer compared to those who had completed high school (OR=0.310; 95% CI 0.190, 0.506; p≤0.001). No other characteristics (age, remoteness, or caring for a child younger than 5 years) were associated with ownership of a laptop or computer (Supplementary Tables S5 and S6).

The likelihood of owning a mobile phone (text and calls only) increased as age increased (per 5-year increase in age – OR=1.222; 95% CI 1.006, 1.484; p=0.0436). No other characteristics (education, remoteness, or caring for a child under 5) were associated with ownership of a mobile phone (Supplementary Tables S7 and S8).

8.6.5 Association between participant characteristics and future mHealth modalities of interest

For every 5-year increase in age, the odds of selecting telehealth as a future mHealth modality of interest increased by 23% (OR=1.232; 95% CI 1.065, 1.425; p=0.0049). No other characteristics (education, remoteness, or caring for a child under 5) were associated with selecting telehealth as a preferred mHealth modality (Supplementary Tables S9 and S10). Women who had not completed high school were less likely than those who had completed high school to select videoconferencing as a future mHealth modality of interest (OR=0.497; 95% CI 0.284, 0.872; p=0.0147). No other characteristics (tertiary education, remoteness, or caring for a child under 5) were associated with selecting videoconferencing as a preferred mHealth modality (Supplementary Tables S11 and S12). No statistically significant associations were found between participant characteristics and the selection of text messaging (Supplementary Tables S13 and S14), social media (Supplementary Tables S15 and S16), health apps (Supplementary Tables S17 and S18) or health tracker (Supplementary Tables S19 and S20) as preferred mHealth modalities.

8.6.6 Relationship between participant characteristics and preferred mHealth topics

Women living in regional and remote areas were 43% less likely than those in urban areas to select cultural engagement as a topic (OR=0.437; 95% CI 0.287, 0.666; p<0.0001) (Supplementary Tables S21 and S22). No statistically significant associations were found between participant characteristics and the selection of eating/diet (Supplementary Tables S23 and S24) or exercise (Supplementary Tables S25 and S26).

8.6.7 Relationship between confidence to discuss a health topic with a health professional and selecting that topic for future mHealth programs

Overall, women showed a similar likelihood of selecting a topic for mHealth whether they were or were not confident to talk to a health professional about that topic (Supplementary Table S27). Topics that showed a similar likelihood of being selected include eating/diet, exercise, family violence, quitting smoking, cannabis and other drug use, mental health, women's health and children's health. Reducing alcohol was the only topic to show significance (p=0.0020). Notably, for most women (170/379, 44.9%), reducing alcohol was not a relevant health topic, and 42.7% (162/379) of women were confident to discuss this topic with a health provider. The number of women not confident to discuss reducing alcohol with a health provider was low (47/379, 12.4%); as such, the number of women selecting alcohol reduction as an mHealth topic who were not confident to discuss it with a health professional was also low (11/379; 2.9%).

8.7 Discussion

8.7.1 Principal results

The findings of our study suggest that Aboriginal and Torres Strait Islander women have high access to smartphones and social media and their interest in using technology for health care is high. SMS text messaging was the most preferred mHealth modality

8.7.2 Strengths and limitations

A strength of this study is that it was led and governed by Aboriginal researchers. MK, the senior author and lead investigator of the larger study, is a Wiradjuri woman working with a team of Aboriginal and Torres Strait Islander researchers. Aboriginal Health Services are full partners and co-owners of this research. The full details of the governance are available in the protocol for the larger study (30). As a non-Indigenous researcher (SJP) leading the mHealth portion of the survey, it was important to be guided by Aboriginal leadership and partnership to ensure cultural safety and best practice of ethical standards of research with Aboriginal and Torres Strait Islander people (36, 37).

A key limitation of this study is that all recruitments were conducted online, and it is therefore biased towards people who have access to digital devices and the internet. We planned to complete a portion of the surveys in person; however, due to COVID-19 restrictions, this was not possible. Unsurprisingly, due to the recruitment strategy, access to devices and the internet was much higher in this study than in other available data. In this study, 99.5% (377/379) of the women owned either a smartphone or a mobile phone. It is unlikely that this proportion reflects all Aboriginal and Torres Strait Islander people, particularly people living in remote locations or in poverty. Two recent studies (38, 39) with Aboriginal and Torres Strait Islander people reported lower access to mobile phones. In one study, 12.9% (39/301) of the women did not have access to a phone (38), and the other study reported frequent sharing of phones (rather than individual ownership), as is common practice in low-resource settings (39). In this study, 93.1% (353/379) of women had access to the internet at home compared to 72% of Aboriginal and Torres Strait Islander people reported in the 2016 Census (40). Further, as this survey was embedded in a larger study on non-pharmacological smoking support, only current or former smokers were included, possibly creating further bias. Lastly, the usage of complete case analysis further limits the generalisability of this study to people with similar characteristics. Although these weaknesses may limit generalisation, overall, these results offer useful insights into the type of mHealth modalities and topics of interest for the future development of mHealth programs.

8.7.3 Comparison with prior work

In this study, SMS text messaging was found to be the most desired modality, with 55.7% (211/379) of the women reporting an interest in using SMS text messaging for future health care. Interestingly, SMS text messaging was the least currently utilised mHealth modality for health care at 18.2% (69/379). There were no significant associations found between participant characteristics and women selecting SMS text messaging as the desired modality; as such, SMS text messaging appears to be equally desirable by women of different ages (16–49 years), women living in cities and in regional or remote areas, women with and without young children, and women with different levels of educational attainment. Two studies using SMS text messaging with Aboriginal and Torres Strait Islander women in remote settings found high acceptability for SMS text messages but no difference in the clinical outcomes, including attendance for appointments for otitis media (41) and postpartum screening following gestational diabetes (39). In a randomised controlled trial with Aboriginal and Torres Strait Islander families in urban and remote settings, SMS text messages were used to retain women; over 96.7% (180/186) of the children remained in the randomised controlled trial until their clinical endpoint at day 21 (38). There is great potential for more effectively using SMS text messaging to reach Aboriginal and Torres Strait Islander women to improve health outcomes.

Social media was the second most preferred modality, with 51.5% (195/379) of the women selecting social media as an mHealth modality of interest for the future. Daily social media use among the women was high at 88.9% (337/379) – much higher than that reported in the rest of the population. A web-based survey in 2021 with 2000 Australians reported that 55% of the population used social media daily (42). A similar trend was shown in a 2014 survey with 400 Aboriginal and Torres Strait Islander people that reported 69% used Facebook compared with 40% of other Australians (20). The *Social media mob: being Indigenous online* report suggests that social media uptake is higher among Aboriginal and Torres Strait Islanders than the rest of the nation, including in remote and very remote areas (21). In this report, Carlson and Frazer (21) outline that Aboriginal and Torres Strait Islander people use social media for a range of positive reasons – to connect with friends and family, share jokes, seek love, find information and seek help, and for political activism – but that ensuring psychological and cultural safety should be a priority.

Several Aboriginal and Torres Strait Islander–led social marketing campaigns for health promotion, such as 'Tackling Indigenous Smoking' and 'Deadly Choices', create posts that appeal to positive emotions, and use photos and (short) videos, simple content and real-time support, among other strategies (43). In an ethnographic study of Deadly Choices, five important principles for the success of the campaign were outlined: 1) create a dialogue; 2) build community online and offline; 3) incentivise healthy online engagement; 4) celebrate Indigenous identity and culture; and 5) prioritise partnerships (44). Future health initiatives on social media for Aboriginal and Torres Strait Islander women should lean on these findings.

The most preferred topics for future mHealth programs were healthy eating (210/379, 55.4%), followed by cultural engagement (205/379, 54.1%), exercise (162/379, 42.7%) and mental health (155/379, 40.9%). A recent qualitative study examined the types of health content that were shared among Aboriginal and Torres Strait Islander people through social media networks as well as how people engage with and are influenced by it (45). They found that posts on mental health and nutrition were more commonly shared than posts on health topics where there is concern about stigma and shame, such as smoking and alcohol consumption (45). The findings in our survey somewhat reflect these findings. Most of the topics associated with shame and stigma, including limiting or quitting cannabis or other drugs, family violence and reducing alcohol, were in the bottom four (out of nine) health topics of interest. Although quitting smoking was the fifth (out of nine) most popular choice, the difference may be due to most of the 20 participants in the qualitative study being smokers, compared to 37.5% (141/379) of participants in this study being non-smokers.

For topics that have concern for shame and stigma, it is suggested that negative messages that have been successful at a whole population level, such as quitting smoking, may need to be adapted for Aboriginal and Torres Strait Islander mHealth initiatives (45). The importance of centring positive cultural identity and narratives in mHealth initiatives is evident (43-45). This was highlighted in a recent qualitative study that found Facebook posts celebrating culture and cultural achievements, as well as challenging racism, were posted by most women (45). The popularity of embedding culture in mHealth programs was shown in the results of this study, with 'culture' as the second most popular topic. The existing evidence suggests that future mHealth programs must integrate culturally relevant content. Further research to determine its effect on engagement and health outcomes is warranted.

Although smartphone ownership was relatively high at 89.2% (338/379), similar to national figures of 92% (42), ownership of other digital devices including laptops was low at 54% (203/379), compared with the national figure of 78% (42). Access to devices (as well as the internet and data), alongside affordability and digital ability are combined to provide a digital inclusion score (out of 100) (46). The digital inclusion gap between Aboriginal and Torres Strait Islander people and the rest of the nation is 7.9 (55.1 compared to 63) (46). Aboriginal and Torres Strait Islander people are less likely to have access to consistent, fast and large amounts of data, more likely to be mobile-only users, and more likely to use prepaid data; these factors all decrease digital inclusion (46). Digital inclusion facilitates efficient delivery and uptake of critical services including health care, as well as employment and education opportunities (46). Digital inclusion remains in the National Agreement on Closing the Gap as part of the Access to Information target (Target 17) – by 2026, Aboriginal and Torres Strait Islander people will have equal levels of digital inclusion. It is imperative that we seek to advance mHealth solutions developed for and by Aboriginal and Torres Strait Islander people.

8.8 Conclusions

Aboriginal and Torres Strait Islander women are avid users of technology and have a strong desire for mHealth. New mHealth initiatives should consider having strong partnerships with ACCHOs, and be designed by and for Aboriginal and Torres Strait Islander women to meet their digital and health needs. Nutrition and culture should be considered as topics of particular interest. Social media and SMS text messages may be the most currently accessible and preferable modalities.

8.9 Acknowledgements

We acknowledge the partnering services and staff for their time and commitment to this long-term project, including the Dhanggan Gudjagang team, Yerin Eleanor Duncan Aboriginal Health Centre, Tamworth AMS, Nunyara Aboriginal Health Clinics, and Waminda South Coast Women's Health and Welfare Aboriginal Corporation. We also acknowledge all the Aboriginal and Torres Strait Islander

women who contributed to this research project — thank you for sharing your experiences with us; it is our honour to privilege your voices.

8.10 Supplementary tables

Table S1. Participant characteristics for owning a "smartphone"

Characteristic	Class/statistic	Unchecked (n=41)	Checked (n=338)
Age	<21		43 (100%)
	21–34	18 (9%)	178 (91%)
	>34	23 (16%)	117 (84%)
ARIA+	Major cities of Australia	15 (8%)	179 (92%)
	Regional and remote Australia	26 (14%)	159 (86%)
Do you have children under 5?	No	29 (12%)	208 (88%)
	Yes	12 (9%)	130 (92%)
What education level have you completed?	Did not complete high school	20 (14%)	119 (86%)
	Completed high school	12 (8%)	138 (92%)
	Completed tertiary education	9 (10%)	81 (90%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S2. Associations between characteristics and owning a "smartphone"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	0.649 (0.512, 0.823)	0.0003	0.651 (0.509, 0.834)	0.0007
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.512 (0.262, 1.002)	0.0507	0.512 (0.255, 1.026)	0.0592
Do you have any children under 5? (Yes vs No)	1.510 (0.744, 3.063)	0.2536	1.271 (0.607, 2.661)	0.5247
What education level have you completed?		0.2158*		0.4526*
Competed tertiary education vs Completed high school	0.783 (0.316, 1.938)	0.5962	1.124 (0.431, 2.930)	0.8108
Did not complete high school vs Completed high school	0.517 (0.243, 1.102)	0.0878	0.685 (0.311, 1.509)	0.3483

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S3. Participant characteristics for owning an "iPad/tablet"

Characteristic	Class/statistic	Unchecked (n=244)	Checked (n=135)
Age	<21	33 (77%)	10 (23%)
	21–34	131 (67%)	65 (33%)
	>34	80 (57%)	60 (43%)
ARIA+	Major cities of Australia	124 (64%)	70 (36%)
	Regional and remote Australia	120 (65%)	65 (35%)
Do you have children under 5?	No	152 (64%)	85 (36%)
	Yes	92 (65%)	50 (35%)
What education level have you completed?	Did not complete high school	102 (73%)	37 (27%)
	Completed high school	99 (66%)	51 (34%)
	Completed tertiary education	43 (48%)	47 (52%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S4. Associations between characteristics and owning an "iPad/tablet"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.165 (1.013, 1.340)	0.0325	1.130 (0.973, 1.311)	0.1097
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.960 (0.630, 1.461)	0.8474	1.105 (0.713, 1.712)	0.6550
Do you have any children under 5? (Yes vs No)	0.972 (0.629, 1.501)	0.8978	1.056 (0.674, 1.655)	0.8116
What education level have you completed?		0.0005*		0.0012*
Competed tertiary education vs Completed high school	2.122 (1.244, 3.619)	0.0058	1.916 (1.095, 3.354)	0.0228
Did not complete high school vs Completed high school	0.704 (0.425, 1.168)	0.1741	0.658 (0.393, 1.101)	0.1113

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S5. Participant characteristics for owning a "laptop/home computer"

Characteristic	Class/statistic	Unchecked (n=176)	Checked (n=203)
Age	<21	18 (42%)	25 (58%)
	21–34	94 (48%)	102 (52%)
	>34	64 (46%)	76 (54%)
ARIA+	Major cities of Australia	84 (43%)	110 (57%)
	Regional and remote Australia	92 (50%)	93 (50%)
Do you have children under 5?	No	105 (44%)	132 (56%)
	Yes	71 (50%)	71 (50%)
What education level have you completed?	Did not complete high school	95 (68%)	44 (32%)
	Completed high school	60 (40%)	90 (60%)
	Completed tertiary education	21 (23%)	69 (77%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S6. Associations between characteristics and owning a "laptop/home computer"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.015 (0.890, 1.158)	0.8249	0.976 (0.843, 1.130)	0.7474
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.772 (0.515, 1.157)	0.2099	0.929 (0.600, 1.439)	0.7424
Do you have any children under 5? (Yes vs No)	0.795 (0.524, 1.207)	0.2821	0.803 (0.513, 1.258)	0.3385
What education level have you completed?		<0.0001*		<0.0001*
Competed tertiary education vs Completed high school	2.190 (1.217, 3.942)	0.0089	2.176 (1.180, 4.012)	0.0127
Did not complete high school vs Completed high school	0.309 (0.190, 0.501)	<0.0001	0.310 (0.190, 0.506)	<0.0001

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S7. Participant characteristics for owning a “mobile phone”

Characteristic	Class/statistic	Unchecked (n=317)	Checked (n=62)
Age	<21	40 (93%)	3 (7.0%)
	21–34	167 (85%)	29 (15%)
	>34	110 (79%)	30 (21%)
ARIA+	Major cities of Australia	164 (85%)	30 (15%)
	Regional and remote Australia	153 (83%)	32 (17%)
Do you have children under 5?	No	199 (84%)	38 (16%)
	Yes	118 (83%)	24 (17%)
What education level have you completed?	Did not complete high school	115 (83%)	24 (17%)
	Completed high school	131 (87%)	19 (13%)
	Completed tertiary education	71 (79%)	19 (21%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S8. Associations between characteristics and owning a “mobile phone”

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.247 (1.036, 1.500)	0.0194	1.222 (1.006, 1.484)	0.0436
ARIA+ (Regional and remote Australia vs Major cities of Australia)	1.143 (0.663, 1.971)	0.6297	1.204 (0.689, 2.103)	0.5155
Do you have any children under 5? (Yes vs No)	1.065 (0.609, 1.864)	0.8251	1.194 (0.672, 2.119)	0.5452
What education level have you completed?		0.2209*		0.4558*
Competed tertiary education vs Completed high school	1.845 (0.918, 3.710)	0.0856	1.590 (0.766, 3.301)	0.2135
Did not complete high school vs Completed high school	1.439 (0.750, 2.762)	0.2739	1.299 (0.668, 2.526)	0.4401

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S9. Participant characteristics for selecting "telehealth"

Characteristic	Class/statistic	Unchecked (n=227)	Checked (n=152)
Age	<21	29 (67%)	14 (33%)
	21–34	124 (63%)	72 (37%)
	>34	74 (53%)	66 (47%)
ARIA+	Major cities of Australia	108 (56%)	86 (44%)
	Regional and remote Australia	119 (64%)	66 (36%)
Do you have children under 5?	No	146 (62%)	91 (38%)
	Yes	81 (57%)	61 (43%)
What education level have you completed?	Did not complete high school	87 (63%)	52 (37%)
	Completed high school	87 (58%)	63 (42%)
	Completed tertiary education	53 (59%)	37 (41%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S10. Associations between characteristics and selecting "telehealth"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.198 (1.044, 1.374)	0.0102	1.232 (1.065, 1.425)	0.0049
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.697 (0.461, 1.053)	0.0862	0.695 (0.455, 1.062)	0.0926
Do you have any children under 5? (Yes vs No)	1.208 (0.792, 1.844)	0.3807	1.286 (0.834, 1.984)	0.2551
What education level have you completed?		0.7111*		0.4648*
Competed tertiary education vs Completed high school	0.964 (0.567, 1.639)	0.8924	0.754 (0.430, 1.324)	0.3261
Did not complete high school vs Completed high school	0.825 (0.515, 1.324)	0.4259	0.759 (0.466, 1.236)	0.2682

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S11. Participant characteristics for selecting "videoconferencing"

Characteristic	Class/statistic	Unchecked (n=279)	Checked (n=100)
Age	<21	33 (77%)	10 (23%)
	21–34	142 (72%)	54 (28%)
	>34	104 (74%)	36 (26%)
ARIA+	Major cities of Australia	141 (73%)	53 (27%)
	Regional and remote Australia	138 (75%)	47 (25%)
Do you have children under 5?	No	176 (74%)	61 (26%)
	Yes	103 (73%)	39 (27%)
What education level have you completed?	Did not complete high school	114 (82%)	25 (18%)
	Completed high school	104 (69%)	46 (31%)
	Completed tertiary education	61 (68%)	29 (32%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S12. Associations between characteristics and selecting "videoconferencing"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	0.999 (0.860, 1.160)	0.9899	1.003 (0.856, 1.176)	0.9677
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.906 (0.573, 1.432)	0.6726	0.972 (0.608, 1.552)	0.9040
Do you have any children under 5? (Yes vs No)	1.092 (0.683, 1.747)	0.7121	1.102 (0.683, 1.778)	0.6901
What education level have you completed?		0.0196*		0.0210*
Competed tertiary education vs Completed high school	1.075 (0.613, 1.886)	0.8013	1.077 (0.597, 1.945)	0.8051
Did not complete high school vs Completed high school	0.496 (0.285, 0.863)	0.0132	0.497 (0.284, 0.872)	0.0147

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S13. Participant characteristics for selecting “a text messaging service”

Characteristic	Class/statistic	Unchecked (n=168)	Checked (n=211)
Age	<21	18 (42%)	25 (58%)
	21–34	85 (43%)	111 (57%)
	>34	65 (46%)	75 (54%)
ARIA+	Major cities of Australia	89 (46%)	105 (54%)
	Regional and remote Australia	79 (43%)	106 (57%)
Do you have children under 5?	No	103 (43%)	134 (57%)
	Yes	65 (46%)	77 (54%)
What education level have you completed?	Did not complete high school	64 (46%)	75 (54%)
	Completed high school	66 (44%)	84 (56%)
	Completed tertiary education	38 (42%)	52 (58%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S14. Associations between characteristics and selecting “a text messaging service”

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	0.996 (0.872, 1.137)	0.9534	0.990 (0.862, 1.136)	0.8810
ARIA+ (Regional and remote Australia vs Major cities of Australia)	1.137 (0.758, 1.706)	0.5342	1.162 (0.770, 1.753)	0.4738
Do you have any children under 5? (Yes vs No)	0.910 (0.599, 1.383)	0.6603	0.910 (0.597, 1.388)	0.6626
What education level have you completed?		0.8463*		0.7991*
Competed tertiary education vs Completed high school	1.075 (0.634, 1.823)	0.7879	1.102 (0.634, 1.914)	0.7313
Did not complete high school vs Completed high school	0.921 (0.579, 1.464)	0.7272	0.916 (0.572, 1.465)	0.7129

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S15. Participant characteristics for selecting "social media"

Characteristic	Class/statistic	Unchecked (n=184)	Checked (n=195)
Age	<21	21 (49%)	22 (51%)
	21–34	94 (48%)	102 (52%)
	>34	69 (49%)	71 (51%)
ARIA+	Major cities of Australia	94 (48%)	100 (52%)
	Regional and remote Australia	90 (49%)	95 (51%)
Do you have children under 5?	No	113 (48%)	124 (52%)
	Yes	71 (50%)	71 (50%)
What education level have you completed?	Did not complete high school	75 (54%)	64 (46%)
	Completed high school	67 (45%)	83 (55%)
	Completed tertiary education	42 (47%)	48 (53%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S16. Associations between characteristics and selecting "social media"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	0.979 (0.858, 1.117)	0.7489	0.984 (0.857, 1.129)	0.8153
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.992 (0.663, 1.485)	0.9697	1.020 (0.677, 1.536)	0.9260
Do you have any children under 5? (Yes vs No)	0.911 (0.601, 1.382)	0.6617	0.901 (0.592, 1.372)	0.6278
What education level have you completed?		0.2656*		0.2716*
Competed tertiary education vs Completed high school	0.923 (0.546, 1.559)	0.7632	0.931 (0.538, 1.612)	0.7993
Did not complete high school vs Completed high school	0.689 (0.433, 1.095)	0.1150	0.691 (0.432, 1.105)	0.1224

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S17. Participant characteristics for selecting "health apps"

Characteristic	Class/statistic	Unchecked (n=195)	Checked (n=184)
Age	<21	26 (60%)	17 (40%)
	21–34	91 (46%)	105 (54%)
	>34	78 (56%)	62 (44%)
ARIA+	Major cities of Australia	103 (53%)	91 (47%)
	Regional and remote Australia	92 (50%)	93 (50%)
Do you have children under 5?	No	118 (50%)	119 (50%)
	Yes	77 (54%)	65 (46%)
What education level have you completed?	Did not complete high school	70 (50%)	69 (50%)
	Completed high school	82 (55%)	68 (45%)
	Completed tertiary education	43 (48%)	47 (52%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S18. Associations between characteristics and selecting "health apps"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	0.993 (0.870, 1.132)	0.9125	0.967 (0.843, 1.110)	0.6366
ARIA+ (Regional and remote Australia vs Major cities of Australia)	1.144 (0.764, 1.712)	0.5128	1.172 (0.778, 1.765)	0.4477
Do you have any children under 5? (Yes vs No)	0.837 (0.552, 1.270)	0.4031	0.842 (0.553, 1.283)	0.4245
What education level have you completed?		0.5567*		0.5061*
Competed tertiary education vs Completed high school	1.318 (0.781, 2.226)	0.3015	1.375 (0.794, 2.381)	0.2555
Did not complete high school vs Completed high school	1.189 (0.749, 1.888)	0.4639	1.192 (0.746, 1.906)	0.4624

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S19. Participant characteristics for selecting "health tracker"

Characteristic	Class/statistic	Unchecked (n=215)	Checked (n=164)
Age	<21	24 (56%)	19 (44%)
	21–34	104 (53%)	92 (47%)
	>34	87 (62%)	53 (38%)
ARIA+	Major cities of Australia	113 (58%)	81 (42%)
	Regional and remote Australia	102 (55%)	83 (45%)
Do you have children under 5?	No	132 (56%)	105 (44%)
	Yes	83 (58%)	59 (42%)
What education level have you completed?	Did not complete high school	73 (53%)	66 (47%)
	Completed high school	92 (61%)	58 (39%)
	Completed tertiary education	50 (56%)	40 (44%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S20. Associations between characteristics and selecting "health tracker"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.013 (0.887, 1.157)	0.8475	0.991 (0.863, 1.139)	0.9020
ARIA+ (Regional and remote Australia vs Major cities of Australia)	1.135 (0.756, 1.705)	0.5411	1.135 (0.751, 1.715)	0.5489
Do you have any children under 5? (Yes vs No)	0.894 (0.587, 1.361)	0.6004	0.904 (0.591, 1.382)	0.6400
What education level have you completed?		0.3098*		0.3264*
Competed tertiary education vs Completed high school	1.269 (0.747, 2.156)	0.3783	1.292 (0.742, 2.251)	0.3648
Did not complete high school vs Completed high school	1.434 (0.898, 2.289)	0.1309	1.427 (0.888, 2.292)	0.1414

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S21. Participant characteristics for selecting "cultural engagement"

Characteristic	Class/statistic	Unchecked (n=174)	Checked (n=205)
Age	<21	26 (60%)	17 (40%)
	21–34	91 (46%)	105 (54%)
	>34	57 (41%)	83 (59%)
ARIA+	Major cities of Australia	69 (36%)	125 (64%)
	Regional and remote Australia	105 (57%)	80 (43%)
Do you have children under 5?	No	102 (43%)	135 (57%)
	Yes	72 (51%)	70 (49%)
What education level have you completed?	Did not complete high school	74 (53%)	65 (47%)
	Completed high school	66 (44%)	84 (56%)
	Completed tertiary education	34 (38%)	56 (62%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S22. Associations between characteristics and selecting "cultural engagement"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.092 (0.956, 1.247)	0.1942	1.081 (0.938, 1.247)	0.2812
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.421 (0.278, 0.636)	<0.0001	0.437 (0.287, 0.666)	0.0001
Do you have any children under 5? (Yes vs No)	0.735 (0.484, 1.115)	0.1476	0.752 (0.488, 1.159)	0.1968
What education level have you completed?		0.0615*		0.1761*
Competed tertiary education vs Completed high school	1.294 (0.758, 2.208)	0.3443	1.028 (0.580, 1.822)	0.9236
Did not complete high school vs Completed high school	0.690 (0.434, 1.097)	0.1169	0.670 (0.414, 1.085)	0.1034

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S23. Participant characteristics for selecting "healthy eating"

Characteristic	Class/statistic	Unchecked (n=169)	Checked (n=210)
Age	<21	16 (37%)	27 (63%)
	21–34	92 (47%)	104 (53%)
	>34	61 (44%)	79 (56%)
ARIA+	Major cities of Australia	85 (44%)	109 (56%)
	Regional and remote Australia	84 (45%)	101 (55%)
Do you have children under 5?	No	100 (42%)	137 (58%)
	Yes	69 (49%)	73 (51%)
What education level have you completed?	Did not complete high school	63 (45%)	76 (55%)
	Completed high school	64 (43%)	86 (57%)
	Completed tertiary education	42 (47%)	48 (53%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S24. Associations between characteristics and selecting "healthy eating"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.031 (0.903, 1.177)	0.6495	1.039 (0.905, 1.194)	0.5856
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.938 (0.625, 1.406)	0.7555	0.929 (0.615, 1.401)	0.7238
Do you have any children under 5? (Yes vs No)	0.772 (0.508, 1.173)	0.2256	0.770 (0.505, 1.174)	0.2243
What education level have you completed?		0.8139*		0.6782*
Competed tertiary education vs Completed high school	0.850 (0.503, 1.438)	0.5459	0.785 (0.452, 1.364)	0.3909
Did not complete high school vs Completed high school	0.898 (0.564, 1.429)	0.6494	0.874 (0.545, 1.401)	0.5763

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S25. Participant characteristics for selecting "exercise"

Characteristic	Class/Statistic	Unchecked (n=217)	Checked (n=162)
Age	<21	31 (72%)	12 (28%)
	21–34	107 (55%)	89 (45%)
	>34	79 (56%)	61 (44%)
ARIA+	Major cities of Australia	106 (55%)	88 (45%)
	Regional and remote Australia	111 (60%)	74 (40%)
Do you have children under 5?	No	135 (57%)	102 (43%)
	Yes	82 (58%)	60 (42%)
What education level have you completed?	Did not complete high school	83 (60%)	56 (40%)
	Completed high school	83 (55%)	67 (45%)
	Completed tertiary education	51 (57%)	39 (43%)

ARIA+ = Accessibility/Remoteness Index of Australia

Table S26. Associations between characteristics and selecting "exercise"

Characteristic	Crude (n=379) OR (95%CI)	p	Adjusted (n=379) OR (95%CI)	p
Age (+5-year increment)	1.095 (0.958, 1.252)	0.1836	1.109 (0.964, 1.276)	0.1468
ARIA+ (Regional and remote Australia vs Major cities of Australia)	0.803 (0.534, 1.208)	0.2919	0.807 (0.534, 1.222)	0.3117
Do you have any children under 5? (Yes vs No)	0.968 (0.636, 1.475)	0.8813	0.992 (0.648, 1.518)	0.9703
What education level have you completed?		0.7477*		0.6217*
Competed tertiary education vs Completed high school	0.947 (0.559, 1.604)	0.8404	0.822 (0.473, 1.429)	0.4868
Did not complete high school vs Completed high school	0.836 (0.524, 1.334)	0.4521	0.800 (0.497, 1.288)	0.3587

ARIA+ = Accessibility/Remoteness Index of Australia

* Overall comparison

Table S27. Relationship between confidence to discuss health topics and likelihood of selecting that topic for mHealth

Health topic	Confident to discuss health topic with a health professional?	Interested in using a mobile phone for health topic: Not selected in top 3	Interested in using a mobile phone for health topic: Selected in top 3	p
Eating and diet	No	25 (16%)	26 (13%)	0.4464
	Yes	136 (84%)	178 (87%)	
	Not relevant	8	6	
Reducing alcohol	No	36 (19%)	11 (48%)	0.0020
	Yes	150 (81%)	12 (52%)	
	Not relevant	170	0	
Exercise	No	32 (16%)	19 (12%)	0.2853
	Yes	168 (84%)	139 (88%)	
	Not relevant	17	4	
Family violence	No	73 (38%)	6 (25%)	0.1992
	Yes	117 (62%)	18 (75%)	
	Not relevant	161	4	
Quitting smoking	No	31 (16%)	18 (15%)	0.8942
	Yes	165 (84%)	100 (85%)	
	Not relevant	61	4	
Cannabis or other drug use	No	50 (37%)	18 (41%)	0.6458
	Yes	85 (63%)	26 (59%)	
	Not relevant	196	4	
Mental health	No	26 (14%)	24 (16%)	0.6522
	Yes	158 (86%)	127 (84%)	
	Not relevant	40	4	
Women's health	No	29 (9.6%)	7 (11%)	0.6494
	Yes	274 (90%)	54 (89%)	
	Not relevant	15	0	
Children's health	No	11 (4.0%)	1 (2.2%)	0.5530
	Yes	261 (96%)	44 (98%)	
	Not relevant	62	0	

Chapter 9 – Development of a maternal and child mHealth program with Aboriginal and Torres Strait Islander mothers: Co-design approach

(Study 2)

Content

9.1 Chapter overview

In Chapter 8, a cross-sectional survey was used to gather formative knowledge on Aboriginal and Torres Strait Islander women's access to and interest in mHealth. The cross-sectional survey identified that smartphone use among Aboriginal and Torres Strait Islander women is high, and women have a strong desire for mHealth. Further, Aboriginal and Torres Strait Islander women were found to be high users of social media, and SMS text messages were the most preferred modality for mHealth. The most preferred topics for future mHealth programs were healthy eating and cultural engagement. The findings in Chapter 8 support the need for targeted mHealth programs for Aboriginal and Torres Strait Islander women. Chapter 9 is the second part of the formative research for this thesis. This chapter describes the co-design methods used to develop the Growin' Up Healthy Jarjums mHealth program.

9.2 Publication details

Perkes SJ, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B. Development of a maternal and child mHealth intervention with Aboriginal and Torres Strait Islander mothers: co-design approach. JMIR Formative Research. 2022;6(7):e33541. https://doi.org/10.2196/33541

A copy of the manuscript can be found in Appendix 14.

Student's contribution to the publication:

80% Research design

80% Data collection and analysis

80% Writing and editing

Co-authors:

Belinda Huntriss

Noelene Skinner

Bernise Leece

Dr Rosie Dobson

Professor Joerg Mattes

Dr Kerry Hall

Professor Billie Bonevski

Authors' contributions to the publication:

SP led the study design; all authors contributed to the design of the study, including the conceptualisation. SP obtained funding for the study, and led data collection and analysis alongside BH, NS and BL. RD, BB, JM and KH provided oversight of analysis, and KH provided cultural guidance. BB, JM and KH provided supervision to PhD candidate SP. SP led writing of the manuscript; all authors read, edited and approved the final manuscript. Co-authorship approval for HDR publication of the Chapter 9 manuscript can be found in Appendix 15.

9.3 Abstract

Background: Despite their growing popularity, there are very few mHealth programs for Aboriginal and Torres Strait Islander people that are culturally safe and evidence based. A co-design approach is considered a suitable methodology for developing health programs with Aboriginal and Torres Strait Islander people.

Objective: The aim of this study was to co-design an mHealth program to improve health knowledge, health behaviours and access to health services for women caring for young Aboriginal and Torres Strait Islander children.

Methods: Aboriginal researchers led engagement and recruitment with health services and participants in three Aboriginal and Torres Strait Islander communities in NSW, . Focus groups and interviews were facilitated by researchers and an app developer to gather information on three predetermined themes: design characteristics, content modules, and features and functions. Findings from the co-design led to the development of an mHealth prototype. Theories of health behaviour change were used to underpin program components. Existing publicly available evidence-based information was used to develop content. Governance was provided by an Aboriginal advisory group.

Results: In total, 31 mothers and 11 health professionals participated in eight co-design focus groups and 12 interviews from June 2019 to September 2019. The six design characteristics identified as important were credibility, Aboriginal and Torres Strait Islander designs and cultural safety, family centredness, supportive, simple to use, and confidential. The content includes six modules for women's health: Smoke-free families; Safe drinking; Feeling good; Women's business; Eating; and Exercising. The content also includes six modules for children's health: Breathing well; Sleeping; Milestones; Feeding and eating; Vaccinations and medicines; and Ears, eyes and teeth. In addition, six technology features and functions were identified: content feed, social connection, reminders, rewards, communication with health professionals, and use of videos.

Conclusions: An mHealth program that included app, Facebook page and SMS text messaging modalities was developed based on the co-design findings. The program incorporates health behaviour change theory, evidence-based information, and the preferences of Aboriginal and Torres Strait Islander women and health professionals. A pilot study is now needed to assess the acceptability and feasibility of the program.

9.4 Introduction

The health and wellbeing of Aboriginal and Torres Strait Islander people has been significantly impacted by dispossession, interruption of culture, and intergenerational trauma since the colonisation of Australia (47). The ongoing impact has resulted in unequal opportunity for good health. The life expectancy of Aboriginal and Torres Strait Islander women is 8 years less than non-Indigenous Australian women (48). In the 2018–2019 National Aboriginal and Torres Strait Islander Health Survey, the majority of women aged 15 years and over were not meeting guidelines for physical activity, vegetable intake or fruit intake; 36% reported they smoked tobacco daily; and 35% reported they experienced high or very high levels of psychological distress (49). Infant mortality continues to be unacceptably high for Aboriginal and Torres Strait Islander babies: 2.1 times the rate of non-Indigenous infants (6.3 and 3.1 per 1000 live births, respectively) (50). Mothers and babies getting the best possible care and support for a good start to life is one of 12 health priorities of the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 (47).

Aboriginal and Torres Strait Islander people make up 3.3% (798,400/24,193,939) of the Australian population (51) and include many distinct groups with their own language and culture. In total, 44% of Aboriginal and Torres Strait Islanders live in regional areas, 37% in cities, and 18% in remote or very remote areas (51). Those living in regional and remote areas have less access to primary health care and overall poorer health (52). Nationally, Aboriginal and Torres Strait Islander people have less access to internet at home (75.3% compared with 85.8% of all Australians); there are significant differences based on location: 82.8% in cities, 73.2% in regional areas, 61.3% in remote areas, and 49.9% in very remote areas (53). More than one in three Aboriginal and Torres Strait Islander people are mobile-only users (35%), compared to a national rate of one in five (19.9%); these figures are linked to socioeconomic factors (54). Using a mobile only is likely to incur more costs for data, less capability, and less access to more sophisticated digital health information and tools (54). It is of importance that mHealth programs are developed with a goal to increase digital inclusion.

MHealth is the use of mobile technology to improve health. Functions include SMS text messaging, MMS, voice, internet access and software apps, which range in complexity. mHealth is used for a range of purposes including health education, health behaviour change, sensors and point-of-care diagnostics, registries and vital events tracking, and data collection (55). mHealth is being used increasingly for health promotion because of its reach, with over 7 billion mobile phone subscriptions globally (56); the Be He@lthy, Be Mobile initiative by the World Health Organization has reached over 3.5 million people (57). There are limited recent national figures on smartphone ownership among Aboriginal and Torres Strait Islander people, although available data indicates ownership is high; a survey with 400 Aboriginal and Torres Strait Islander people in 2014 reported that 70% of Aboriginal and Torres Strait Islander people owned a smartphone and 69% used Facebook, compared with 66% and 40%, respectively, for non-Indigenous Australians (20). The top reason for using a mobile phone in this group was to send SMS text messages (20).

Studies focused on Aboriginal and Torres Strait Islander people using SMS text messages to improve health show high acceptability (39, 41, 58). SMS text messages have the advantage of being accessible on all phones and not requiring access to data. There are few technical barriers to SMS text messages and high acceptability of the modality among new mothers (19, 59). In a meta-review (23 systematic reviews, 371 studies, 79,665 participants) on the impact of mHealth on a range of outcomes, including clinical outcomes, adherence to treatment and care, health behaviour change, disease management and attendance rates, SMS text messages was the most frequently examined function and reported to be most successful overall (60). SMS text messaging appears to be particularly effective at increasing smoking cessation rates (in adult smokers from mostly high-income countries) (61). The evidence for SMS text messaging helping to improve nutrition and physical activity is not as strong; however, SMS text messaging used in conjunction with other mHealth functionality has shown significant positive effects for healthy eating (60).

Health apps continue to be popular, although the evidence suggests apps have limited effectiveness on changing health behaviours (60, 62-64). Some studies have found that apps can be effective at changing behaviour among some clinical groups (60), although overall there is limited evidence to date. Of the few trials focused on indigenous populations, app usage has been reported to be low (65, 66). A recent pilot randomised controlled trial of a smoking cessation app with 49 Aboriginal people in Australia reported low to moderate levels of app usage, and at 6-month follow-up only one participant was abstinent (66). The authors concluded that while there was broad acceptability for the app, mHealth programs should be designed with functions that are commonly used, including social media platforms (66). A co-designed mHealth app developed in New Zealand with Māori and Pacific Island people was tested in a cluster randomised controlled trial in 2019 (n=1451) (65). Adherence to health-related behaviour guidelines increased at 12 weeks in both groups, with no difference between groups. Engagement with the app overall was low, although those that did engage with the app as it was designed saw greater benefit. The co-design approach was reported to be very positive from community, as was reflected in the high participation and follow-up rates (65).

Social media is a form of mHealth with potential to support health. The Aboriginal and Torres Strait Islander health sector were early adopters of social media networks to promote health (44, 67). Social media campaigns on COVID-19 by Aboriginal and Torres Strait Islander health organisations is a recent example (68). A recent Cochrane review on behavioural programs delivered through social media for health behaviour change, health outcomes and health equity (88 studies; n=871,378) reported varied effects; overall, social media was found to improve physical activity, weight loss and general wellbeing, and small to no effect was found for other outcomes (69). No studies focusing on Aboriginal and Torres Strait Islander people were included in the review.

In response to the limited mHealth programs available to Aboriginal and Torres Strait Islander women and children, we aimed to co-design a prototype focused on the needs and ideas of Aboriginal and Torres Strait Islander mothers. Co-design is a partnership approach where end users are actively involved from conception to dissemination (70). Using co-design methodologies is one of the guiding principles of the AH&MRC of NSW ethical guidelines for conducting health research with Aboriginal people (71). In this paper, we describe the co-design processes and findings, and give a description of the mHealth prototype.

9.5 Methods

9.5.1 Study design

In total, 8 focus groups and 12 interviews were conducted from June 2019 to September 2019. Surveys were used to collect demographics at the start of focus groups and interviews. An Aboriginal advisory group including Aboriginal team members who were also members of the participating communities met quarterly to oversee design, implementation, analysis and reporting. An expert mHealth research group were consulted for opinion on research and program design. Human research ethics approval was received from the AH&MRC (1485/19) and the University of Newcastle (H-2019-00760).

9.5.2 Co-design framework

A co-design framework for an mHealth program with Māori and Pacific communities in New Zealand (70) based on work by Bratteteig (72) was used to guide methods of this study. Co-design is a coherent methodology with a range of tools and techniques used to favour the preferences of end users (72). The co-design methods used included focus group and interview discussions, card sorting, storyboarding, design activities, survey, guidance from expert groups, and an iterative design phase with the research team.

9.5.3 Setting

Focus groups and interviews were held in three regional NSW locations: Newcastle, Coffs Harbour and Inverell. In total, five Aboriginal organisations (including three Aboriginal health services, an Aboriginal preschool and an Aboriginal corporation) and three NSW Health sites participated. Venues for focus groups and interviews were decided in consultation with participants.

9.5.4 Participants

Women aged 16 years and over who were either mothers or primary carers of an Aboriginal or Torres Strait Islander child aged 0 to 5 years, or pregnant (30+ weeks gestation), owned or regularly used a smartphone, and had accessed a participating service (Aboriginal health service or NSW Health service) were eligible to participate. Health professionals at participating services who worked with women or children were eligible.

9.5.5 Procedures

Convenience sampling was used to recruit participants. Aboriginal researchers (BH, NS and BL) who worked within the participating communities used their personal networks. In addition, participants were asked if they would like to recommend a friend or family member to the study. Potential participants were screened for eligibility when contacted by the researcher via phone. The researcher explained the study and gained informed consent over the phone initially and again in person before the start of the focus group or interview. Participants were reimbursed with a A$30 shopping voucher for attending focus groups and interviews and provided with refreshments. Health professionals were recruited using a snowball methodology through the participating services. Health professionals were not reimbursed.

Mothers and health professionals participated in separate focus groups and interviews. Focus groups and interviews were co-facilitated by a combination of Aboriginal researchers (NS and BH), a PhD student (SJP) and an app developer. Interviews and focus groups were 20–90 minutes in length. The number of participants in focus groups ranged from two to six. Focus groups and interviews were recorded and transcribed, and field notes taken.

9.5.6 Measures

Different surveys and discussion guides were used with mothers and health professionals. Discussions and activities were used to identify: 1) design characteristics; 2) content modules; and 3) features and functions.

9.5.7 Mothers

Survey: The survey comprised 16 items, including demographic, cultural and socioeconomic items. The items were selected from a previous study (73), with all items having been tested with Aboriginal and Torres Strait Islander mothers previously.

Discussion guide: Three main questions were asked in all focus groups and interviews with mothers. Follow-up questions were asked depending on responses. Additional questions about mobile phone use to inform features and functions were asked in focus groups co-facilitated by the app developer. The three main questions were as follows:

1. How would an mHealth program designed for healthy living for Aboriginal and Torres Strait Islander people differ from other mHealth programs?
2. Are you more interested in mHealth for your own health or your child's health? What topics and features interest you?
3. What do you think stops or prevents some women from accessing health information and services for themselves and their children?

Activities: Card-sorting activities were used to identify current mobile phone use (functions used, frequency of use and reasons for use). Storyboarding activity was used to elicit creative descriptions of the mHealth program using drawings and words on what the program should include. Design activity was used to gain feedback on potential designs.

9.5.8 Health professionals

Survey: The survey comprised five items related to demographic and professional practice characteristics.

Discussion guide: In all focus groups and interviews with health professionals, three main questions were asked. Additional follow-up questions were asked depending on the response. The three main discussion questions were as follows:

1. What do you think are the most important health and wellbeing topics to include for Aboriginal or Torres Strait Islander women, children and/or family?
2. What are the barriers for Aboriginal or Torres Strait Islander families to having good health?
3. What types of mobile technology do you think could support Aboriginal or Torres Strait Islander women's and children's health?

9.5.9 Co-design analysis

A generalised thematic analysis was completed. An Aboriginal researcher (BH) and PhD candidate (SJP) independently coded themes. NVivo software (version 12.0; QSR International) was used to complete independent coding and comparison by the two coders. In total, three predetermined codes were used based on a similar co-design study (70). The three codes were: 1) design characteristics; 2) content modules; and 3) features and functions. The coders met to agree on subcodes and definitions. Survey findings are presented using descriptive statistics.

9.5.10 Program development

The findings from the co-design stage were then used to develop a prototype program incorporating an app, SMS text messages, social media and videos. The program development was an iterative process with meetings among the team to decide the final features and functionalities. Not all ideas could be adopted for various reasons, such as time, funding and technology constraints. We used a combination of building new functions (app) and using existing functions (Facebook page and SMS text messaging).

The program was grounded in behaviour change theory. The Health Belief Model was used to underpin the app portion of the program. The Health Belief Model is considered to be well suited to mHealth programs with use of the ‘cue to action’ component (74). The basic constructs are perceived threat of illness, perceived benefits of health behaviour change, perceived barriers to change, cues to action, and self-efficacy (75). Behaviour change techniques were used to formulate SMS text messages. SMS text messages were coded for behaviour change techniques by two coders (Sam McCrabb and SJP) using behaviour change technique taxonomy (v1) (76) and the process outlined by Michie et al (77). Of the two coders, one was experienced in coding behaviour change techniques (Sam McCrabb) and the other was a PhD student (SJP). Disagreements were resolved through discussion and key messages adapted to include further effective behaviour change techniques.

Key messages were developed on health topics identified from focus groups and interviews. Content was formulated from publicly available evidence-based health resources. Key messages were adapted to SMS text messages, small pieces of written information for the app, and Facebook posts.

The prototype program comprised an app, videos, Facebook (Meta-Platforms, Inc) page and SMS text messaging:

> *App:* A web-based prototype app was developed. Key messages were developed in text and video form on the 12 included topics. Rapid iterative cycles between the app developer and

research team were used to refine the design. An Aboriginal graphic designer developed graphics for each module and logo.

Videos: Twelve short videos were captured on a Canon camera. All presenters were health professionals from participating sites or contacts of the research team. Short scripts were provided to health professionals based on key messages. Staff were encouraged to use their own knowledge and expertise on each topic. Videos were filmed by a videographer and professionally edited. Captions were completed by rev.com and voiceovers were completed by two Aboriginal researchers (BH and NS). Length of videos ranged from 112 to 300 seconds. Vimeo (Vimeo, Inc) was used as the platform to host videos.

Facebook page: A Facebook group was developed and administered by two Aboriginal researchers (BH and NS). Both researchers were regular Facebook users and had significant networks and knowledge of Aboriginal and Torres Strait Islander organisations, events and health services. Key messages were predeveloped in text and video format. Other content shared was decided by administrators, including sharing posts from their personal accounts if suited to the broad aim of the program.

SMS: SMS text messages were developed based on the processes described by Abroms et al (78). Steps included choosing a behaviour change goal, choosing communication objectives and behavioural techniques, designing a framework, and writing a text message library (78). SMS text messages were written to allow tailoring using the mother's and child's name, child's age and topic interest of the mother. Tailoring SMS text messages around timing of key behaviours, such as after a baby is born, can improve saliency and likelihood of behaviour change (79). SMS text messages were written by an Aboriginal researcher (BH) and PhD student (SJP). A web-hosted SMS text message server (SMS Express) will be used to send all SMS text messages.

9.6 Results

A total of 42 participants were recruited to the study: 31 mothers and 11 health professionals. Demographics and cultural characteristics of mothers are presented in Table 9.1 and demographics of health professionals in Table 9.2.

Table 9.1. Demographic and cultural characteristics of mothers (n=31)

Characteristics	**n (%)**
Age (years), mean (range)	31.17 (19–50)
Indigenous status	
Aboriginal	21 (68)
Torres Strait Islander	2 (7)
Non-identified	7 (23)
Did not answer	1 (3)
Identified with an Indigenous community	
Yes	25 (81)
No	1 (3)
Unknown	4 (13)
Did not answer	1 (3)
Maintain cultural connections at home, yes	25 (81)
Ways of connecting to culture	
Music/dance	19 (61)
Storytelling	19 (61)
Indigenous television	18 (58)
Art	15 (48)
Food	14 (45)
Indigenous internet sites	10 (32)
Indigenous newspapers	7 (23)
Traditional medicine	6 (19)
Indigenous radio	5 (16)
Other	1 (3)
Family members from Stolen Generations[1]	
Yes	6 (19)
No	12 (39)
Unknown	13 (42)
Education of mother	
Did not finish high school	6 (19)
High school	6 (19)
Certificate	10 (32)
Diploma	2 (7)
Bachelor’s degree	4 (13)
Postgraduate degree	1 (3)
Did not answer	2 (7)

Characteristics	**n (%)**
Currently pregnant, yes	1 (3)
Partner, yes	16 (52)
Number of people living in household, mean (SD; range)	4 (1.31; 2–7)
Number of children (under 18 years) living in household, mean (SD; range)	2.39 (1.41; 1–5)
Smoking status of mother	
Non-smoker	21 (68)
Yes, daily	5 (16)
Yes, at least once a week	2 (7)
Yes, less often than once a week	1 (3)
Did not answer	2 (7)
Number of cigarettes smoked per day (on days smoking), mean (SD; range)	8.5 (3.21; 4–12)
Number of smokers in household	
0	14 (45)
1	10 (32)
2 to 3	4 (13)
More than 3	1 (3)
Child exposure to indoor tobacco smoke, yes	1 (3)
Child exposure to outdoor tobacco smoke, yes	15 (48)
Child exposure to tobacco smoke in the car, yes	0 (0)

1. The Stolen Generations refers to a period in Australia's history when Aboriginal children were removed from their families through government policies. This happened from the mid-1800s to the 1970s (80).

Table 9.2. Demographics of health professionals (n=11)

Characteristics	**n (%)**
Health service type	
Aboriginal medical service	6 (55)
NSW Health service	5 (45)
Sex: Female	11 (100)
Indigenous status	
Aboriginal	4 (36)
Torres Strait Islander	0 (0)
Non-identified	7 (64)
Role at health service:	
Registered nurse	7 (64)
Aboriginal health worker	3 (27)
Senior family health practitioner	1 (9)
Number of years at service, mean (SD; range)	12 (8.7; 3–32)

9.6.1 Design characteristics

We identified six main design characteristics: 1) credibility; 2) Aboriginal and Torres Strait Islander designs and cultural safety; 3) family centredness; 4) supportive; 5) simple to use; and 6) confidential.

Credibility: Mothers talked about the difficulty of finding information online that was evidence based. Most mothers said that they used Google to find real-time health information for themselves and for their children: “*Literally, I Google everything.*” Many of the mothers said that it can be difficult to know what websites are most up to date and accurate, and that it is difficult to find information: “*The biggest thing I find on Google, you get everything. You don’t get the ones that are reputable.*” Another mother said, “*I’m finding you’re having to like…scroll…scroll and scroll to try and find that information.*” Mothers said that they want current health information from reputable health professionals and organisations including “*useful websites links*”. Health professionals talked about the importance of credible health information to improve health literacy: “*I think lack of knowledge that they are so sick. Recognising the signs of illness that can lead to them being really, really [sick].*” This highlighted the importance of all content included in the prototype program being sourced from credible evidence-based health resources and broken down into palatable small chunks with links to further information.

Aboriginal and Torres Strait Islander designs and cultural safety: Most of the mothers said that Aboriginal designs, language and representation were important for engagement. A mother said, "*I think if it had Aboriginal designs that would be really good, because if I download an app and it doesn't have the look, like being culturally aware [I don't use it].*" Another mother said, "*Don't make it black and white, it's got to be like colourful.*" A mother spoke about the program needing Aboriginal representation in images and videos: "*If it's going to be an Aboriginal app, I think you have to have Aboriginal people.*" Another mother discussed using an app for quitting smoking that was not representative of Aboriginal people: "*It was easy to use, but I couldn't relate to it…didn't seem like it was aimed at black fellas even though we thought it was.*"

It was evident from mothers' experiences of racism that the program needed to be centred in cultural safety. Some mothers talked about feeling fearful and judged when seeking health care. A mother said, "*Being an Aboriginal mum especially, I was just worried about DoCS [Department of Child Services]. Like whether they could see if I was handling having two children on top of my own family breakdown. Like my mum's kids are in DoCS. So that's what my biggest fear was.*" Other mothers expressed feeling judged about certain health behaviours and topics. A mother said, "*The biggest thing is why people do hide it [smoking], because they don't want to be judged. They don't want to hear all that stuff.*"

To centre cultural safety in the program, all aspects of the program were co-developed by Aboriginal people: the research was governed by an Aboriginal advisory board and co-led by an Aboriginal academic (KH); four of the eight members of the research team are Aboriginal; an Aboriginal graphic designer designed the module icons and logo; Aboriginal researchers were administrators of the Facebook page and shared cultural links, events, activities, affirmations and images; an Aboriginal videographer filmed all videos; Aboriginal health professionals presented in the videos; an Acknowledgement of Country and 'welcome' message by an Aboriginal researcher was on the main page; and all content was co-written by Aboriginal researchers.

Family centredness: It was decided unanimously that the program should include content for both mother and child. One mother said, "*Is this just for children's health? Because I feel like it should incorporate the mother's health too.*" The mothers asked for information on "*things to do with our kids*", "*and stuff for us women too. Pap smears and stuff like that.*" Many mothers and health professionals suggested that the program needed to encompass the entire family including the extended family. One health professional said, "*Put the main focus on the child and then how their [family] health affects the baby's health,*" and a mother said, "*I think a family app would be really good. Like, I know my husband, he's never been around babies.*" Some participants talked about how other family members help bring up children: "*It's nothing to see an aunt bringing up a child, or a grandparent or a sister*" [health professional]. Family centredness in the program was therefore conveyed through messaging that families are the most important role models for jarjums (a Yugambeh word used on the East Coast of Australia meaning children) across modules and functions. Links to websites, events and health information for partners and other family members were included.

Supportive: Most mothers and health professionals indicated that it was important that the program promoted positive self-esteem and wellbeing of mothers. A health professional said the program should give new mothers "*understanding [of] how tired you are going to be, and it's okay, ask for help, everyone feels like that but you're not failing or not doing something wrong*". A mother suggested we include "*some sanity sayings or something like that, or some little sage advice from mums that have been there, done that before, that'd be really helpful*", and another mother said the program could be "*like a reassurance type thing*". Mothers and health professionals recognised that motherhood can be "*totally exhausting*" [health professional] and challenging at times. A mother described the initial period after coming home from hospital; she said, "*I didn't know what to do with him. What do I do with this kid? I was lost.*" To create a program that was supportive of motherhood and of Aboriginal and Torres Strait Islander women, positive and affirming messages were posted on Facebook, sent via SMS and included in the app. Links on where to seek help for mental health concerns were included.

Simple to use: Mothers and health professionals recommended that the program be intuitive, with simple language, and have few technical barriers. Some mothers talked about trying to use other health apps but not being able to due to technological challenges; for example, "*It was just too hard to log in and get started so I gave up or just called someone.*" Many mothers and health professionals emphasised that language used in the program needed to be non-jargon. One mother said, "*Don't put it in a textbook. Because I'm telling you, if my family member downloaded that and it was a textbook way, they would be like – No.*" Another mother said the content should be "*just little pieces of information…then links to the bigger pieces*". We aimed for simple, intuitive app design and utilised other mobile functions commonly used by mothers (Facebook, SMS text messages). To ensure the program was simple and easy to use, health information was presented in short key messages with links to websites for further information. All key messages were written to be at an 8th-grade reading level using the Flesch-Kincaid Grade Level Test as recommended by Abroms et al (78).

Confidential: Mothers and health professionals talked about the importance of confidentiality. Health professionals focused on confidentiality in the health care setting, and the complexities for some staff knowing patient health details. One health professional said, "*There are big things surrounding our health services confidentiality. People don't know or want to know what other people's business is.*" Some mothers spoke about confidentiality; regarding being anonymous if communicating with other mothers or health professionals in a hypothetical mHealth program, a mother said, "*Oh God, yeah. I'd ask an anonymous person on a phone. Rather than ask the doctor face-to-face.*" Other mothers were happy to not be anonymous: "*It wouldn't bother me having my name, because it would just be, this is my experience, and it is what it is. But I would understand if some women didn't.*" To ensure women can choose to remain anonymous and their information confidential, the program design meant that no personal data was collected in any part of the program, other than a mobile number for the SMS text messaging component. Joining the Facebook group is an optional part of the program.

9.6.2 Content modules

Most of the mothers and health professionals suggested the program needed to cover a wide range of health topics for both the mother and child. Health topics identified in the data included *'pains after birth', 'breastfeeding', 'normal speech for toddlers', 'signs of autism', 'earaches', 'behaviour', 'rashes', 'hot temperatures' and 'coughs'.* Similar topics were grouped by the research team and combined into six key content modules for women's health and six key content modules for child health. For example, 'birth', 'reproductive health', 'urinary leaking' and 'Pap smears' became 'Women's business'. All health topics captured in interviews and focus groups were included in the program, either within a module on the app, in SMS text messages or through Facebook posts. Health modules for women were: Smoke-free families; Safe drinking; Feeling good; Women's business; Eating; and Exercising. Health modules for jarjums were: Breathing well; Sleeping; Milestones; Feeding and eating; Vaccinations and medicines; and Ears, eyes and teeth.

9.6.3 Features and functions

Eight features and functions were identified: 1) content feed; 2) social connection; 3) diary and storage of health information; 4) local context; 5) reminders; 6) rewards; 7) talk with health professionals; and 8) use of videos.

Content feed

A content feed was chosen to be a feature of the program, based on the mothers' current mobile phone use. During the card-sorting activity, most of the mothers reported scrolling the content feed on Facebook numerous times per day. Of the 13 women who were asked how many hours per day they used Facebook, 12 (92%) reported using it >4 hours per day. When asked what kept them going back to Facebook, a mother responded, "The content keeps changing." Mothers frequently talked about watching photo and video stories that were uplifting, funny or motivating on Facebook. They talked about using Instagram and Snapchat, too, although less frequently. The intervention was therefore designed to include a Facebook page with daily posts covering a variety of health content.

Social connection

Mothers talked about the social connection and learning from other women when becoming a mother including from their 'mum', 'mother in-law' and 'girlfriends'. The importance of positive relationships when first becoming a mother was well recognised by health professionals and mothers. It was acknowledged by many mothers that some new mothers "*don't have a big support network*". A mother described mothers at playgroup being "*more like a family to each other*". Some of the mothers said that connecting to other mothers would be helpful because they may be going through the same situation or challenge: "*Yeah [I would like to chat to mums in the program] because they might have experienced something that I'm starting to experienc*e." Some mothers talked about the possibility of meeting up with mothers outside the program: "*It's hard to meet people…[could there be] like a mums and bubs thing [as part of the program].*" Another mum said, "*Say if I needed to ask them a question or something that I wouldn't want to write on Facebook [I would like to meet up with them in person].*" Another mother identified that connection is important for mental health: "*When they [new mothers] don't have anybody, depression kicks in.*" The Facebook page was designed to facilitate mothers to connect and share stories and ideas. Discussion points were created to be posted on the Facebook page to facilitate discussion, for example, "Tell us how you engage your jarjums in cooking or take a pic or video of your deadly [great or excellent] lil' chef in the kitchen."

Diary and storage of health information

A feature that enabled users to store specific information about a child's health received mixed responses. Some of the mothers thought that having their child's health information on hand would be of practical benefit when attending medical appointments: "*Like a diary section…I found, when [my child] was sick I started recording when I gave the medication, those sorts of things. That'd be* *good to have an app when you go into the hospital you go 'this is his recordings'* " [mother]. Another mother said, "*So they [health professionals] could just add in medication, add in reports…it'd be good because like [the health service] is only open during the week. Usually, like on the weekend, I'd have to go up to the hospital…So it would be good if there was information like after the visit. Because you don't always take everything in. It goes right over your head.*" Other mothers and health professionals thought there would be confidentiality concerns. Because of the confidentiality concerns raised in the co-design process, a diary feature was not included, although it may be considered as an optional feature in future iterations.

Local context

Many of the mothers and health professionals spoke about the uniqueness of their community and said that the program needed to be relevant to each community, including language, environment (e.g. coastal, desert), and health services and other resources. One mother suggested, "*You could put in your post code, location, or area or something and then it could be localised,*" and a health professional said, "*The contact numbers, if they can't get into emergency, the [local] health line numbers where they can get a bit of advice would be handy on there as well.*" The program included phone numbers of local health services for each community in the app, and Facebook posts were designed promoting localised health services, events, organisations and languages.

Reminders

Many of the mothers talked about how useful SMS text message reminders were from their health services for appointments, and that reminders for other parts of health care would be useful too. One mother said, "*I would probably like all of them [milestone reminders]. I'd like the whole lot, make sure I'm not missing anything,*" and another mother said, "*If someone notified me on this app, that I'm due for a [Pap smear] or something like that, I would like being reminded of things like that.*" Most women said they would prefer reminders via SMS text messages rather than a push notification from an app as they could go back to the message and re-read it. For the program, SMS text messages were developed covering a range of reminders including vaccinations, developmental milestones, check-ups, smoking quit date, exercise and eating well. Reminders about local health initiatives and events were also created to be posted on the Facebook page.

Rewards

The mothers talked about rewards and incentives from health programs and services increasing their motivation. They talked about material rewards such as 'shirts', 'caps' and 'supermarket vouchers', as well as social rewards, including 'comments' and 'likes' on social media, and 'clapping' and 'cheers' on health apps. The mothers who were asked about receiving rewards for a variety of health behaviours were unanimous in their opinion that rewards were enjoyable and motivating. In the program, weekly competitions were created for posting on the Facebook page involving mothers sharing a picture of a health activity, for example, active play or exercising with their children. Prize draws were also incorporated into the program for those who participated in the competitions.

Talk with health professionals

Some mothers suggested being able to communicate with health professionals using SMS text messages or a live chat function would be beneficial. Some mothers said this function would be useful to confirm if they required face-to-face health care, and for reassurance; a mother said, "*Sometimes you don't know if you should go up there [health service] or not, so you could kind of message and say, 'hey, this is what's happening…is it worth coming up or is it just a viral thing going around?'* " Another mother said, "*I know a lot of women, are just like, 'what do I do?'. So just having that reassurance I suppose online.*" Another mother suggested it would be helpful to be able to ask health questions anonymously: "*The option to be anonymous or not known by people [health professionals] would be handy I guess for more embarrassing health concerns.*" Mothers living in rural areas mentioned being anonymous more often in the discussions. Although it was suggested, facilitating a chat directly with health professionals was out of scope for the current prototype due to cost and resources. Telephone numbers for national, state and local health services were listed in the app to enable users to connect with health professionals, if needed, regarding questions they might have.

Use of videos

Most of the mothers reported during the card-sorting activity that they frequently watched short videos on social media and YouTube. A number of mothers and health professionals advised us that videos and images may be more accessible and preferable for some mothers. One health professional said, "*Videos, everyone can watch a video and understand.*" Therefore, a video for each health module was developed for the program. Each video was stored in the app and added to the Facebook page. Additional health videos from external sources were also able to be shared on the Facebook page.

9.6.4 Final overall prototype

The final mHealth program, named Growin' Up Healthy Jarjums, aimed to improve health knowledge and health behaviours, including access to health services. The program comprises three delivery modalities: app, SMS text messages and Facebook page.

App

The app is a central place for users to access all content. The app is primarily for the user that wants in-depth information and has the necessary digital device, internet connection and literacy skills to access it. It is designed to allow the user to navigate to the topic of interest, for example, 'exercising', where they will find small amounts of written information, videos, links to websites and useful contacts. The user may choose to access any topic, in any order, and consume as much information as they like.

The app has four menu screens: 1) home screen; 2) women's health; 3) jarjum's health; and 4) contacts (Figure 9.1). The home screen includes four buttons: 1) My health; 2) Jarjum's health; 3) Facebook page; and 4) Contacts. The user may select a button to move to the next screen, or scroll down to access the embedded Facebook content feed. The embedded Facebook content feed allows the user to remain in the app and read posts, but to comment or 'like' a post, the user needs to access the Growin' Up Healthy Jarjums Facebook page. An Acknowledgement of Country and a spoken welcome message are also included on the home screen. The women's health ('My health') menu page includes six buttons, one for each of the women's health modules: 1) Smoke-free families; 2) Safe drinking; 3) Feeling good; 4) Women's business; 5) Eating; and 6) Exercising. The 'Jarjums health' menu page has the same layout including six buttons for the children's health modules: 1) Breathing well; 2) Sleeping; 3) Milestones; 4) Feeding and eating; 5) Vaccinations and medicines; and 6) Ears, eyes and teeth. Each module, for example, 'Breathing well', includes: 1) 'key messages' incorporating perceived threat of illness and benefits of changing health behaviour; 2) 'tips' to address barriers to change through reassurance and credible advice; 3) cues to action, for example, "Each time jarjum sees a nurse or GP ask them to have a quick look in bub's ears to check if there is any infection"; and 4) links to further information including skills and activities, for example, exercises and healthy recipes to support self-efficacy. Information is presented using small chunks of written information and videos, using the same layout in each module.

SMS text messaging

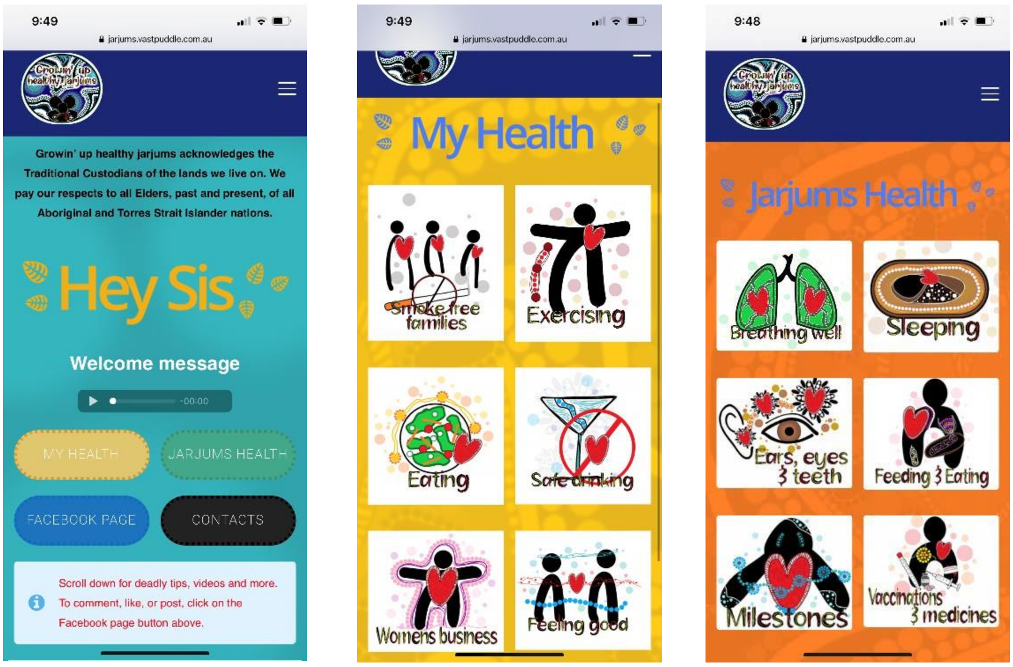
Alongside the app, the prototype included an SMS text message library comprising 112 SMS messages (see example SMSs in Table 9.3). The SMS text messaging component allows users access to health information regardless of phone type, wi-fi access or digital literacy. The SMS text messages covered the content topics identified by the participants. The SMS portion of the program is one-way (unidirectional), other than three SMSs developed for users indicating that they want to quit smoking when registering for the program. In total, 23 behaviour change techniques from 15 behaviour change clusters were incorporated in the SMSs (Supplementary Table S1).

Facebook page

The final modality included in the prototype was the Facebook page. The purpose of the Facebook page was to create community and connection, allow two-way communication, and use a platform that is highly popular among users. Daily content was designed to be added to the Facebook page including: 1) links to reliable health websites; 2) activities for families; 3) weekly competitions; 4) key messages (written and video); 5) events in the community; and 6) supportive affirmative posts. The page was administrated by two Aboriginal team members (NS and BH) who shared posts relevant to their community and region. The Facebook page was embedded into the main screen of the app; it could also be accessed through Facebook. Examples of posts are presented in Figure 9.2.

Figure 9.1. Examples of Growin' Up Healthy Jarjums app screens

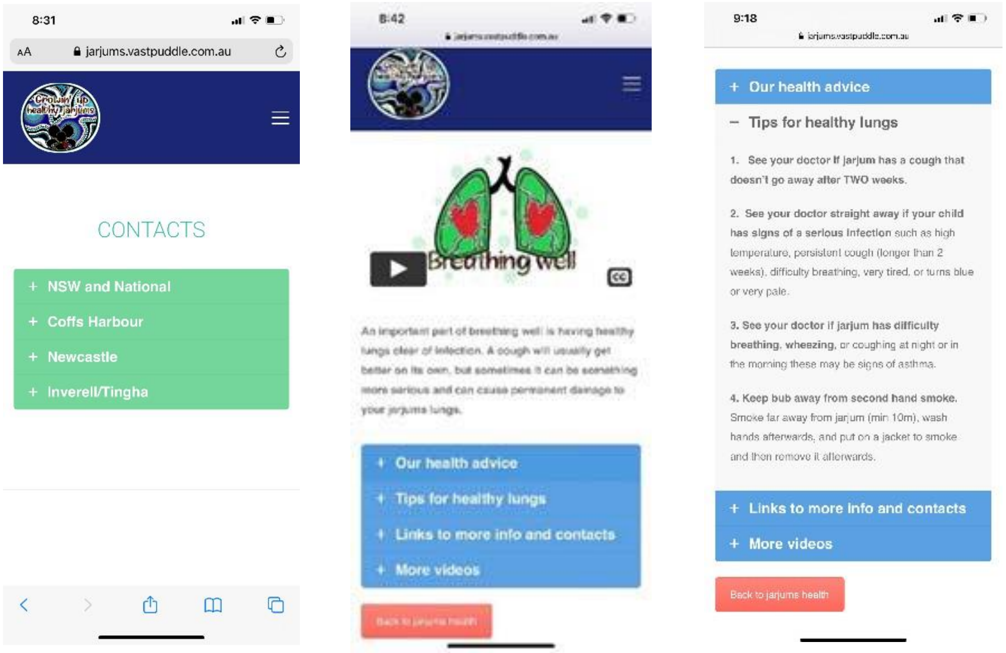
1. Home screen 2. Women's menu screen 3. Jarjum's menu screen



Growin' up healthy jarjums acknowledges the Traditional Custodians of the lands we live on. We pay our respects to all Elders, past and present, of all Aboriginal and Torres Strait Islander nations.

Scroll down for deadly tips, videos and more. To comment, like, or post, click on the Facebook page button above.

4. Contacts screen 5. 'Breathing well' screen 6. Our health advice (accessed from 'Breathing well')



An important part of breathing well is having healthy lungs clear of infection. A cough will usually get better on its own, but sometimes it can be something more serious and can cause permanent damage to your jarjums lungs.

1. See your doctor if jarjum has a cough that doesn't go away after TWO weeks.

2. See your doctor straight away if your child has signs of a serious infection such as high temperature, persistent cough (longer than 2 weeks), difficulty breathing, very tired, or turns blue or very pale.

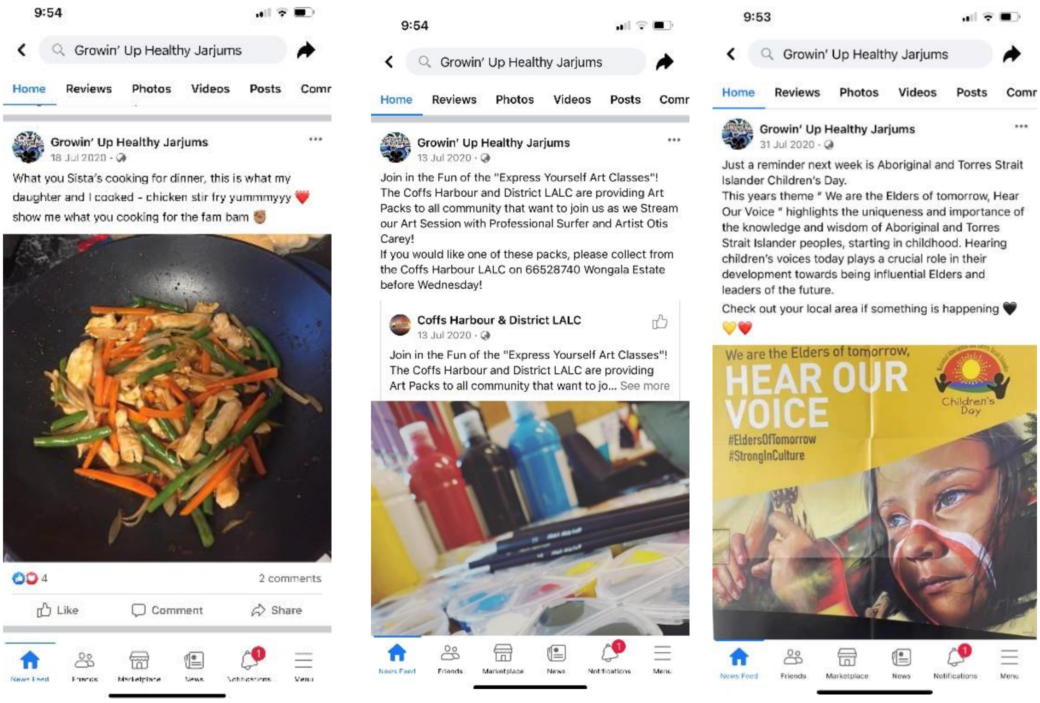
3. See your doctor if jarjum has difficulty breathing, wheezing, or coughing at night or in the morning these may be signs of asthma.

4. Keep bub away from second hand smoke. Smoke far away from jarjum (min 10m), wash hands afterwards, and put on a jacket to smoke and then remove it afterwards.

Table 9.3. Growin' Up Healthy Jarjums modules and example SMS text messages

	Module	Example SMS
Women's health	**Smoke-free families**	Text4jarjum: Giving up the smokes is the best thing you can do for your health. Be a role model and be smoke free. Get support from Quitline 13 78 48 or a doctor and quit for good!
	Safe drinking	Text4jarjum: While under the influence of alcohol, people can make less safe decisions about their jarjums. Check out 'Safe drinking' for tips to set limits.
	Feeling good	Text4jarjum: You're probably not getting much sleep right now. Try to make time for yourself, ask for support from family & friends, and nap when bub does. If you feel that you are not coping, talk to your doctor or midwife. There is help.
	Women's business	Text4jarjum: Be kind to yourself. Your body has gone through some big changes during and after birth. It will take time to bounce back. Whether you had a caesarean or vaginal birth, both may require rest & time for recovery. Here's what to expect after birth.
	Eating	Text4jarjum: The Australian Breastfeeding Association has some useful tips on nutritional needs for breastfeeding mums.
	Exercising	Text4jarjum: Any amount of movement is good for you. Start by doing a little, and gradually build up. You could start with a walk around the block a few times a week and then gradually increase.
Jarjum's health	**Breathing well**	Text4jarjum: A cough is often caused by a cold. Usually, a cough gets better on its own and is not serious, but if your child has a cough that doesn't go away after TWO weeks, or if you are concerned sooner – see your doctor or child health nurse.
	Sleeping	Text4jarjum: A routine that includes relaxing time like bath, book, a gentle song before bed and a regular bedtime each night can help your child settle better.
	Milestones	Text4jarjum: Playgroups, day care and pre-school are great places for jarjums to play and develop. Contact your AMS or health nurse and find out what's on.
	Ears, eyes and teeth	Text4jarjum: Ear infections are really common and can cause long term hearing loss if not treated. Often there are no signs. Ask your doctor to have quick look in [insert child name] ears each visit to make sure there is no infection.
	Vaccinations and medicines	Text4jarjum: Immunising [insert child name] is a safe and easy way to keep jarjums healthy and prevent disease. To check that [insert child name] is up to date with immunisations click here.
	Feeding and eating	Text4jarjum: It's recommended you breastfeed exclusively until [insert child name] starts solid foods at around 6 months of age. Keep breastfeeding until at least 12 months and beyond.

Figure 9.2. Examples of the content feed shared on Growin' Up Healthy Jarjums Facebook page



Growin' Up Healthy Jarjums
18 Jul 2020

What you Sista's cooking for dinner, this is what my daughter and I cooked - chicken stir fry yummmyyy ❤️ show me what you cooking for the fam bam 👊

Growin' Up Healthy Jarjums
13 Jul 2020

Join in the Fun of the "Express Yourself Art Classes"!
The Coffs Harbour and District LALC are providing Art Packs to all community that want to join us as we Stream our Art Session with Professional Surfer and Artist Otis Carey!
If you would like one of these packs, please collect from the Coffs Harbour LALC on 66528740 Wongala Estate before Wednesday!

Coffs Harbour & District LALC
13 Jul 2020

Join in the Fun of the "Express Yourself Art Classes"! The Coffs Harbour and District LALC are providing Art Packs to all community that want to jo... See more

Growin' Up Healthy Jarjums
31 Jul 2020

Just a reminder next week is Aboriginal and Torres Strait Islander Children's Day.
This years theme " We are the Elders of tomorrow, Hear Our Voice " highlights the uniqueness and importance of the knowledge and wisdom of Aboriginal and Torres Strait Islander peoples, starting in childhood. Hearing children's voices today plays a crucial role in their development towards being influential Elders and leaders of the future.

Check out your local area if something is happening 🖤💛❤️

9.7 Discussion

9.7.1 Principal results

We co-developed a prototype mHealth program focused on the knowledge of mothers of young Aboriginal and Torres Strait Islander children. The aim of the program is to improve health knowledge, health behaviours and access to health services. The final prototype incorporates three modalities (Facebook, SMS text messaging and an app), and includes a range of health topics. In addition, it is centred on being supportive of mothers and culturally safe.

The modality choices were based on a few factors: 1) early discussions with mothers and health services about wanting an app that is culturally relevant and safe; 2) evidence suggesting SMS text messages are the most effective mHealth function for health behaviour change; and 3) findings from focus groups and interviews indicating that women were high users of Facebook and SMS text messages. As suggested in a recent pilot study of a smartphone app with Aboriginal Australians, a 'one app fits all' approach is unlikely to be successful (66). Using mHealth modalities commonly used by the target group to deliver a health program may appeal to more families.

9.7.2 Strengths and limitations

The first limitation of this research is that it was initiated by a research institution rather than by the community itself. True co-design should begin with completing a needs assessment with communities to see what the health priorities and potential solutions are for that community (79). This is well described in a New Zealand co-design study (70, 81). To ensure that adequate time and resourcing is available for relationship building and needs assessment, both should be specified in protocols and funding applications so that sufficient budgets and timeframes are allocated. Second, although the program covers a range of topics briefly, it does not cover any topic in depth. Although an mHealth program with wide-ranging topics seems to be preferred by participants, this may dilute the impact of the program on any one risk behaviour. Providing links within the Growin' Up Healthy Jarjums program to specific mHealth programs for target behaviours may overcome this limitation by providing more intense behavioural change for those who are 'ready' to change. Third, because the participants were from only three NSW communities, the intervention may have limited generalisability in other Aboriginal and Torres Strait Islander communities. Aboriginal and Torres Strait Islander communities are made up of >250 language groups in which there is great diversity. If this program is to expand to other communities, systematic adaptation of the program, would need to be carried out to ensure that the program is suitable to the context of each community (82).

A key strength of this study is that Aboriginal researchers (BH, NS and BL) led engagement with participants and community organisations. Understanding the importance of trusted and strong cultural relationships, we only engaged with communities that the Aboriginal researchers had a relationship with, which likely resulted in trust as well as interest in participating in this study. Another strength of this study is the thorough reporting of the co-design processes. Inadequate reporting of intervention development was identified as a weakness in a recent systematic review on mHealth development (74). An additional strength is the involvement of primary health services and professionals. A recent review on health promotion programs in Aboriginal communities highlighted that an important consideration is to partner with primary health care services because they are well placed with frequent patient contact, health expertise and often intricate knowledge of the community (83). A final and important strength is that we developed a flexible portal for ongoing development and enhancement. The COVID-19 experience has reinforced how important it is to have alternatives to face-to-face health care. Useful additions in future iterations of this mHealth program might include development of a flexible platform suitable for inclusion of initiatives inspired by the COVID-19 pandemic, such as subsidised telehealth and videoconferencing. There are also opportunities to develop content on this platform in Aboriginal and Torres Strait Islander languages to better suit users.

9.7.3 Comparison with prior work

Design characteristics identified in this study, including ‘social connection’ and ‘family centredness’, reflect Aboriginal and Torres Strait Islander perspectives of health. Connection to family, community and culture, among other factors, are understood to be equal contributors to health (84). Arabena et al (85) suggest that communities and social connection can ultimately be the health promotion program for Aboriginal and Torres Strait Islander communities.

The finding that Aboriginal and Torres Strait Islander women were high users of social media, in particular Facebook, was unsurprising. Aboriginal and Torres Strait Islander health organisations have capitalised on the popularity of Facebook among Aboriginal and Torres Strait Islander people, and have been early and adept users of social media for health promotion (67). An Aboriginal-led social marketing campaign for health promotion, ‘Deadly Choices’, has a following of 94,035 Facebook followers, 19,300 Instagram followers and 9000 TikTok followers (44, 86).

As stated earlier, the methodologies used in this study were based on a co-design study for a health app with Māori and Pacific Island people (70, 81). There were a number of similar co-design findings. In both studies, participants expressed a holistic view of health and connections to people and place as being central components to health. Participants in both studies talked about a family approach to health, rather than an individual approach, as well as accessible healthy activities in the community. Social support was found to be an important strategy in both studies.

Culture was also identified as important in both studies, although cultural representation may have been a more nuanced finding in the New Zealand study. In our Australian-based study, participants expressed the importance of Aboriginal and Torres Strait Islander representation in terms of designs, colours, images, people, organisations and safety. Participants in the New Zealand-based study expressed the need to include Māori knowledge, Whakapono (faith, spirituality) and Whakataukī (traditional proverbs), which were to be woven throughout the intervention; for example, the app depicts the completion of challenges as coloured footsteps, which is analogous to the journey that the participants’ tūpuna (ancestors) embarked on. There may be differences in participants’ connection to culture. In Australia, up to one in three Aboriginal and Torres Strait Islander children were removed from their families during the period from the mid-1800s to the 1970s. These children are known as the Stolen Generations (87). Of the 31 mothers in this study, 6 (19%) reported that they had family members from the Stolen Generations and13 (42%) were unsure. The effect of the Stolen Generations on loss of culture is profound (87), and is likely reflected in the findings of this study. This program may, in a small way, help to promote culture through links to Aboriginal and

Torres Strait Islander organisations, connection to mothers of Aboriginal and Torres Strait Islander children, and culturally safe health information.

9.8 Conclusions

An mHealth program including an app, Facebook page and SMS text messaging modalities was developed based on co-design findings. The program incorporates health behaviour change theory, evidence-based information, and the preferences of Aboriginal and Torres Strait Islander women and health professionals. The next step of this research is to assess the acceptability and feasibility of the program in a pilot study. The pilot study will be conducted with the Aboriginal health services and NSW Health sites that participated in this co-design study. Participating mothers will also be invited to participate in the pilot study. If the Growin' Up Healthy Jarjums program is shown to have adequate acceptability and feasibility, the next phase will be to measure its effectiveness in improving health knowledge and changing health behaviours. Assessing the effectiveness of this program will provide valuable evidence for the use of mHealth in improving the health and wellbeing of Aboriginal and Torres Strait Islander populations, and contribute to the evidence for using co-design methodologies, both of which have been highlighted as gaps in the literature (88).

9.9 Acknowledgements

The authors would like to acknowledge and pay their respects to the Aboriginal and Torres Strait Islander women who shared their views and knowledge in the study. They would also like to acknowledge the ACCHOs that participated – Armajun AMS, Galambila AMS, Awabakal AMS, Kulai Aboriginal preschool and Muloobinba Aboriginal Corporation – and the NSW Health sites that participated – Aboriginal Maternal and Infant Health Services located in Inverell, Coffs Harbour and Newcastle. Thank you to researchers from the National Institute for Health and Innovation, University of Auckland, for sharing expertise on mHealth, and to Sam McCrabb for coding behaviour change techniques.

9.10 Supplementary table

Table S1. Behaviour change technique clusters and components coded in text messages (112 messages)

Behaviour change cluster	Component	N (100)
9. Comparison of outcomes	9.1 Credible source	55 (28.6)
5. Natural consequences	5.1 Info about health consequences	36 (18.6)

1. Goals and planning	1.4 Action planning	25 (13.0)
4. Shaping knowledge	4.1 Instruction on how to perform a behaviour	17 (89)
10. Reward and threat	10.4 Social reward	11 (5.7)
3. Social support	3.1 Social support (unspecified)	8 (4.2)
5. Natural consequences	5.6 Info about emotional consequences	5 (2.6)
13. Identity	13.1 Identification of self as role model	4 (2.0)
7. Associations	7.1 Prompt/cues	4 (2.0)
6. Comparison of behaviour	6.2 Social comparison	3 (1.6)
8. Repetition and substitution	8.7 Graded task	3 (1.6)
12. Antecedents	12.6 Body changes	3 (1.6)
11. Regulation	11.1 Pharmacological support	3 (1.6)
1. Goals and planning	1.1 Goal setting (behaviour)	2 (1.0)
4. Shaping knowledge	4.2 Information about antecedents	2 (1.0)
9. Comparison of outcomes	9.2 Pros/cons	1 (0.5)
12. Antecedents	12.3 Avoidance/reducing exposure to cues for the behaviour	1 (0.5)
10. Reward and threat	10.9 Self-reward	1 (0.5)
7. Associations	7.8 Associative learning	1 (0.5)
11. Regulation	11.2 Reduce negative emotions	1 (0.5)
12. Antecedents	12.4 Distractions	1 (0.5)
15. Self-belief	15.3 Focus on past success	1 (0.5)
15. Self-belief	15.1 Verbal persuasion about capability	1 (0.5)
15	**23**	**192 (100)**

Chapter 10 – Evaluation of an mHealth program (Growin' Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: Engagement and acceptability study (Study 3)

Content

10.1 Chapter overview

As outlined in the introduction section of this thesis (Chapter 4), there are several sequential steps for developing and evaluating mHealth programs including formative research, pilot testing, randomised controlled trial and evaluation of implementation impact. For this body of work, the formative research (Chapters 8 and 9) included a cross-sectional survey and co-design focus groups. Based on this formative work, a prototype mHealth program, Growin' Up Healthy Jarjums, was developed. The final prototype included six modules for women's health – Smoke-free families; Safe drinking; Feeling good; Women's business; Eating; and Exercising – as well as six modules for children's health – Breathing well; Sleeping; Milestones; Feeding and eating; Vaccinations and medicines; and Ears, eyes and teeth. A Facebook page, a web-based app and SMS text messages were used to deliver small chunks of written information and short videos on these health topics. The Facebook page was also used for women to connect with one another and for weekly competitions. This chapter will report a pilot study used to evaluate acceptability of and engagement with the Growin' Up Healthy Jarjums mHealth program. Pilot testing is important to evaluate content and regimen from the user's perspective to improve and refine the program prior to examining effectiveness.

10.2 Publication details

> **Perkes SJ**, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B. Evaluation of an mHealth intervention (Growin' Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: engagement and acceptability study. JMIR Pediatrics and Parenting. 2023;6:e43673. https://doi.org/10.2196/43673

A copy of the manuscript can be found in Appendix 16.

Student's contribution to the publication:

80% Research design

80% Data collection and analysis

80% Writing and editing

Co-authors:

Belinda Huntriss

Noelene Skinner

Bernise Leece

Dr Rosie Dobson

Professor Joerg Mattes

Dr Kerry Hall

Professor Billie Bonevski

Authors' contributions to the publication:

SP led the study design; all authors contributed to the design of the study, including the conceptualisation. SP obtained funding for the study, and led data collection and analysis alongside BH, NS and BL. RD, BB, JM and KH provided oversight of analysis, and KH provided cultural guidance. BB, JM and KH provided supervision to PhD candidate SP. SP led writing of the manuscript; all authors read, edited and approved the final manuscript. Co-authorship approval for HDR publication of the Chapter 10 manuscript can be found in Appendix 17.

10.3 Abstract

Background: Aboriginal and Torres Strait Islander women have access to and interest in mHealth, although few culturally relevant, evidence-based mHealth programs are available. We co-developed an mHealth program in NSW with Aboriginal and Torres Strait Islander women, focusing on women's and children's health and wellbeing.

Objective: This study aims to assess the engagement with and acceptability of the Growin' Up Healthy Jarjums program among mothers caring for Aboriginal and Torres Strait Islander children aged ≤5 years and assess the acceptability of the program among professionals.

Methods: Women were given access to Growin' Up Healthy Jarjums – a web-based app, a Facebook page and SMS text messages – for 4 weeks. Short videos of health professionals presenting health information were tested within the app and on the Facebook page. Engagement with the app was examined through the number of logins, page views and links used on the app. Engagement with the Facebook page was examined through likes, follows, comments and the reach of posts. Engagement with the SMS text messages was examined through the number of mothers who opted out, and engagement with the videos was examined through the number of plays and videos watched, and duration of the video watched. The acceptability of the program was examined through post-test interviews with mothers and focus groups with professionals.

Results: A total of 47 participants joined the study (n=41, 87%, mothers; and n=6, 13%, health professionals). Interviews were completed by 78% (32/41) of the women and 100% (6/6) of the health professionals. Of the 41 mothers, 31 (76%) women accessed the app, 13 (42%) scrolled the main page only, and 18 (58%) clicked on other pages. There were 48 plays and 6 completions of the 12 videos. The Facebook page received 49 page likes and 51 followers. The post with the most reach was a supportive and affirming cultural post. No participants opted out of the SMS text messages. Almost all mothers (30/32, 94%) reported that Growin' Up Healthy Jarjums was useful, and all mothers reported that the program was culturally appropriate and easy to use. Of the 32 mothers, 6 (19%) reported technical problems with accessing the app. Moreover, 44% (14/32) of mothers suggested improvements to the app. All the women reported that they would recommend the program to other families.

Conclusions: This study demonstrated that the Growin' Up Healthy Jarjums program was perceived as useful and culturally appropriate. SMS text messages had the highest engagement, followed by the Facebook page and then the app. This study identified areas for technical and engagement-related improvements to the app. A trial is needed to assess the effectiveness of the Growin' Up Healthy Jarjums program in improving health outcomes.

10.4 Introduction

Aboriginal and Torres Strait Islander people are the longest-surviving culture in the world (89). The health of Aboriginal and Torres Strait Islander people changed significantly upon colonisation and has continued to be disrupted by subsequent policies (90). Improving the health and lives of

Aboriginal and Torres Strait Islander people is a national priority. Mothers and babies getting the best possible care and support for a good start to life is one of 12 health priorities of the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 (47). Providing access to culturally responsive health information and services is an important strategy to achieve this goal (47).

Improving health literacy provides a foundation for individuals and communities to take action to improve their own health (91). There is limited evidence on effective health literacy programs for Aboriginal and Torres Strait Islander people (92). A systematic review examining programs to improve health literacy among Aboriginal and Torres Strait Islander people included five studies with the following programs: exercise classes, nutrition and cooking workshops, discussions and role plays, presentations, other learning activities, incentives, and reducing the cost of fresh/frozen produce and low sugar beverages and education at the point of sale (92). All included studies demonstrated statistically significant improvement in at least one health literacy-related outcome measure, although it should be noted that study quality was compromised due to small sample sizes and poor attendance (92). More rigorous trials are needed on health literacy programs designed and implemented by Aboriginal and Torres Strait Islander people for Aboriginal and Torres Strait Islander people.

An array of mobile technology is available to find, share and generate health information (93). The major benefit of mHealth is the ability to reach large numbers of consumers, including those who cannot attend health services. Aboriginal and Torres Strait Islander women have a high interest in using mHealth (94) but have different preferences for delivery as well as content. Evidence to date shows that Aboriginal and Torres Strait Islander people are frequent users of Facebook (21, 44, 45, 95) and SMS text messaging (20, 39, 41) , and report high acceptability of, but low engagement with (66), apps, as is often the case universally (96). Content that centres on culture and frames positive health messages has greater acceptability (43-45). Furthermore, certain delivery mechanisms may be particularly engaging to mothers. A report on Australian women’s use of digital health found that women caring for infants and young children were more likely than other women to use social media and online forums to share and create health information (93), whereas other studies have found SMS text messaging to have high acceptability among mothers (39, 41).

Available mHealth programs for Aboriginal and Torres Strait Islander mothers or their children are limited but growing; examples include an app, website and SMS text messaging on infant feeding (97); SMS text messaging, videos and MMS for otitis media in children (41); SMS text messaging, phone calls, Facebook or email for postpartum blood glucose screening (39); a prototype app for social and emotional wellbeing during pregnancy (98); and a mindfulness app for women and children of all ages (99). In the grey literature, the authors are aware of the Deadly Tots app and interactive website on child development (100), and Facebook pages such as the Stay Strong and Healthy page for health during pregnancy (101), and Yarn and Heal – Our Way for Aboriginal women of all ages to connect and yarn (102). It is important that we seek to advance mHealth solutions developed by and for Aboriginal and Torres Strait Islander women to promote digital inclusion and access to health information, particularly as it is known that cultural minorities are less likely to use mainstream web-based health technologies (93).

In 2019, we co-designed a multi-modality mHealth program for Aboriginal and Torres Strait Islander women's and children's health (103). The aim of the program is to improve health literacy and health behaviours as well as increase access to health services. Formative research with 31 women and 11 health professionals took place in three communities in NSW and included focus groups with storyboards, card sorting and design activities (103). On the basis of the findings from the formative research, we developed a web-based prototype app, SMS text message library and Facebook page, collectively called the Growin' Up Healthy Jarjums program.

Following a formative research phase, subsequent steps to develop and evaluate mHealth programs include conducting a pilot study, a randomised controlled trial and evaluation of implementation impact (104). The purpose of the pilot study stage is to determine acceptability, improve and refine the program, and test content and regimen early in the research process (104). Refining the program is often an iterative process in each research phase and beyond (104). Continual improvements to mHealth programs are important, given the constant upgrades to technology and that long-term engagement with mHealth can be difficult to achieve (24). We have used a pilot study design to evaluate the acceptability of and engagement with the Growin' Up Healthy Jarjums prototype program.

The aims of this study were: 1) to assess the engagement with the Growin' Up Healthy Jarjums program among mothers (or other women) caring for Aboriginal and Torres Strait Islander children ≤5 years of age; 2) to assess the acceptability of the Growin' Up Healthy Jarjums program among mothers (or other women) caring for Aboriginal and Torres Strait Islander children ≤5 years of age; and 3) to assess the acceptability of the Growin' Up Healthy Jarjums program among health professionals and early educators.

10.5 Methods

10.5.1 Project design

A 4-week pilot study of the Growin' Up Healthy Jarjums mHealth program was undertaken with Aboriginal and Torres Strait Islander women caring for children ≤5 years of age. Health professionals and early educators from participating services provided feedback on the program in focus groups. Details on the development of the Growin' Up Healthy Jarjums mHealth program can be found elsewhere (103). The AH&MRC *Ethical guidelines: key principles (2020) V2.0* were used to guide implementation of this pilot study (71).

Research team

This research was governed by an Aboriginal advisory board in partnership with Aboriginal organisations (listed in the 'Acknowledgements' section) and co-led by a Kuku Yalanji, Lama Lama investigator (KH), as well as two non-Indigenous investigators (BB, JM). In total, three team members were Aboriginal women from (or connected to) the communities where the research took place: a Gumbaynggirr woman (NS), a Gomeroi woman in the Kamilaroi Nation (BL), and a Worimi woman working in the Awabakal community (BH). The cultural identities of the remaining team members are Macedonian-Australian (BB), German-Australian (JM), Pakeha or European New Zealand (RD) and European-Australian (SJP). The team has various professional backgrounds: four women with Aboriginal lived experience (KH, NS, BL, BH), a behavioural scientist (BB), a paediatrician and academic (JM), a nurse and public health researcher (KH), an mHealth and public health researcher (RD), an early educator (BH), Aboriginal health practitioners (NS, BL), and an occupational therapist and PhD candidate (SJP). All team members contributed to the conception of this study. Aboriginal researchers from the participating communities (NS, BH and BL) led the implementation of the project to support cultural safety.

Participant sampling

Women aged 16 years and over who were either mothers or primary carers of Aboriginal or Torres Strait Islander children aged 0 to5 years or were 30+ weeks pregnant), owned or regularly used a smartphone, and had accessed a participating service (an Aboriginal health service or NSW Health service) were eligible to participate. Health professionals from participating health services and early educators from participating preschools of all cultural identities at participating services who worked with women or children were eligible.

Procedures

This study was conducted remotely from August 2020 to March 2021 using telephone, SMS text messages and videoconferencing owing to COVID-19 restrictions. Participants were recruited from three regional locations in NSW. A total of five Aboriginal organisations (two Aboriginal health services, two Aboriginal preschools, and an Aboriginal family and parenting corporation) and three NSW Health sites participated. In total, two Aboriginal researchers (NS, BH) completed most of the recruitment, consent procedures, interviews and communication with the participants and services in line with the AH&MRC ethical guidelines to ensure culturally safe, best-practice research procedures (2.2.3, 2.3.3, 2.5.2 and 3.3.1) (71).

Women who participated in the co-design phase (103) were contacted via phone and invited to participate in the pilot study. Convenience snowball sampling was also used (105). The Aboriginal researchers (BH, NS and BL) used their personal networks to recruit additional participants. The participants were also asked if they would like to recommend a friend or family member to the study. The participating health services also reached out to potential participants. Potential participants were screened for eligibility when contacted by the researcher via phone. The researcher explained the study and obtained informed consent. The participants were sent an SMS text message with a link to a baseline survey on REDCap before starting the pilot study. During the 4-week study period, the participants were given access to the program (Box 10.1). The participants were sent a link via an SMS text message to access the app, and where possible, the research team contacted the participants to check whether they were able to access the app, explain the use of the app, check whether they were receiving SMS text messages, and explain how to 'like' the Facebook page. The participants were asked to access the app as often as they felt compelled to, that is, there was no required amount of time that women needed to spend on the app or other parts of the program. Following the Facebook page was optional. After 4 weeks, the participants were contacted via telephone for an interview. Semi-structured interviews with a mixture of open- and closed-ended questions (106) were conducted by Aboriginal researchers (NS and BH) and a non-Indigenous PhD student (SJP). The interviews were 6 to 25 minutes in length. They were recorded and transcribed, and interview notes were taken as a backup to recordings (106). The participants were reimbursed with a shopping voucher worth A$20 (US$30) at baseline; a shopping voucher worth A$10 (US$15) per week for the 4-week pilot study, A$40 (US$60) in total to cover data use; and a shopping voucher worth A$20 (US$30) for participating in the follow-up interview. The interviews were completed between August and September 2020.

The professionals who participated in the co-design phase were contacted via phone and invited to participate in the pilot study. Where these professionals were no longer working at the service, other professionals known to the Aboriginal researchers were contacted to participate. A total of two focus groups were conducted in February and March 2021. Focus groups (106) were conducted rather than individual interviews as per the professionals' preference. Consent was initially obtained over the phone and then again in person, videoconference or email before starting the focus group. A brief survey was conducted at the start of the focus group. The professionals accessed the program during the focus group only (not during the 4-week pilot study). We were interested in the professionals' feedback on the content only, not in how they might engage with the program over 4 weeks, as they were not the target end users. It was important, however, to obtain feedback from professionals who routinely provide health information to mothers, as they may be instrumental to the implementation of the program, if the program is effective. One focus group was conducted in person (as COVID-19 restrictions had been lifted) and another over videoconference. The focus groups were 13 and 21 minutes in length. The professionals were not reimbursed.

Box 10.1. Components of the prototype program

App

The app is a central place for users to access all content. The app is primarily for the user who wants in-depth information and has the necessary digital device, internet connection and literacy skills to access it. The app has four menu screens as follows: 1) home screen; 2) women's health; 3) children's health; and 4) contacts. The Facebook page content feed was embedded into the home screen. The women's health menu page includes six buttons, one for each of the women's health modules as follows: 1) Smoke-free families; 2) Safe drinking; 3) Feeling good; 4) Women's business; 5) Eating; and 6) Exercising. The jarjum's health modules are: 1) Breathing well; 2) Sleeping; 3) Milestones; 4) Feeding and eating; 5) Vaccinations and medicines; and 6) Ears, eyes and teeth. Each topic includes: 1) key messages incorporating the perceived threat of illness and benefits of changing health behaviour; 2) tips to address the barriers to change through reassurance and credible advice; 3) cues to action, for example, "Each time jarjum sees a nurse or GP ask them to have a quick look in bub's ears to check if there is any infection"; and 4) links to further information, including information regarding skills and activities such as exercises and healthy recipes to support self-efficacy. The information is presented using small chunks of written information and videos, using the same layout in each module.

Videos

A total of 12 videos were developed (one per topic). The length of the videos ranged from 1 minute and 42 seconds to 5 minutes. The videos included health professionals from the participating sites or contacts of the research team presenting key messages on each health topic. The presenters were given short scripts and encouraged to use their own expertise and experience. The videos were displayed in the app under each topic as well as added to the Facebook feed at least once. The users were able to watch the videos within the app; however, on Facebook, the users were taken to an external Vimeo platform to view.

Facebook page

The purpose of the Facebook page was to create community and connection, allow two-way communication, and use a platform that is highly popular among users. Daily content was added to the Facebook page, including 1) links to reliable health websites; 2) activities for families; 3) weekly competitions; 4) key messages on the health topics listed earlier (written and video); 5) events in the community; and 6) supportive affirmative posts. The page was administered by two Aboriginal team members (NS and BH), who shared posts relevant to their community and region.

SMS text messaging

The SMS text messaging component allowed the users access to health information regardless of their mobile phone type, wi-fi access or digital literacy. The SMS text messaging portion of the program was one-way (unidirectional). The SMS text messages included two core topics – 1) breathing well, and 2) smoke-free families – and the participants chose three additional topics (from the topics covered in the app). The women received one message per day for 5 days per week for 4 weeks (20 SMS text messages in total).

Measures

Demographics and cultural characteristics

The survey completed by mothers was a 16-item survey including demographic, cultural and socioeconomic items. The items were selected from a previous study (73), with all items having been tested with Aboriginal and Torres Strait Islander mothers previously. A survey completed by professionals comprised five items related to demographic and professional practice characteristics.

Engagement

Objective measures are common for measuring the engagement of apps (107). The user activity metrics collected included the number of logins, number of page views, length of page view and links used on the app. We used user activity metrics in combination with interview data to identify user typologies. Data collected for the videos included the number of plays in total and per video, number of videos watched in full (completions), duration watched (in seconds; mean seconds and percentage), and number of unique videos. Data collected for the Facebook page included the number of posts by administrators, number of page likes, number of comments, number of followers, and the reach of posts and videos. Data were collected on topics women chose to receive SMS text messages on and the number of women who opted out of receiving SMS text messages. User engagement was evaluated only for the women participants (end users), not for the professionals.

Acceptability

An interview schedule was adapted from a previous study on the acceptability of a culturally tailored SMS text messaging program for mothers (19). The interview schedule included the following topics: usefulness of the program, cultural appropriateness of the program, ease of understanding, appropriateness of the program, relevance of the program, perceived impacts, and suggestions for improvements. A shortened and adapted version of the interview schedule was used with professionals, which included items on usefulness and cultural appropriateness.

10.5.2 Data analysis

The interview data were analysed and summarised using descriptive quantitative analyses including means, SDs and proportions (108). Qualitative comments were analysed using simple thematic analysis with predetermined codes based on the research areas, for example, cultural appropriateness (106). One of the researchers (SJP) cleaned and coded the responses for each predetermined code. Then, three researchers (SJP, BH and NS) reflected on and discussed the participant quotes to form a summary statement for each code and select representative quotes.

10.5.3 Ethics approval

Human research ethics approval was received from the AH&MRC (1485/19) and the University of Newcastle (H-2019-00760).

10.6 Results

10.6.1 Overview

A total of 47 participants were recruited for the study: 41 (87%) women and 6 (13%) health professionals. The average age of the women was 31 (SD 7.35) years. The women were from 15 different communities; Kamilaroi (12/41, 29%) and Gumbaynggirr (10/41, 24%) were the most common. Almost half of the women (20/41, 49%) in this study had participated in the co-design phase of the project. The demographic characteristics of the participants are presented in Tables 10.1 and 10.2.

Table 10.1. Demographic and cultural characteristics of women (n=41)

Characteristics	**n (%)**
Age (years), mean (SD; range)	31.54 (7.35; 17–50)
Participation in co-design phase	
Yes	20 (49)
No	19 (46)
Not sure	2 (5)
Indigenous status	
Aboriginal	34 (83)
Torres Strait Islander	0 (0)
Both	0 (0)
Non-identified	6 (15)
Unknown	1 (2)
Identified with an Indigenous community	
Yes	25 (61)
No	5 (12)
Unknown	11 (27)
Maintain cultural connections at home, yes	28 (68)
Ways of connecting to culture	
Music/dance	22 (82)
Storytelling	21 (78)
Art	20 (74)
Indigenous television	18 (67)
Food	12 (44)
Indigenous internet sites	12 (44)
Indigenous newspapers	7 (26)

Characteristics	**n (%)**
Traditional medicine	5 (19)
Indigenous radio	4 (15)
Other	3 (11)
Family members from Stolen Generations[1]	
Yes	14 (34)
No	13 (32)
Unknown	14 (34)
Education of mother	
Did not finish high school	7 (17)
High school	13 (32)
Certificate	11 (27)
Bachelor's degree	4 (10)
Diploma	3 (7)
Postgraduate degree	2 (5)
Not applicable	1 (2)
Number of people living in household, mean (SD; range)	4.17 (1.72; 1–8)
Number of children (aged under 18 years) living in household, mean (SD; range)	2.44 (1.48; 1–6)
Smoking status of mother	
Non-smoker	31 (76)
Yes, daily	10 (24)
Yes, at least once a week	0 (0)
Yes, less often than once a week	0 (0)
Number of cigarettes smoked per day (on days smoking), mean (SD; range)	10 (4.32; 2–15)
Smoking status of partner, yes	9 (36)
Number of smokers in household	
0	24 (59)
1	14 (34)
More than 2	3 (7)
Child exposure to indoor tobacco smoke, yes	0 (0)
Child exposure to outdoor tobacco smoke, yes	7 (17)
Child exposure to tobacco smoke in the car, yes	0 (0)

1. The Stolen Generations refers to a period in Australia's history when Aboriginal children were removed from their families through government policies. This happened from the mid-1800s to the 1970s (87).

Table 10.2. Demographics of professionals (n=6)

Characteristic	**n (%)**
Service type	
Aboriginal medical service	3 (50)
Aboriginal preschool	3 (50)
Sex: Female	6 (100)
Indigenous status	
Aboriginal	2 (33)
Torres Strait Islander	0 (0)
Non-identified	4 (67)
Role at health service	
Registered nurse	2 (33)
Midwife	1 (17)
Co-director/early educator	3 (50)
Number of years at service, mean (SD; range)	10.5 (8.8; 1–25)

10.6.2 User engagement (n=41 women)

App

Of the 41 women, 31 (76%) participants accessed the app. Among these 31 participants, there was a total of 154 logins, an average of 5 logins per person. Of these 31 women, 13 (42%) users scrolled the main page only, but the remaining 18 (58%) users moved past the main page by clicking on other pages. A total of 23% (7/31) users clicked on 10 website links.

A total of four user typologies were identified: 1) could not use the app; 2) obligated to use the app; 3) reviewers; and 4) researchers. The 'couldn't use the app' group were those that could not log in or download the app. The 'obligated to use the app' group were those that used the app to provide feedback in a research context and probably would not use the app in a real-world setting. The 'reviewer' group were those that logged in once or twice out of curiosity to see what the app included, though did not consistently use the app. The 'researcher' group used the app more regularly; they were users that likely wanted more information than available in the SMS text messages or on the Facebook page. By analysing the user activity metrics, we estimate that 20% (8/41) of the women were 'researchers', indicating that they may have long-term engagement with the app in the real world.

Videos

There were 48 plays of the 12 videos (Table 10.3). The number of plays ranged from 0 for ‘Milestones’ and ‘Exercising’ videos, to 11 plays for the ‘Sleeping’ video. The number of unique viewers ranged from 1 to 5 per video. The highest number of unique viewers was for the ‘Feeling good’ video. Among the 48 plays, there were only 6 (13%) video completions. The mean viewing time was 38 seconds. The ability to obtain feedback on video content may have been limited by the fact that the videos were not watched by most women. One reason for this was that to watch videos on the Facebook page, the user needed to leave the Facebook page and watch in an external host (Vimeo). Another reason may have been that videos were not clearly displayed in the app. Finally, the videos may have been too long in duration.

Table 10.3. Engagement with app videos (n=41)

Video	Plays (n=48), n (%)	Completions (n=6), n (%)	Viewing time (seconds)[a], mean	Unique viewers, n[b]
Sleeping	11 (23)	1 (17)	22	3
Ear health	9 (19)	1 (17)	77	3
Eating well	7 (15)	1 (17)	6	3
Breastfeeding	5 (10)	1 (17)	115	4
Feeling good	5 (10)	0 (0)	63	5
Women’s business	4 (8)	1 (17)	72	1
Smoke free	4 (8)	0 (0)	11	1
Safe drinking	1 (2)	0 (0)	0	1
Vaccinations	1 (2)	0 (0)	0	1
Breathing well	1 (2)	1 (17)	89	1
Milestones	0 (0)	0 (0)	0	0
Exercise	0 (0)	0 (0)	0	0

[a] Total mean viewing time was 38 (SD 42.2) seconds.

[b] The average number of unique viewers was 2 (SD 1.62).

Facebook page

Facebook administrators (Aboriginal researchers BH and NS) posted 101 posts over the 4-week pilot study. The page received 49 page likes and 51 followers, indicating reach beyond the study participants. The post with the most reach was a supportive and affirming cultural post which reached 308 people and had 17 reactions, comments or shares. The second most popular post was a competition post which reached 58 people and had 23 reactions, comments or shares. The videos posted in Facebook (n=12) had an average of 20-person reach, though only 1 to 2 reactions, comments or shares, or clicks to watch externally.

SMS text messages

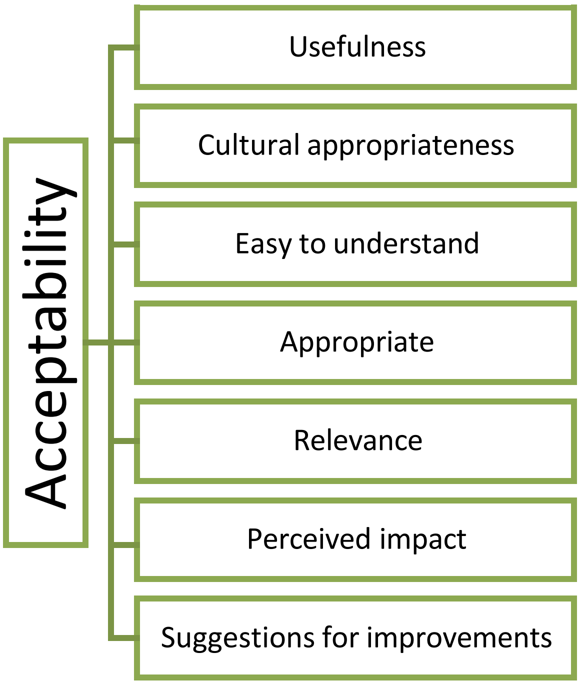
No participants opted out of SMS text messages. The participants selected three topics to receive SMS text messages on. In the order of popularity, the topics chosen were ears, eyes and teeth (23/41, 56%); sleeping (19/41, 46%); exercising (17/41, 41%); feeding and eating (13/41, 32%); eating (12/41, 30%); women's business (12/41, 30%); milestones (10/41, 24%); feeling good (10/41, 24%); vaccinations and medicines (6/41, 14%); and safe drinking (0/41, 0%).

10.6.3 Acceptability

Overview

Of the 41 women, 32 (78%) were interviewed at the end of the pilot study. All the six professionals were interviewed. There were seven themes identified in the analysis related to the acceptability (Figure 10.1).

Figure 10.1. Themes



Usefulness

Almost all women (30/32, 94%) reported that the Growin' Up Healthy Jarjums program was useful. On a scale of 1 (a little useful) to 5 (extremely useful), the mean rating of usefulness was 3.9. Furthermore, 84% (27/32) of the women reported that the program was relevant to them.

All women (30/32, 94%) reported that they would recommend the program to other families; the reasons included the following: helpful to first-time mothers, younger mothers, and mothers without family and other supports; ease of having all information in one spot; connection with other mothers; provides a sense of community; visually appealing and representative of Aboriginal and Torres Strait Islander people; and an accessible place for women feeling too ashamed or isolated to go the hospital or physician to access reliable health information:

> *I reckon just the feeling of still being connected, and being supported. I think it's a nice way, especially for mums with little, little kids, I reckon sometimes you feel pretty isolated, especially if you're not working and stuff. I think it's a nice way to still feel like someone's looking out for you or thinking of you.* [Participant 6]

> *I think it's a good tool for our community, especially the young ones that we've got who may not have anywhere else to go to find that information or who are too ashamed to ask. I think having it in a way that they can find it themselves in an easy format is a good thing.* [Participant 27]

All professionals (6/6, 100%) reported that the Growin' Up Healthy Jarjums program was useful. On a scale of 1 (a little useful) to 5 (extremely useful), the mean rating of usefulness was 3.3. All professionals reported that they would recommend the program.

The professionals reported that the program would be useful to families for different reasons. Some of the cited reasons were: the program is relatable to mothers as a result of co-design methods; using Facebook will result in family and friends seeing the health information; 'Storytime' would be good for families that have less access to books; the Facebook page was welcoming, easy to access and visually attractive; the app was easy to navigate, and would be easy for mothers to look through while 'on the go'; overall, the program has a good balance of content including health information, affirmations and what's on in the community; the Facebook page may be a good place for women to get ideas from each other and chat about recommendations from the posts; the Facebook page would be a good place for women to connect and not feel isolated; and the content is largely positive which is important.

> *I like, on the Facebook page, it gives you a sense of not being so isolated. The Facebook page is a really nice place for Aboriginal mums or families to not feel isolated if they're being recommended all this stuff and things to do outside of their lives, and then there's the affirmations. It's probably a really nice place for them to be especially if they're suffering any mental health or with any isolation in their own lives.* [Participant 6]

Cultural appropriateness

All the women (32/32, 100%) reported that the program was culturally appropriate. They reported that the colours, graphics and language used were culturally representative. Of the 32 women, 1 (3%) woman recommended using different languages depending on what community the program is intended for. Another woman who had no exposure to her culture said that it was a helpful way to learn about her culture:

> *I'm Aboriginal, but I only just learnt of my Aboriginality, so I wasn't actually brought up that way [with culture]. So it was helpful for me to learn new terminologies and stuff like that.* [Participant 3]

All the professionals reported that the program was culturally appropriate. A total of 33% (2/6) of the professionals commented on the cultural appropriateness of the language in a positive light. Overall, 17% (1/6) questioned whether the language would be difficult for some women to understand. She emphasised the need to ensure that representatives from each community that the program would be used in be involved in developing the content as well as to administer the Facebook page to ensure that the program continues to be relevant to women from different communities:

> *You've got different lingos, different meanings, different sayings that's going to grab attention [in different communities]. When I look through these text messages there are some words in here that I would think some of our women wouldn't really understand. You actually need the women to do it, they're very different to the workers. They're the ones that are going to give you the right language.* [Professional 1]

> *It's all culturally appropriate…the language is really nice. It's really easy to read and interpret. It doesn't have any of those big, yukky words that can be quite clinical.* [Professional 5]

Ease of understanding

All the women (32/32, 100%) reported that the content was easy to understand. They talked about the program being jargon free, but not too simplified.

> *It was spoken to you normally, not like all the medical jargon, do you know what I mean? It was understandable and relatable. I think if it's too technical sometimes, it gets overwhelming.* [Participant 20]

> *It wasn't dumbed-down. Like some things that we give to Aboriginal families that we get, some of them are so simplified that makes people think that we're stupid, but this wasn't. It was easy to understand, but it didn't make me feel stupid, didn't make me feel bad.* [Participant 27]

Appropriateness

Most women (28/32, 88%) reported that the activities and information were appropriate. However, of the 32 women, 1 (3%) woman suggested that the language in the SMS text messages could have been more professional rather than colloquial:

> *We followed what was on those messages each day. We made it a project with our kids because we thought we would see how it would go. My son likes looking at the pictures of it when they've had the Facebook competitions because it was all kids that he knew.* [Participant 27]

Relevance

Most women (27/32, 84%) reported that the program was relevant to them and their family. They said that it was good having other mums to relate to and access to reliable health information to talk to family about.

> *Just sort of seeing other women with kids and stuff and sort of just having someone to relate to, somebody that's a little bit more similar to me. So you don't feel so alone in what you're kind of going through. Things that you might think are silly or you're a bit shamed to ask anyone. At least the messages address it and then you can see other women on the Facebook page.* [Participant 4]

> *I learnt some good stuff. I think the thing I like most about the program for us personally, it allowed me to have conversations with my partner about smoking. With the program I was able to say 'hey I got a text about smoking', 'do you know*

> *this', it meant that it wasn't just me making points. I sort of used the app as the conversation starter.* [Participant 18]

The women who did not find the content relevant to them (2/32, 6%) said that they already knew the information or felt that the information was targeted towards women caring for younger children. Of the 32 women, 2 (6%) women also made comments about some SMS text messages not always being relevant to their family:

> *Some of them [SMS] might not be relevant to me personally, but I think as a community they are. The messaging was consistent, and I think that's really important.* [Participant 6]

> *My little boy is older now, he's 2. So I felt like a lot of the messages and stuff like that, was more around the newborn stuff. But in saying that, if I had a newborn still, then it would have been more relevant.* [Participant 10]

Perceived impact

Of the 31 women who commented on the overall positive impact of the program, 22 (71%) women reported that the program had an overall positive impact on themselves and their family. Table 10.4 presents a summary of the perceived impacts. The most common perceived impact was feeling more supported (21/29, 72%), followed by improvements in knowledge or understanding of child health (13/26, 50%), eating habits (11/29, 38%) and exercise (11/29, 38%). Many women commented on the supportive and affirming aspects that the program provided, including the validation of how hard parenting can be; information that certain health problems, such as ear infections, are common in children (validating that it was not their fault); the feeling that a service cared about their child's health; and the feeling that someone cared about them, which arose because of the reception of regular messages:

> *The favourite text of mine was the reminder that we all have rough days…And that it was okay, I thought you know what, yeah, I am going to take a breath right now, and it is all okay.* [Participant 10]

> *It was good to know that there was a service out there that did care I guess or had an interest in my son's health.* [Participant 14]

Other positive impacts that the women discussed included getting their child's ear health checked by a GP, more play with children, spending time together as a family, taking children for hearing and vision tests, more exercise, taking care of themselves, talking to friends and family about quitting or reducing smoking, cooking with children, limiting alcohol, getting their child immunised, improved knowledge of contraception, and improved family eating:

> *Usually I'm the type where I walk to the park and then watch her play. When I read the messages, I'm like, I should actually try with her more, and be more active with her at the park.* [Participant 24]

> *I was drinking far too much, it was just a stress-handling thing, because we did have a lot of problems, and it was difficult the first couple years. And so, getting that information, that really helped me to kind of kick that habit and to look at my own lifestyle and stuff.* [Participant 9]

Other women had stressful life situations at the time and had competing priorities, limiting the potential impacts of the program.

Table 10.4. Perceived impact (n=32)

	Participants who responded, n (%)	Participants whose response was yes, n (%)
Overall positive impact	31 (97)	22 (71)
Improvements to your smoking habits (if a smoker)	30 (94)	5 (17)
Improvements to family or friends' smoking habits (if a smoker)	30 (94)	2 (7)
Reduction in child's exposure to second-hand smoke	29 (91)	8 (28)
Positive impact on family eating habits	29 (91)	11 (38)
Positive impact on physical activity	29 (91)	11 (38)
Improvements to knowledge of women's health	28 (88)	8 (29)
Improvements to knowledge of child health	26 (81)	13 (50)
Feeling more supported	29 (91)	21 (72)

Suggestions for improvements

The most common suggestion for improving the program was to make changes to the app to overcome technical challenges. Of 32 women, at least 6 (19%) experienced technical problems. Difficulty in downloading and saving the web-based app rather than accessing an Android or iOS (Apple Inc) app, was the main difficulty. Almost half of the women (14/32, 44%) suggested improvements to the app, including making the web-based application an Android or iOS app so that it 'looks' like an app, removing the step of saving the application to the home screen, implementing single login, making navigation simpler, making the app accessible on all phone types, localising the app to specific communities, and making the app more interactive:

> *I had to log back in and it would take me to the web page. It kept wanting me to resave it to my home screen, but it was already saved to my home screen. I wasn't too sure what was going on there.* [Participant 30]

The next most common suggestion related to the SMS text messages. A total of 59% (19/32) of the women reported that there was just the right number of SMS text messages, but 38% (12/32) of the women reported that the SMS text messages were too frequent. The women indicated the preferred timing of SMS text messages to be earlier in the day and a preference to have SMS text messages from the same sender phone number for ease of reviewing.

Other suggestions to improve the program overall included suggestions to ensure better tailoring to the child's age, as well as suggestions for alternate topics (e.g. parenting, toilet training, separation, toddler development, mental development for boys, available services, preschool readiness, allergies, and resources and services specific to Aboriginal people), suggestions to provide less content about smoking, suggestions to provide more links to further information (e.g. local mothers' groups), and suggestions to make the program more interactive:

> *If it is targeting under 5, some of the information could be more around toilet training, difficulties with separation, entry to preschool, advice on services and stuff, like Koori stuff around.* [Participant 9]

In total, 6% (2/32) of the women talked about web-based groups: one woman suggested a Facebook group (rather than a Facebook page) and another suggested a chat group within the app (to discuss specific topics). Moreover, 6% (2/32) of the women talked about the importance of the continuation of the program and the longevity of Aboriginal and Torres Strait Islander health programs in general, as Aboriginal health programs often have short funding cycles and the community is left with a gap:

> *I would have benefited more with the Facebook group if it was an actual group created, because normally you get notifications and stuff when you're in the group and it tells you who's posted what. I probably would have had more interaction with that if that was a constant notification coming up.* [Participant 13]
>
> *Keep it going. We find sometimes that programs are really good and then they stop. When the funding runs out or it doesn't get approved or whatever it stops and then that's a gap.* [Participant 27]

The professionals suggested several ways to improve the program, including continued involvement of women in the development of the program to ensure that the language and content remain relevant and appropriate, including for families living in regional and remote areas. Another professional suggested that the content should be current and tailored to the age of the child. Another suggested a 'search' feature in the app so that families could easily search for the health issue or topic that they are interested in (otherwise, mothers will likely Google health information, which can make it difficult to determine reliable sources). Another suggested more specific steps about how to manage certain illnesses and to include more common childhood illnesses. Another suggested that the app needs to be more interactive, for example, tailored specifically to the child's age, with notifications for activities for that age group or milestones. One other professional suggested forums or private group chats so that discussions are not public, whereas another suggested providing grandparents and other family members access to the program.

10.7 Discussion

10.7.1 Principal results

Overall, the Growin' Up Healthy Jarjums program was found to have high acceptability. The results indicate that women found the program to be useful, culturally appropriate and easy to use, and most women reported positive impacts. None of the participants withdrew from the SMS text message portion of the program, which indicated the high acceptability of and engagement with this component. Engagement with the Facebook page was found to be higher than that with the app. Individual users preferred different modes (SMS text message, Facebook page or app), indicating that a multi-modal intervention increases reach. Importantly, this pilot study showed several ways to improve the program, including technical changes to the app.

Similar to other studies with Aboriginal and Torres Strait Islander people, the SMS text message component of this program appeared to have high acceptability and engagement (20, 39, 41). This pilot study provided an additional opportunity to focus on mothers and examine the desired frequency of SMS text messages. The frequency of SMS text messages sent in mHealth trials is often one SMS text message per day, although it can vary from multiple SMS text messages per day to weekly SMS text messages. In our study, women were sent one SMS text message per day for 5 days of the week over 4 weeks. Most women (19/32, 59%) reported that the frequency was just right, 38% (12/32) of the women reported that the SMS text messages were sent too often, and 3% (1/32) of the women reported that the SMS text messages sent were not enough. This finding is similar to that of another study that reported that one SMS text message per day was preferred by the majority (42%), whereas the remaining 58% preferred either more or less frequency (104). Giving a choice of frequency of either one SMS text message per day or three SMS text messages per week may be more appealing to users.

The women reported that they liked having a choice of topics for SMS text messages, as this increased relevance. Some women commented on the core (requisite) topics, indicating 1) breathing well and 2) smoke-free families as being irrelevant to them and their families. SMS text messages on smoking cessation and child lung health were requisite based on the original focus of the intervention to promote child lung health, including smoking cessation. The focus on child lung health was based on the call for more culturally appropriate information on childhood coughs (109). In addition, there is strong evidence that SMS text messages are effective for quitting smoking (61); thus, we decided to keep the focus on child lung health, including smoking cessation, for the SMS text message portion of the pilot. Furthermore, many of the SMS text messages were targeting the first 2 years of life, as that was the age range in which we expected to recruit most children; however, many of the children were older, which meant that some of the information was not relevant, although most women commented that they could see how beneficial the information would have been when their children were young. Encouragingly, the number of women who reported the SMS text messages to be irrelevant was low (3/30, 10%), similar to another study on SMS text messages for new mothers (6/22, 21%) (19); however, giving users the choice of all topics may be a more acceptable and useful approach allowing for better tailoring to end users' health information needs and interests.

Many participants experienced technical challenges in accessing the app, with nearly one-fourth (10/41, 24%) having been unable to access it. The prototype app used in the pilot study was a web-based application. A web-based application is accessed through an internet browser, such as Google Chrome (Google LLC) or Firefox (Mozilla Foundation), and is essentially a website designed to look like an Android or iOS app. Android or iOS apps are downloaded from an app store and saved on the phone (110). The benefits of web-based applications are that they are fast to build, they are cost-effective, and their content can be changed easily (110). The benefits of Android or iOS apps are that they are faster than web-based applications; they can work without internet connection; and end users are generally more familiar with them, including with downloading and saving them (110). Using a web-based application for this trial resulted in many women having difficulty logging in and saving the app their home screen. The women also commented that it did not 'look' like an app and that it was slow. Other application trials with Aboriginal and Torres Strait Islander people have largely used Android or iOS apps (66, 111, 112). Of these studies, one was unable to collect use data for 34% (21/61) of the participants reporting flat batteries, connectivity issues and other problems (112). A second study reported technical difficulties for participants with using the 'challenge' function and signing in and out, although it was noted that technical challenges did not significantly impact the use for many participants (66). In a third study, an app was used by clients with a practitioner present, and technical difficulties were reported with an Android emulator to enable compatibility with Windows (111). The fourth study used the same app as the previous study (111) with a different population; thus, it was also used by clients with a practitioner present, but no technical difficulties were reported (113). Although many studies evaluating mHealth apps have reported technical challenges, it seems that using a web-based application may have resulted in more users experiencing technical challenges and a more substantial challenge of not being able to log in or save the app. With a large proportion of women having had difficulty accessing the app, most of the feedback on the app was centred on the technical challenges, and there was limited feedback on the content. However, it was useful to discover during this early phase that a web-based application is not feasible. An Android or iOS app will need to be considered before further evaluation with a small group of end users to provide detailed feedback on content and navigation.

In addition to considering the technical barriers to accessing apps, careful consideration must be given to long-term engagement (96). In a longitudinal study examining the reasons for continued use of mHealth apps, two connected factors were described: 1) users' assessment of the mHealth app (related to the technology and content); and 2) users' persistence of health goals (i.e. those who have higher persistence towards reaching their goals appear to have longer engagement with health apps) (96). The authors concluded that long-term engagement with health apps occurs when there is high user assessment and high persistence towards health goals (96). With improvements to the technical aspects of the Growin' Up Healthy Jarjums app, we expect to see improvements in initial access and a small increase in long-term engagement, although it is evident that an app is not going to be engaging to all users. Health apps are suggested to be most engaging for users who are younger, are more educated and have higher levels of eHealth literacy skills (114). It is also suggested that the use of health apps can improve when support from a clinician or another medical professional is provided (115). The findings from this pilot would also suggest that those experiencing distressing life situations may find it difficult to engage with a health app, similar to the findings that suggest mental health apps may be more suitable for those with less severe illness (115). As health apps are likely to continue to improve as technology continually does, engagement with health apps will also improve. However, at this point in time, it seems apparent that mHealth tools should be provided in a range of delivery modes to increase reach, digital inclusivity and equity.

One such delivery mode is social media. It has been established that Aboriginal and Torres Strait Islander people are avid users of social media, Facebook in particular (21, 44, 45, 95), which is a key reason why a Facebook page was part of the Growin' Up Healthy Jarjums program. The qualitative findings from our pilot suggest that the Facebook page had high acceptability. The women commonly reported that they valued the connection and seeing what other families were doing. It can be difficult to track engagement with Facebook using objective data because of privacy measures and the complexity of identifying whether users accessed the page as 'observers' rather than more active users, which can be done only by examining page likes, comments, shares, etc. (45). A qualitative study examining social media and health information sharing among Aboriginal and Torres Strait Islander people shed more light on how social media are used for health promotion by identifying six typologies: 1) observer; 2) post sharer; 3) positive supporter; 4) educator; 5) expert; and 6) influencer (45). Although we do not have the data to compare all typologies with the previous study, our results indicate that mothers were more likely to be 'observers', with many women reporting the value of connection and seeing what other families were doing, but not often commenting, liking or sharing posts during the study. Posts that were shared or commented on were more likely to have been posts uploaded by Aboriginal organisations, posts affirming Aboriginal culture, or posts about competitions where a prize could be won. The previous study used a methodology different from the one used in this study, wherein they had participants monitor their social media accounts for health-related content and conducted weekly interviews to explore perspectives and actions on posts. Interestingly, the authors found that users moved between typologies depending on the health topic and how information was provided (45). In future research on the Growin' Up Healthy Jarjums Facebook page, it may be useful to use a similar methodology with a subset of participants to better understand what and how health information is shared among mothers with young children, as well as how this correlates with changes in health literacy offline; given the high acceptability of and engagement with Facebook among this group of end users, Facebook has great potential to improve health literacy.

10.7.2 Limitations

A limitation of this study was the need to conduct all recruitment and instruction of the program remotely using SMS text messages, links and phone calls owing to COVID-19 restrictions. In the initial protocol, we proposed recruiting women, setting up the app and providing instructions on how to use the app in person to reduce technical problems. Unfortunately, this was not possible, and women experienced a high number of technical problems. With a large proportion of women having had difficulty accessing the app, most of the feedback on the app was centred on the technical challenges, and there was limited feedback on the content; however, it was useful to discover during this early phase that a web-based application is not feasible. An initial in-person set-up would be considered important for further use of the program.

Another limitation of this study is that generalisation to other communities is limited. Aboriginal and Torres Strait Islander communities are made up of many diverse cultural and language groups (89). Each community has a unique history, cultural practices and health needs. The Growin' Up Healthy Jarjums program would need to be adapted, including by making changes to language, images and health advice, to ensure cultural safety and relevance to women from other communities.

10.8 Conclusions

This study demonstrates that the Growin' Up Healthy Jarjums program was perceived as useful and culturally appropriate by users and health professionals. The SMS text messages had the highest engagement, followed by the Facebook page and then the app. This study identified suggestions for improving the app. A trial is needed to assess the effectiveness of the Growin' Up Healthy Jarjums program at improving health outcomes.

10.9 Acknowledgements

The authors would like to acknowledge and pay their respects to the Aboriginal and Torres Strait Islander women who shared their views and knowledge in the study. They would also like to acknowledge the ACCHOs that participated – Armajun AMS, Galambila AMS, Awabakal AMS, Kulai Aboriginal preschool and Muloobinba Aboriginal Corporation – and the NSW Health sites that participated – Aboriginal Maternal and Infant Health Services located in Inverell, Coffs Harbour and Newcastle. We would also like to acknowledge the incredible graphic designs completed by Krystal Randall of Culture, Art & Digital Design. Lastly, thank you to researchers from the National Institute for Health and Innovation, University of Auckland, for sharing expertise on mHealth.

Chapter 11 – Respiratory, birth and health economic measures for use with Aboriginal and Torres Strait Islander infants: A modified Delphi with an Aboriginal and Torres Strait Islander panel (Study 4)

Content

11.1 Chapter overview

In Chapters 9 and 10, an mHealth program to improve women's and children's health was co-developed and pilot tested. The pilot study found that the Growin' Up Healthy Jarjums mHealth program was perceived as useful and culturally appropriate. SMS text messages had the highest engagement, followed by the Facebook page and then the app. The pilot study identified areas for technical and engagement-related improvements, mainly related to the app.

The steps for developing and evaluating mHealth programs provided in the introduction section of this thesis (Chapter 4) suggest a pragmatic randomised controlled trial to follow pilot testing. The purpose of the trial is to assess the effectiveness of the mHealth program in improving health outcomes for women and children using robust trial methods. Valid, reliable and acceptable outcome measures are necessary for determining health outcome changes. In Aboriginal and Torres Strait Islander research, it is particularly important that the outcome measures used in evaluation research are culturally safe and relevant.

Chapter 11 describes the development of culturally safe birth and infant respiratory health measures. A modified Delphi methodology was used to systematically consult Aboriginal and Torres Strait Islander academics, clinicians and mothers about the most accurate, culturally safe and feasible birth and respiratory health measures for use with Aboriginal and Torres Strait Islander mothers and infants in a research trial.

This study was the first study completed in the student's candidature when the thesis was focused on child respiratory health. While the measures identified and developed in Chapter 11 may well be used to measure respiratory health outcomes of the 'Growin' Up Healthy Jarjums' mHealth program, additional outcome measures will need to be identified to capture other outcomes.

11.2 Publication details

Perkes S, Bonevski B, Mattes J, Hall K, Gould GS. Respiratory, birth and health economic measures for use with Indigenous Australian infants in a research trial: a modified Delphi with an Indigenous panel. BMC Pediatrics. 2020;20:368. https://doi.org/10.1186/s12887-020-02255-x

A copy of the manuscript can be found in Appendix 18.

Student's contribution to the publication:

80% Research design

90% Data collection and analysis

90% Writing and editing

Co-authors:

Professor Billie Bonevski

Professor Joerg Mattes

Dr Kerry Hall

Professor Gillian Gould

Authors' contributions to publication:

SP led the study design including surveys used; all authors contributed to the design of the study. SP collected and analysed the results and wrote all manuscript drafts. JM provided expertise on respiratory health items. KH provided expertise on respiratory health and cultural guidance. BB, GG, JM and KH provided supervision to PhD candidate SP throughout study. All authors read, edited and approved the final manuscript. Co-authorship approval for HDR publication of the Chapter 11 manuscript can be found in Appendix 19.

11.3 Abstract

Background: There is significant disparity between the respiratory health of Aboriginal and Torres Strait Islander and non-Indigenous Australian infants. There is no culturally accepted measure to collect respiratory health outcomes in Aboriginal and Torres Strait Islander infants. The aim of this study was to gain end user and expert consensus on the most relevant and acceptable respiratory and birth measures for Aboriginal and Torres Strait Islander infants at birth, between birth and 6 months, and at 6 months of age follow-up for use in a research trial.

Methods: A three-round modified Delphi process was conducted from February 2018 to April 2019. Eight Aboriginal and Torres Strait Islander panel members, and 18 Aboriginal and Torres Strait Islander women participated. Items reached consensus if 7/8 (≥80%) panel members indicated the item was 'very essential'. Qualitative responses by Aboriginal and Torres Strait Islander women and the panel were used to modify the 6 months of age surveys.

Results: In total, 15 items for birth, 48 items from 1 to 6 months, and five potential questionnaires for use at 6 months of age were considered. Of those, 15 measures for birth were accepted: gestational age, birth weight, neonatal intensive care unit (NICU) admissions, length, head circumference, sex, Apgar score, substance use, cord blood gas values, labour, birth type, health of the mother, number of people living in the home, education of the mother, and place of residence. Seventeen measures from 1 to 6 months of age were accepted: acute respiratory symptoms (7), general health items (2), health care utilisation (6), exposure to tobacco smoke (1), and breastfeeding status (1). Three questionnaires for use at 6 months of age were accepted: a shortened 33-item respiratory questionnaire, a clinical history survey and a developmental questionnaire.

Conclusions: In a modified Delphi process with an Aboriginal and Torres Strait Islander panel, measures and items were proposed for use to assess respiratory, birth and health economic outcomes in Aboriginal and Torres Strait Islander Australian infants between birth and 6 months of age. This initial step can be used to develop a set of relevant and acceptable measures to report respiratory illness and birth outcomes in community-based Aboriginal and Torres Strait Islander infants.

11.4 Introduction

Aboriginal and Torres Strait Islander Australian children experience unacceptably high rates of respiratory disease (116-119). Up to one in three Aboriginal and Torres Strait Islander infants are hospitalised for acute respiratory infections in their first year of life (120). Rates of chronic respiratory disease are also high among Aboriginal and Torres Strait Islander children, including asthma (19.5%), bronchitis (16.8%), bronchiolitis (12.2%), pneumonia (7.2%) and bronchiectasis (1.5%) (121). Poor respiratory health continues across the lifetime for Aboriginal and Torres Strait Islander people, leading to a shorter and poorer quality of life (121). In 2011–2015 there were 1092 respiratory disease deaths among Aboriginal and Torres Strait Islander Australians (8% of Aboriginal and Torres Strait Islander deaths), twice the non-Indigenous rate (122).

A combination of social, historical and cultural contexts contribute to the high and unacceptable rates of disease (117). Risk factors include overcrowding, malnutrition, young maternal age, low birth weight, anaemia, poverty, illiteracy, exposure to tobacco smoke and parental smoking (123), pollution, socioeconomic status, social behaviours, cultural exposure, family history, and a history of prior illness (117). Addressing the social determinants of health will see the greatest reduction in respiratory disease among Aboriginal and Torres Strait Islander children, though clinical care must be improved simultaneously (117, 124).

Despite respiratory disease being a leading contributor to the total burden of disease among Aboriginal and Torres Strait Islander children, there is scarcity of community-level data (116). One single urban centre study with 180 Aboriginal and Torres Strait Islander children under 5 years of age used monthly interviews over 12 months to measure acute respiratory illness (125). One in five children experienced at least one episode of chronic cough (73). More than half of the children identified with chronic cough were diagnosed with an underlying lung disease, mostly protracted bacterial bronchitis, asthma and bronchiectasis (73). A second study in remote Aboriginal and Torres Strait Islander communities with 651 children under 6 years of age using observations to measure illness reported a point prevalence for cough (acute or chronic) of 39% (118). In national parent-reported data from 2012–2013, asthma prevalence was 15% as compared to 9% in non-Indigenous children (126).

As well as limited data, inconsistent measures have been used to capture respiratory illness. There are no standard measures for respiratory symptoms or illness specifically developed for Aboriginal and Torres Strait Islander children (116). In research trials, respiratory symptoms are typically collected via parent-reported questionnaires, interviews or symptom diary cards (127). Parent-reported measures are valuable and clinically relevant with wide reach at relatively low cost. However, parent report is reliant on accurate recall, and health literacy and response rates can be low (128). Cough is the main outcome collected via parent report for respiratory illness (127). Reliability of parent-reported cough for children is reported to be good for daytime cough and poor for nocturnal cough (127). Accuracy of parent-reported wheeze is reported to be low (129). Gold standard measures for detecting respiratory illness are clinical assessment, including observation and objective tests such as spirometry and/or X-ray (130), though these measures can be impractical for trials due to the ongoing and fluctuating nature of symptoms, as well as being costly, time intensive and burdensome for families.

Culturally safe, effective measures for detecting respiratory illness in Aboriginal and Torres Strait Islander infants need further development to improve respiratory health outcomes (116)). Accurate data is vital to enable us to understand the current state of Aboriginal and Torres Strait Islander infant health, to acknowledge progress, and to determine how to reduce inequalities between Aboriginal and Torres Strait Islander and non-Indigenous children (131). There is an entrenched lack of trust from Aboriginal and Torres Strait Islander Australians in health care professionals and systems (132), and medical research (133), due to historical and current policies (including the Stolen Generations), which requires intense consultation with Aboriginal and Torres Strait Islander leaders, consumers and topic experts to ensure that cultural safety of Aboriginal and Torres Strait Islander people is paramount in research (133). The purpose of this study was to systematically consult a group of Aboriginal and Torres Strait Islander academics, clinicians and women on the most accurate, culturally safe and feasible respiratory health measures for use with Aboriginal and Torres Strait Islander mothers and infants (birth to 6 months) in a research trial.

11.5 Methods

11.5.1 Study design

A modified Delphi with an Aboriginal and Torres Strait Islander expert panel was used. The Delphi method is a culturally acceptable method of gaining consensus and has been used in other areas of Aboriginal and Torres Strait Islander health research (134, 135). The consensus process was completed between February 2018 and April 2019. The Delphi technique is a method used to collect opinions from a group of experts to achieve consensus on a particular research question (136). Repeated questionnaires are used to facilitate independent, gradual and considered opinions (137). Modified versions involving group discussion may be used where feasibility and operational aspects are solved through group problem-solving (138-140). In this study, discussion was also an opportunity for dialogue on cultural safety considerations. This study was conducted in the context of identifying Australian Aboriginal and Torres Strait Islander culturally acceptable measures for use in a trial to assess infant respiratory symptoms and illness. The measures would be used to follow up infants born to mothers enrolled in the SISTAQUIT (Supporting Indigenous Smokers To Assist

Quitting) smoking cessation trial (Australian New Zealand Clinical Trials Registry; ACTRN12618000972224).

11.5.2 Participants

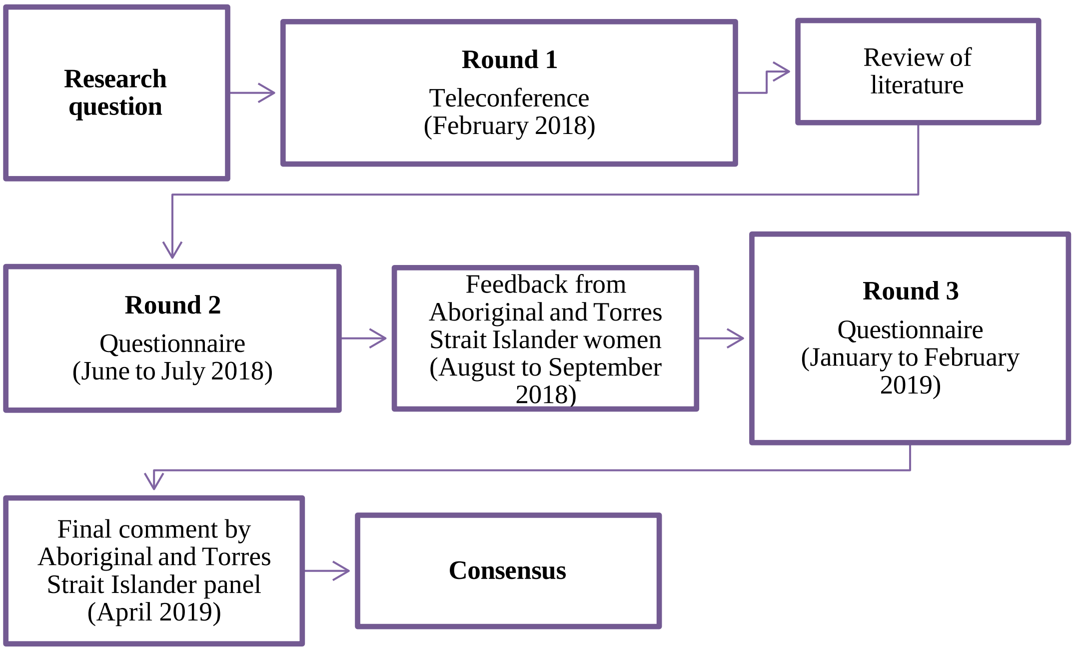
An Aboriginal and Torres Strait Islander expert panel participated in the three-round Delphi process and Aboriginal and Torres Strait Islander women provided feedback on the 6-month surveys. Using a snowball recruitment strategy, a list of 12 potential expert panel members known to study investigators were invited to participate by email. The 12 potential participants were sent a summary of the study and asked to share the invitation with colleagues. Twenty Aboriginal and Torres Strait Islander health organisations were also contacted via email and phone and invited to participate. Eight panel members agreed to participate in total. The eight panel members were emailed the full SISTAQUIT study protocol prior to the first round. Panel members included: 1) postdoctoral researcher in acute respiratory illness with Aboriginal and Torres Strait Islander children; 2) Principal Research Fellow in mothers and babies health; 3) representative of HealthInfoNet; 4) Associate Professor at an Aboriginal and Torres Strait Islander research unit; 5) representative of Indigenous Allied Health Australia (IAHA); 6) obstetrician; 7) paediatrician; and 8) representative of the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM). The eight panel members participated in each round for each measurement tool, with the exception of one participant who did not attend round one.

Aboriginal and Torres Strait Islander women (n=18) were recruited as part of a separate study (unpublished) on resources used for Aboriginal and Torres Strait Islander women's and children's health. Women were recruited through known networks of Aboriginal and Torres Strait Islander research assistants in Hunter New England and the Mid North Coast of NSW. Women were 16 years of age or over and mothers of young children.

11.5.3 Description of the modified Delphi method used

A three-round modified Delphi with teleconference and two repeat questionnaires was used. An overview of the consensus process is presented in Figure 11.1. Round one involved a group discussion with the Aboriginal and Torres Strait Islander expert panel, and rounds two and three used repeat online questionnaires. Feedback from 18 Aboriginal and Torres Strait Islander women on potential respiratory questionnaires for use at 6 months of age were gathered between rounds two and three.

Figure 11.1. Overview of consensus process



Review of literature

The lead author (SP) reviewed the literature to identify outcome measures used with Aboriginal and Torres Strait Islander Australian infants up to 6 months of age. Outcomes of interest were: 1) birth outcomes related to adverse impact of exposure to tobacco *in utero* (as per the broader SISTAQUIT study); 2) respiratory symptoms and illness; 3) health care utilisation; and 4) developmental outcomes. Keywords were used to search electronic databases including HealthInfoNet, Google Scholar, ScienceDirect, Cochrane Library and CINAHL. Reference lists and grey literature were also searched. Known experts in the field were contacted and asked of knowledge on measures used in clinical practice.

Round one: Teleconference

The first teleconference was used to provide an overview of the study, and to seek preferences for the Delphi process, that is, online questionnaires or interviews. During this call, participants were also asked to share knowledge on potential measures, and were given guidance on the information required by the panel to support decision-making.

Questionnaire development

The questionnaire of potential outcomes included items on types of outcome measures, mode and frequency of data collection, and acceptability of existing surveys for use at 6 months of age. Potential birth outcome measures were derived from a Cochrane review on smoking cessation programs used during pregnancy (141), acute respiratory symptoms from a survey used in a longitudinal study on respiratory symptoms in Aboriginal and Torres Strait Islander children (125), and items on health care utilisation from a systematic review and a cost-consequence analysis (142, 143). Two additional items on breastfeeding and exposure to environmental tobacco smoke were added from the respiratory symptoms survey (125). Potential questionnaires identified from a literature review for use at 6 months included two respiratory screening tools – 1) a 50-item respiratory questionnaire (144), and 2) an 18-item respiratory questionnaire adapted into Creole (145) – as well as a clinical assessment form developed for the purpose of the larger SISTAQUIT study. A development screening tool with an adapted version for remote Aboriginal and Torres Strait Islander communities was also identified (146, 147). A respiratory paediatrician (JM) and health research economist (SD) provided expertise on respiratory health and health care utilisation items, respectively.

Round two: Questionnaire

An online questionnaire delivered on REDCap software was used. The questionnaire consisted of three sections with 58 items. Participants were also asked for feedback on four existing questionnaires for use at 6 months of age. In total, participants took approximately 30 minutes to complete the questionnaire. In section one, participants were asked to answer two multiple-choice items. The first item was to identify measures to be collected at birth, including birth weight, gestational age, Apgar score, NICU admissions, sex, length and head circumference. The second item was to identify how to collect birth information, including hospital discharge summary or data linkage. Consensus was predetermined for multiple-choice items as 80% agreement (139, 148). Items were included if 80% agreement was reached (7 of 8 participants selected a measure), items progressed to round three if agreement was between 50% and 80% (4 to 6 participants selected a measure), and were omitted if agreement was below 50% (fewer than 4 participants selected a measure). Two open-ended questions were also included in section one on additional measures to collect at birth and other modes of data collection. Additional items suggested in qualitative responses were added to the round three questionnaire.

In section two, participants were asked to rate respiratory symptoms and health care utilisation items using a 4-point Likert scale (very essential, somewhat essential, non-essential, and unsure) as to whether each item should be collected in the trial. As above, consensus was predetermined as 80% agreement (using ‘very essential’ only). Items progressed to round three if agreement was 50% to 80% and were omitted if below 50%. In the final section, participants were asked for qualitative feedback on four potential questionnaires for use at 6 months: two respiratory, one developmental, and one clinical assessment form. Qualitative responses were synthesised and used to modify questionnaires.

Feedback from Aboriginal and Torres Strait Islander women

Two focus groups were held by Aboriginal and Torres Strait Islander research assistants to gain feedback from 18 Aboriginal and Torres Strait Islander women on two respiratory questionnaires. Both focus groups were conducted in regional areas of NSW. The focus groups were part of a separate study on resources used for Aboriginal and Torres Strait Islander women's and children's health. Women were 16 years of age or older, and were all mothers of young children. Questions used to gather feedback on acceptability were: 1) Are the questions easy to understand?; 2) Is the language appropriate?; 3) What do you think of the length of the questionnaire?; and 4) Would you feel comfortable answering this questionnaire? Women provided feedback verbally and in writing. Feedback was used to modify questionnaires.

Round three: Questionnaire

The round three survey was sent via email to the panel and took participants approximately 45 minutes to complete. Additional information was provided as requested by participants in round two to aid decision-making. In section one, participants were asked to indicate 'yes' or 'no' for inclusion of additional birth measures added by participants in round two (substance use in pregnancy, cord blood gas values, labour [induction, spontaneous], birth type [caesarean, vaginal], health of the mother, number of people living in the home, education, and place of residence). Items were included if 80% agreement was reached (7 of 8 participants selected a measure) and omitted if below 50% (fewer than 4 participants selected a measure). If consensus was not reached, a fourth round would have been conducted over phone or email.

In section two, participants were asked to rate respiratory symptoms and health care utilisation items that had not reached consensus in round two using a 4-point Likert scale. A rule was enacted to combine 'very essential' and 'somewhat essential' responses. Items that reached 80% agreement when 'very essential' and 'somewhat essential' were combined were included. This rule was not predetermined and enacted due to the timeline of the larger SISTAQUIT study.

In section three, participants were provided summary points of the qualitative feedback, as well as the modified versions of the three questionnaires and asked to indicate 'yes' or 'no' for the acceptability of the modified versions. A space was available for qualitative feedback. The final questionnaires were presented to the panel. If consensus had not been reached, a fourth round would have been conducted over phone or email.

11.6 Results

11.6.1 Round one: Teleconference

Four of the eight panel members attended a group teleconference and three members were interviewed individually by SP. The panel agreed to participating in online questionnaires rather than interviews to increase flexibility in participation for future rounds. The panel recommended qualitative feedback be included as well as the rating of items.

11.6.2 Birth outcomes

Round one: Teleconference

Birth outcomes discussed as important included birth weight, small for gestational age, head circumference, Apgar score, delivery at less than 37 weeks gestation, stillbirth, NICU admissions, and sex. Panel members considered it essential to limit women’s burden to answer surveys straight after birth by using discharge summaries or data linkage.

Round two: Questionnaire

Seven measures at birth (birth weight, gestational age, Apgar score, NICU admissions, sex, length, head circumference) were presented for consensus. Three items reached consensus and four progressed to round three (Table 11.1). The panel suggested an additional eight outcomes in qualitative responses: substance use in pregnancy; cord blood gas values; labour type (induction, spontaneous); birth type (caesarean, vaginal); health of the mother; number of people living in the home; educational attainments of the mother; and place of residence. Seven members (>80%) indicated the best mode of data collection to be hospital discharge summary.

Round three: Questionnaire

Twelve items were presented for consensus (Table 11.1). All 12 items in round three reached consensus (Table 11.1). A total of 15 items were accepted as essential items to collect. (See Appendix 20 for data extraction form.)

Table 11.1. Consensus for birth outcomes

Items	**Round 2 n=8**	**Round 3 n=8**	**Consensus**
Gestational age	7	–	✓
Birth weight	7	–	✓
Neonatal intensive care unit admissions	7	–	✓
Length	6	7	✓
Head circumference	4	8	✓
Sex	5	8	✓
Apgar score	5	8	✓
Substance use in pregnancy	–	8	✓
Cord blood gas values	–	8	✓
Labour (induction, spontaneous)	–	8	✓
Birth type (caesarean, vaginal)	–	8	✓
Health of mother	–	8	✓
Number people living in home	–	8	✓
Educational attainments of mother	–	8	✓
Place of residence	–	8	✓
Total	**7**	**12**	**15**

11.6.3 Data collection from 1 to 6 months of age for respiratory symptoms and health service utilisation

Round one: Teleconference

Panel members were asked to consider the best mode of data collection from the mothers of the infants from 1 to 6 months of age. Options discussed included phone call, face-to-face, text message, and online diary using phone app or weblink. The panel recommended phone calls or face-to-face (with use of text message to organise time/venue). The panel advised that women were unlikely to use a mobile phone app to report data. The panel recommended gaining feedback from Aboriginal and Torres Strait Islander women on their preference for the modality of data collection, that is, phone call, face-to-face, email or mobile phone app. Options discussed for personnel to collect data included an onsite research facilitator (a volunteer for the service who would be aiding the main trial) or other female health worker with a trusted relationship with the woman. The panel members advised additional information would be required to form a decision on the inclusion of respiratory items and requested input from the respiratory paediatrician (JM) as required to support decision-making.

Round two: Questionnaire

Forty-eight items were presented in total for consideration. Five items were presented on how data should be collected (frequency, number of survey questions, modality, personnel to collect data, and reimbursement amount) (Table 11.2). Two items reached consensus: 1) frequency of data to be collect monthly rather than fortnightly; and 2) modality of collection for women to choose their preference. Three items progressed to round three (number of survey questions, personnel to collect data, reimbursement amount). Forty-three items were presented on acute respiratory symptoms, health care utilisation, exposure to tobacco smoke and breastfeeding status. Of the 43 items, one item reached consensus (exposure to tobacco smoke). Twenty-eight items progressed to round three and 14 items were omitted (Table 11.3).

Table 11.2. Consensus for outcomes for frequency, number of questions, mode, personnel to collect data and reimbursement

Items	Round 2 n=8	Results 3 n=8	Consensus
Frequency of data collection			
Fortnightly	0	–	
Monthly	7	7	✓
Number of questions			
1 to 5	0	–	
6 to 10	4	5*	✓
11 to 15	1	1	
16 to 20	2	2	
Modality			
Phone call	3	–	
Survey	2	–	
Phone app	2	–	
Email	1	–	
Women's preference	7	7	✓
Women randomised to different modality	1	–	
Who should collect data			
Research facilitator (based on site, Aboriginal and Torres Strait Islander or non-Indigenous)	6	2	
Aboriginal and Torres Strait Islander researcher (based at research institution)	5	3	
Non-Indigenous researcher (based at research institution)	2	–	
Research facilitator, if not possible, Aboriginal and Torres Strait Islander researcher	–	3*	
Unsure	1	–	✓
Reimbursement to mother, amount per survey			
$15 voucher	3	1	
Baby bundle (value of $15)	3	2	
$10 voucher	1	–	
$5 voucher	0	–	
Research site to choose either $15 or $15 baby bundle	–	5*	✓

* Rule enacted, highest frequency accepted if consensus not achieved in round three

Table 11.3. Consensus for outcomes for acute respiratory symptoms, health care utilisation, exposure to tobacco smoke and breastfeeding status from 1 to 6 months of age

Item	Round 2 n=8	Round 3 n=8	Consensus
Has your baby had wheeze or whistle in the past 4 weeks?	4	7	✓
Has your baby had a moist or wet cough in the past 4 weeks?	6	7	✓
Has your baby had a dry cough in the past 4 weeks?	6	7	✓
Has your baby had shortness of breath in the past 4 weeks?	4	7*	✓
Has your baby had an earache in the past 4 weeks?	4	7*	✓
Has your baby had a runny nose in the past 4 weeks?	4	7*	✓
Does your baby have a cough today?	6	5*	✓
Have you been worried about your baby’s health for any reason in the past 4 weeks?	5	7*	✓
If yes, what have you been worried about?	4	8*	✓
Has your baby been hospitalised in the past 4 weeks?	6	7*	✓
If yes, what were the reasons your baby went to hospital?	5	7*	✓
If yes, how many days was your baby hospitalised?	6	7*	✓
Has your baby been to see a doctor at any time in the past 4 weeks?	5	7*	✓
If yes, what were the reasons?	5	7	✓
Has your baby been given medications in the past 4 weeks?	6	7*	✓
Has exposure to tobacco smoke changed?	7	–	✓
Has breastfeeding changed in the past 4 weeks?	6	8*	✓
Any out-of-pocket expenses to care for your baby’s sickness?	4	3	×
Has your baby had any feeding difficulties in the past 4 weeks?	4	3	×
Has your baby had a fever/temp/felt hot in the past 4 weeks?	2	–	×
Has your baby had chills in the past 4 weeks?	1	–	×
Has your baby vomited in the past 4 weeks?	1	–	×
Has your baby had diarrhoea in the past 4 weeks?	1	–	×
Has your baby had irritability in the past 4 weeks?	0	–	×
Has your baby had increased tiredness in the past 4 weeks?	0	–	×
Has your baby had unsettled sleep in the past 4 weeks?	0	–	×
Has your baby had fast breathing in the past 4 weeks?	4	0	×
How many days has your baby had the cough for?	6	6	×
Are you worried about your baby’s cough becoming worse?	5	1	×
What is your baby’s cough like in daytime?	5	0	×
What is your baby’s cough like in night-time?	5	0	×
Total number of days the baby was in hospital	3	–	×

Item	**Round 2 n=8**	**Round 3 n=8**	**Consensus**
Anything else that affects your family getting health care for your baby?	4	3	✗
If yes, how many times has the baby been to the doctor?	3	–	✗
Total number of days baby was in hospital	3	–	✗
Amount of time spent from work/home to get health care for your baby?	3	–	✗
How many hours per week have been spent getting health care for your baby?	1	–	✗
Has your baby been given antibiotics in the past 4 weeks?	6	1	✗
What is the name of the hospital?	0	–	✗
Has any person in the baby’s household had a respiratory illness?	2	–	✗
Has your baby seen any other health professional?	5	4	✗
How many times has your baby been to see the health professional?	3	5	✗
Reason(s) baby seen by other health professional	3	7	✗
Total	**43**	**28**	**17**

* Rule of combining ‘very essential’ and ‘somewhat essential’ enacted

Round three: Questionnaire

Thirty-one items were presented in total. Of the three items presented on how data should be collected, consensus was reached that the number of questions should be 5 to 10, each site to choose personnel to collect data, and each site to choose reimbursement of a $15 gift card or $15 baby bundle. Of the 28 measures to be collected that were presented in round three, 17 were accepted (see Appendix 21 for final version of the monthly survey). Five items reached consensus by achieving a response frequency of ≥80%, and 12 items reached consensus through enacting the rule to combine votes for ‘very essential’ and ‘somewhat essential’. Items accepted include seven acute respiratory symptoms, two general health items, six items on health care utilisation, one item on exposure to tobacco smoke, and one item on breastfeeding status. Additional recommendations from the panel were to provide families and health providers with education on detecting and managing chronic cough, and to ensure adequate follow-up of infants with chronic cough.

11.6.4 Measures for respiratory illness and development for 6-month-old infants

Round one: Teleconference

Five measures were discussed: 1) 50-item parent report respiratory symptom screening questionnaire (144); 2) 18-item respiratory screening questionnaire adapted into Creole (145);

3) a clinical assessment form developed for the purpose of the larger SISTAQUIT study; 4) the Ages and Stages Questionnaire (ASQ) (146); and 5) an adapted version of the ASQ for remote Aboriginal and Torres Strait Islander communities, ASQ-TRAK (147). Participants were not aware of any other suitable measures or existing surveys.

Round two: Questionnaire

Of the five assessments tools, none reached consensus for use in the existing form. Qualitative feedback from the panel recommended a shorter length questionnaire. The questionnaire adapted into Creole language from the Torres Strait was not considered suitable for most Aboriginal and Torres Strait Islander women. Participants recommended specific language changes or inclusion of definitions for words such as ‘posset’, ‘wheeze’ and ‘rattles/ruttles’. Minor feedback was received on the clinical assessment form including a recommendation to ask more broadly about a child’s respiratory health and then use prompts for specific respiratory conditions, for example, bronchitis.

Five of eight participants indicated it was important to collect developmental outcomes at 6 months and five of eight indicated that the ASQ and ASQ-TRAK were suitable tools. Key feedback on how the data should be collected included: a health professional should complete it with the woman and infant; the health professional must be familiar with working in Aboriginal and Torres Strait Islander communities; and the questionnaire should be completed prior to a clinical assessment and the results provided to the clinical assessor.

Feedback from Aboriginal and Torres Strait Islander women

Overall, feedback from the Aboriginal and Torres Strait Islander women indicated a preference for the 50-item questionnaire compared to the 18-item questionnaire adapted into Creole. There was an overwhelming consensus to shorten the length and clarify certain terms, such as ‘posset’ and ‘rattly breathing’. Similar to the Aboriginal and Torres Strait Islander panel, women advised that the Creole language was only suitable for Aboriginal and Torres Strait Islander people who speak Torres Strait Creole. Women also recommended a simpler layout, particularly if surveys are to be parent completed.

Round three

Based on the feedback gathered from participants, several changes were made to the 6 months of age questionnaires presented in round three. The 50-item questionnaire was reduced to 33 items (see Appendix 22). The clinical assessment form was reduced to one page, and included growth parameters, immunisations, respiratory illnesses since birth, other significant illness since birth, and current medications. The clinical assessment form (see Appendix 23) was recommended to be completed with information extracted from the clinical notes and parent report. A consensus from participants (8/8; 100%) was achieved for use of the three assessment tools in their amended form.

11.7 Discussion

A modified Delphi process was completed with eight Aboriginal and Torres Strait Islander experts, and focus groups were conducted with 18 Aboriginal and Torres Strait Islander women about culturally safe measures for infant respiratory health. To our knowledge, this is the first consensus-based study on measures for detecting respiratory illness in Aboriginal and Torres Strait Islander Australian infants. Measures that reached consensus included 15 measures at birth, 17 measures from 1 to 6 months of age, and three questionnaires to be used at 6 months of age. The preferred mode for data collection differed for the different time points. Consensus was reached that birth measures should be collected via a hospital discharge summary; 1- to 6-month measures via parent report, with the mode decided by the woman, that is, phone call, mobile phone app or online survey; and 6 months of age measures collected using parent report questionnaires completed with a trusted health professional in conjunction with clinical notes.

Birth measures had a high rate of inclusion (15/15), which might be due to the standard nature of measures and minimal burden to participating women. In contrast, respiratory symptoms collected on a regular basis were much slower to reach consensus, with only five items accepted for inclusion in rounds two and three. The five items were ‘wheeze/whistle’, ‘moist/wet cough’, ‘dry cough’, ‘reasons for seeing a doctor’ and ‘change in exposure to tobacco smoke’. These are well aligned with the literature. Wheeze is the most reliable symptom to detect asthma (149) and wet cough for bronchiectasis (119, 124, 150). Seeing a doctor may indicate severity, and exposure to environmental tobacco smoke during infancy doubles the risk of hospitalisation for respiratory illness in infancy (151), so is an important variable to collect.

Two potential respiratory questionnaires for use at 6 months of age were presented to the panel. It was consistent between the panel and women in the focus groups that Torres Strait Creole is not suitable for most Aboriginal and Torres Strait Islander women, though a questionnaire with fewer items was preferred. The language of the 50-item questionnaire was largely understood and accepted by women, which is unsurprising as it stems from the ISAAC (International Study of Asthma and Allergies in Childhood) protocol which has been tested in 97 countries (152). The 50-item questionnaire was ultimately shortened to 33 items based on feedback. A developmental screening measure, the ASQ (153), as well as the adapted version for remote Aboriginal and Torres Strait Islander communities (147), were also presented to the panel. Interestingly, all panel members indicated inclusion of a measure on child development, which is not typically measured in studies on respiratory health. The strong interest to include a developmental measure raises the question of what other measures may be important, and perhaps more meaningful, to Aboriginal and Torres Strait Islander communities. Other less commonly reported measures in child respiratory studies include child and parent quality of life (154, 155) and child functioning (156).

This study had several limitations. The involvement of Aboriginal and Torres Strait Islander women was limited. Women participated in one focus group to provide feedback on one type of measure (6 months of age respiratory questionnaires); we did not obtain final feedback from women on changes made to the questionnaire recommended by the expert panel (removal of 17 items). The measures identified in this study may be more confidently used if greater end user involvement had occurred (157). While we strongly acknowledge the importance of end user involvement, the focus here was to gain expert consensus from Aboriginal and Torres Strait Islander academics and clinicians on essential respiratory measures; future studies should place emphasis on pretesting the identified measures with end users from a range of communities. A second limitation was that findings may not be generalisable to the diversity of Aboriginal and Torres Strait Islander peoples of Australia. While panel members were from different regional, remote and urban communities, the number of panel members was relatively small, and women were from NSW communities only. The number of participants in a Delphi study is usually 11 to 25, though less than 10 is also common (158). A third and important limitation was that the measures identified focus on a rather short period in a child's life, birth to 6 months of age. The 6 months age range was of focus as it is the follow-up period of the larger SISTAQUIT trial. As many chronic respiratory illnesses only develop later in childhood and are uncertain in infancy, for example, asthma and bronchiectasis, accepted measures for use throughout childhood are needed. Lastly, if further rounds of consensus were completed, the number of items may have been reduced, which can result in higher response rates for trials (159). This is an important consideration to be examined if pretesting measures.

The strength of this study was the engagement of Aboriginal and Torres Strait Islander experts from several disciplines to work together and identify a comprehensive set of respiratory measures in the context of cultural safety for Aboriginal and Torres Strait Islander infants. Knowledge was generated with Aboriginal and Torres Strait Islander academics, clinicians and women to optimise the cultural safety of data collection in a trial examining infant respiratory outcomes. The measures identified are for a number of time points in the first 6 months of life using a range of sources (medical records, parent report and observation). A range of sources is important given the known pitfalls of relying on any one of these sources alone (128).

A modified Delphi process may be a useful method to systematically involve Aboriginal and Torres Strait Islander people in decisions for trials. The Delphi has been used in other areas of Aboriginal and Torres Strait Islander health research, including to develop mental health guidelines (134) and data collection strategies for maternity experiences (135). Other high-level consultative methods to develop measures for use with Aboriginal and Torres Strait Islander people have also been used. A recent example is the development of a survey for the Mayi Kuwayu Study, a national longitudinal study on the wellbeing of adult Aboriginal and Torres Strait Islander Australians (160). Consultation was completed with 165 Aboriginal and Torres Strait Islander people attending 24 focus groups across Australia from 2014 to 2017. Pilot testing of the survey was completed in two studies with 160 and 209 Aboriginal and Torres Strait Islander participants. A second example is the Healing the Past by Nurturing the Future study, a study in part to develop a measure to identify complex trauma experienced by Aboriginal and Torres Strait Islander parents (161). Consultation includes four large-scale co-design workshops across three states with Aboriginal and Torres Strait Islander parents, service providers, community leaders, researchers and wider community members. Comprehensive consultation is expected from conception to conclusion in research with Aboriginal and Torres Strait Islander peoples (36). With varying methods and approaches for consultation, a Delphi methodology is one approach that can provide a systematic, transparent and feasible process for expert consensus in trials.

The Aboriginal and Torres Strait Islander panel that participated in the consensus process made two important unexpected recommendations that may aid more accurate data collection and increase recruitment and retention in trials. The first was to provide education to participating families and health providers on respiratory symptoms and management pathways. This recommendation aligns with a recent qualitative study with 40 Aboriginal and Torres Strait Islander community members reporting 70% considered chronic cough normal in children (109). By providing culturally appropriate definitions of respiratory terms such as ‘wheeze’ and ‘wet cough’, and information on the importance of seeking treatment, the accuracy of parent report may improve and lead to better disease detection and optimal treatment (162). The second recommendation was to provide adequate follow-up of participating infants. Cough guidelines recommend children aged 14 years or under with a chronic cough of 4 weeks should have a chest radiograph and spirometry test (when age appropriate) (163). In research studies on infant respiratory health, we have opportunity and ethical responsibility (37) to ensure that children receive adequate treatment during the study and on study completion. Studies designed with a reciprocal approach, including assured access to quality treatment, may improve retention rates, as in a recent study on the incidence of respiratory illness in Queensland (73).

This Delphi study is a preliminary step in developing a set of standard measures to detect respiratory illness in community-based Aboriginal and Torres Strait Islander infants. Future research is needed to test the validity of the identified measures for use in trials and practice. The 6-month respiratory questionnaire has been found to have good repeatability, though the authors acknowledge that validity testing is needed (144). We anticipate that results from the larger SISTAQUIT trial will allow for comparison of self-report to clinical notes, which will give an indication of validity for certain questions, including questions on health service utilisation and diagnosed respiratory illness. To validate questions on acute respiratory symptoms such as runny nose, ear ache, wheeze, shortness of breath and cough, a comparison to objective measures such as recordings of cough or wheeze, and clinical observation is needed (144). This is a resource-intensive process that may involve twice-weekly home visits (164) or potentially videoconferencing. While it was not feasible for the measures to be validated as part of this study, the process we undertook in development of these measures consulting with a range of consumers and stakeholders – has contributed to strengthening the tool’s face validity when used with Aboriginal and Torres Strait Islander Australians. Additional considerations for testing these measures may include information for families to combat the normalisation of respiratory illness (109); flexible mode of delivery, given the many other needs and problems Aboriginal and Torres Strait Islander families experience (133); and trusted and skilled interviewers to ensure cultural safety.

11.8 Conclusions

A modified Delphi process with Aboriginal and Torres Strait Islander multi-disciplinary experts determined culturally safe measures to identify respiratory illness in Aboriginal and Torres Strait Islander infants from birth to 6 months of age. We set out to develop a set of measures that would meet the needs of families, clinicians and researchers that were culturally safe and feasible. In total, 15 items for birth, 17 items from 1 to 6 months and three surveys for use at 6 months of age were identified. Future studies are required to assess the validity and reliability of and participation in surveys using these relevant and acceptable measures.

11.9 Ethics approval and consent to participate

This consultation process was part of a larger study, SISTAQUIT (Supporting Indigenous Smokers To Assist Quitting): a cluster randomised controlled trial to improve strategies for the management of smoking cessation in pregnant Aboriginal and/or Torres Strait Islander women. The consultation was approved by the University of Newcastle Human Research Ethics Committee (HREC; Ref H-2015-0438) and several other HRECs. The HRECs approved that a committee would be convened to consult on the collection of the infant outcomes, and the recommended outcome measures were later accepted into the protocol by the ethics committees. Ethical approval for participation of Aboriginal and Torres Strait Islander women in focus groups was obtained as part of a separate study from the University of Newcastle HREC (REF H-2017-0247) and the NSW AH&MRC (1303/17) HREC. Written consent was obtained from the women participating in the study.

11.10 Acknowledgements

We acknowledge and give sincere thanks to the Aboriginal and Torres Strait Islander women, Aboriginal and Torres Strait Islander research assistants, Delphi panel members, and Aboriginal and Torres Strait Islander organisations that contributed to and mentored us in this process. Women who participated were from Gumbaynggirr country and Kamilaroi country. Delphi panel members included Dr Kerry Hall, Dr Marilyn Clarke, Dr Sandra Campbell, Associate Professor Maree Gruppetta, Dr Dennis Bonney, Ms Kathy Ride (representing HealthInfoNet), Ms Kylie Stothers (representing IAHA), and Ms Karel Williams (representing CATSINaM). This study was developed with the guidance of Associate Professor Maree Gruppetta, who passed before this manuscript was developed. We acknowledge her important contribution to this work as a leading Aboriginal academic. We also thank Simon Deeming for his contributions to items on health economics.

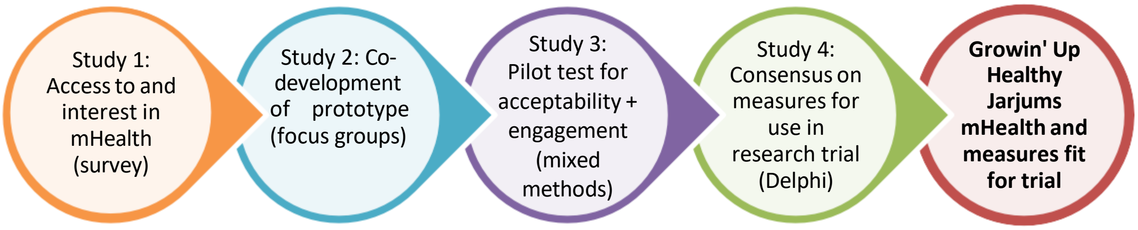
Chapter 12 – Discussion

Content

12.1 Thesis summary

This thesis includes a review of the literature and four linked studies which have resulted in a co-designed mHealth program developed for women caring for young Aboriginal and Torres Strait Islander children in NSW (Figure 12.1). The aim of the program is to improve health knowledge, health behaviours and access to health services. It is centred on being supportive of mothers and culturally safe. The final prototype incorporates three modalities – an app, SMS text messaging and Facebook page – and includes a range of health topics for women and children. A framework for developing and evaluating mHealth programs was used, as well as behaviour change techniques. In Study 1 (Chapter 8), a national cross-sectional survey was conducted to determine interest in and access to mHealth. In Study 2 (Chapter 9), the Growin' Up Healthy Jarjums mHealth program was co-designed. Study 3 (Chapter 10) was a pilot study to evaluate engagement and acceptability of Growin' Up Healthy Jarjums, and Study 4 (Chapter 11) was used to develop culturally appropriate respiratory, birth and health economic measures for use with Aboriginal and Torres Strait Islander infants in a research trial, which could be used in a randomised controlled trial of the Growin' Up Healthy Jarjums mHealth program.

Figure 12.1. Thesis summary



There were a few important findings in each of the included studies. In Study 1, it was identified that the most preferred mHealth modalities were SMS text messaging, followed by social media, and the most preferred topics were healthy eating and culture. In Study 2, design characteristics identified as important for an mHealth program were credibility; Aboriginal and Torres Strait Islander designs and cultural safety; family centredness; and being supportive, simple to use and confidential. The content modules identified as important for women's health were smoke-free families; safe drinking; feeling good; women's business; eating; and exercising. For children's health, content modules identified as important were breathing well; sleeping; milestones; feeding and eating; vaccinations and medicines; and ears, eyes and teeth. The technology features and functions identified were content feed; social connection; reminders; rewards; communication with health professionals; and use of videos. In Study 3 examining engagement with and acceptability of the Growin' Up Healthy Jarjums mHealth program, the program was perceived as useful and culturally appropriate; SMS text messages had the highest engagement, followed by the Facebook page and then the app; and areas for technical and engagement-related improvements to the app were identified. Further pretesting will need to be completed on content prior to a randomised controlled trial. The modified Delphi used in Study 4 developed culturally safe measures for infant respiratory health to be used in a research trial: 15 measures for birth, 17 measures from 1 to 6 months of age, and three questionnaires for use at 6 months of age were accepted. The outcome of this thesis is a co-developed mHealth program fit for an effectiveness trial.

12.2 Key lessons

In considering the key findings of this thesis, it is sensible to reflect on the aim of the thesis. The overall aim of this thesis was *to use co-design approaches to develop an mHealth program and robust culturally sensitive measures for a research trial with Aboriginal and Torres Strait Islander mothers of young children (under 5 years)*. Key lessons after the completion of this work are:

1. Centring relationships
2. Co-designing may lead to greater interest in, acceptability of and engagement with a health program
3. Striking the right balance between what end users want, what the evidence suggests, and the researchers' or funders' agenda
4. Rethinking outcome measures and research benefit
5. Involving end users from the beginning
6. Ensuring that the right expertise is on the research team
7. Researching during COVID-19 restrictions.

12.2.1 Centring relationships

The first key learning from this thesis is to establish strong relationships prior to co-designing a health program. The importance of centring relationships in Aboriginal health research is well known (36). A commitment to building and valuing lasting relationships is essential in public health research (165) and is particularly important in Aboriginal health research due to historical wrongdoings (36). In a practical sense, focusing on relationships throughout this thesis included taking time to consult, attending events, sharing food, out-of-hours (evenings and weekend) meetings and phone calls, listening to team members and community, flexible working hours, understanding of competing life events, extending time lines, following cultural norms, and perhaps most importantly, having an understanding that end users and researchers brought equally important knowledge, a recognised element in co-design (166).

To co-design well, end users who join the co-design activities must have trusting relationships with the researchers so that they feel free to be open to share their opinions and ideas about various issues (166, 167). Trusted relationships were established and valued at all levels of the research. The Aboriginal research assistants co-facilitating the focus groups had implicit and mutual trust with the participants and organisations as they were from the communities where the research took place, as recommended in the AH&MRC ethical guidelines (71). The women who joined the co-design focus groups were the Aboriginal research assistants' family, friends and colleagues, and the participating organisations were the Aboriginal research assistants' health services and workplaces. It is likely that having Aboriginal research assistants from the communities where the research took place led to high recruitment and follow-up rates.

Another important relationship was between myself as a PhD student and the Aboriginal research assistants. We worked together with a mutual respect for each other, and were able to have two-way learning of knowledge, skills and values (36, 166). In many instances, we travelled together, presented together, developed content together, facilitated focus groups and interviews together, analysed the data together, and presented the work back to participants and communities. My close working relationship with the Aboriginal research assistants and their trust in me afforded me a privileged position, which resulted in participants and Aboriginal organisations extending their implicit trust to me, which I would not have been able to achieve otherwise.

12.2.2 Co-designing may lead to greater interest in, acceptability of and engagement with a health program

Evidence to date suggests that co-design can lead to better quality research (168), higher acceptability and applicability of programs and measures (169), positive emotional outcomes for participants, increased skills for managing health issues, increased knowledge and interest for contributing to research (169), empowerment of communities negotiating and participating in research, as well as ownership of the research and the program (65).

It is anticipated that using co-design methodologies results in a more effective program, though without comparative studies, this is not certain (169). Furthermore, it is unclear which co-design methodologies may be most useful. Co-design is an umbrella term that can incorporate numerous methodologies; some studies use a comprehensive set of methods, while others use the term co-design while not involving end users at all (169). In addition, the researcher's approach is just as important as the selected methodologies, as any method can be used either authentically or inauthentically (166). It was a pragmatic decision rather than a political or ethical one to use co-design approaches in this research (72), in that there was an understanding that end users are the experts on their lives and how they would like to use mHealth. We anticipate that using co-design approaches led to greater interest, higher participation and completion rates, and improved health knowledge and health behaviour change.

12.2.3 Striking the right balance between what end users want, what the evidence suggests, and the researchers' or funders' agenda

A well-known challenge in co-design is weighing up different opinions and ideas of researchers and end users on what the health program should include (169). Though difficult at times, constructive tensions and disagreements between researchers and end users are an important element of co-design (166). Discussions with various mHealth research teams identified a common view that end users often want more advanced technology than will fit in with their daily life. During the co-design focus groups, end users were enthusiastic to develop an app with an array of features, rather than SMS text messages or a Facebook page. Features suggested included a content feed, social chat, reminders, rewards, communication with health professionals and use of videos. Adapting the program and compromising based on ideas from end users is unsurprisingly a key element of co-design (166); one study refers to this as having ‘space to talk’ and a ‘space to change’ (166).

In the prototype mHealth program, we decided to utilise three delivery mechanisms – a Facebook page, an app and SMS text messages. We made this decision to satisfy what the end users requested in the focus groups (an app), what end users reported using daily (SMS text messages and Facebook), what the survey results found end users wanted (SMS text messages), and what the evidence suggests is effective (SMS text messages). Using multiple delivery modes for the mHealth program seems to have been a good compromise, particularly given the technical challenges with the app. Developing an app was valuable as it allowed the research team to honour what the end users called for in focus groups. It also allowed for the end users and researchers to improve digital skills, and have a prototype app that can continue to evolve as technology and end user digital skills grow. Perhaps what was a more difficult compromise was deciding which health topics to include. End users suggested numerous health topics, which were then combined into 12 health topics (six women’s health topics and six children’s health topics). An mHealth program developed with mothers in New Zealand also found end users were wanting the program to cover a range of topics (19). We were aware that an mHealth program covering a wide range of health topics may reduce the impact on any one health risk behaviour, though other important outcomes were likely to be achieved, most importantly greater acceptability of and engagement with the program.

12.2.4 Rethinking outcome measures and research benefit

Researchers, health organisations, end users and other stakeholders have different conceptions of the value and nature of research, what it should achieve and the kinds of benefits expected (170). This is particularly true in Aboriginal and Torres Strait Islander health research due to the Western knowledge base of research practices (170):

> “The current state of Indigenous research assessment embodies a Western cultural framework based on measurable units and quantifiable methods and indicators. As a result, biomedical and economic indicators of research assessment do not account for measurable aspects of community living and wellbeing that are not easily measured. These less easily measured aspects include intangible cultural heritage and wellbeing, Indigenous people’s worldviews, associations and relationships.” (170) (p. 7)

There is no one-size-fits-all approach to measuring health outcomes or benefits; solutions should be innovative and tailored to the program and context by identifying and prioritising issues of relevance to the Aboriginal and Torres Strait Islander people concerned (170). The decision to focus on infant respiratory health outcomes in this thesis was a pragmatic decision based on an opportunity to work within a larger study on supporting Aboriginal and Torres Strait Islander mothers to quit smoking in pregnancy (171). While the respiratory measures may be useful in a trial of the Growin' Up Healthy Jarjums mHealth program, further discussion with end users, participating organisations and other stakeholders will be needed to identify what benefits, health outcomes and outcome measures are of most relevance and importance.

Other considerations in selecting outcome measures is how the program may work in certain contexts, in what circumstances the program may bring about change, and what are the mechanisms of change (172). These are questions for complex interventions. An intervention is considered complex for a number of reasons: the range of health behaviours targeted, the number of groups, setting types, the skills and expertise required by those receiving or delivering the program, or the permitted level of flexibility in the program (172). The Growin' Up Healthy Jarjums program could be classified as a complex intervention because it targets multiple health behaviours, and a diversity of groups with adverse health and social inequities. It is suggested that complex programs need to be assessed through a whole systems approach, rather than the binary approach of effectiveness (172). Properties of complex systems include emergence, feedback, adaptation and self-organisation (172). For example, a program like Growin' Up Healthy Jarjums, which targets women and children, could see the emergence of improved health outcomes for the women's partners by them being exposed indirectly to health information and behaviours. Careful consideration with stakeholders will be needed to decide which outcomes are most important, and how to deal with multiple outcomes in the analysis (172).

An additional approach to evaluation is the APEASE (Acceptability, Practicability, Effectiveness, Affordability, Safety, Equity) criteria, which is a mechanism to evaluate behaviour change programs (173). Examples of how the Growin' Up Healthy Jarjums mHealth program meets the APEASE criteria are shown in Table 12.1.

Table 12.1. APEASE (Acceptability, Practicability, Effectiveness, Affordability, Safety, Equity) criteria met by the Growin' Up Healthy Jarjums mHealth program

Criterion	Definition	How Growin' Up Healthy Jarjums meets the APPEASE criteria (173)
Acceptability	To what extent is the program likely to be acceptable to key stakeholders, including users, funders and those charged with implementing it?	Overall, the Growin' Up Healthy Jarjums mHealth program was found to have high acceptability. The pilot study results indicate that women found the program to be useful, culturally appropriate and easy to use, and most women reported positive impacts. None of the participants withdrew from the SMS text message portion of the program, which indicated the high acceptability of and engagement with this component. Engagement with the Facebook page was found to be higher than that with the app. Individual users preferred different modes (SMS text message, Facebook page or app), indicating that a multi-modal intervention increases reach. Importantly, this pilot study showed several ways to improve the program, including technical changes to the app.
Practicability	To what extent can the program be implemented as designed to the intended users at scale?	The Growin' Up Healthy Jarjums program is a practical program providing real-time health information when people need it. The program was co-designed with end users in an attempt to have the program fit in with their day-to-day phone use. Implementing the program at scale (in different communities) would require further research. A limitation of the program is that generalisation to other communities is limited. Aboriginal and Torres Strait Islander communities are made up of many diverse cultural and language groups. Each community has a unique history, cultural practices and health needs. The Growin' Up Healthy Jarjums program would need to be adapted, including by making changes to language, images and health advice, to ensure cultural safety and relevance to women from other communities.
Effectiveness	To what extent is the program likely to achieve or exceed a desired level of effectiveness for a given target behaviour and how cost-effective is it likely to be in relation to a desired outcome?	Based on the data collected during the pilot study, it is likely that the Growin' Up Healthy Jarjums program would have a positive impact on the end users, and potentially their families. Data was collected on perceived impact following the 4-week pilot study. Twenty-two (71%) women reported that the program had an overall positive impact on themselves and their family. The most common perceived impact was feeling more supported (21/29, 72%), followed by improvements in knowledge or understanding of child health (13/26, 50%), eating habits (11/29, 38%) and exercise (11/29, 38%). Many women commented on the supportive and affirming aspects of the program, including the validation of how hard parenting can be; information that certain health problems, such as ear infections, are common in children (validating that it was not their fault); the feeling that a service cared about their child's health; and the feeling that someone cared about them, which arose because of the receipt of regular messages. Other positive impacts that the women discussed included getting their child's ear health checked by a general practitioner, more play with children, spending time together as a family, taking children for hearing and vision tests, more exercise, taking care of themselves, talking to friends and family about

Criterion	Definition	How Growin' Up Healthy Jarjums meets the APPEASE criteria (173)
		quitting or reducing smoking, cooking with children, limiting alcohol, getting their child immunised, improved knowledge of contraception, and improved family eating. A trial is needed to assess the effectiveness of the Growin' Up Healthy Jarjums program in improving health outcomes.
Affordability	Can the program be implemented at the desired scale to the intended users within a realistic budget?	Overall, the Growin' Up Healthy Jarjums program is affordable to implement. Costs to implement the program could include rebuilding the web-based app as an Android or iOS app, further pretesting of content in focus groups, staff to administer the Facebook page in each community, and a project manager to monitor and manage any arising challenges with the app and SMS text messages, or any other aspect of the program.
Safety	To what extent is the program likely to have unwanted side effects?	Growin' Up Healthy Jarjums is a low-risk program; there were no unwanted side effects during the pilot study. Safety would need to be reevaluated prior to a larger trial
Equity	To what extent is the program likely to increase or decrease economic, social or health inequalities?	The program may make some improvements to health inequalities by improving health knowledge and health behaviours, such as increased access to primary health services.

12.2.5 Involving end users from the beginning

A key limitation of this thesis was that it was initiated by a research institution rather than by the community. True co-design should begin with completing a needs assessment with communities to see what the health priorities and potential solutions are for that community (79). This was done well in a New Zealand-based mHealth co-design study (70, 81). Not including end users from the beginning of co-design studies is a common challenge, largely due to funders not allowing for meaningful co-design in advance of research studies being funded, which places restrictions on how much end users and other stakeholders can have meaningful input on study design, program type and evaluation (174). While the funders of this PhD were flexible with change to the program itself, the concept of developing an mHealth program for women's and children's health was a core part of the application that was funded. End users were involved at the stage of deciding on delivery mechanisms, features and functions, and content modules. Funders' reluctance to fund end user contributions from the beginning of research may be a result of the pressures of the health research system, and the reluctance to share greater power with other groups (174). Other considerations for both funders and researchers include the increased time and financial resources required for co-design, and tensions between researchers and end users in decision-making and sacrificing scientific rigour for end user preferences (169). A final challenge stemming from funding is the difficulty of planning for continuity of the research. It is important for communities to know what will happen after initial co-design and pilot testing phases. We have tried to be upfront with communities about the uncertain future of the program, and assured them that we will keep them informed.

12.2.6 Ensuring that the right expertise is on the research team

Co-designing mHealth is about mutual learning, where both users and researchers learn about potential mHealth technologies and designs that may be of most benefit to the end user (167). During the co-design process, the end users needed knowledge of potential mHealth options, how the different options work, and public health messaging, while the research team needed to understand how the end users used their phones day to day, their use of mHealth, and their challenges and desires for accessing health information. It was important to have sufficient expertise on the team to be able to provide the end users with sufficient information to participate meaningfully in co-design focus groups. The research team included four women with Aboriginal lived experience (KH, NS, BL and BH), three of whom are from communities where the research took place; a behavioural scientist and leader in public health (BB); a consultant paediatrician and paediatric respiratory researcher (JM); a nurse and Aboriginal health and public health researcher (KH); an mHealth and public health researcher (RD); an early educator (BH); Aboriginal health practitioners (NS and BL); and an occupational therapist and public health PhD candidate (SJP). We also contracted an app developer who joined several focus groups. Having the right expertise on the team meant that we were able to plan and problem-solve effectively to achieve research aims (72).

12.2.7 Researching during COVID-19 restrictions

It has to be noted that the studies within this thesis were impacted by COVID-19 restrictions. In Chapter 8, the cross-sectional survey of Aboriginal and Torres Strait Islander women's access to and interest in mHealth, we had planned to complete a portion of surveys in person to capture access to and interest in mHealth of women not able to participate in an online survey. The inability to complete surveys in person due to COVID-19 restrictions was a key limitation of the study biasing the results. In Chapter 10, the engagement and acceptability study of the Growin' Up Healthy Jarjums mHealth program, all recruitment and instruction for the program needed to be completed remotely using SMS text messages, links and phone calls owing to COVID-19 restrictions. In the initial protocol, we proposed recruiting women, setting up the app and providing instructions on how to use the app in person to reduce technical problems. Unfortunately, this was not possible, and women experienced a high number of technical problems. With a large proportion of women having had difficulty accessing the app, most of the feedback on the app was centred on the technical challenges. Finally, it was difficult to disseminate results in a meaningful way. We had planned to have a morning tea at each site; however, due to COVID-19 restrictions, we cancelled all in-person meetings. We had also planned a workshop on co-designing mHealth with multiple stakeholders, including international speakers, as an opportunity for organisations and community members to upskill in research, and potentially generate future mHealth ideas. Unfortunately, this workshop also needed to be cancelled.

12.3 Future research directions

This thesis has generated knowledge on the access to, interest in and preferences for mHealth among Aboriginal and Torres Strait Islander women of reproductive age, an area where there has been limited data to date. Furthermore, a co-designed mHealth program that aimed to improve health knowledge and health behaviours among Aboriginal and Torres Strait Islander mothers and their young children in three NSW communities has been developed and pilot tested. This work provides a solid foundation to further develop this mHealth program, and test it for effectiveness. The measures identified and developed in Chapter 11 may well be used to measure respiratory health outcomes of the 'Growin' Up Healthy Jarjums' mHealth program, though additional outcome measures will need to be identified to capture other outcomes. It would be the first effectiveness trial of an mHealth program for Aboriginal and Torres Strait Islander mothers and children. If effective, the Growin' Up Healthy Jarjums mHealth program would be provided to the same communities that co-designed it.

12.4 Conclusion

This research contributes to addressing individual risk factors that impact women's health (nutrition, exercise, smoking, sexual health, use of alcohol and other drugs, and mental health) and children's health (nutrition, sleep, development, ear health, lung health and immunisation). Improving a mother's health not only benefits her, it also benefits the health of her family and community. The mHealth program developed through this research aims to improve health knowledge and health behaviours among Aboriginal and Torres Strait Islander women and their children in a culturally safe way. mHealth was selected as the delivery mechanism for the program, as it is a valuable mechanism for delivering relevant health information and support to people at the points in time when they need it. The use of co-design methodologies was a useful approach to ensure the technology and content was acceptable and engaging to the target population. This co-designed mHealth program may be an accessible way for some Aboriginal and Torres Strait Islander mothers to improve their health knowledge and behaviours, and ultimately improve health outcomes for themselves and their families.

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